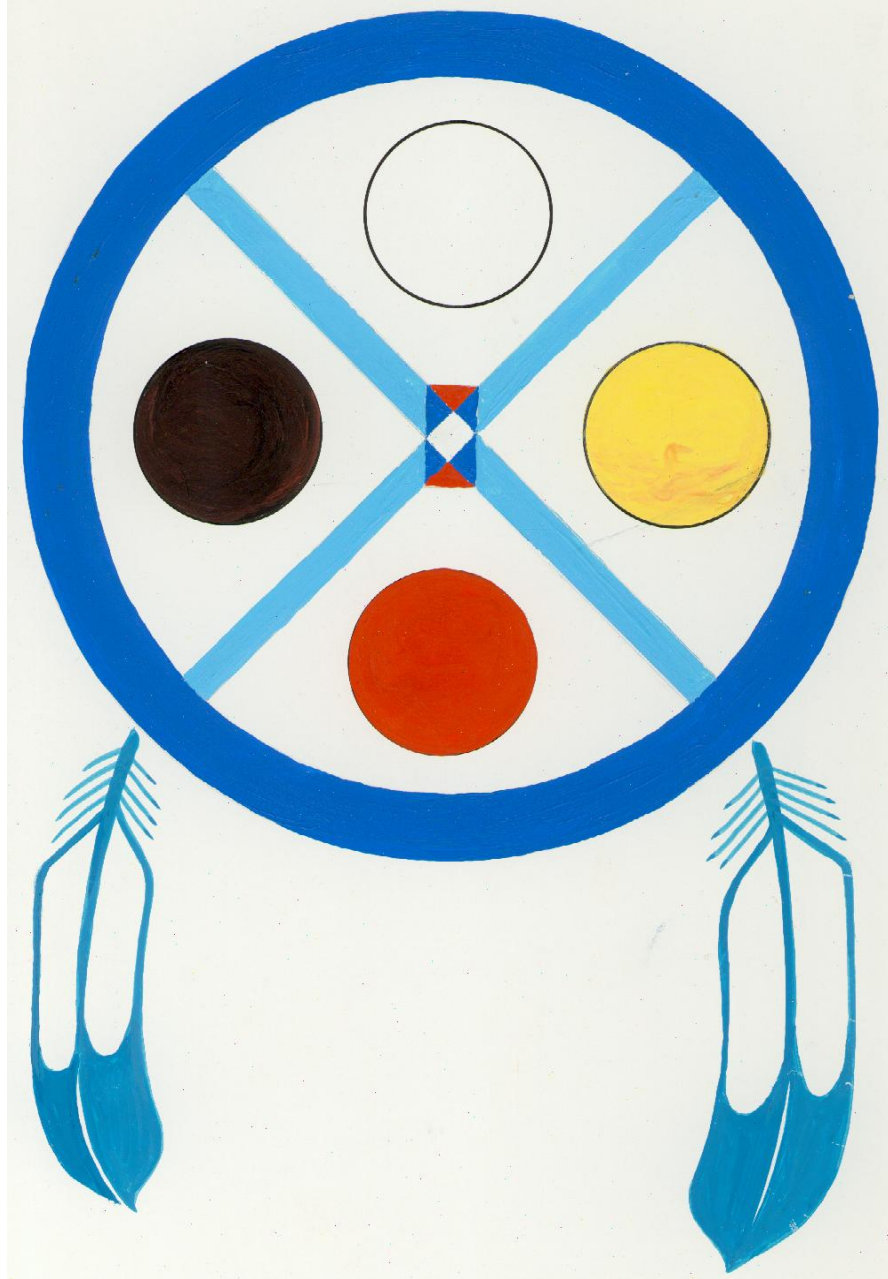
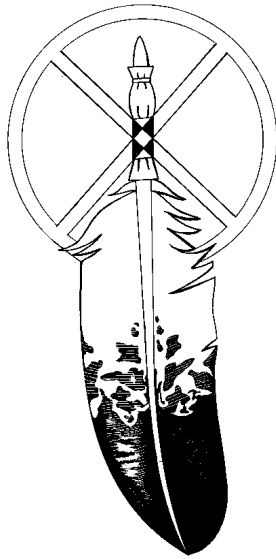


NASHINE GINWENIMAWAZIWIN

Constant Care



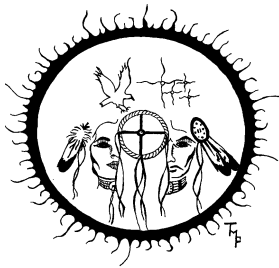
**2-SPIRITED PEOPLE
OF THE 1st NATIONS**



*NASHINE
GINWENIMAZAWIN*

Constant Care

Written By: Shelly Vanderhoef
Edited By: Wendy Gray



**2 SPIRITED PEOPLE
OF THE 1ST NATIONS**

Nashine Ginwenimawazawin

2-Spirited People of the 1st Nations

14 College Street, 4th Floor
Toronto, Ontario
M5G 1K2

Telephone: (416) 944-9300

Fax: (416) 944-8381

© 2-Spirited People of the 1st Nations, March 1998

© 2-Spirited People of the 1st Nations, reprinted March 1999

© 2-Spirited People of the 1st Nations, reprinted 2001

© 2-Spirited People of the 1st Nations, reprinted CD-ROM, 2002

- ◆ Thanks to the **AIDS Committee of Toronto** for the use of the sections of the manual; **Living with Dying, Dying at Home: An AIDS Care Team Resource Manual**. By Andrew S. Johnson

ADDITIONAL COPIES OF THIS MANUAL ARE AVAILABLE FREE OF CHARGE THROUGH THE;

NATIONAL AIDS CLEARINGHOUSE

(613) 725-3769

All Illustrations and artwork provided by:

SIMON PAUL-DENE

FUNDING PROVIDED BY:

**Government of Canada
Health Canada**

**Gouvernement du Canada
Santé Canada**

Funding for this publication was provided by Health Canada. The opinions expressed in this publication are those of the authors and do not necessarily reflect the official views of Health Canada.

ACKNOWLEDGEMENTS

The production of this manual would not have been possible without the help of many caring, courageous and generous people. The vast knowledge and intimacy contained in the stories helped to bring a vital human touch to information that could otherwise be seen as outside the realm of many people's lives. Due to confidentiality issues, we did not identify the speaker of each story; however, for those who wished to be acknowledged for their tremendous gift, we have listed them here as recognition for their contribution. In no particular order, they are;

"Natará"	Patricia Saşakamoose-Tait	Andy Kematch
Darin Trimble	Thomas Williams	"June Thunderchild"
Cyndy Baskin	Joey McKay	Ruth Carey
Noelle Spotton	Charlotte Kayenderes Green	LaVerne Monette
Anthony J. Nobis	Charlotte Brooks	Dr. Janet Smylie
Doreen Gill	Vern Harper	Cary Thompson
Roger A. Jones	Christina Pawis	Dr. Sally Ford
Sandra LaFramboise	Nancy Bell	Holly Brant-Butcher
Diane Calback	Terrence Sands	Corena Ryan
Gilbert Deschamps	Verna Nicholls	Paul W.
Duane Etienne	"Vena"	Dr. Sarah Whitehead
Rene Boucher	Dr. Shayna Watson	Yvonne Kuscner
Jeanne Korobanik	Anne-Marie Dicenso	Rick Lines
Ken Oliver	Heather Bruce	Leonard Sisson
Laurie Poirier	Debby Danard	Vera L. Martin
Shawani Campbell-Star		

Thanks go out as well to the agencies that helped provide information for much of the text. They are;

The Native Sons of Guelph	Voices of Positive Women
Community Care Access Centres	Sioux Lookout Zone Hospital
Village Clinic	ACT-Now
AIDS Committee of Toronto	CATIE
Shawanaga First Nations HIV/AIDS Awareness Team	

The production of this manual was an extremely time consuming task and many thanks go to those people who helped to make it look fabulous.

Paul Lau

Julie Royal

SPECIAL NOTE: TO BELINDA MCKAY AND RUSS KREBS FOR GOING ABOVE AND BEYOND THE CALL OF DUTY – THANKS FOR EVERYTHING!

INTRODUCTION

ABOUT NASHINE GINWENIMAWAZIWIN

Nashine Ginwenimawaziwin, from the Ojibway language, translates loosely into “Constant Care.”

What is Constant Care all about?

Constant Care is about Aboriginal people who have AIDS that are in need of palliative care. It provides suggestions and ideas of how to support someone who is going through the last stages of AIDS.

What is Palliative Care?

At this time there is no cure for AIDS. When HIV has damaged the immune system to where it can no longer fight off diseases, the focus of care changes from treatment of illnesses to symptom management and making sure she is as comfortable as possible. When someone has reached this point in their disease, the care they are given is called palliative care.

The Text

In each section, you will find the words *he* and *she*, used to speak about the person you are caring for. The purpose for referring to the person you are caring for as both he and she, is done to reflect the fact that both men and women are living with AIDS.

The Stories

This project began as a manual, a step-by-step document. Through direction from the Aboriginal Palliative Care Manual Committee and consultations with First Nations people in Ontario, the project became more about education and awareness through the sharing of stories and experiences. It seemed the best way to capture what the storytellers had to say was to tape record interviews with people and then type out what they said. It kept the stories accurate and made sure that they didn't get distorted through interpretation.

While every effort was made to ensure accuracy in the interpretation of the stories, it became clear that the written word was no substitute for speaking with someone. One story is very sad and painful, yet the woman who told it, laughed and breathed life into it. Her humour and expression made the story hysterically funny and emotionally vibrant. So please, try to imagine where the storyteller might be coming from and keep an open mind and heart.

The stories, which are in *italics*, are the experiences of Aboriginal people living with HIV/AIDS; the people who care for them; and the people who provided care to those who have already passed. In the stories are ideas and skills to help you provide care for someone. You can pull out ideas that may help you in your experience, simply ignore anything that doesn't apply to your situation. The storytelling is the main content of this document. The writing between is the string that links the stories together.

When you are providing care to an Aboriginal person living with AIDS, you are creating your own story. As it is completely unique to you, only you can capture it. Also, because the stories and information presented to you in this manual may be new and sometimes confusing, you will probably need to process and absorb what you have read. For these reasons, we have provided room at the end of

each section so that you can jot down notes for yourself. In this way you can begin weeding through the stories and using the ideas that you need so that you can help to provide the best possible care.

Who will use Constant Care?

What is caring all about? In this case, care is about wanting to help someone who is dying to maintain as high a quality of life as possible. When it is one person who is providing care they are called a caregiver. When more than one person is contributing to care, the group is called a care team.

The stories are not meant as a set way of thinking or doing things. It is up to you to decide whether you agree or disagree or think something is missing. The ideas presented are meant to be used as guides, to help provide insight and to stimulate your own ideas. Only you can decide what direction you want your care team to go in.

Why do we want to help others? Is wanting to help someone, who is in need, a natural thing to do?

THE STORYTELLERS

“an Aboriginal person living with HIV/AIDS”

These are the words of Aboriginal people that are living with HIV or AIDS.

“an Aboriginal Elder”

These are the words of First Nations Elders.

“an Aboriginal support person”

These are the words of Aboriginal people who contribute to the care of Aboriginal people with HIV/AIDS. They are the family, friends, counsellors, doctors, nurses, lawyers and volunteers. They are found under the blanket term “an Aboriginal support person” because they all have the support in common.

“a support person”

These are the words of non-Aboriginal people who contribute to the care of Aboriginal people with HIV/AIDS. They too, come from many professions and backgrounds. What they have in common is that they provide support to an Aboriginal person or Aboriginal people with HIV/AIDS.

Look at the crisis in Manitoba with the floods. Over and over again you have people talking about the helpfulness of other people, how everybody is willing to help. Someone will say, "It's unreal!"

But, all that other crap has gone into the mental realm. We're so distorted that what happened in Manitoba is described as unreal. That is the normal condition of who we are as Spirit beings.

- an Aboriginal Elder

That's what it amounts to if you break it down to its lowest common denominator. One human being is ill and in need of help and support. The other one is in the position to offer it. That's the lowest common denominator.

- an Aboriginal Elder

There's lots of people with compassion out there, but they just need some help to break through a barrier. It requires time and education. I would also suggest people use prayer. You're looking for somebody to help. Offer your own prayers and tobacco, offer them to (the) Spirit, and ask the Spirit to help you find the people you need, and trust that they'll come. It's going to require time because there is so much work, but you can do it.

- an Aboriginal Elder

It's always been our way to look after our own. That's how we survived as people. We don't delegate. We don't categorize our community the same way mainstream society does. Everything has to live together. When a crisis happens, everything does work together.

Sure, the Chief might take a leadership role. The Family Support Worker might (also) kick in and take a leadership role. Depending on the situation, the community almost instinctively reacts appropriately. Where that's learned, I'm not sure. Who cares? The point is, that it works.

- an Aboriginal person living with HIV/AIDS

ORAL TRADITION

How should an Aboriginal-specific document be produced, especially when written word violates Aboriginal tradition? There are various different opinions and insights into the oral tradition, here are a few.

Well, because it's a manual, that already violates oral tradition.

- an Aboriginal person living with HIV/AIDS

In our tradition and culture, for thousands of years, our people passed our teachings in an oral way, with our language that we were given in the beginning. The reason this was done was so that we would live those teachings and put it into our life, into our own being. We would carry that knowledge and that wisdom with us, wherever we walked.

Whoever we came upon, who asked us in a proper way to share with them, we would share with them and it would come from our spirit, from our own being; from our own heart. It was part of our life, everyday life.

Nashine Ginwenimawazawin

When we put things on paper, we tend to put limits to those things that we write down. In our teachings about life, they are never-ending. Each time you give a teaching orally, you get something out of it, even though you may tell it a hundred times. Because the Creator and the Spirits will allow you to understand a little bit more, or understand in a little different way, we can never say we know the teaching. We may know a little bit about it.

As history has taught us, because we did not write before the newcomers came (that) everything was oral, we did things physically, mentally and spiritually. We put it into our everyday life in that manner. We didn't write. It wasn't part of us.

When they began to try to learn from us, they would speak to our Elders in our communities. They would watch our rituals. They would take that and put their understanding down on paper. They didn't live that life. They didn't understand that life. Those books that are written do not tell our teachings. It's an interpretation of the writer.

When we use our language, there are no English words to describe things about life. So with that, I say that what is written, it's only a guide. It's only a guide to you.

I immediately allow people to write down or record my workshops. If it's going to help somebody, I don't have a problem with that. You see, the old ways, when everybody was sitting in the Big House or the Long House every night getting teachings, they wanted you to focus and not be distracted. So, nothing was written down. But, you were hearing them day after day after day. We don't have that. A person may come once or twice.

Then, there are people who say, "That's not traditional."

I've been the subject of that more than once, where someone has tried to really shame me and embarrass me. It's part of a power shift. It's the same as any other group that says, "We have all the answers and you don't."

- an Aboriginal Elder

We keep the oral traditions alive because our culture was based on oral and our teachings we passed on by oral. There are people who are documenting, writing things. A lot of medicine people still feel that we should keep it alive, the storytelling, the oral teachings.

It reinforces the part about listening, learning how to listen. A lot of people are concerned if they don't write it down. I like what one of the Elders said about writing, "When you write things down you're giving yourself an excuse to forget." So with the oral teachings you can't you've got to remember.

There have been times where people feel that some of the writing down stuff leads to exploitation. People will exploit our culture by making money off of it with books. There's less chance of that with one that's kept oral.

I know there's some oral teachings that are only kept into certain families. But usually oral teachings are for everybody.

Storytelling, the oral teaching, has made a comeback. In the last decade, there is more and more storytelling, more oral teachings.

By passing it on, the oral teachings keeps the history and keeps it alive. It keeps the culture alive. Ours is a living culture in the oral teachings. It keeps it a very personal thing.

A person who is given the oral teaching, we put our own personal kind of feelings into it. It's important to pass these on, these stories and teachings and legends.

There's a time that we could be living in an era where we're not going to have the computers. What is old is new and what is new is old. I think it is going to be very important to keep the oral teachings alive and teaching people to be good storytellers. It is an art.

- an Aboriginal Elder

CELEBRATING OURSELVES

His collection of stories provides an opportunity to observe the many wonderful and diverse views of each storyteller. Many of the stories took a tremendous amount of emotion and courage to share. Each story provides a valuable and unique insight into Aboriginal people living with AIDS and the people who provide him or her with care and support.

The stories are a chance to learn about and celebrate the lives of Aboriginal people living with AIDS. The strength of the storytellers can enrich your understanding of the depth and quality that are possible in constant care. This may provide you with inspiration when you are providing constant care on a care team.

The stories found in this book are gifts, given by the people who took the time to share them. It is an occasion to discover the joy and inspiration that the spirit of a human being has to share.

TABLE OF CONTENTS

Section One: Introduction to Palliative Care

A CARE TEAM: WHEN DO YOU NEED ONE?	Page 35
• How would you like to be treated?	36
• Going home	38
• Challenges to Going Home	40
• Making Care Possible	43
• HIV and AIDS	44
• What is HIV and AIDS?	49
• A little bit of Biology	51
• The Immune System and HIV	51
CARE TEAMS	53
• Information List	58
• Decisions: It's not always easy	62
• Getting Volunteers	66
• The Environment for Constant Care	69
• Equipment and Money	71
• Record Keeping	74
• Medications Chart	80
CARE TEAM STORIES	84

Section Two: Physical

OPPORTUNISTIC INFECTIONS & AIDS RELATED ILLNESSES	95
• Opportunistic Infections	95
• Viral Infections	96
• Bacterial Infections	98
• Fungal Infections	100
• Protozoal Infections	102
• AIDS-Related Illnesses	104
SYMPTOM CONTROL: COMFORT MEASURES	107
• Some basic assessment skills	107
• Basic comfort measures	109
• Personal hygiene	118
MEDICATIONS	122

• The categories of drugs	122
• Recording, storing & disposing of drugs	124
• The golden rules for giving drugs	126
• Giving medications	128
• The effects of drugs	135
ANTIVIRAL DRUGS	138
• Access to drug therapies	146
BODY MECHANICS: LIFTS AND TRANSFERS	148
• Basic body mechanics	149
• Moving someone in bed	152
• Moving from bed to chair or from one chair to another	154
• Falls to the floor	157
• Walking	158
• Fire Safety	158
INFECTION CONTROL	160
• Universal Precautions	161
FOOD & FOOD SAFETY	164
• Dietary needs	165
• Traditional Aboriginal Foods	165
• Nutrition	166
<i>Section Three: Spiritual/Traditional</i>	
TRADITIONAL CARE	170
• Traditional treatments	170
• Symptom Management	178
SPIRITUALITY	191
• Approaching an Elder	197
• The Sweatlodge	203
<i>Section Four: Emotional</i>	
PAIN	208
• Pain Management	212
• Pain information checklist	213
• Breakthrough Pain	214
LIVES WITH HIGH STRESS	215
• Prisons	215

• Stress	224
• Substance abuse	230
CARING AND SHARING	238
• Communication in emotional times	241
• Confidentiality and gossip	249
• Conflict	253
DEATH & DYING	258
• Funerals	268
• Grief	278
CARE FOR THE CAREGIVER	285
• Supporting yourself	285
• “I’m not doing enough!”	288
• Burn out	289
• Staying objective under pressure	294
• Helping each other	295
• Talking circles	298
• Depression	304
<i>Section Five: Mental</i>	
COMMUNICATION	312
• Doctors	320
• Nurses	325
• Advocacy	328
• Two-spirited people	333
• First Nations languages	338
LEGAL	341
• Questions and answers	346
• Euthanasia and assisted suicide	357
• Aboriginal voices speaking about euthanasia and assisted suicide	358
RESOURCES	362
• Places you May Get Information, Support and Services	372
• Resource list	373
• AIDS Service organizations and programs: Aboriginal	373
• AIDS Service organizations and treatment: Information	377
• Palliative care information	380

Nashine Ginwenimawazawin

- Housing, Home care and Palliative Care 381
- Life Long Care and Homecare Programs 382
- Medical Services Branch 383

A CARE TEAM: WHEN DO YOU NEED ONE?

When is there a need to put together care teams for Aboriginal people living with HIV/AIDS?

Kou may be in a position where someone you are caring for may have decided he wants a care team and has expressed this to you. You may be caring for someone right now. If this is the case, it is very obvious to you that, yes, he needs a care team.

Other times, it is not so clear. You may not be sure if he wants a care team or not. Not everyone is able to ask someone for help. If you see he needs help and you want to offer your care, simply ask him if he would like you to contribute.

You could also see he needs help, even if he has told you he does not want a care team. It may be hard to come to terms with this decision. When you want to help someone and see that it is needed, you will have to respect his decision, whatever that may be. If this is what he has decided about his life, it is his choice to make. His is the only voice that can express whether or not he wants help as he becomes sick. This is a choice only he can make, as it is his life.

The decision to have a care team begin with the person who has AIDS. How do Aboriginal people living with AIDS feel about the idea of a care team helping them during the palliative stage?

I would definitely want someone to be there to take care of me. That's basically how, on my reserve, we would take care of one another. I would do the same for anyone who came and asked me to take care of them. I would, without hesitation. I would want the same option given to me.

- an Aboriginal person living with HIV/AIDS

It was nice to know that someone actually took the time out of their busy schedule to come and see how I was doing. It made me feel good, it made me feel like I wasn't alone. Real friends are hard to come by, what can I say.

- an Aboriginal person living with HIV/AIDS

I would like to be able to go home, if I could do that. I'm the type of person that's independent. I wouldn't want to be a burden on anybody although that's where I am right now in my life. It may be different ten years down the road.

Nashine Ginwenimawazawin

I would rather be at home on my reserve if I was getting ready to die. I would also want to be buried close to home. I'd want people that I grew up with, fought with, hated and loved. I'd want those people close to me.

- an Aboriginal person living with HIV/AIDS

I would like to have a group of people to help me along the way. I think it's very important, you've got to have that support there.

You can never feel like a burden when you're ill like that. You know that you can't do things for yourself. You know it and you know that it's just hurting you by not getting the help you need.

If you're honest and open with your friends and they are honest and open with you, there is no reason why you can't put your trust in them to do the right thing for you, to take care of you if you can't take care of yourself.

Well, I'd only want the people around me that I trust. I have a very small group of people which I would call friends. Everyone else is an acquaintance. That's really important. You really have to trust the people who are taking care of you because if you don't, get rid of them. Find someone you can trust and don't take second best, never take second best. Always take the best. You are the judge of that. You are the judge of who is best at taking care of you and what's best for you.

I wouldn't have any problems at all if my friends took care of me. No problems at all. In fact, I'd probably love it. It's about time somebody takes care of me!

- an Aboriginal person living with HIV/AIDS

HOW WOULD YOU LIKE TO BE TREATED?

Hf you know someone who needs a care team, you may be concerned about whether or not you can help her during this time. Fortunately, the words of our Elders give us a clear message on how to relate to one another in a good way. When you are caring for someone, one of the most important skills is being able to communicate with that person in a way that shows respect.

Often, people that are dying want others near them to assist during this process. You may find it natural for yourself to want to contribute to her care team; yet, you may not know exactly how you want to accomplish this.

If you have been fortunate enough to sit with an Elder, you may have learned skills on how to communicate respectfully with others. Not everyone, however, has had the opportunity to sit with an Elder and learn these teachings.

Each of us has our own dignity. We would like to be treated in a way that lets us keep that. I wouldn't want to be treated in a way as though I was an object.

- an Aboriginal person living with HIV/AIDS

When your communication with her is left up to intuition, her care team will be based on guessing. If this were to happen, there is no way of really knowing what she wants. If her care is left up to guessing, it means she will no longer be in control of her life.

To avoid this, a good place to begin would be to ask her how she wants to be treated by her care team members. As you now understand that there is a need, being able to respond to this need means listening to what she has to say about how she wants to be treated.

Somebody that's loving and caring and shows respect. Someone that understands what it's like to be sick. Somebody that would treat me as a human being. Whether it be a man or a woman, it doesn't matter.

- an Aboriginal person living with HIV/AIDS

I'll want to be able to relate to someone, since I'm totally bed-ridden. If I am able to relate to people and talk to people, I would like to talk to people and share stories. I'd like things read to me or something done to occupy my mind, especially if my physical body is totally immobile. I wouldn't want to worry about whether I have to do my laundry or what I am going to eat. I don't want to dust!

- an Aboriginal person living with HIV/AIDS

I would want a person that was basically respectful of my space, very helpful, and understanding. I would like someone who has a real sensitivity to my needs. Someone who could basically do things without me actually having to tell them.

- an Aboriginal person living with HIV/AIDS

I would like a positive-thinking person. I wouldn't want someone who was always feeling pity for me. I don't want someone who is always depressed and bringing me down. It would be too heavy if I'm stuck in bed twenty-four hours a day, day after day. If I have to see this person again and again, if that's how they come across or if they're like, "Oh God, I have to do this again." If it's too much for them, then I wouldn't want them around.

- an Aboriginal person living with HIV/AIDS

At that point, I don't want to worry about little things because they're not important to me anymore. They wouldn't be a part of my life. I'd be at the final stages and I'm just waiting for my body to be overtaken. Once it takes my last source of livelihood, then my mental and spiritual side goes onto the universe.

If that's all I have left, that's what I have to relate to with other people around me. If they could be considerate of that and realize how I need to be related to, it's so powerful at that point. It's so much more meaningful, what they say to me and how they treat me. I'm totally strapped to that bed, and the care team is the only thing surrounding my aura, my spiritual self.

- an Aboriginal person living with HIV/AIDS

I would want a heck of a lot of understanding because it's one thing to love somebody and to see them through the illness process and the dying process, but it's also something to be able

to relate to an individual and to offer comfort and understanding. Not only to the situation but to the individual's attitude and lifestyle.

- an Aboriginal person living with HIV/AIDS

GOING HOME

There are more choices for the person who is dying, especially around where he chooses to be for his care. In today's world, there is plenty of traveling away from home. People move away from home to try and find jobs, get education, find excitement or even to leave unfriendly environments. Often, young people are put in the foster care system or adopted away from their communities.

When Aboriginal people think about dying, there seems to be a natural pull to want to be at home. Does he want to remain at his home? Is he away from home and want to go back to the place where he is originally from?

There can be an intimacy found in family and home settings that can't always be found in a hospital. Choosing to die at home may provide him with the opportunity to have more control over this stage of his life cycle. In having a choice over where he can go, he is able to have control during a time he is losing control over other areas. Perhaps he is losing the ability to get up and go for a walk. He could be losing the ability to eat a meal without vomiting. Pain may be stopping him from having a decent night's sleep.

While he may be losing different parts of his life, he still has control and can make choices around how he will die. One of those choices is whether or not he wants to go home.

When the time comes when I feel I'm getting closer to incapability of keeping up with the pace of work and having my mind sharp, then at that point I feel I would like to be close to my reserve and my relatives. I would like to spend some time with them, get to know them better and let them get to know me better as being HIV positive.

- an Aboriginal person living with HIV/AIDS

I also do a lot of work around birthing and to me, I just see palliative care and caring for people around the time of death, like, it's just another end of the spectrum. A lot of the issues are the same. I think it's really important in a lot of Aboriginal communities for people to be born in their communities and I think it's important for people to die in their communities. It's a tie to the community and to the land.

- an Aboriginal support person

If I were to die in the city, then my reserve could have my body shipped back there, where I would be buried in the reserve graveyard.

- an Aboriginal person living with HIV/AIDS

If I do get ahead a bit, I probably will make the changes gradually towards my reserve. As long as there is accessible support through a hospital when the time comes that I become totally bed-ridden.

- an Aboriginal person living with HIV/AIDS

I guess if someone was going to make a decision to go home, it would be a good idea in advance to check out support for that person and to do community education in advance. I think it would depend on who the

Nashine Ginwenimawazawin

community leaders were, that is always the key. If the person could get the support of the community leaders, whoever they are. They may be Elders or they may be associated with the church. It would be important to check in advance. Most of the health care workers are not overly homophobic or AIDSphobic but you can never predict how people will react. It would take a lot of courage for the first couple of people who do it.

Despite all these adverse conditions, we always see many examples of people being courageous and working for change in a community. It could be difficult but it would be good to plan in advance and get a support network. Get the support of the nursing station and the support of the band in advance.

- an Aboriginal support person

Well if need be, that I get so bad that I needed to go to the hospital, well then that's where I'd like to go. I'd prefer to stay at home. There's some things that you can't receive while you're at home.

- an Aboriginal person living with HIV/AIDS

I'd love that. Yeah. I would really like to stay at home because I think my family would constantly be around me. I guess if it really ever comes down to it, if anything ever really happens to me, I think they will be there.

- an Aboriginal person living with HIV/AIDS

I never liked being cared for in a hospital. I didn't think that was very good, seeing people who were cared for in a hospital. I don't see any....I never saw any improvements to anybody who was taken care of in a hospital.

I've seen improvements for people who were taken care of at home. People like in Casey House and places like that. Those are kind of like more private, more intimate places. The nurses at Casey House and the doctors at Casey House, they don't have a stigma attached to HIV and AIDS, like they do in other hospitals.

I'd prefer, myself, if possible, I would prefer to be taken care of at home. If that was possible, but in life, sometimes things are impossible. But, I would prefer to be taken care of at home.

- an Aboriginal person living with HIV/AIDS

It's common for Native people to want to go home to their environment. That's where we were born. When we were born, we inherited all this. We come from this environment, we inherited it all. That's why these people want that. It's a common factor with Native people, regardless of if they were born in the cities, they still inherited that place called home.

That's one of the issues that they didn't look at, even within this residential abuse, the idea of home. If you don't have a home, you're moving around and you don't feel safe. With Native people, a lot of tribes would move from settlement to settlement, but a lot of tribes didn't move. They stayed just within their own areas. We didn't move from here, way to the south. We couldn't handle it in that environment. We might have been hunters and gatherers, nomads, but we were nomadic just in the state of our own environment. That was significant and that was inherited to us.

Home, having a home, coming from that, that's part of the Native belief also. That we always have a place to go. That there's always a place there for us. Even urban Natives, they'll say that, too, "Where are you from?"

"Oh, I'm from Six Nations."

"Where are you from?"

"I'm from Blind River."

Even if they haven't lived there, they still have that inherited connection. It's like a cord, an invisible cord, that deep down within us, that's where we're from. It was so strong, the Native culture and still is strong. It's been interfered with and jerked around so much. It's still there with us, this bloodline. It'll come back, the thinking, the consciousness, the spiritual belief and the awareness of the environment.

- an Aboriginal Elder

CHALLENGES TO GOING HOME

Unfortunately, going home is not always easy. Some people have left home because there was violence or abuse and they simply don't want to go back. She may be unwanted or rejected from her community. It may seem as though a home environment won't be able to handle caring for her.

Although some people do want to go home to die, there is hesitation around whether this is possible. Are there enough resources? Has she been away from home for a very long time? Can the home community handle someone who has AIDS and is dying?

My reserve might not be at the stage of being able to take care of someone who has AIDS. They might not know some of the issues around AIDS or have a team set up to take care of someone. They would have to overcome all these prejudices and fears.

- an Aboriginal person living with HIV/AIDS

In an ideal world, she could go home to receive care and be surrounded by family and friends. The family and the community could come together to care for her and honor her during the rest of the time she has.

The reality is, going home may present many challenges for her. The following experiences tell of some of the challenges and concerns people living with HIV/AIDS and caregivers have around going home.

I haven't cared for people with advanced HIV and AIDS in northern settings but I know it's going to be a problem. I've cared for people with other advanced illnesses and often there's conflict. Some people wish strongly to stay in their community but they end up being forced out because there aren't the resources there for them to die in their community. I've had the situation where either family or health care workers fly in and decide they can no longer be cared for in that community. When I see that person, it's clear that they would have rather stayed in the community.

- an Aboriginal support person

The city has a lot of resources, so it would make more sense to me to stay here. So, I'd have to choose between the two. If I was to go home, I would need my community to accept that one of their community members is gay. One of their community members is dying of AIDS and that's no reflection on the community. It's not a negative thing. It's not something shameful. There is a lot of stereotyping and irresponsibility on the media's part that perpetuates the negative stigmas attached to this whole cycle.

- an Aboriginal person living with HIV/AIDS

I don't really know my community well enough right at this moment to say that they would have a (care)team. I really don't know what they have to offer right at this moment. If they did already have this set up and were willing to help out, that would be great.

- an Aboriginal person living with HIV/AIDS

I wouldn't go home. Mainly because there aren't the services available on the reserve, such as money to have people come in for respite care. There are a lot of things that have to happen on a reserve level first, in order for any kind of services to be available.

If I go back to the reserve, the mentality is still that AIDS isn't an Indian concern and that it's a gay disease. All the stereotypes are pretty prevalent.

- an Aboriginal person living with AIDS

One elderly gentleman had been sent out of his nursing station as he was having a lot of difficulty with his breathing and his heart. So, when he arrived by ambulance from the airport he was very combative, like he was fighting any kind of treatment. The consent was unclear at that time, but because he was having so much trouble with his breathing (people get confused when their oxygen gets low), I had to go ahead and treat him.

I was able to have a conversation with him later when it appeared that he was less confused. He still didn't want to leave his community. He was also an Oji-Cree speaker and it was a particular dialect that, luckily some of his family was in town, so they could come and translate. The translator on call at the hospital couldn't translate.

I didn't feel good about treating someone who possibly didn't want to be treated, especially an Elder. When you're working in Emergency and you don't know if they're able to think clearly or not because they're quite sick.

I went in and talked to him later. I said I understood that he wasn't all there (sic) and I didn't want to treat him against his wishes and he responded very positively to that. At first he was very angry and he wouldn't talk to me. The problem is his family and the nurses in his community decided to send him because they couldn't care for him in his community.

Later on, when he was less confused, I think he was expressing he was angry that he had to leave his community. He felt he was a community Elder and he didn't want to be in the hospital. I think people get afraid when they come to the hospital when they're old because they think they're going to die there. It's just a strong wish, I think, of some of the Elders to die at home, rather than die in the hospital.

- an Aboriginal support person

Nashine Ginwenimawazawin

There is still a lot of homophobia and HIV/AIDS-phobia. Especially from some of the communities that are very religious, people might be seen very negatively or blamed for their infection. People would also be very curious and there would be a lot of gossip about how they got it. If somebody was gay or an IV drug user, that kind of information would probably spread through the community very quickly.

We try and promote safer sex. There is a lot of sexually transmitted infections. If I was to go to one of the northern nursing stations and give a safer sex talk targeted at gay men or talk about clean needles targeted at people who were using IV drugs, I think I would be received fairly negatively. There are a lot of taboos of what we talk about and what we don't. I know that material has been sent to the nursing stations in the northern communities but I don't see it around that much.

The people who I've met in the north, who are having same-sex relationships, it is pretty tricky for them to reveal that. There is lots of trust issues, fear of judgement and fear of being rejected in one's home community. Then it is like, where do they go from there?

I think there are a lot of mental health issues attached to that too. For young gay people, I am aware that there are mental health problems arising from those kinds of stresses. So, where do I refer somebody who comes to me with those kinds of issues? In the city there would be a lot of great resources for this person, but they are not from the city and that's not where their ties are. They are going to be at high risk in the city but if they came out in their home communities it just wouldn't be accepted by a large number of people.

- an Aboriginal support person

I think it's a fallacy to say family is biological and blood. One of the things that we do is ask the individual, "Who is your family as defined by you? Who is it in an emergency situation, you would like me to contact? If you end up in jail, if you end up in the hospital, who is it?"

The sad part is 50% of our clients told us it is here. It's really heart wrenching for me. It just draws a tear. The reason why it's heart-wrenching is because we deal with 188 people, so that's about 90 people telling me, "I have no family."

Being a transgendered organization, people think our community is so small. 90 people, that's quite a huge portion of people.

It's important to find out who their friends are. That could be their family and to recognize that family is not biological. Family could be a lover. Family could be a sex-trade worker friend that they've had for ten or fifteen years and they've done drugs together.

Agencies that can go in and that have care teams and outreach workers. We do that a lot. We bring chocolate bars to our girls. We're not supposed to, but we do it! I mean, they're dying.

It's a hard process, but it's a process of life. For me, where I'm at with the dying process is to be there as a catalyst, to help that transition, "You are dying, your body is dying, your soul is going on. To be part of that is a huge honour. The honour for me is to ensure that you are

okay. You are pain-free, you are not afraid, you are ready and you are not alone in the transition from one world to the other.”

- an Aboriginal support person

MAKING CARE POSSIBLE



reating care, when there are challenges such as going home, is still possible. Most people are very helpful; however, there are barriers that can get in the way of what your team is trying to accomplish.

In order to meet the many challenges your care team will encounter, take the time to search around for different ways to make it happen. You will need flexibility to change the information you receive, so that it will suit his needs, his home and his community. For example, if you are working with a non-Native homecare worker, you may need to educate them about not being able to touch his bundle of medicines.

It is possible for reserves to become educated about HIV/AIDS, so that they will be able to care for a community member who is at home with AIDS. It is possible for them to work with outside resources, such as HIV/AIDS educators, Community Care Access Centres and Pain and Symptom Managers. By asking others for help, reserves can become educated and start taking over responsibility for the care of their own community members.

Yes, I do believe it is possible to set up a care team. For somebody to go home to their community and die there, that's their choice. I think it's possible. But, a lot of work has to be done for the person to be able to do that.

- an Aboriginal person living with HIV/AIDS

I think it is possible a reserve could respond to someone coming home with AIDS. Whether they will is the question. Whether or not they can do it quickly enough.

All that awareness and open-mindedness has to happen in order for them to provide the services. They're not going to provide services for something they don't think is a risk.

- an Aboriginal person living with HIV/AIDS

Reserves have their own type of structure. There has to be leeway. It has to fit in with the reserve lifestyle. They have ways of living and habits that are carried out on a daily basis. If they gave extra time to provide palliative care, it would have to fit into their whole schedule of living.

- an Aboriginal person living with HIV/AIDS

I think they would probably be able to set aside certain individuals who wanted to take care of someone. Sharing the workload, they would probably be able to do it. It might be a formal thing where they would have to be there on a regular basis. There has to be a sharing of the workload. There has to be a lot of education to those individuals because they don't live in the city life. They don't realize things that you take for granted in a large city because you don't have them on a reserve.

- an Aboriginal person living with HIV/AIDS

The band council could take the initiative to set up some sort of structure. They could deal with another organization who already has the experience around palliative care. They can bring in those structures into the reserve and ask whether or not, "Will this work for us? How can we adapt these structures to our way of living? Who can take on these roles and be flexible enough to adapt to the structure?"

It could come from another organization. There would probably have to be someone who is knowledgeable enough to answer a lot of questions from the band members who are offering their help. The band members could then transfer the education to other people, not just the core care team. Then, all the band members could help anyone with any disability on the reserve, whether it's AIDS or any other type of disability, they could adapt those methods and be able to help.

- an Aboriginal person living with HIV/AIDS

If they're isolated and something needs to get done, well they might have to bite the bullet and do it. It's really extraordinary what people will do. They might do the unexpected and pull through and everything will be fine.

We don't live in an ideal world. The point is you just have to deal with what you can. If you think you can, then try it.

- an Aboriginal person living with HIV/AIDS

You proceed to dispel some of those myths. People have fears of AIDS, just from touching somebody. You have to bring it out and start talking about it. There are a lot of people with compassion out there, they just need some help to break through a barrier. It just requires time and education.

- an Aboriginal Elder

HIV AND AIDS

AIDSphobia and Homophobia



IDSphobia generally means fear or dislike of someone who has AIDS. If someone is afraid of AIDS, they may be uncomfortable around a person living with AIDS. They may even be afraid to be near her.

Homophobia is a fear or dislike of a two-spirited person. This can come across in such ways as teasing, name-calling, ostracizing, silence, threats, and violence. Being judgemental of anyone, including two-spirited people, goes against Aboriginal belief systems, which tell us to care for all our relations.

Reserves have to be more educated to become more liberal-minded towards HIV and AIDS. I don't understand these things totally myself, let alone seeing how they can understand it.

I think they could adapt to a care team. As long as they feel they will be safe from AIDS that they can't pick it up, like through the air. If they know that it can only be passed by semen or blood and they take precautions, they should be fine.

- an Aboriginal person living with HIV/AIDS

There is plenty of AIDSphobia and homophobia, both on and off reserve. For you to be able to do your work on the care team, you may have to rely on the help of other people in your community. If AIDSphobia and homophobia exist with the people you are

turning to for help, it is going to be a barrier to your work.

There are many reasons why someone could be afraid of a person who is living with AIDS. Often, it is because they know very little about HIV/AIDS and how it is transmitted between people. Some people are afraid of death. If the person that is dying is very young, this may add to the fear.

When people are faced with something that scares them, a natural reaction is to deny that it exists. If something else forces them to realize that AIDS does exist, the next thing that often happens is to blame. If people are blaming and attacking an individual or a family, this is not caring for their community members. It also puts more stress on the care team, during a time when they need a lot of energy to provide good care.

Throughout the following quotations, people speak about their experience with why AIDSphobia and homophobia are found in our communities.

Elders and traditional people talk about caring for each other and having love motivate how we interact with people. This caring and love is a right for people with HIV/AIDS. Unfortunately, caring is not always the case because that fear gets in the way and comes across as AIDSphobia and homophobia.

A lot of people are afraid and wouldn't want to be on a care team. They think they might "get" it. They just don't know enough about it.

It is hard to watch somebody die. As Indian people, we've suffered so much grief and loss, collectively, with our history. The genocide agenda, the oppression, the Native spirituality going underground. I wasn't alive when that happened but I still feel the results of it. Even though I wasn't alive, I still feel it.

We have so many grief issues and abandonment in the cultural context that it's harder for us to have the capacity to take on something else, especially if you feel that you really don't have to.

- an Aboriginal person living with HIV/AIDS

In the wider community there is the whole concept of the "innocent victim." They're people who got it through transfusions or some kind of indirect way. They should have our sympathy. Anybody else who got it through sexual contact or through IV drugs, well, they brought it on themselves.

I don't think anybody would point fingers at somebody who was dying of lung cancer, who smoked all their lives. Or, somebody who had sugar diabetes and ate a diet that leads to sugar diabetes or had a sedentary lifestyle. I don't think there is that kind of blame or a guilt-trip attached to those diseases as there is attached to AIDS.

Historically, other epidemics, the community reaction is to blame a certain minority within society. When there was a Tuberculosis epidemic, a lot of people's reactions were, "That's because Aboriginal people are filthy people. They live in squalid conditions and they brought it on themselves. Stay away from them because they're spreading it to white populations."

There's stigmatization of a lot of people. In a way, it's trying to contain it, by blaming it on a certain segment of the population, "If you stay away from gay people, you won't get AIDS." or "If you stay away from promiscuous people then you won't get AIDS."

There's always someone to blame. It's the attitude, "Not in my back yard. We don't have them around here. If you stay away from Toronto, if you stay on the reserve, you're safe and you don't have to use condoms."

- an Aboriginal support person

AIDSphobia is from fear and ignorance. They don't know how the disease is passed. They're still at that stage in the far north where people haven't heard of the disease or have the most vague impressions that they may have seen on TV.

There is some literature out there produced by fundamentalist Christian organizations about HIV/AIDS. That's really scary. It's scare tactics and hate mongering. In small communities the Pentecostal churches and fundamentalist Christian churches are very, very powerful. A lot of them still dominate the community. At one time in my community the priest was like God. Jesus walking into the reserve himself. Everything he said, went. You can see this AIDSphobia being propagated by churches.

- an Aboriginal support person

I don't think Aboriginal leadership or the people elected to speak on behalf of Aboriginal people have responded in any way to HIV and AIDS. Very few leaders have made public statements and very few have listed it as a priority to deal with. Very few communities have taken action or provided educational sessions or brought the community together. There have been a few people but they have been people alone. Why is this? AIDSphobia and homophobia.

I think we are about ten years behind mainstream society in this epidemic and the problem is that HIV and AIDS were first linked with gay people. That has really not gone away. In our communities, particularly the isolated ones, people feel if they are not gay or not an injection drug user, they won't get it. What it focuses on, is people who have traditionally been seen to have HIV and AIDS, as opposed to the activities that facilitate the transmission of HIV.

Once you start looking at people, you get into the blame mode and the fear and panic mode. Our communities over the past two hundred years have been under a foreign system and foreign beliefs have been imposed on us. Our traditional beliefs and responsibilities to our people have fallen by the wayside because we have adopted this sort of white Anglo Christian attitude about all sorts of things...health, sexuality, community responsibility, families and the role of men and women. All of these foreign values mean that we have adopted some of the worst aspects of the foreign culture and we use those attitudes and behaviours to deal with HIV and AIDS.

HIV is going to hit our communities mainly through sexual activities. We have a lot of problems talking about sex because of Christianity, because of missionaries and priests, the residential school system and the abuses which took place there, the fostering and adoption of

Nashine Ginwenimawazawin

our children in non-Aboriginal homes through the intervention of Children's Aid Societies. We have lost at least two generations of parents. We don't know how to deal with each other intergenerationally, as men and women, or with each other in terms of sexuality.

We have huge obstacles of AIDSphobia and homophobia in our communities and Aboriginal leadership comes from those communities. They live the same way, were brought up the same way and have the same experiences as did their parents. This whole ugly set of attitudes is forced upon us and it is not traditional.

In the past, when people were ill they were cared for: mentally, spiritually, physically, and emotionally. We had healers, we had families taking on responsibilities, children were not orphaned or abandoned. Everybody knew what they should do and they contributed. Everybody contributed to the community's health.

Now we have fractured, discordant, broken communities who reject people with HIV and AIDS because they think it has to do with sex or they think it has to do with homosexuality. This was not a problem before the Europeans arrived and now it is a huge problem. We have two-spirited people accused of spreading AIDS and people with HIV and AIDS being accused of being two-spirited. We have attitudes about sex not being natural and healthy, the way it was before. We have the post-Christian attitudes that sex is sinful and dirty. We carry this baggage because of the last couple of hundred years. These attitudes don't belong to us and we should send them back where they came from.

I saw a wonderful button the other day. It said, "Your God. Your Rules. You go to hell." I thought it was wonderful because it expressed how we as Aboriginal people are responding to things these days, for example education, justice, and health.

We talk about the imposition of foreign values but we keep grabbing little bits of them as if they mean something to our culture. We bring these foreign values to ours, I attempt to return to traditional practices, then we say we cannot question these things because they are traditional. We have people who don't even understand how Christianized they have been and they adopt these values like confession and redemption. People wave around Sweetgrass as if it were incense being waved around by a priest in a Catholic Church.

We have all of these things happening and we have Aboriginal leadership responding to issues the same way. They come from these communities and have the same experience. So, their response to HIV and AIDS is of necessity, ignorant, panic ridden and full of fear. They don't know what they're talking about. They have no idea and no one is helping them understand anything except a few Aboriginal AIDS service organizations who are marginalized, understaffed, under-resourced and talking at brick walls constantly. Nobody wants to listen.

We have AIDS educators being told they can't tell young people or kids about HIV if they talk frankly about sex. Where does that come from? If you look at how our communities are set up, how closely family units lived in longhouses and tipis, you know children were aware that sex occurred quite naturally. The idea that a young person or child did not know about sex is ridiculous.

So now, we are saying that because this Euro-Canadian based community has imposed these foreign values upon us, our children should not know about sex or should not know about

Nashine Ginwenimawazawin

HIV or how it is transmitted and that we cannot talk to these young people. This is completely stupid and is based on an erroneous understanding of our own culture.

- an Aboriginal support person

Somebody that has AIDS or is HIV positive, there are all those stigmas, as well as, "Obviously the person deserved it or wasn't careful enough," or "Oh, that person must have done something really wrong." There's a lot of that negative stigma.

So, somebody going back to a reserve, whether they're two-spirited or not, if they're HIV positive, they're going to be assumed to be gay anyway because of the stigma that it's a gay disease.

- an Aboriginal person living with HIV/AIDS

HIV and AIDS can seem very complicated. There is a lot of information on HIV and AIDS, and not all of it is accurate or up-to-date.

Although the Aboriginal community has produced its own written material and there are Aboriginal HIV/AIDS educators throughout the province, AIDSphobia is still around.

One of the ways AIDSphobia is displayed is through denial. There is denial that there are people with HIV or AIDS on reserves. There is denial that there are people in Native communities that are infected. People use denial to avoid something that they are afraid to deal with. It is much easier to try and separate yourself from a threat by saying, "AIDS is a gay disease" or "AIDS is only in the city." There is not much caring and sharing displayed when a person who is dying and in need of help is threatened and thrown off a reserve.

There are some classic cases we can talk about many times. It was like a huge vendetta against the entire family on certain reserves when one of the family members came home to die and has AIDS. Rocks were thrown through windows, they had threats and people turn their backs on the entire family.

It got really, really ugly. Then, the band BCR'd (passed a band council resolution to banish them) people off the reserve because they thought they were a threat to the community.

- an Aboriginal support person

If someone is turned away from a reserve or if they are threatened until they are forced to leave, clearly they will then die away from the reserve, away from home.

It would be extremely unfortunate. When we're born, there are usually people around. When we're born into the Spirit World, we need to have people there, too, to support that process.

When you come into the world, it's like a re-integration with the world. When we go, the different systems fall apart in order for Spirit to get free. It's very important to have somebody there, somebody that you can trust. It's very important to be relaxed, it's not good to die in a place of fear.

How much better it would be, to be in a place of peacefulness and comfort, where you know someone and they're holding your hand.

WHAT IS HIV AND AIDS?

H Taking time to understand HIV and AIDS plays a part in removing fear. You may already have some knowledge about HIV and AIDS, but you could find you have to educate others because you need their help.

HIV STANDS FOR HUMAN IMMUNODEFICIENCY VIRUS

The virus attacks and destroys the immune system. When HIV is attacking the immune system it becomes weakened. It begins to have a hard time fighting off different illnesses. As the immune system becomes weaker, more illnesses enter the body. The immune system loses its ability to fight infections that lead to sickness and death.

There are different illnesses called *opportunistic infections*. Some of these opportunistic infections have been put into a category of “AIDS defining” and when someone who is HIV positive becomes diagnosed with one or more “AIDS defining” opportunistic infections they are diagnosed with AIDS.

AIDS STANDS FOR ACQUIRED IMMUNODEFICIENCY SYNDROME.

Acquired

- ◆ means the disease is inherited or genetic.

Immuno

- ◆ is the body’s immune system, which protects against infection and disease.

Deficiency

- ◆ means the immune system is not working properly.

Syndrome

- ◆ means that AIDS includes a collection of symptoms or diseases.

When I am looking at health issues in our community, it is always important to look at the big picture. In palliative care it is interesting because the scope is huge when you are dealing with HIV and AIDS. We don’t have a cure, so the focus is quality of life from time of infection. It is important to look at the whole continuum in terms of life cycle, from child to youth to adult to parent to grandparent to Elder.

If I’m dealing with one particular client, it would be important for me to look at their whole life within that perspective. They might have to accelerate when they are going through those stages of life. It is important to look at their family and their community if we are planning a strategy.

How can we provide education, for example, AIDS 101, in a community? It will be important to get the information to all of these groups, so we would have to do more than one thing. The Elders may need their information in a different way so it would more effective. It may be good to have a couple of key informants who are grandparents in the community who would go out and spread the message.

If you just had a community speak, it might only meet the needs of the young adults who come. Then, how do you get the message out to the children in the schools? It is important to look at them in the context of their communities and all of the groups within the community.

- an Aboriginal support person

People that have AIDS-phobia often have more personal judgements than correct information. If you are knowledgeable about AIDS, you may be able to explain to them that their fears are unfounded. Through time, it becomes possible that they could become someone who offers you support in your role as a care team member.

You may also recognize that there are people who simply don't have an open mind. Someone who is AIDS-phobic will stick to their judgemental view. Your time and energy is important. If you are putting a lot of effort into providing palliative care for someone, you may decide to accept that some people simply have too much fear.

How is HIV transmitted (passed from one person to another)?

The priority is education, letting people know the risks. It's not just a white man's disease, it's not just a gay disease. If you have sex, you can get it. If you do IV drugs, steroids, you can get it. If you tattoo unsafely, you can get it. They have to realize it's not a disease that discriminates. I guess it kind of also forces us not to discriminate. So, maybe that's a good thing.

- an Aboriginal person living with HIV/AIDS

There are specific ways someone can pass HIV to someone else. HIV is very fragile. It can only live a few seconds once it has been exposed to air.

The following are the ways a person may become infected with HIV:

- ◆ Anal and vaginal intercourse without the use of a condom
- ◆ Sharing hypodermic needles and syringes
- ◆ Transfusion of blood or blood products that have HIV
- ◆ Through child-birth or breast-feeding
- ◆ Sharing contaminated instruments from tattooing or ritual scarring

HIV cannot be passed:

- ◆ Through coughing or sneezing
- ◆ By sharing dishes or eating utensils
- ◆ By insects
- ◆ Through food or water
- ◆ Kissing
- ◆ Hugging
- ◆ Donating blood

A LITTLE BIT OF BIOLOGY

The Immune System



Everyone has an immune system. The immune system is what protects us against different infections. For example, when you have a cold, the immune system goes to work to make this cold leave the body.

The immune system is made up of blood cells. There are two types of blood cells; red blood cells and white blood cells. The white blood cell directly affects the immune system. White cells defend the body from foreign molecules called *antigens*.

What happens if the body is invaded by an antigen?

- ◆ The immune system produces *antibodies* when an antigen is in the body. The antibodies fight the antigen.

Lymphocytes are one kind of white blood cell. There are two different lymphocytes, B-cells, and T-cells. B-cells are the ones that produce antibodies when an antigen (for example, bacteria) invades the body. The antibody attaches itself to the antigen and neutralizes it, allowing the rest of the immune system to destroy it.

The T-cell is an assistant to the B-cell. It is used when it has to fight a stronger invader such as a virus or a poison.

What Do T-Cells Do?

There are different kinds of T-cells, each with a specific task.

T-HELPER CELLS

- ◆ they help the B-cell attach itself to antigens and destroy them. T-helper cells also activate other T-cells, such as those that fight cancers.

T-SUPPRESSOR CELLS

- ◆ they stop the antigen from reproducing itself.

T-KILLER CELLS

- ◆ they look for and destroy antigens that may have been missed by the rest of the immune system.

THE IMMUNE SYSTEM AND HIV



Here is a nerve center in a cell, called a nucleus. A virus takes over the nucleus of cells. Viruses can't reproduce without a host cell.

When the nucleus is taken over by HIV, it makes the cell stop whatever it was doing. It directs the nucleus to start replicating more viruses. The cell is then destroyed and it releases more particles of HIV into the body.

The human cell understands DNA. DNA has codes for the cell to reproduce. HIV has RNA instead of DNA. Cells usually can't understand viruses with RNA, because they are used to reading DNA.

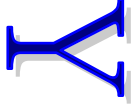
HIV can grow because it has something called *reverse transcriptase*. Reverse transcriptase is a chemical that translates RNA into DNA. It tricks the cell into thinking it is reading DNA and allows the virus to integrate with the cell. The cell begins to reproduce the virus and eventually, it is destroyed.

Why is HIV so Damaging?

HIV has a protein that fits together or interlocks, with a protein in T-cells. Since the HIV fits together with T-cells, it is a direct attack on the cells that are supposed to be fighting infections. It directly invades and weakens the immune system.

In addition, HIV can also directly infect cells of the brain, lungs, and intestinal tract.

A LAST NOTE

 You may be in a position where an Aboriginal person living with AIDS has asked for your help. Having made that decision, you may have asked him how he wants to be treated in a respectful way. Where he will be cared for could be due to circumstances or a definite decision. You may have started talking with him about how he wants to form his care team.

You also may know you could meet people who are afraid of AIDS. That awareness is the starting point for creating responses to work through that AIDS-phobia.

As you will find in the next chapter, these decisions are only just the beginning of his care team journey.

CARE TEAMS

Your Care Team

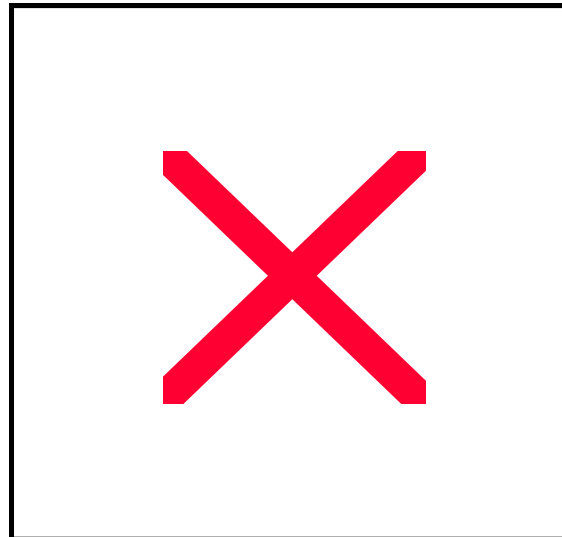
A care team is like a spider web. A healthy person would have the time and energy to be able to work on building up the strands of their spider web. The person you are caring for won't be able to make that possible. She is the center of the web, and while she is the one who will determine what the web will look like, it is the care team that will build the strands.

From the center of the web, she expresses to the care team members what her needs are. The care team members take direction from her and work towards meeting the needs that build the web. The strands of that web connect, weave together, and work with each other to create a care team circle that will surround and support her.

The following stories and experiences are not definitions of why Aboriginal people care for one another as each community and nation has different teachings and different reasons as to why they take care of one another. Each care team will create and define its own unique reasons for why they want to help. Ideas found in these stories may offer a starting point for this process.

When you are trying to build the strands of the web, understanding why you are doing this work will give you purpose. When you have meaning behind what you are doing, your strands get built with the strength that is needed to keep your care team together. You will also not forget to work on this small strand over here or that small strand over there.

While the make-up of all care teams will be unique, here are a few suggestions about standard care team practices. If you already have a firm idea about what direction your team will be taking or the types of care you wish to contribute, you may want to glance over this section or skip it altogether.



Clearly, you want to help her during this time of her life. The following stories may be a starting point for you, a place where you can think about what things will make up the webbing of your care team.

Nashine Ginwenimawazawin

It's always been our way to look after our own. That's how we survived as a people. We don't delegate, we don't categorize our community the same way mainstream society does. Everything has to live together. When the crisis happens, everything does work together.

Sure, the Chief might take a leadership role or if it's something to deal with a crisis situation, then the Family Support Worker kicks in and takes a leadership role.

Depending on the situation, the community almost instinctively, reacts appropriately. Where that's learned, I'm not sure. Who cares? The point is, that it works.

- an Aboriginal person living with HIV/AIDS

Ideally, in any landmark passage of life, it would be a special story that is unique to each person. It would be something that the family would have to hang onto and it would be reflective of the individual and what kind of person they were and what their community context was.

I guess that is where the choices come. That is how we make our own history. We need these stories. We are not listening yet to the stories of the people who are dying. We need to start listening and hear what they have to tell us.

As a caregiver, I am trying to help the person tell the story that they want. I have had patients tell me that they just want to die with dignity and they trust me to do that. That is why it is important to know who you are caring for and what their wishes might be. Then you know this relationship, and the process starts unfolding and that is the process as it should be.

That is where there is a common ground between bio-medicine and traditional healing. As care givers, you are there witnessing the unfolding of this passage as it should be and supporting this person the way they need to be supported.

Most of the time, doctors are providing physical support, but they have other needs such as emotional, mental and spiritual support. That is why it is so important that people have some kind of cultural celebration or ritual. Even as you are providing the physical care, that becomes apparent.

We also need to work on providing people options in support, spiritually and culturally. Especially with these displacement issues on reserve and in the cities, people might not have these choices or may not be accessing them. That is a big loss.

Death was meant to be a time of spirit and a community and family event. In hospitals, it seems like this is often missing or hidden. No matter how much we try and intervene with this process of death, it is going to unfold. The spirit in the end, will always be present. It is important to try and recognize and support and celebrate that. It doesn't have to be only a change and a loss. It is also a birth.

- an Aboriginal support person

That's the capsule, the foundation for palliative care work and that is to empower the person. That's why we talk about all these other things, creating supportive space.

It's always been our way to look after our own. That's how we survived as a people. We don't delegate, we don't categorize our community the same way mainstream society does. Everything has to live together.

- an Aboriginal person living with HIV/AIDS

If you think about it logically, more than any other portion of their life, they need to be empowered to deal with their spirit. Not only their spirit, but emotional stuff, they have carried enough.

The empowerment of the terminally ill person is the bottom line of the whole

program. Empowerment in terms of their physical arrangements or empowerment by getting rid of old hurt and trauma or empowerment for them to ask for what they need for spiritual welfare, what they need to help them there.

- an Aboriginal Elder

I just basically winged it. I had experience with being on a care team, previously. I kind of just flew by the seat of my pants. I just kind of picked it up as I went along. I had the help of two other care team members who were pretty knowledgeable about it.

I was his roommate for many years. It just kind of happened. I was there and I just felt he needed my help. He was a long-standing friend of mine. It was my responsibility I felt I had to fulfill. Nobody else was really coming forward. I really had no choice in the matter. I just felt it was my responsibility to help him out.

- an Aboriginal support person

The body will be left behind. It is the thing that has come from the Creator and is returning to the Creator. Whatever we do to help us return in a good way, in a peaceful way, we're also looking after the Earthly part of the person. Their emotions and their physical body and even their mental experience. That is the part that is actually here, being left in this plane. To have the Spirit go, that's why so many traditions have their ceremonies and way of comforting that person, to help them go in a good way.

When there is someone there who cares, going in to rejoin the Spirit World, it's now made easy. If there's any way that any kind of environment was created or whether that's ritual or whether that's just a peaceful environment. A harmonious environment and not an anxiety-ridden environment.

- an Aboriginal Elder

One thing I found was that nobody had the opinion, "This is right."

They were more like, "I'm going to do this because I want something in the end out of this. I would like their car. I want that picture over there."

It wasn't just one or two people. It was all of them. I was really taken a-back from that.

I thought, "Well, you're here because you care about somebody. But then again, you're also here because you want physical, materialistic shit."

That's not cultural. What happened with the cultural, "No materials, live like this and be like that?" It's all changed. It's not like that.

- an Aboriginal support person

I think there's that kind of relinquishment for that person, to the honor of their own path, even though we could do all we can at this earthly level to make it comfortable and harmonious. Whether it's a matter of giving them some food that's appealing to them or making sure that they're comfortable. Whatever space they're at, making sure that it's pleasant, whether they have music or whatever.

But then releasing them to walk in a good way. Just making it okay for them to find somebody that they can talk to. I think that's the most important part of a dying person. Creating for them a place where they can talk things out, if they wish. Which, they cannot talk to their immediate family or even the care team group (about).

Getting them the feeling where they can be perfectly frank with someone. There are people who have that ability to make it safe. Some palliative care workers have that ability to make it safe for that person to speak what is inside, usually some old hurts that they haven't dealt with. That would be a really important aspect for palliative care workers to know, "How can we make it safe for that person and less anxious?"

- an Aboriginal Elder

What are the Needs?

Having given some thought to why your care team has come together, you now have to look at finding out what his needs are. Naturally, he is at the center of this spider web and only he can design what he wants done to it. When you ask him what his needs are, you will learn what needs to be done and how many people you need to do it. There are certain questions you can ask him to help him convey to you the type of care he wants from you (or the care team). Some of them include;

WHAT TYPE OF HELP DO YOU WANT FROM THE CARE TEAM?

- personal care (bathing, grooming, toileting)
- housework
- pet care
- hands-on medical care (dispensing medications, etc.)
- errands (shopping, picking up prescriptions, etc.)
- buddy (social/emotional support)
- food preparation

WHAT ARE THE MEDICAL NEEDS?

- Are they bed ridden or have limited movement?
- Do they require someone to help them with taking medications?
- Are there any medical conditions, other than HIV/AIDS, that the team needs to be aware of? (ex. active TB)
- Do they have any allergies to medications?

DO YOU NEED HELP IN GETTING MEALS? IF SO;

- Do you have any allergies (lactose intolerance, etc.)?
- Does Meals on Wheels provide any of them?
- Do you need/access any food banks?
- Do you have problems drinking or eating (thrush, etc.)?
- What are your likes and dislikes (vegetarian, traditional diet)?

DO YOU HAVE YOUR LEGAL AFFAIRS IN ORDER? (GET COPIES IF POSSIBLE)

- Do you have a (living) will?
- Is there a power of attorney?
- Have funeral arrangements been made?
- Is someone looking after finances (insurance policies)?

Someone who can communicate very well with him would be the ideal person to work with him when he is expressing what he wants from the care team. This can be anyone involved in his life: a partner, family member, friend, Elder, Senator (Metis Elder), health care worker, HIV/AIDS support worker.

If he has only a few needs, your care team may be on an on-call basis. Perhaps he only needs someone to come by every now and then to take him outside for visits. He may simply want help with laundry and shopping.

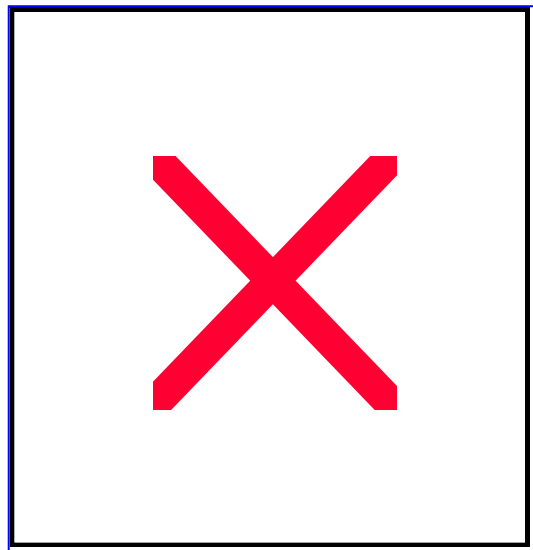
I would like someone who could delegate the tasks that need to be done. Then the team could just do them. Once they're done, fine, that would be it.

- an Aboriginal person living with HIV/AIDS

He could also be in need of a lot of people to work with him. This could require someone to organize all the different strands of the care team tasks.

These stories are not meant to apply to every aspect of your situation. The ideas found within them are meant to be taken and reshaped to fit what his care team needs. Does he want someone to delegate his needs? Is spirituality important to him? Does he want someone to change his diapers? The answers to these questions and many others are essential in creating his design of what the care team should be.

The Information sheet included here is merely a draft of some of the things that you may need, some may apply to your situation, while others may not. This list is used to not only help in setting up a new care team, but also as an information sheet for the care team log book. All the information that is gathered using this form may, at some time, be useful, especially if the person you are caring for develops any type of cognitive disorders (dementia). Some of the questions may seem too personal to ask someone, but if you explain that it, like everything else that is heard or seen is completely confidential and only in their best interest. If the person is extremely resistant, then respect their choice and have them fill out only the section(s) they are comfortable with.



INFORMATION LIST

Personal Information:

FULL NAME: _____ DATE OF BIRTH: / /

ADDRESS: _____ (street name)
_____ (apt. #/postal code)
_____ (apt. entrance code)

TELEPHONE NUMBER: _____
CALL ANSWER PHONE
NUMBER & PASSWORD _____

Identification Number's:

STATUS CARD NUMBER: _____

HEALTH CARD NUMBER: _____

Emergency Contacts:

NEXT OF KIN: _____ (name)
_____ (phone #)

OTHER CONTACTS: _____ (name)
_____ (phone #)
_____ (name)
_____ (phone #)

Doctors

FAMILY DOCTOR: _____ (name)
_____ (address)
_____ (phone #)

SPECIALIST(S) _____ (name)
_____ (address)
_____ (phone #)

INFORMATION LIST

Page 2

Care Team Members Phone Numbers:

NAME:

PHONE NUMBER:

Medications:

DRUG NAME

DOSAGE

DETAILS

Foods:

LIKES:

DISLIKES:

Other Agencies Involved: (ex. Homecare)

AGENCY NAME:

PHONE # & CONTACT PERSON:

Nashine Ginwenimawazawin

The specific mechanics, like moving, we just did what we had to do. We didn't receive any specific training or have a manual. If he needed his Depends changed, we had to do it. No one else would.

My role, I think it was basically emotional support for him. He needed to have me around because he was used to me. He felt very comfortable with me. It was also to help him out, financially. There was no way, financially, he could have done it on his own. He had my income, as well as his in order to make ends meet.

- an Aboriginal support person

Culture changes and evolves. It's important to know that some people will choose to include ceremonies. Maybe Sweatlodge or maybe they want to go Sundance. Those kinds of things have to be included if that's what the person wants.

It would have to be a case-by-case type of scenario because each person has a different way of doing things. You may be consulting with different Elders from different areas with different ways of doing things. Each community has diverse ways of doing things.

You can't really standardize a "how-to." It is important to acknowledge that spirituality is an option and to ensure the opportunity exists. Somebody on the care team should have that type of background and knowledge and can support them. They can do the legwork needed, like gathering medicines or tobacco.

- an Aboriginal person living with HIV/AIDS

The living conditions are of primary importance. Whether they have sanitary water, whether they are able to keep living areas clean. I'm talking about beds, especially in a palliative situation. It's important that they be clean, there's nothing worse than being sick and dirty.

- an Aboriginal support person

If someone was afraid to be alone at night, most of the time that would be seen as one of their needs and that would be arranged. If there weren't someone available the staff would make a special effort for that person or if there are resources in the community, we would work on planning for that.

- an Aboriginal support person

The principles, in terms of palliative care, is the continuity of care issue. Continuous care providers. That is a problem almost in any Aboriginal community, at least for physicians. We have a high turnover in the Northern communities and when I worked in the city, there was a high turnover of providers there as well.

There are certain places in medical care where it's real important to build a trust relationship with your care providers. Often, people have confusing or lengthy histories. I think just having one or two care providers that a person knows can go a long way in making a person feel safer and better.

Some of the stuff that would have to be talked about are things like Moon time, if a person is a Medicine Person, Pipe Carrier, Drum Carrier or Bundle Carrier.

You'll have to talk about picking somebody's stuff up when you are cleaning or moving it around. Somebody on the care team would have to be aware of that.

- an Aboriginal person living with HIV/AIDS

Nashine Ginwenimawazawin

That would mean having palliative care workers in the fly-in communities. There would need to be at least one person who was a Registered Nurse and the other nurses willing to pitch in with the shift work. In reality, if you're working forty-hour weeks, you'd need at least three people to provide twenty-four hour care.

The other thing is options. That's the other principle. It is really important that people have choice so that they can self-determine what the end of their life is going to be (like). There are a lot of choices that should be available. Choice of where to be, if they want to be in their home communities or if they want to be in the city. If they want to be in either of those settings, do they want to be in the hospital or be at home. Who their providers are. If they want biomedical providers or if they want traditional healers or a combination of both. Those things change, too. It's constant decision-making.

That's where the trust issues come in. What I would try to do as a care provider is understand where a person is with those things in advance, because later on it's going to be harder for them to communicate to me what their choices are.

It's tiring for the person who's already ill to make these constant decisions or to have to constantly be informed, usually about another secondary infection that they have. I would like to inform my patients, but that can be pretty horrible every day to have me come in and have more bad news. I think the choices would be important.

What's happening right now is neither of those things. There's not continuity of care and there's no choice for people with advanced HIV/AIDS. There isn't the resources and the knowledge of even the palliative care principles.

- an Aboriginal support person

If you can sort of nail their spirit when you're talking to them, so that they see, hear, feel what you're saying, it's very important for this person to be able to walk this journey in their own way. In their own power, making their own decisions. This is all that's left to them at this point.

You have to do it in as graphic a way as they can understand it. Their body is falling apart. They're going through all this pain and suffering. But, their mental capacity is going to be strong and their spiritual capacity and their emotional capacity is still there.

Are we willing to give them an opportunity to walk in that way for this next chapter?

- an Aboriginal support person

When it comes to stopping medication, ideally, you would try to leave that decision with the person. Sometimes, it is just not comfortable for someone to take their medications. When people are very weak they often cannot take their medications by mouth anymore. If they had a bad yeast infection in their throat, it may be too painful. Then, they may be getting medications intravenously.

Some of those medications might have side effects, so you are always weighing it. Some of the pills are very big, for example, a calcium supplement. It might not be that crucial in the last couple of days of someone's life, but it may be important to keep on Septra to keep PCP away.

So, we go through the medications with the person. Maybe the person is saying "That's enough, I've suffered enough now." It would be mean prolonging their suffering if they are ready to move to the next stage. You wouldn't want to be giving them antibiotics or be actively treating an infection. This decision is made in coordination with the person and their family. These are different stages and so we shift our decision-making. Any medication is an intervention, and palliative care is about balancing interventions.

- an Aboriginal support person

I guess the thing about caring for people with advanced HIV and AIDS is that things could change pretty quickly. Most of the time there are different levels of palliative care decision-making. Hopefully people would already decide in advance that they would want all acute interventions and they'd want everything done.

The next level of decision-making might be they just want reversible things treated. If they have *Pneumocystis pneumonia*, they would want it treated. If they had a Kaposi's sarcoma tumor in their abdomen, they wouldn't want to have an operation to have that taken out.

Then the next stage might be if their hearts stopped beating, they wouldn't want to have a full resuscitation.

The next level might be that they don't want their infections treated at all, they just want to have pain management. You try to get a feel for where your patient's at.

- an Aboriginal support person

If I was to get so sick that I actually died, I wouldn't want to be resuscitated (or else, I'd kill them)! I died! Let me die. Do you want to prolong the agony?

When you look at people that are dying of AIDS or people that have died, they get all skinny and their faces sink in. They're always in pain or they're on so much medication that they're flying way off on different tangents or have no idea what's going on. Why would you want to keep somebody in that state? If they died, then let them go! I think it's the selfishness, keeping that person alive. It's certainly not benefiting the person that's dying.

- an Aboriginal person living with HIV/AIDS

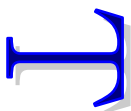
That was just my choice. I guess, well there was one gentleman on our First Nation here, who was diagnosed with full-blown AIDS. I seen some of the things that he went through, taking medication. It just sort of turned me away from it.

I'm not one to take pills. I have a really hard time taking them. My stomach is weak.

Once I started to go downhill, my T4 counts went down quite a bit. I talked with my family about it. We decided that maybe we should try it.

- an Aboriginal person living with HIV/AIDS

DECISIONS: IT'S NOT ALWAYS EASY



he emphasis of palliative care is to have the person who is dying make decisions about their own life. This could happen if we lived in an ideal world; however, we don't live in an ideal world. There are many challenges that could stand in the way of her decision making.

The reality is, she may not be able to make or be interested in making decisions. Decision-making is a skill that takes time to develop. It can't be assumed that everyone has had the opportunity to learn decision-making skills.

She may have experienced abuse, where other people have controlled her life. If she has been abused it will probably affect her self-esteem. If she doesn't believe she deserves good things, she may not want to make the decisions that will benefit her, such as asking for help from an Elder.

If she has lived a lot of her life on the streets, healthy decision making may not have been a big priority when her focus was surviving minute-to-minute. Perhaps she was in prison, where she would have been told when to wake up, when to go to sleep, when to eat, when to Sweat, where she can and cannot go and how she should be living her life. If she leaves prison and suddenly has to make all these decisions, the stress could be very overwhelming.

She may make decisions that you, as a care team member, may not agree with. What if she

I think it's important that the individual have somebody who knows them well around them. Are they able to make the necessary decisions? I think it's important for that person to know the decisions.

were to reject traditional medications and only take Euro-western medications? What if she rejected Euro-western medications for Traditional medicines? She may decide she doesn't want to take any medication at all.

I think there's some responsibility, obligation or friendship, to find out what can be done. If an individual doesn't see to their problems for whatever reason, I think people may have to take the initiative to help the person. That might cause a bit of controversy because there's a whole thing about making decisions for somebody else, kind of overstepping the boundaries.

How will you be able to respond if she is using IV drugs, such as heroin or cocaine? When traditional beliefs are that you don't abuse yourself, what do you do if she is abusing substances? The behaviours that come from using drugs or alcohol may also present some challenges for your care team. Could you put your beliefs aside and continue to provide her with care?

- an Aboriginal person living with HIV/AIDS

Our Elders speak about being non-judgemental. Often, you will hear people describing themselves as non-judgemental, yet their behaviour doesn't agree with this claim. Putting aside your personal beliefs and still providing care under difficult circumstances may be something your care team will have to look at. You may want to talk about defining a line where you provide non-judgemental care and where you are taking advantage of her vulnerability to try and influence her.

There is a value system of non-interference that is a natural belief in some communities. Non-interference is about restraining yourself from trying to convince her to do something. Non-interference includes respecting her independence and individuality.

Nashine Ginwenimawazawin

When one of the most important things is to make sure she is in control of the decisions affecting her life, what do you do when decision-making is a challenge for her?

If someone rejected mainstream medicine altogether, I would hopefully catch them before they made a decision. I would remind them of what the options are and what the consequences are. If they still want to do it, then essentially, it's up to them.

Personally, I might not agree with it. If I was on a care team and I couldn't come to terms with the decision, I'd either have to leave or come to terms with it. I think it's up to the individual.

- an Aboriginal person living with HIV/AIDS

If, as happens to so many people, they become really clear about things, then the care team will just have to go with that. It is always respecting their right to make decisions.

To us, not good decisions, or not sensible decisions, I think an interesting empowerment is that there is a place on non-intervening, if it's going to take away some of that power.

Again, that is part of the Aboriginal tradition of non-interference. That's a very valuable tradition with people. Sometimes, again, we need that wisdom of prayer, to know where we're going to intervene.

The Aboriginal tradition of non-interference is a very strong one. I think it's a good one that affirms the sovereignty of that person. Even if they're in bad shape, they still have that sovereignty.

- an Aboriginal Elder

One situation, this guy had an advanced lung disease and the nurse and the community was getting exhausted from caring for him. He wanted to stay at home. It was an irreversible condition. He refused to go to the nursing station to get a chest x-ray. I mean, ideally, if we're treating him as an acute illness, I'd need that information but those were his choices. In theory with palliative care, people should have these choices. He refused those things, so his family had to sign the consent to refuse treatment.

In palliative care it's okay to refuse treatment. We go with the person, but I think the other issue was I think there wasn't the support for this person to be at home. I think that's where the physician can sometimes be helpful. I think the physician is more used to seeing people that are sicker. If I had been next door to the patient I could have gone over in the middle of the night and said, "Fine, I'm not seeing things changing here."

I think one of the major ideas I would suggest is to allow that person to be autonomous within the framework of their illness. One of the first things that people start losing is a sense of power. A helplessness. If we can't give them carriage of their own illness, then we are taking from them the last place of power they have to make a decision.

- an Aboriginal Elder

If he wanted to be cured or it was important that he was receiving every intervention, then it would be important to have a chest x-ray. If he's choosing to be at home and knows that in his choosing palliative care, it's okay to just give him antibiotics at home or not give him antibiotics at all, if that is what he and his family choose to do. I would have been there to see the patient and kind of reassure everybody that it was okay. A lot of the time that is the role of the physician in palliative care.

- an Aboriginal support person

On the surface it looks like they're lost, they can't make a decision about anything. If that's the condition they live in, there is a place where you offer. I think most of all, when the love comes through the care person, anybody in any condition can recognize that. They can recognize that feeling that this person really loves and cares for them.

If I don't have the skills to articulate something or the thinking processes to go with it, it's just not there. At that point in time all that would have to happen is to give love and support in a way that that person can feel loved and cared for. The actual technical or mechanical things that have to get sorted, if they're not forthcoming, they're not forthcoming, period.

- an Aboriginal Elder

I know that people get to the point where sometimes you have to say the same thing again and again, before it starts to sink in. Sometimes they're so fired up with their own thoughts about it but it's a long way to go to a place to say, "The honorable thing, the respectful thing to do is to let this person be, so they can make their own decisions." I'm not saying it happens instantly but it would have to be repeated like a broken record.

The other part of that is for the dying person to know that their care givers and the people around them have this view about non-interference. They have this view about empowerment.

Even if some member in the family group doesn't have that, it shouldn't unbalance because you can help these people understand the empowerment process. Even if this one doesn't, okay, let's put it in perspective, "One person doesn't but there's three people who do," so that they're not pulled down by it.

Be able to explain to them that you're working with that person that you're trying to bring them along.

- an Aboriginal Elder

Look at how you reached the decision. Why? Sometimes you'll find that the person will be, "Yup. I made my decision this is what I'm going to do."

Then you start exploring, how come they've made that decision, and it's, "Well.....because I feel like I don't really have a choice."

It's important to do that, to allow them to be clear as they possibly can with themselves about their decision and why they're doing it. It's more like helping them explore that, rather than saying, "I think you should do this..."

That's the thing. It's one of those like-it-or-not-things. You're still in a position of authority. It's where you have to be very careful. You can't just say, "Well, I think you should do this..." Most of the time the person will just go do it because you said so, it's not really their decision. They give you all the power to make a decision for them.

- an Aboriginal support person

GETTING VOLUNTEERS

There is no neat and tidy package to show you how to approach people and get them to help your care team, but there is plenty of help out there. First, there is yourself, you have the gifts within you that you already know about and some that will surprise you as you go along. There are the people who are close to him, maybe a partner, friends and family. There are resource people, who work in the medical profession or organizations that provide HIV/AIDS or health services.

The reality for some people is that they don't have any contact with their family. Some people have been adopted or fostered away from their family. Others have left because of homophobia and they don't want to go back. Others have been turned away from their home communities.

There are all kinds of circumstances that will have any number of people readily available to be on his care team. There may be a small number of people or it could be only you.

You may have to find additional people to volunteer their time and help out on the care team. When you are looking for volunteers, can you look within your own community for help? The answer to that is one that only you can answer.

Well, somebody has to go and spend the time to talk to them. Go and educate them and tell them, "We're looking for help. I see what you do, you do good work. Can you come and help?"

- an Aboriginal Elder

There have been many instances where people with HIV/AIDS have returned to rural communities or reserves. Some have been met with violence, threats and harassment. Band councils have passed Band Council Resolutions to kick people off the reserve.

There have also been people who have returned and survived, despite limited resources and knowledge among the health profession and community. These people have had the courage to educate others, challenge discrimination, use resources and have even created new ones.

Still, some people live in communities that have been very supportive and loving. The communities have taken the initiative to learn about HIV/AIDS. More importantly, they have taken the time to understand what the life of one of their community members is like, living with HIV/AIDS.

The full range of experience also exists in cities. Aboriginal people are still fighting racism, homophobia and AIDSphobia. For all the resources in cities, there have been and still are Aboriginal people who are isolated and in need of helpers.

Quality of life is so extreme between here and a reserve. It's unreal. Find out what you can do first, with your reserve, the family and the friends. You know how fast work of mouth goes around.

- an Aboriginal person living with HIV/AIDS

There also have been very courageous people who have taken the responsibility

to form care teams. They have learned skills, looked for and used resources and learned from both their successes and difficulties.

Between the people who are close to him, his Elder and the people in the health profession, you may have enough people to meet his needs. This could easily change. He could decide he wants more help. He could develop further AIDS related complications or side effects from drugs. As he gets closer to death, his emotional and spiritual needs may intensify.

When you finish going through his needs assessment, you will have to speak to him about the number of people he has in mind to be on his care team. He may have chosen some or all of the people.

He may also not have anyone in mind; he may not be well enough to ask people to join his care team. If this is the case, he may ask you if you can speak to others on his behalf.

Tell people there's a need for a palliative care team, "I know you've done this and this in the past. Would you be interested?"

If you don't have a pool of people, you go to the clients' sources, their family and friends. Sit down with them. It could be at the clients' home because the client may very well be a part of this planning stage. It could be at an office or the home of a family member. Get them all together and say, "Look, this is what's going on. Jim needs a lot of help. Let's set everything up."

Get your photocopies of all your information, such as doctors phone numbers. Throw together a book.

Explain to everyone what the client would like. Maybe they need a palliative care team. Maybe they're ready to die and they want somebody to sit there with them all the time. That may be all they need.

If they want somebody to come in to run errands for them, you would select someone who has a car. You have to sit down with the client and find out what they want help with.

- an Aboriginal support person

One of the things is to approach people one to one. Talk to them, one on one. It's the talking. When I meet people, I don't wonder whether they're traditional or non-traditional. I see people. What difference does it make? Let's just talk. Creator doesn't look at how much blood we've got, I don't think it really matters when you're working with someone one on one. It sure as hell doesn't matter when you die. The whole political mentality, it doesn't belong there.

- an Aboriginal Elder

I was on a care team before. With my own experience, people, if they want to just be massaged, how would you do that? Put the oil on your hands, you have to rub it together, then you massage. You don't just pour baby-oil on them and start rubbing it in. It's little things like that.

Nashine Ginwenimawazawin

Somebody wants to smudge. Somebody's going to have to be familiar with that. Bringing cups of tea to them. Their bedside manner is what's going to count. You don't want somebody going in there who's got a trashy mouth. F-this and F-that.

Other things to do with this is, TV time. If the person just wants somebody to sit with them, while they're in bed watching TV. They have to be prepared to do that. Simple things like that. Maybe you'll find somebody that can't sit down for an hour and watch TV. Then, what are you going to do?

Taking messages, being able to say on the phone, "I'm sorry, so-and-so's not able to come to the phone, can you leave a message?"

You find a lot of people can't even do that, they're like, "Oh, phone's for you. Just take it, it's for you, it's for you, it's so-and-so, you have to take it."

Well, bedside manner is taking into consideration that person's needs and who they wish to talk to, who they want as visitors and who they don't want. It can change on a daily basis.

- an Aboriginal support person

If they're kleptomaniacs then I'm not going to let them go into people's homes. Find out the past, you always have to look into the past. Yes, people do change and stuff. Find out what it is that triggers them. Ask them if they have a temper.

Most people that do would be like, "Oh yeah, I do."

Well, find out why and what the triggers are. What type of scene or environment makes them go that way?

- an Aboriginal support person

I let it be known right away that, "This is what you are getting into. You are expected to come to the care team without being under the influence; you are not to come if you are hungover; you are not to come if you are on drugs. No swearing. Do you have problems with any of those things, tell me now, I'd like to know."

I would say on my reserve, go to the band council and bring it up with them. They're the ones who make all the decisions. They may even make it easier, too. They may be able to reimburse people for their time or for gas. They may be able to set up a fund where you can have food or them when they come to somebody's house.

- an Aboriginal support person

influence or really hung over, you can just go up to them and go, "You know what, I told you before." Then, you can take whatever route you want to take.

It clears it up right away. If there is an incident, and it has happened to me where somebody has come under the

If you don't have any ground rules, if you don't have any base, what are you going to use? You've got to think about a lot of the background stuff because it's easier that way.

- an Aboriginal support person

THE ENVIRONMENT FOR CONSTANT CARE

Hn creating a comfortable environment for her, it will be helpful to think about environmental conditions that cannot be changed.

If it takes hours to fly or drive from her community to a hospital, this could play a big part in deciding where she is going to stay. Rain, snow, and ice are environmental conditions that are unpredictable, and will affect travel, both by car and air.

In some communities, the first sign that there is something wrong with the water is when someone gets an infection from it. With her immune system already very compromised, she may not survive another infection.

Although medications can be flown into communities, bad weather conditions may delay this from happening. Since some medications will stop working if they are interrupted, this is also something to consider.

There may be other environmental conditions that are unique to your community and your area. These will contribute to what she may expect in the journey of her care team.

If someone is stuck in the community and the weather is bad then it's the pilots that make the call. Usually there's somebody at air ambulance making the decisions about who's flying.

I have to say, as a physician, whether I think someone needs to come to hospital. If it's an emergency, we'll fly in a physician with an ambulance. If someone was having a heart attack or about to have their baby prematurely, then I would send a physician in the air ambulance. If somebody's more stable and they need to be seen, then they can come in the air ambulance and the paramedics can take care of them or a nurse could come with them. Sometimes, if it's something pretty major and I know it would require more resources than we have at the hospital then I would fly them from a community directly to the city. Sometimes there's no use stopping at the hospital if we don't have the resources.

- an Aboriginal support person

With the fly-in communities, I guess what would be more confusing is if you had somebody who was at one of the more interventionist levels of treatment. I mean, it's still palliative care. We'd still need that person treated somewhere where there are the resources, someone who could attend an intravenous line or do whatever we're doing to treat things. Ideally you would go over this in the beginning with somebody and keep revisiting it, not at the time when there's a crisis.

- an Aboriginal support person

From the nursing station to the airport it wouldn't take very long. Most of the communities are very small and it would take about ten or fifteen minutes to get to the airport. It depends. Probably what might happen in some communities, is one of the Community Health Representatives would be woken up. Some communities actually have an ambulance. The staff at the nursing station, either the nurse or the community health representative would go

Nashine Ginwenimawazawin

with the ambulance and take them to the airstrip. From first call, it might take twenty minutes or half an hour. It can be pretty fast.

It also depends on whether the air ambulance is available because there are a couple of air ambulances and they might be already on a flight. It depends on where they are, sometimes they are parked in other communities. If it is busy, we might borrow one that is parked in another community. Most northern communities are about a three-hour trip. So you have to get out there and then come back. Some are short, some take an hour one way. It depends on the weather conditions.

- an Aboriginal support person

There is a medical officer of health. Usually it is public health people who are in charge of water quality. I'm not sure how often they test the water.

There are some waterborne intestinal infections we see and it is endemic in some communities. It is usually bacteria in the water, like salmonella. There would be infections that would indicate that there is contamination in the water. Once it is pinpointed that it is happening in a particular community, that community would be warned about it.

Usually the pharmacies are pretty good and there are flights going up every day. Some of the trickier medicines need to be monitored more. So with HIV and AIDS, there are special medicines for eye infections and they need to be monitored closely. In the city, someone might go in on an out-patient basis to get their IV for CMV retinitis. Sometimes we do that at home, but people wouldn't be able to do that in their communities.

- an Aboriginal support person

Some of the communities might not have adequate septic or sewage systems or garbage disposal. If you're getting fecal matter in the water then someone is drinking it a little further down, e.g. if someone's outhouse is too close to the water or someone has dumped diapers into the water, that would be a concern for somebody who is immuno-compromised and that kind of illness could be devastating.

What we try to do, and depending on what the infection is, is not treat it with antibiotics. We try to develop a herd immunity. For salmonella infection or shigella, we might not treat the kids because eventually everybody in the community will have been exposed to it and have developed a resistance to it. That is better than treating one person with antibiotics. But if a person was immuno-compromised he wouldn't be able to develop an immunity. That would be a problem.

Somebody who wanted to find out could contact the medical officer of health. They might be able to tell them what infections have occurred in the community. An option would be to use bottled water, which would be expensive. There are filters that you can get. There is a pump, you could use it to pump your water through the filter. You can buy them from travel stores like Mountain Equipment. You can treat with Javex or chlorine but people might not be into that. The medical officer of health might be able to help with those guidelines. Usually, it would be boil the water for a certain period of time or water purification tablets or one of the pumps.

- an Aboriginal support person

EQUIPMENT AND MONEY

Money is a concern for a care team. In maintaining a care team, you may need supplies, such as; sheets, laundry and cleaning supplies, bedpans, adult diapers and bed pads. All of these supplies require money.

Things that are often taken for granted may not be there, such as a refrigerator. Since some medications need to be kept in a refrigerator, other alternatives have to be looked at. Another consideration, whether or not you can keep food stored safely. Food that has gone bad can give him infections, which he may not be able to fight off when his immune system is already very weak.

If he needs a wheelchair, can his environment accommodate this? As one story tells, being able to respond by preparing a house for wheelchair accessibility may be a slow process. You will have to be very creative in looking at what can speed this up.

There are some organizations you can turn to for help with equipment and money. Resources for palliative care and AIDS are available, both on and off reserve. When you combine that with what your community has to offer, you have the potential for a strong foundation.

This chapter on contacting resources is found in section five. By first identifying what you need, it will then help you when you approach those different organizations for help.

You have some money. There's some organizations, Aboriginal organizations, AIDS organizations, or palliative care. They may provide equipment, personnel and services that are free.

- an Aboriginal person living with HIV/AIDS

You will be surprised at what you can accomplish when you want to provide him with excellent care. Most people in service organizations are there because they want to help. Look within your care team and try brainstorming possible solutions when you have a shortage of money. When your focus is on surrounding him with the care that he needs, refuse to accept it when someone tells you something isn't possible. Health needs change constantly. Expressing that you need services that aren't there may be the first step to creating a new program.

My reserve might be the only one in my area that has a house specifically designed for wheelchair accessibility. It took them about half a year just to secure funding for it. It took them about eight months to get the shell up and then they had to stop because they ran out of money. Then, it kind of just stayed where it was at, no work was done on it. Several months later, they finally got their last bit of the funding for it and they finished it. They built in the handrails and the lower counters, the wider doors for the wheelchair. In all that time, we still had trouble trying to get people to look after her, to do bed-lifts and toilet-lifts.

If you look at the time it took for all that to come into place, if somebody came home and they were at the latter stages of the AIDS cycle, there couldn't be a whole lot done. They would probably try to send the person back into a hospital or something.

- an Aboriginal person living with HIV/AIDS

In order for them to respond, not only do they need the mentality and the emotional stability to take on that responsibility, but they also need the physical. Medications, where is that covered? When you're living on reserve, does your status card kick in? How do you get the medications, the beds, laundry facilities on reserve? If somebody is going through bed sheets like crazy, just having that many bed sheets to change all the time is also an issue. There's the family's poverty and the whole bureaucratic system. Unfortunately, you've got to apply for a lot of that stuff if you don't already have it out there.

A lot of reserve communities don't have enough forethought to get all that stuff ahead of time because there are so many other issues that Native people are dealing with, like the suicide rates, diabetes, addictions. So, they try and get the stuff around that. There's also a big cultural revitalization that's been happening for the last few decades. A lot of program money gets directed into nurturing that.

I guess in that sense, what it comes down to is prioritizing and who does the prioritizing. How can AIDS and the needs of AIDS be incorporated into that priority list?

- an Aboriginal person living with HIV/AIDS

I think the sources of money that flow into the community are very limited. You have money flowing to the band, federal and provincial money. You have jobs at the nursing station.

In terms of what the traditional means of livelihood were, in a lot of the communities, they are not available anymore. People might still be hunting or fishing, but I'm sure there is a big difference in what game is available.

Then there are all these other things that cost money like housing, clothing, TVs and dishes but the money is not flowing in. There is high unemployment. People who leave their communities for further schooling often don't return. I don't see a lot of money coming into the community or options for people to provide an adequate livelihood for themselves or their families. People are motivated and very creative, but it would be very difficult if you wanted to start a small business, because you would have all of the expenses of transportation to get materials in and out. So I don't see a lot of options.

- an Aboriginal support worker

I think there's the whole aspect of he's not receiving the kind of care I want him to receive. I don't think ideal care exists. Maybe if you're ultra rich and are able to afford your own hospital. For the average person and the less than average, like an Aboriginal person or reserves who don't have the standard of living we do here in the city, then there's going to be a lot of hardships. Money is definitely going to be one of them.

I'd say beg, borrow and steal are all three options at the top of the list. You know, there's always an appeal to other people for equipment or supplies. You might need to bite the bullet and ask. Ask for things.

- an Aboriginal person living with HIV/AIDS

Nashine Ginwenimawazawin

There can be problems getting things like fridges to these communities. It might be a problem if someone needed medicine to be kept in the fridge. There might need to be some cooperation with the nursing station to keep it there or (with) someone with a fridge.

- an Aboriginal support person

For some reserves, their medical situation is that they fly people to the nearest hospital. If you're planning on dying at home and you don't want to go to the hospital, I don't know what the band or chief and council may do.

Some bands won't transport the family in. I think what it comes down to is you have to know what you need and want and advocate for those needs, if it's a question of equipment or food then you have to push, push, push. If it means going to the Band Council a whole bunch of times or going to Indian Affairs or the Ministry of Health, (then) that's what you might have to do.

- an Aboriginal person living with HIV/AIDS

You need money. It's expensive for somebody to stay at home. On top of all the other expenses, like if their drugs aren't covered. There's always little extra incidentals like bedpans.

- an Aboriginal support person

That was another expense to come to think of it, was taxis. There was no reimbursement for it. There is now, through the PHA (person living with HIV/AIDS) fund. At the time, taxi chits were not available. A chit is like a form that you give to the taxi driver and they mail it in to get the money sent to them. Usually, they have an account set up with a certain taxi company.

- an Aboriginal support person

In the rural areas, there are always delivery charges for medications. If you don't have a car to go pick it up, then there's that expense.

Laundry like crazy if someone is incontinent. You have to keep them clean and dry. If there is a bedpan, sometimes they aren't covered. The sheets, the bed pads. Some people need syringes. Depends (adult diapers), bedpans, (and) wheelchairs.

Some of it is covered and some of it isn't. It's really hard to get it covered. In order to access it, you need an advocate or to really know your stuff.

Someone who is on FBA or general welfare is pretty much scraping by to begin with. There's already your rent and stuff, and then you add all these other expenses on top of that. You don't have any money to do anything.

- an Aboriginal support person

Food. Basic needs. Food, lodging, utilities. The big thing was keeping up with laundry. We ran out of laundry money. It's a huge expense, you don't realize it. It's a dollar-fifty to wash and a dollar-fifty to dry and we didn't have that many sheets. You go through a lot of sheets.

As far as I know, I don't think there's a laundry service for PHA's or people at the palliative stage that are dying at home. I think that could be really helpful if someone could go over in a truck every day and pick up everybody's laundry and drop it off the next day.

His medications were covered. Our rent was quite high, so that took a big chunk out of our salary. We were basically existing and running out of money by the middle of the month.

There were other people I know. A good friend of mine, who died in Thunder Bay. They were both on welfare. They had to depend on their relative up there to bring food up. They didn't even have food. I think poverty is a big issue for people who have AIDS and are dying, especially Native people because we just don't have the resources, the financial wherewithal that mainstream Canadians have. We're already coming from poverty situations.

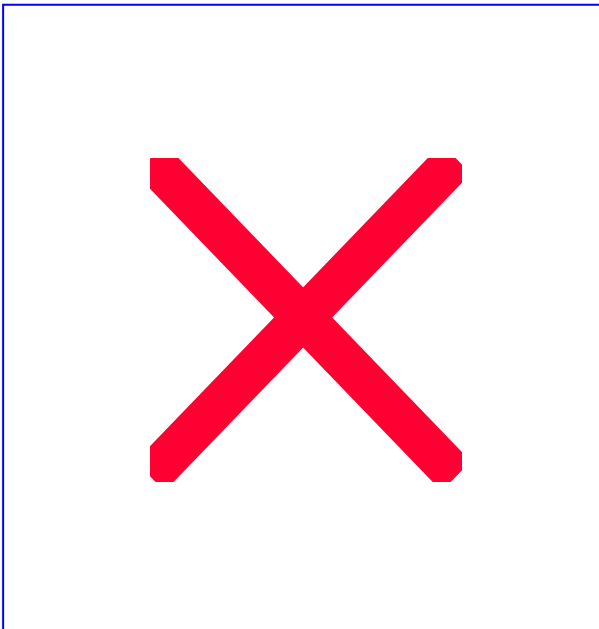
You have to borrow! Ask for handouts. TPFN didn't have a PHA fund then, so it was through friends. This only happened a couple of months because, like I said, his deterioration was very rapid. I was seeing that financially, I couldn't swing it. At that point, I was already saying, "I've got to get him into the hospital."

He couldn't afford to live outside an institution. To me, dying at home, is like a luxury for a lot of people. You really have to have a lot of things in place financially. You have to have some kind of support. It's very expensive to die at home.

- an Aboriginal support person

RECORD KEEPING

If it's on a reserve or in a remote community, it still has to be structured. When you're talking about taking care of someone who is ready to die, it has to be structured.



If you don't have a schedule, then you're just doing things by the seat of your pants. Everybody's going to get so fried and so burnt out. There's going to be so much anger and hatred. It's going to be a big catastrophe waiting to happen. It won't be worth it to them or to the client. You want to ensure quality of life, not quantity. The person's not going to live that long.

Organizing everybody and making sure everything is taken care of, it doesn't matter whether you're on the Rez or not. It has to be structured, especially with the scheduling. Otherwise it's going to be a big disaster.

A lot of times people don't have the training on reserves. They don't even have regular family doctors. There's so less of everything. As soon as you find somebody who does have experience, they can help the family. Then, they can start structuring themselves. Maybe they just need a little push to begin and then they can take over themselves.

- an Aboriginal support person

Schedules and logbooks

A care team needs to be aware of many details. Emergency lists, release of information forms, phone lists, care team schedules, a care team logbook and medication schedules are tools that can help the care team organize itself. You can keep your records in this binder or a separate binder only for your records. The next several pages include sample forms of the care team and medication schedules, feel free to copy or change them as you see fit.

In addition to keeping written records, care team meetings can assist in the organizing process. Some care teams meet once a week and others will get together less frequently. It will depend on the circumstances of the care team.

Your care team could go through an emergency list as though it were a fire drill exercise. By preparing yourselves ahead of time, you will know what to do if the person you are caring for has an emergency, such as a fall or extreme difficulty with breathing. Without emergency preparations, there is a possibility of panic. Preparation to go to the hospital could include keeping her identification, a clean set of clothes and other personal effects together so that they are easily taken on the way out. How the care team responds to an emergency is her decision. She may not want you to call an ambulance if she were to stop breathing.

The care team schedule can help organize when the shift of a care team member will be and what they will do during their shift. Some members may want to be listed on the schedule to cook a few meals each week. Another care team member may want to stay with her during an overnight shift. Someone may be available to provide personal care, such as assisting her with bathing, changing her diaper or cleaning up after she has vomited. If she wants to visit friends, she may need help with the transportation of her wheelchair. Designating these tasks may take place in a care team meeting.

A care team logbook can help each care team member organize their shift. Regular logbook entries can maintain open lines of communication between care team members. Logbook entries can be used to make sure that important tasks are completed. For example, if you are on overnight shift, you may see that she developed a fever at 3:00 am. If you enter in the logbook: the time, her temperature and how long the fever lasted, the next shift will have the essential details to tell the medical staff later on in the day. In addition, the dayshift care team member will read the logbook entry and understand she is angry because she stayed up all night in extreme discomfort.

A medication schedule will clearly outline when and how to administer her medication. This is very important if she is taking medication that won't work without regular administration. She may need to take her medication at timed intervals throughout the day. Some of her medication may need to be taken with food. Ask the doctor or pharmacist to help you set up a schedule to administering her medication.

Care team Binder

I have a whole binder at the apartment or house. It has a list of all the other care team members, their phone numbers, their doctor's numbers, family contacts, Form 14's, which are

release of information.

There's a copy of when outside agencies are going to come and visit. Home Care, VON. Stuff that's usually set up when that person just gets out of hospital.

Sometimes we'll have the actual identification, but usually photocopies of birth certificates and drivers license. That's only because if you go to an appointment with someone and you have the ID, then you don't have to count on the person that may have dementia.

The list of drugs, the drug schedule. The care team's schedule. Doctor appointments. Maybe there are psychiatrist appointments. Therapeutic touch, massage appointments.

I like to keep it all in one book. The only problem that we've ever come up with is when the person has dementia and you keep the care team logbook there. They may hide it in their apartment. I don't know what the way around that is. Keeping it in a place where they won't find it, like up in a cupboard.

- an Aboriginal support person

Emergencies

He had his IV changed every day. He was hooked up to the IV for a couple of weeks, twenty-four hours. If the thing came out, it was a big disaster because I didn't know how to put it in. It came out in his sleep, from just moving around. It just accidentally came out. It was in the afternoon, thank goodness. He phoned his doctor. They told him to go to the emergency. I had to take him to emergency so they could re-insert it. I had to take him in his wheelchair, down Wellesley Street, with him cursing and swearing the whole way. You know how busy that street is. He was yelling at people to get out of the way. I had to wheel him and the IV as well.

- an Aboriginal support person

Release of Information

Sometimes there are more than one person on the release of information form (Form 14), doctors, and other agencies. It's good to have that around in case they say, "Well, we can't say anything about that client until we have the Form 14."

Sometimes, a care team member has specific tasks. Other times, it's like, "Well, this needs to be done, so I'll do it."

Then, you fax it to them or you can say, "I have a copy and we've already faxed it to you."

Some people don't want to do sponge baths. They'll just sit and talk and visit. People decide for themselves what they're comfortable doing.

- an Aboriginal support person

To get a doctor to come to a meeting, you get your client to sign a Form 14, a release of information. Then, you have to fax them the form and a request for them to go to a case conference. You have to have a very clear agenda, why you want them to go, otherwise, they won't attend.

- an Aboriginal support person

Care team schedules

See what they can do and what they can't do. Be a good judge in that way. If you're not, then you're just going to hurt a whole lot of people. The client, their family, their friends, your

Nashine Ginwenimawazawin

time, your organization and the volunteers, too. The best way is to find good matches for each task.

A lot of times I have specific positions. In the past it was general and that was inconsistent, too up in the air. I've found when you're on a palliative care team, have specific people to do something. Have a palliative care team leader and have somebody else as a back-up leader.

Tell the other people on the team by calling them up and going, "This is what happened, or we brought this person over here."

I always say, make sure everything is clear and organized. Add on the responsibility of specific tasks. It clears their minds, "Hey, I know I can do this, that's why they're giving me this responsibility."

- an Aboriginal support person

You can think of other positions for people to do. Somebody's in charge of the logbook, apart from their regular palliative care duties.

They can pick amongst themselves who will do this or who will do that. You can even set up little job descriptions for them. They'll have that piece of paper, which will make things tangible for them.

- an Aboriginal support person

The Logbook

One time, he fell and cut himself. Another time he was so dehydrated that he had to go in and they were trying to build him up again. I think he insisted that his doctor get him into hospital because he wasn't getting any better being treated at home.

- an Aboriginal support person

I don't know about such a detailed logbook. Most people don't plan their life by the hour, like every day living stuff. This person is still trying to live a normal life, as much as possible. There needs to be some time in the afternoon, some time for two hours, then so-and-so will be there.

It has to be flexible because maybe they don't feel like going out at 9 o'clock if that's when the caregiver's respite hour is. It has to be flexible.

- an Aboriginal support person

It's important to keep a logbook. It's also important to inform the other agencies, like the homemakers and the nurses. Make sure that they're also filling out the same logbook that you are. Most places like that have to do their own documentation, anyway. Make sure they're on board too, and keeping notes in the same log book that you are.

It's important because people's physical conditions can change, like, even within the hour. At one point, you could go in and they're talking, they're sitting up. The next day you could go in and they're comatose.

I review it, usually once a week. I go over it and then bring it to meetings.

- an Aboriginal support person

Nashine Ginwenimawazawin

Realistically, most care teams don't meet once a week. People's schedules are too hectic to pull it all together. That way, with a logbook, you can just read what's going on.

It's easier to understand the behaviours of that person. Whether that person's cranky. Maybe they talked to their long-lost brother that they hate.

- an Aboriginal support person

If you don't want to write it down, tell somebody. Tell the leader of the group. You tell the person who's coordinating it. If you don't want to write something down, verbalize it to the next person who takes over for you.

It wouldn't be like, "Well, so-and-so is really down today. They asked me to rub their back."

None of that other stuff happens. All that other stuff, really when you write all those details in, that's helping the volunteer process their shit that they have to go through while they're on the team. It doesn't really help the client out.

The team leader needs to know the basic facts. If culturally that's what they want, then don't write anything down. As long as you verbalize it.

I think that's a really lame excuse. Everybody on the reserve that I know that's in their 80's and over, under and everywhere in between, they know how to write.

There are people that are illiterate. If that person can't write, you should have more than one person looking after the client, anyway. So, the other person can write it down for them. If you don't want to write, somebody else will.

- an Aboriginal support person

I usually just put in lined paper in a binder. They write the date, the times they were in, and the things that happened.

"Today, they're angry." or "Today, they're happy-go-lucky."

After that, put any medical concerns, "Was sick after they ate a meal."

Writing down when they were fed. If they were given a bath. Laundry was done. What needs to be done. Then, initial (your name).

- an Aboriginal support person

It wasn't just a book where they scribbled in medications. It was a book where people wrote down what they thought the person was going through. They wrote down what they believed was needed. It was more like inner feelings.

Then again, that's an identity thing. It's a cultural thing. People don't want to write down on paper, "Oh, I felt really bad because so-and-so threw up all over the kitchen table."

They might just write, "Threw up. 1:00 pm."

Nashine Ginwenimawazawin

The positive thing is that everybody knows how everyone else is. They know the person who wrote it down probably felt really shitty they threw up all over the place.

- an Aboriginal support person

Medication Schedules

If there are medications, then you need to have that down but that's a separate chart. It's a day-by-day, hour-by-hour chart, depending on what the person's on. You have to put, "How many pills," "If you have to take it with food", "If you have to take it with water."

Most times, you can get your pharmacist to do a bubble pack. Then, they're already pre-filled in each time slot. They can do it so that the ones you take with food are all together. The ones that you can't eat with food are all together. They can organize it by the hour for you. It's way easier than messing around with bottles. I know in the city, they deliver it once a week.

- an Aboriginal support person

Nashine Ginwenimawazawin

I would get one of those containers. You can buy them at any pharmacy. They have the little slots.

Anywhere that you're going to get medications, I would make the pharmacist write out a drug schedule for you. They can do that at any pharmacy. Then, you can write out the daily schedule for each shift.

Some interact with others, so you shouldn't take them at the same time. How would you know that? It says, "Take one every hour."

I would get the daily pack. Write it down, "You take the little green pill at 9:00 am. You need to drink water with this."

- an Aboriginal support person

Originally, he was able to crush up his medication and eat it in ice cream. Once he got better he could swallow the pill. "It doesn't taste very good," he told me.

One of the other things that happened was the family doctor and some of the people that cared about him told him to stop smoking, so that he wouldn't suppress his immune system. He had quit drinking, he did a joint every now and again, but like it was nothing major. He had quit party-hardyng; however you say that, because of his disease.

So he went to the doctor and said, "You're going to have to give me some tranquilizers for me to quit smoking."

In his infinite wisdom, the doctor gave him some tranquilizers. In itself, it is a wonderful drug, but he forgot to tell him not to take one every time he had the urge to smoke. He didn't tell him to just take it two or three times a day.

So he overdosed because he took a pill every time he wanted to smoke. Like, I would have been dead by noon, but he was the live one. He had a seizure, he was admitted to hospital and that's sort of when the downhill slide began.

I said to him, it's easier for you to smoke. You're going to die, so why not enjoy the last little bit of your life that's here? Why put yourself through all that stress? We talked about that for a little while and he agreed so he resumed smoking and we got rid of all the tranquilizers.

- a support person

Care Team Meetings

We try and do it every other week, where all the players get together. All the volunteers and all the agencies and all the primary workers get together and talk about what's going on and what needs to be done.

At that point, the client also gets a chance to say, "There's way too many people in my house." or "This isn't being done, I don't like it when this happens."

Nashine Ginwenimawazawin

It also gives the care team members a chance to say, "I'm feeling a little bit burnt out. I need some time off." or "I can take more shifts."

- an Aboriginal support person

I would suggest to do is start off with a general check-in, "How is everybody?" Find out how they're feeling. Even if it's not even related to the team, let them have a time to voice that to an audience because that puts the light on them. The focus is on them and they can talk about whatever they want. That's always important, it's self-recognition.

Find out, "Oh, did everybody write in the log book? Let's review the book. Let's talk about his medications. Has anybody spoken to him about anything that has been pressuring him?"

Maybe he or she told only one person that they're having a problem or they're constipated. Nobody else knows. Talk about it out in the group, say what's been going on every day.

Make sure, every meeting, that you always reassure them everything is confidential. A lot of volunteers might think, "Oh no, they're going to go back to the client and they're going to tell them that I said this and I don't want that."

Find out how they feel about being on a care team. Find out if they still want to continue. Find out if there's any issues with pets in the house. If they really do not enjoy scrubbing toilets. Anything that they dislike about going there, let it all out. It's a great opportunity to

The meetings were just bitching sessions. They were brothers and sisters fighting about, "Well, if they aren't going to live there, I'm coming in to get everything I bought that person." Shit like that.

Sometimes the client was in the room and everybody was talking about them. Why? You don't do that. That's not respecting them. Talk about it at your meeting outside the house. Don't go to the client's house to have your meeting there.

- an Aboriginal support person

Process everything then and there. Go through it. If they need more time though, say it's running really late, just say, "I'm glad you've addressed it to the group. Does anybody have any comments?"

If they don't, say, "I'll talk to you after the meeting."

If it's not a good time then, set a time up. The best is to do it as soon as possible. You don't want your volunteers leaving, left hanging, "I just poured my heart out and they slammed the door on me."

You don't want that. You don't want hurt feelings at all. Try to process everything.

Ask other people for input. It is your meeting. They can talk to one another, they'll know

what's going on because they're in the dynamics or that relationship constantly.

Ask the group what they would like to do. For the first meeting, suggest someone take minutes, if somebody would volunteer to take minutes, just for our group. You could have it in a logbook, somewhere they can go look at it.

Find out if they even want to keep minutes. If they don't want to keep any record or anything, that's purely up to them. It's their thoughts and their feelings. They have the right to choose whatever happens to it.

Flip chart, I would use a flip chart definitely, for an agenda. Just write up the agenda, scribble it up there. Have an agenda ready for all meetings. You have to have some sort of structure set there or else everything's going to be up in the air.

"Where we are at," meaning the state of the client. What's going on with that person? "Meds," to talk about any new medication. "Change in diet, change in sleep"; "What the goals are for next week."

- an Aboriginal support person

There may be a project. Say this person wants to start tidying up his room and starts giving away his stuff to people. You have to be prepared to do that. You have to sit down and think, "Well, who can come in? Which extra people can you get in?"

You can do a schedule and have a sign-in sheet go around the group. If nobody signs your sheet don't take it out on them.

Just say, "Well, thank you, if anybody changes their mind, let me know because I really need people to do this. It would be really nice if somebody could."

- an Aboriginal support person

A LAST NOTE

Looking at why we care for one another can shape how we do things. When you examine what motivates you, what you want to accomplish can become clear and focused. This is very important because being on a care team is very challenging.

In looking to the person living with AIDS for direction, you will support them during this part of his journey. Even when identifying his needs may be challenging, there still are opportunities to ask and listen.

These are the first steps that can help you figure out how many people you will need to be on the care team. Looking within your own community may provide some challenges, as well as some wonderful surprises.

Environment and equipment are some of the more practical considerations. Having an awareness of the challenges created by a remote environment can help you set up strategies to meet these challenges and think about your options.

CARE TEAMS STORIES

In Native culture, we believe that gift-giving is so important, that the Creator gave us everything. The Creator gave us this environment. We didn't pay him a thousand dollars. The Creator gave us this life, gave us this water. So, in Native culture, what is given to us is an important issue.

In tribes, with people, if you admired something of theirs, it was totally their belief that they give it to you. If you admired their barrette or if you admired their shirt, they'd give it to you. That comes with us. It's embedded in us. That's the difference with us and the non-Native. The gift giving came to us from the Creator because he taught us that.

- an Aboriginal Elder

Sharing gifts is part of who we are as Aboriginal people; we share with each other all the time. When there is a family or a person without money or food, community comes together and contributes. It is one of the ways we have survived as people. You will often hear Elders speak of one person who shoots an animal and shares it with the entire community.

The following are stories of palliative care teams that have previously come together to help an Aboriginal person living with AIDS. They are about the Aboriginal person who is living with AIDS. They are about the people that came together and formed a care team. They are about thoughts and emotions that emerge from being on a care team.

The stories of the care team members show the courage they possess. Often, care team members found themselves working alone, under very emotional conditions.

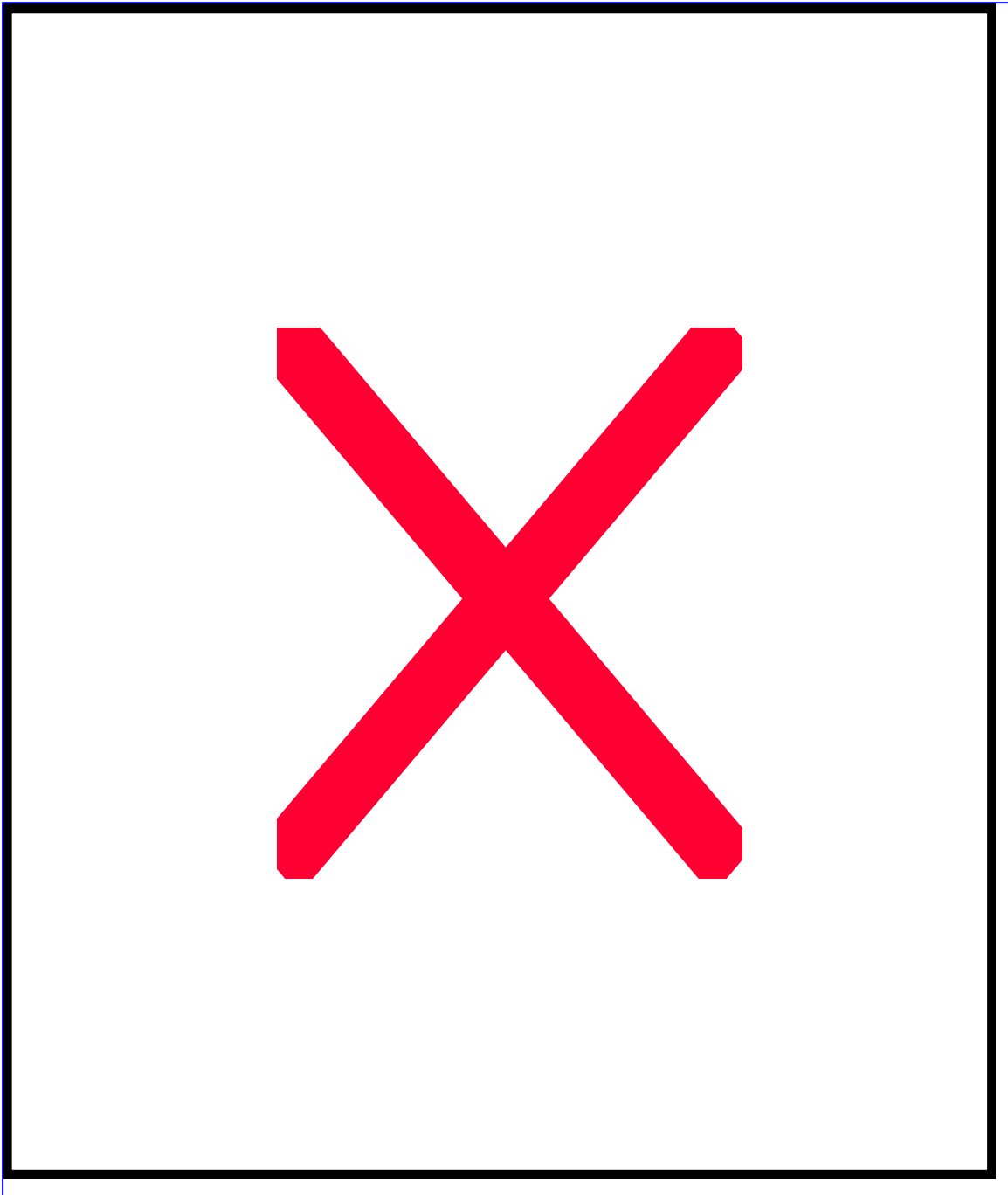
The stories found in this book are gifts. They are experiences from First Nations people that don't often get talked about or shared. They also include stories of the support people, both Aboriginal and non-Aboriginal.

Seeing someone you love in physical, emotional and spiritual pain is extremely hard to watch and even harder to discuss. Our Elders talk about death being a natural part of life, yet it is still uncomfortable for some people. Expressing our grief is painful when someone we love, someone we once shared life with, has died.

The difficult nature of some of these stories is what makes them so valuable. The people that shared their life experiences talk about many things that are not easy to tell.

When you ask a care team member, "What happened when he went into a coma?" They are talking about someone they love and care for. They are also talking about someone who has died. It is a very personal question that can bring up some very intense emotions.

The strength of the storytellers can be seen within the gifts that they give, when they share their experiences and their lives. Many people seemed very relieved to be able to talk and share. It was almost like they had been living with the experience inside of them, just



waiting for a chance to tell the story. By sharing, they are offering their experience, thoughts, feelings and lessons.

The limitations of writing became clear, because it couldn't capture the laughter, expressions and emotions that came up.

Nashine Ginwenimawazawin

Isolation seems to be a concern for a lot of people. Feeling alone in their work as a care team member or family member was often spoken about. It didn't matter if they were in a remote area, on a reserve, in a town or in a city.

If you are feeling isolated while you are caring for someone who is dying, reading these stories may help you realize that you are not alone. Perhaps you are feeling overwhelmed by all the details. The emotions may be something you aren't sure how to cope with. Maybe you are experiencing fear and frustration. Knowing other people have gone through a similar experience may be something that can help you continue with your work. By sharing how they met challenges, they offer a wonderful gift of different approaches working through difficult barriers.

When you are reading a story, the meaning may not be immediately clear. Stories don't outline, in point-by-point form, the direction, and information on what to do. When our Elders tell stories, often they use symbolism that is not explained. They do this because they know you have a mind that you can use to figure out your own understanding of what that symbol may stand for. Your mind is very important here, as it is with all the other areas of your life, in being able to make your own interpretations and decisions about things.

The key is your mind. You have to think. You have to decide how you want to interpret a story. When you come across something you have never seen or thought about before, can you allow it to come into your understanding? Can you invite it in and allow it to become part of you and your experience?

Can you pull out a direction from a story? Much of Aboriginal teaching is by role modeling. When you are reading a story, they are examples you can turn to when you aren't sure how to go about doing something. You have choices. Often, one model is different from another.

The following stories have been gathered from people who have been care team members, they have cared for Aboriginal people living with AIDS, some under very difficult circumstances and some under ideal conditions. Some care teams had a lot of people who could help out while others were working alone. Some of the people that were being cared for were able to be at home, with family. Others were very far away, with one very important person from a chosen family, available to help them.

There's a couple, two guys. It was one of the guy's uncles who had called us and asked for some help in setting up a care team.

The one guy, he was really sick, he had neuropathy in his arms and his legs. He couldn't move. He had to be shifted around. He also had a degree of dementia or something. He'd go kind of in and out of reality.

The uncle called and said, "We've got a lot of people that are interested, but we don't know where to go. We don't know how to set it up."

Basically, it was just sitting down with everyone and saying, "What are the things that you need?"

His partner was saying, "I can do this and I can do that but I really need help with these things."

Then, everyone around there was like, "I can do this."

Some of them couldn't go into the house and volunteer time but they could do other things. Basically, it was just sitting down with them and making a day-by-day schedule.

It was like, "Who can watch the overnight stuff?"

It was making sure his partner could have time off, where he was totally out of the house. That was the big thing, that was why he was so burned-out, he was always with this person. We arranged that he would have a couple of nights out of the house. There were also times where people were just dropping in, unexpectedly. It was letting everyone know that, "These are the rules. I want certain days to myself. Yeah, you can drop by but don't come late at night like you used to when he was well."

Because he had neuropathy, we showed them some lifts and transfers. It was so they could do it more safely. One person was the grandmother. There were ways she could move him without hurting herself. So, we showed the basic moves of how to turn him.

Another part was accessing maximum amount of time from the Home Care people. They offer up to 60 hours a month and they didn't tell him that. If you know, then you can say, "Wait a minute. I'm entitled to more hours." They'll just give you the minimum.

There weren't any AIDS-specific organizations in that area.

We went to a cancer place and they have day programs. They have crafts and people can stay there and they'll entertain them. People will read to them if they can't move.

He asked us to do smudging for him. We took him cedar and tobacco. Most of the people on his care team were Aboriginal.

- an Aboriginal support person

Nashine Ginwenimawazawin

It came about as a natural progression of his illness. It wasn't like a conscious decision, it was an emergency situation. He deteriorated very rapidly. My friends could see I was having a hard time dealing with the situation at home and that the two of us were basically isolated as a result of his being sick.

This was five years ago. Attitudes were still different in a sense that a lot of people were in denial. They didn't really want to deal with the issue. They were very afraid of the disease. This is in Toronto. I'm sure this attitude still exists in more remote communities.

As a result, a lot of people who we knew, and we had a lot of friends, just disappeared into the woodwork. At the time, 2-Spirited People was a very small organization. It didn't have the staff that it has now. I had a couple of close friends who started to help me. So, I guess it was a natural progression.

What happened was he had Hepatitis. He already had some symptoms but the Hepatitis really destroyed his immune system. After that, it was just chronic diarrhea, the wasting syndrome, the inability to eat. He lost a huge amount of weight.

He had to leave his job and his income was cut in half. He was on long-term disability and he didn't make that much money to start with. It was based on a very low salary.

Whenever he felt well enough, he was still going out to drink. He was not giving his body time to heal. He would feel better, go out and drink, and feel sick all over again.

From December to about the summer time, he went from being fairly independent to being totally dependent on me. He was unable to leave the apartment because of his diarrhea. He was afraid he was going to dirty himself. So, we were basically housebound.

Well, at the time, 2-Spirited People had one employee. She and her partner were good friends of mine and they decided to pitch in and help me.

They were coming over, taking him to doctors appointments and helping me clean up and do laundry and stuff like that. Basically, it was only four of us that were on his care team.

I was the primary care giver. Part of it was his personality. Other people wanted to help but he didn't want anything to do with them. He wasn't a person that was easy to get along with.

I would say, "Oh, so-and-so wants to come over and help."

He would say, "No. I don't want to be around that person."

So, it was a very thin care team. It was very disorganized because the people had all sorts of other responsibilities. A lot of it was just down to me and another care team member. It was to two of us. Whenever the other two could come over, they would help out. His family lived out of town and they had no contact with him, except by phone.

His care team is a good example of how care teams can go wrong or not come into existence. Each one is different. I don't think you can read a book or pick up one of those manuals and say, "Well, this is how it's going to go."

Every one has it's own unique dynamics. It all depends on the individual you're caring for.
- an Aboriginal support person

We lifted his bed up against the wall so he could reach the ashtray at the window. This was so that he could have a cigarette. When he got bad, we moved the bed back in; so more people could stand around the bed to be with him.

He was starting to get a bit grumpy, which is fine. He was getting demanding, I think because his health was failing. I sort of felt that death was imminent and that we should be doing this. I didn't want us to kick ourselves later. It wasn't a problem. We just sat there in his room.

We were all his friends. It evolved with us having said that we would never, ever leave him alone. It was just having to mobilize everyone to assist us in meeting this need of his, not to be left alone. It was for own need too because we knew he didn't want to be alone. Most people just don't want to be alone when they're dying.

I think we had talked about that earlier. I said to him, "You have to tell me when you think its time to start staying with you around the clock." We actually had to suggest to him it was time. He agreed

His mothers were constantly massaging his body. I guess that was the thing that they felt the most comfortable doing in his care taking. It was comfort for the both of them. They massaged him, cleaned his mouth and took turns running to get whatever he wanted to eat. They changed the movies, changed his jammies.

He had his own sheets on the bed in the hospital. He had the dark prints that the men like. He had his own pillows, too. He had a Dreamcatcher up and a Feather and his sweetgrass.

Up to about the last three days, you could give him the toothbrush and he could still brush his teeth. He could still use mouthwash and spit it out. Then, they had to use those sponge sticks.

I knew all the nurses at the hospital. I told them to call me if he needed anything. They were really very good about it. I only live a few minutes from the hospital. It was no problem for me to come in the middle of the night if he had an anxiety attack or anything like that. They only called me twice. They called me one day when they thought he was going to die. Then, they called me the night that he died.

- a support person

One of the fields that struck my interest was HIV and AIDS. At that time I was ignorant to the whole aspect of it until my first exposure to a couple. One of them did carry the virus. Since then, I have been going to a lot of sessions, a lot of educational workshops regarding the illness.

My first recollection of a palliative care situation was in the hospital when a man within the intensive care unit had a terminal illness. I thought he should be given palliative care and not

Nashine Ginwenimawazawin

go in the hospital, so I made arrangements for the family to take him back to the reserve and make his life comfortable.

I followed his discharge from the hospital. I made sure he had a lot of personal care, family care and I would visit him every second or third day. There were Elders who came in.

He decided to go the traditional way to begin his journey back home to the Great Spirit. I sat back with open eyes and astonished mind as to exactly what was going on. The term palliative care didn't mean anything to me, it was just a definition within a book. To see this experience first time, well, it brought new meaning to my life.

- an Aboriginal support person

My friend developed his pneumonia again. I remember I was getting up for work. He came down and sat by me, had a couple sips of tea and said he was very tired and going to go back to bed. He took about three or four steps up the stairs and he stopped. He was panting, trying to gasp for air.

He just sat on the stairs and he was trying to catch his breath. We went back to the hospital and the doctor gave him a shot to ease the pain. I took him back home and he fell asleep.

We were traveling. We hopped the plane and we arrived at the airport. His stomach got very upset and he was throwing up all the way. When we got to the airport, we went immediately from the airport to the hospital. There he was in the hospital for one month.

I slept beside him there on an armchair for a month. I ate there. I changed the sheets, bathed him and gave him medication. I stayed up at night when he was coughing and trying to catch his breath.

I noticed he was in a better state of health. He was still sick but he was able to sit up and feed himself. He was discharged and I brought him back to the apartment.

During that time he got sick. He lost approximately thirty pounds. He was very thin at this time. He was at the apartment for about a week and a half, when he got sick once again. We rushed him back to the hospital and he was diagnosed with PCP.

He came back to the apartment for approximately two weeks. He had a doctor's appointment one morning. I woke him up. I made breakfast and I heard him get up and go to the washroom. Then I heard him trying to gasp for breath.

He said, "I can't catch my breath."

I said, "Calm down and breath slowly."

He said, "I am calm. I am breathing slowly. It's like someone shoved something in my lungs. I can't breathe."

He was gasping for air and turning colour. I carried him to the couch. I ran to the phone and dialed 911. The ambulance came within five minutes.

Nashine Ginwenimawazawin

We got to the hospital and he was crying. He had oxygen and a facemask and he was saying, "I don't want to die."

He was gasping for breath. The nurses pushed me away and escorted him quickly to the room. He calmed down and his breathing came back. It wasn't very good, very unstable. They put him in the intensive care unit for approximately a week and a half until he was stabilized. They were trying to control the amount of PCP and the amount of fluid in his lungs.

He was, at one time, 185 pounds, now he was down to 143 pounds. I guess I forced myself into thinking there was hope that he will not get sick and he will never die.

I guess he was in there for about another month. There, he developed thrush in his mouth, his throat, in his stomach lining and around his intestines. It was very painful. He was taking painkillers for that. He also developed herpes around the mouth, anal herpes and other sorts of herpes. He was going through treatment for that, the doctor was burning them off his skin. That would be effective for one month and then they would slowly come back again.

The doctors said the medication he had started, Ganciclovir, he had an option to get a catheter directly into his chest, into the artery that led to his heart. The doctors said he would need it intravenously and otherwise would have to stay in the hospital seven days a week for the rest of his life. That shocked him. They said, "We can put a catheter into your chest and you can administer your own medication at home. You have to go through the operation first."

He had the operation and had the catheter inserted. I started cleaning the place on his chest where the catheter was inserted. When he went back to the hospital for a check up, he had picked up infection around the place where the catheter was inserted. He was hooked up with personal home care and they gave me training to clean it properly.

Home Care and Meals on Wheels came in every day and gave him meals. He was taking approximately 35 types of medications. His life was revolving around medications. He didn't like that because it would mix him up in his mind: when to take it, how to take it, how many to take, take it with food, take it without food. If he takes this and his stomach is upset then he can't take his medication with food because his stomach's upset. He had to work out a schedule.

He was given an option in 1995. Ganciclovir was coming out in tablet form. He could start on that if he wanted to. However, it would not be as effective as the liquid form, which was being administered through the catheter. He decided that he didn't care, he would go ahead and take the tablets. The surgeon took the catheter out and he started on the pills. He felt better about it.

He was going through emotional trauma. He was extremely upset at what was happening to him and the limited time he had in his life. He also confessed he was jealous because I was healthy and I was able to go out and make friends. I could go out there for three or four hours, go on a trip, or go home and visit my family. He couldn't go anywhere for more than two hours because he had to go home and take medication.

He did go away and came back about half a month later. When he arrived back, I met him at the bus terminal. Here was a man, when I first met him, who was once quite an athlete. What

Nashine Ginwenimawazawin

stood in front of me was almost a walking skeleton. But yet, with a smile on his face that would outshine anyone else's I have seen. We went straight from the bus terminal to the hospital. He was in the hospital for one week.

I called him at the hospital and with a raspy voice he said, "Please get over here." He was talking very slow and somewhat incoherent. I went to the hospital and he was very ill.

He said, "I'm not sure if I am going to last the night." I stayed with him, held onto his hand and slept by his bed.

The next day he felt a lot better. About a week later, the doctors discharged him. He said, "I made contact with a hospice and made arrangements to move in today."

We moved everything to his new apartment in the hospice. He got introduced to all the other people. He loved it there and began to make new friends.

Within one week, he had to go back to the hospital again. He had a fever and his pneumonia came back. He was in a bad situation.

The doctors told him, "We've tried everything. We cannot stabilize your temperature. We cannot do anything for your pneumonia. You have a choice now. We can still administer the medication and pray for a miracle or you can go off the medication, go back to the hospice and make yourself comfortable."

I went to the waiting room and I bawled my eyes out. I was shocked. I had no idea how a person could go through this in a lifetime. The shock and anger that was within me. The sadness. I bawled my eyes out like a little baby in the waiting room.

I went to the hospital room about half an hour later and he said he had come to a decision. He said, "I am going on all the medication. It is April and it isn't Spring out. The flowers haven't bloomed yet. I want to see the trees with their leaves and the flowers bloom. I want to see the Great Spirit make nature come to life. I want to see the beauty of my last summer. I just moved into my new apartment and I want to get to know my new neighbours."

We had a nice evening together. The next day I went to school. When I came back, he said he had made another decision.

He said, "I don't want any more medication. I think I just want to go back to my room, see my friends and enjoy. You have to understand. I don't want to live my life on medication anymore. I don't want to have to worry about medication. I want to go out for walks at three or four hours at a stretch, even if you have to carry me."

I said, "The choice is yours and I'll back you up, all the way."

He got discharged by the hospital the next day. He still had a fever and he could not walk at all. I had to carry him from the front door of the hospital to the taxi.

Nashine Ginwenimawazawin

A few days later he was okay to walk by himself for a short distance, so I put on his jacket and we went for a walk. We sat down at a beautiful park. We talked about life; everything and we just enjoyed the day. That was the last time he was outside.

There were many times I tried to convince him to eat. He refused to eat. He would just look at me and say, "You know I'm not going to eat."

I looked at him and you cannot imagine the joy, the happiness, the calmness, and for lack of a better word, the peace. He told me, "I am at peace now. I'm ready to go back home."

That was the most difficult thing to hear my friend now preparing to go. I bawled almost every night.

He was now over four days without eating. Every time I left the room for a little bit, I would say, "I am leaving but please don't go, I will be right back."

He was very incoherent. He would slip in and out of reality. He would fall asleep and wake up, pass out and wake up.

The notary came in and we did his will together. We were talking about how he wanted to be cremated and how he wanted to wear certain clothes.

I said, "I will go home and wash these." I took the clothes and I said, "You will be here when I get back right?"

He said, "I will be here."

I finished the laundry and took the subway back to the hospice. I walked into the hospice and the nurse said, "Did you check your messages? I think there is an important message there and I think you should check it right away."

I said, "Well, I'm going upstairs to see my friend."

She said, "It's important you check your message first."

The message said, "This is your friend calling and I just thought I'd tell you that your friend passed away fifteen minutes ago."

I dropped the telephone. I went upstairs very quickly. As soon as I got to the door, I was so afraid to open it. When I opened the door, there lay my best friend on the bed. He looked so peaceful.

I walked up to him and I knelt down by the bed. I grabbed his hand and I said, "Why did you leave without saying good-bye?"

I held him as hard as I could and I cried and I cried. It was the most difficult thing to see, to experience.

Nashine Ginwenimawazawin

Since then, I was hospitalized about six times. I was having extreme abdominal pains. I would keel over, I would shake, I would sweat and no one could talk to me and I couldn't move. It was extremely painful. My back was killing me.

The doctor didn't know what was going on with me. I got all sorts of blood tests from TB to HIV. I got a physical from gallstones to ulcers to kidney stones.

The doctor said, "We can't find a thing wrong with you. You're healthy. Since we can't find anything wrong with you, we can't treat you and you will go through the same pain over and over again. How about if you change your lifestyle? It seems like you're not happy. You're quite depressed."

So, I thought I have to change my lifestyle and I made arrangements to see an Elder in Quebec. I saw an Elder and began to go to Healing Circles, Talking Circles. Once I started working with the old people, the pain never came back. I started accepting the unacceptable.

The Elder told me that Great Spirit puts on this earth to experience other souls, other energies, other peoples. You have to give thanks that you are spending that time with them, you have to be happy that you share their experiences with them. When it is their time to go, don't be selfish, let them go. If you cry, it's good to mourn, but don't mourn them the rest of your life because you're being selfish. You're not letting them go home. They want to go home. That made sense so I began working on that. The pain went away and it hasn't come back since.

- an Aboriginal support person

OPPORTUNISTIC INFECTIONS & AIDS RELATED ILLNESSES

I think the first need for anyone receiving palliative care is information or knowledge about their condition. I think it's important that someone know what their opportunistic infections are and how it affects them. The treatment options they have greatly affect(s) not only their health, their physical health, but their mental health as well. It affects the people around them, their caregivers, family, friends, (and) partners.

- an Aboriginal person living with HIV/AIDS

If someone doesn't know what they're dealing with, then it's pretty scary, not only for the individual but also for the people around them. If you're sick, and you don't know what's causing it, then you can be shortening your life.

- an Aboriginal person living with HIV/AIDS

The following is a list of some of the more common opportunistic infections. There are others that have not been listed, if you are experiencing any of the symptoms listed here, or any that are not, please contact your doctor immediately. **This section does not provide diagnosis or recommend treatment. Consult your doctor for all health-related help and information. This is for reference only.**

The person you are caring for may have one or more opportunistic infections. If she doesn't understand what is going on inside of her body it may cause her a great deal of fear and turmoil; knowing what the opportunistic infection is will help her deal with symptoms that she may experience as a result.

OPPORTUNISTIC INFECTIONS

The immune systems of people living with AIDS are weakened, leaving them unable to fight common germs, making them susceptible to serious infections. These infections are called *opportunistic infections* because they take the *opportunity* to invade the weakened immune system.

There are many infections that can affect someone with AIDS. There are four kinds of germs that cause infections.

- ◆ *a virus*
- ◆ *bacteria*
- ◆ *fungus*
- ◆ *protozoan.*

A virus is an individual cell. It can't reproduce without a host cell and is therefore not considered a living organism. It hides in a host cell, reproducing and causing disease.

Bacteria, fungus, and protozoa are all individual, microscopic cells. They invade cells, reproduce, and cause disease. They are given different classes because each behaves differently.

VIRAL INFECTIONS

Herpes Simplex

SYMPTOMS:

- ◆ Herpes Simplex 1 affects the mouth, causing blisters or ulcers and itching.
- ◆ The blisters or sores of Herpes Simplex 2 are on the genitals (penis, vagina, rectum, and genital area). They may cause pain, itching and bleeding.

Herpes Zoster (Shingles)

Herpes Zoster is the virus that causes chicken pox in children and shingles in adults.

SYMPTOMS:

- ◆ It infects nerve roots and causes flare-ups (of blisters), often along the upper back, upper arms, buttocks, thighs, and chest.
- ◆ Because the flare-ups are on nerve endings, the blisters are very painful.

Cytomegalovirus (CMV)

I've been diagnosed with CMV Retinitis. I was told I was going to go blind. I started beading, of all things. Trying to find those little holes in the beads, it's hard to believe, but it helps my eyes.

- an Aboriginal person living with HIV/AIDS

There's some blindness involved or spotting in the eyes. It's often alarming for the person to experience. Like any kind of loss, the loss of sight is a big one. It's treatable, but again, it's identifying it. If people don't know what it is, and they don't tell anybody, it'll get progressively worse. Some people think, "Oh, that's just my contacts" or "My eyes are tired."

- an Aboriginal person living with HIV/AIDS

CMV, which belongs to the herpes family, can infect different parts of the body. It is passed through contact of mucous membranes (kissing, sex), or blood and body fluids. The parts that can be infected include: the eyes, digestive system, lungs, and brain.

CMV Retinitis can cause blindness. It usually affects one eye at a time, but can spread to both eyes. In general, CMV Retinitis is usually painless.

SYMPTOMS:

- ◆ blurred vision
- ◆ tunnel vision
- ◆ spots floating in your vision

- ◆ blind spots

If the person you are caring for has any vision problems have the doctor examine his eyes immediately. The doctor may refer him to an eye specialist. It is important to diagnose CMV Retinitis immediately because it can cause blindness in a very short time and early treatment and diagnosis may be able to halt this process. People with a cell count below 100 have a higher risk of developing CMV Retinitis.

CMV Colitis or Gastrointestinal CMV

Infects the colon (large intestine) or small intestine.

SYMPTOMS:

- ◆ fever
- ◆ watery diarrhea
- ◆ weight loss
- ◆ loss of appetite
- ◆ abdominal pain
- ◆ infection of the esophagus (the tube between your mouth and stomach) can cause difficulty swallowing, burning or pain.

Hepatitis A, B and C

I was feeling tired and I couldn't understand why, so I went to see my General Practitioner. He ran some blood tests (and) two weeks later I found out I had a mild case of Hepatitis B, (but I felt) no other symptoms.

- an Aboriginal person living with HIV/AIDS

This is a virus that infects the liver, causing it to become inflamed.

SYMPTOMS:

Early Stage(s):

- ◆ tiredness
- ◆ joint and muscle pain
- ◆ loss of appetite

Mid- Stage(s):

- ◆ nausea
- ◆ vomiting
- ◆ diarrhea
- ◆ fever

Late Stage(s)

- ◆ chills
- ◆ weight loss
- ◆ jaundice (yellowing of eyes and skin)

There is currently no cure for viral hepatitis, and people with HIV usually have even more severe reactions to Hepatitis. Hepatitis can also cause cirrhosis, a disease where the liver begins to break down.

There are three kinds of Hepatitis:

Hepatitis A

- ◆ It is **transmitted** (spread) by contaminated food or water; it can also be transmitted by contact with the **stool** (feces) of someone who is infected. It takes 14 to 40 days for Hepatitis A to incubate, (the time it takes the infection to develop signs or symptoms).

Hepatitis B

- ◆ Contact with blood, saliva, semen, stool, or contaminated needles are the mode of transmission for Hepatitis B. It takes 40 to 180 days for Hepatitis B to incubate. There is a vaccine (immunization) for Hepatitis B, which is available for people that haven't already come into contact with it.

Hepatitis C

- ◆ Hepatitis C is transmitted in a similar way to Hepatitis B, but has an incubation time similar to Hepatitis A. There is currently no vaccine for Hepatitis C.

BACTERIAL INFECTIONS

Mycobacterium Avium Complex (MAC) or Mycobacterium Avium Intracellular (MAI)

MAC bacterium is found in bird droppings. Soil, water, and household dust can contain MAI bacterium.

SYMPTOMS:

- ◆ persistent fever and tiredness
- ◆ night sweats
- ◆ loss of appetite
- ◆ abdominal (stomach) pain
- ◆ chronic diarrhea
- ◆ weight loss
- ◆ swollen lymph glands
- ◆ enlarged spleen and liver
- ◆ anemia (not enough oxygen into the cells of the body)

Mycobacterium Tuberculosis (TB)

TB was a big epidemic in the Aboriginal community for decades, the 20's, 30's, 40's, 50's, (and) 60's. It's killed thousands of Aboriginal people. A lot of my relatives have passed away because of TB.

It spreads so rapidly in the Aboriginal community because the environmental conditions are so conducive for spreading disease. There is terrible overcrowding, lack of sanitation, and lack of medical care. There is a lack of knowledge around TB and a real fear about it. A lot of people would hide it because they were scared to go to the hospital or scared that they'd be put in the sanitarium.

It's almost like AIDS is now. The conditions are very ripe for AIDS to spread in the Native community because of environmental conditions, social conditions, lack of knowledge, and denial around the disease. I see a parallel going on, with both TB and HIV spreading in our community. It could really devastate us if we don't address it.

- an Aboriginal person living with HIV/AIDS

TB bacteria can be spread by being around someone, in the same physical space and for prolonged periods of time, who is coughing, sneezing, and breathing when that person has active TB in their lungs or throat. People who have active TB infection are not sick or contagious, but still have the bacteria in their bodies.

In someone with a weakened immune system, TB is more likely to become active. TB is not just confined to the lungs or throat; it can spread to other parts of the body, such as kidneys, brain, and bones.

SYMPTOMS:

- ◆ a wet cough due to mucous or fluid
- ◆ chest pain
- ◆ difficulty breathing
- ◆ night sweats
- ◆ lack of appetite
- ◆ weight loss
- ◆ tiredness
- ◆ fever

Bacterial Pneumonia

Bacterial Pneumonia is the swelling of the lung tissue, and is more common in HIV positive women than in HIV positive men.

SYMPTOMS:

- ◆ sudden fever
- ◆ wet cough, producing lung fluid

Pelvic Inflammatory Disease (PID)

This is an infection of the organs within a women's pelvis, such as the vagina, cervix, uterus (womb), fallopian tubes, and ovaries.

SYMPTOMS:

- ◆ itching, burning, stomach pain
- ◆ pain during intercourse
- ◆ unusual vaginal discharge
- ◆ changes in menstrual period

FUNGAL INFECTIONS

Candida (Thrush)

I couldn't keep anything down. I thought it was the flu. My nurse tried to give me some water, but I was really gagging. I couldn't breathe. I went to the hospital and they diagnosed me with esophageal thrush and gave me medication for it. If you don't take it (the medication) consistently, the thrush comes back.

- an Aboriginal person living with HIV/AIDS

I can tell when it's thrush because my throat becomes sore and itchy. It burns and you can't scratch it.

- an Aboriginal person living with HIV/AIDS

This is the most common fungal infection related to AIDS. Thrush is a yeast infection, belonging to the fungus family. Eating sugar can make Thrush worse, so you may want to cut down or avoid it as much as possible.

SYMPTOMS:

Oral Candida (mouth and throat)

- ◆ white patches on sides of tongue
- ◆ white patches on gums
- ◆ burning, swelling and redness
- ◆ changes in taste

Esophagus (the tube that allows food to go into the stomach)

- ◆ sore throat
- ◆ difficulty swallowing

Vaginal Candida (yeast infection)

- ◆ itching around the outside of the vagina
- ◆ burning around the outside of the vagina
- ◆ thick, white or yellow vaginal discharge

Pneumocystis Carinii Pneumonia (PCP)

The first time I had it I didn't know what I had, I got a cold and it seemed to come on all of a sudden. I remember just feeling every day like I just couldn't breathe. I wasn't smoking crack or anything. I felt like I was being smothered. It got to the point where it actually felt as though somebody was holding a pillow over my face. I'd cough and cough and cough and no phlegm would come up. I felt like there was so much phlegm in there, but I couldn't get it out. I got a high fever and was real sweaty. I went to the doctor, at the clinic, and was admitted into the hospital with PCP.

- an Aboriginal person living with HIV/AIDS

They put me in the hospital and gave me Septra. I was in intensive care. Now, I'm on a prophylaxis.

- an Aboriginal person living with HIV/AIDS

I was in the hospital for four months with pneumonia. I kept throwing up ever time I ate. Every time I breathed I had dry heaves.

I was stubborn. About a week later I went to see my doctor because I was starving, I couldn't eat anything. He checked me out and threw me in the hospital. They gave me an IV to feed me. I was pouring with sweat.

- an Aboriginal person living with HIV/AIDS

PCP is caused by a fungus called *Pneumocystis Carinii*. It causes the swelling of lung tissue.

SYMPTOMS:

- ◆ dry cough (no production of phlegm or mucous)
- ◆ fever
- ◆ difficulty breathing, grasping for breath
- ◆ sweating
- ◆ tiredness
- ◆ fingernails and lips may turn blue from not receiving enough oxygen

Cryptococcosis

Caused by a fungus found in bird droppings, it enters the body through the air passages (breathing it in).

Cryptococcal Meningitis

Is an infection of the central nervous system and brain, it can cause a swelling of the lining around the spinal cord or brain.

SYMPTOMS:

- ◆ fever
- ◆ headache
- ◆ tiredness
- ◆ stiff neck

- ◆ blurred vision
- ◆ confusion
- ◆ nausea

Cryptococcus Neoformans

Is an infection of the lungs that can cause pneumonia.

SYMPTOMS:

- ◆ low-grade fever
- ◆ coughing
- ◆ difficulty breathing

Other Organs or Tissue

SYMPTOMS:

- ◆ skin lesions (painless sores)

Histoplasmosis

This is a fungus that is also found in soil. It is breathed in and can infect the lungs and other parts of the body.

SYMPTOMS:

- ◆ high fever
- ◆ weight loss
- ◆ difficulty breathing
- ◆ skin lesions
- ◆ *anemia*
- ◆ enlargement of the liver and spleen
- ◆ swollen lymph nodes

PROTOZOAL INFECTIONS

Cryptosporidiosis (Crypto)

Is caused by protozoan found in undercooked meat or contaminated water, it may also be spread to humans by oral-anal sex (rimming).

Isosporiasis

Is caused by a protozoan found in tropical or subtropical climates.

SYMPTOMS:

- ◆ severe, chronic stomach cramps
- ◆ nausea
- ◆ vomiting
- ◆ tiredness

- ◆ weight loss
- ◆ loss of appetite
- ◆ there may be no symptoms

Microsporidiosis

Microsporidiosis is caused by two kinds of protozoa, one that infects the intestines, and another that infects the lungs, liver, kidney, intestines and eyes.

How people get Microsporidiosis is not known; however, it is thought that it may come from contaminated water or food OR through feces and/or oral-anal sex (rimming).

SYMPTOMS:

- ◆ diarrhea
- ◆ nausea
- ◆ abdominal cramps
- ◆ gas
- ◆ malabsorption (an inability to absorb nutrients that go through the intestinal tract)
- ◆ slow weight loss

Toxoplasmosis (Toxo)

A protozoan that can be found in raw or undercooked meat or eggs, causes Toxoplasmosis. By thoroughly cooking meat and eggs, the possibility of getting Toxo can be almost eliminated. The protozoan that causes Toxo is also found in the feces of a small percentage of cats. In order to avoid transmitting Toxo from a cat litter box:

1. Wear latex gloves.
2. Wash your hands after cleaning with disinfectant soap.
3. As Toxo becomes infectious after 24 to 48 hours, clean the box daily.

SYMPTOMS:

Initial Symptoms:

- ◆ a dull and constant headache
- ◆ fever

As Toxo progresses:

- ◆ mood changes
- ◆ confusion
- ◆ difficulty thinking
- ◆ seizures

AIDS –RELATED ILLNESSES

Cancers

Cancer cells are produced when a cell reproduces itself in an irregular way, making them become abnormal, and life threatening. They grow quickly and take over the tissues of the affected area. When this happens, because they are defective, they don't perform the tasks that the body needs for survival.

In a healthy person, these cells are fought by the *lymphocytes* (B-cells and T-cells), but someone with AIDS does not have enough lymphocytes that can fight these cells. Cancer drains the body of nutrients and energy, and may produce toxic substance in the body.

Kaposi's Sarcoma (KS)

KS is a form of skin cancer. It is a tumor found on the wall of small blood vessels. Homosexual or bisexual men mainly get KS and is rarely seen in women and children.

SYMPTOMS:

External KS:

- ◆ lesions can appear anywhere on your body
- ◆ most common on the face, neck, chest, back and soles of feet
- ◆ lesions may be:
 - purples, red, blue or black
 - usually flat, painless and don't itch
 - an early lesion may look like a small lump under the skin or a bruise
 - later lesions can become raised and may flow together
 - a lot of little lesions may appear for a short amount of time

Internal KS:

- ◆ can appear on the intestines, lungs or in the lymph nodes.

Cervical Cancer

Cervical Cancer is developed in the *cervix*, which is the lower-most part of the womb. The lesions that form before cancer develops are called *cervical dysplasia*.

SYMPTOMS:

- ◆ bleeding from the vagina after intercourse
- ◆ bleeding between periods
- ◆ bleeding after menopause
- ◆ unusual discharge
- ◆ problems urinating
- ◆ pain in the genital area

Lymphoma - Non-Hodgkins

Lymphoma is a cancer that affects the cells of the *lymphatic system*. The lymphatic system is similar to the circulatory system in that it carries germs away from the cells to the tissues called the *lymph nodes*, which filters and destroys them. Clusters, or glands, of lymph nodes are in the neck, stomach, groin and armpits.

Non-Hodgkin's Lymphoma usually begins in the lymph nodes or in the channels where the lymph fluid flows. It can spread to the bone marrow, internal organs, and gastrointestinal tract.

SYMPTOMS:

- ◆ swollen, sometimes painful lymph nodes in groin, neck or armpits
- ◆ fever, night sweats
- ◆ weight loss

Lymphoma - Primary Central Nervous System (CNS)

CNS is a cancer that affects the brain.

SYMPTOMS: (depending upon where the tumour is)

- ◆ headaches
- ◆ paralysis
- ◆ seizures
- ◆ memory loss

AIDS Dementia Complex (ADC)

Sometimes people with AIDS have AIDS Dementia Complex. Because of physical changes in a person's nervous system, the person's mind does not work properly. HIV can cause dementia when the virus gets into your brain and indirectly damages the nerve cells found there.

SYMPTOMS:

- ◆ poor concentration
- ◆ forgetfulness
- ◆ loss of short-term memory (can't remember what happened a short time ago); it may progress to loss of long-term memory

The person with ADC may feel like they are losing their minds when remembering things becomes difficult. They may forget addresses, where they put personal items, or what day of the week it is. When the person you are caring for starts to forget things like what day it is or what they were just doing or where they live, this could make them feel anxious and they may try to cover up any memory loss by blaming other people.

Caregivers need to be patient as they may be accused of taking misplaced items. The person you are caring for is not in control of what they are saying or doing and they aren't being difficult on purpose.

HOW TO HELP:

- ◆ Being comforting to them by touch or speaking gently
- ◆ The person you are caring for may find walking becomes difficult. You may need to help them.

IF THE PERSON YOU ARE CARING FOR IS HAVING DIFFICULTY REMEMBERING THINGS, SUGGESTIONS INCLUDE:

- ◆ Use large calendars, with the current date circled.
- ◆ Use clocks with large, digital readouts.
- ◆ Put the phone numbers of friends on a pad near the phone.
- ◆ Remind them to bathe and brush their teeth, wash their hands before meals and after using the bathroom.

SYMPTOM CONTROL: COMFORT MEASURES

*This entire chapter has been taken, with permission, from Andrew S. Johnson's "Living with Dying, Dying at Home." AIDS Committee of Toronto, (Canadian Cataloguing in Publication Data.)

INTRODUCTION

One of the most important things you can do for your friend is to make sure that she is as comfortable as possible. Comfort measures aim to relieve the pain and suffering of physical symptoms such as nausea, diarrhea, and so on. These symptoms can be side effects of your friend's illness or of the drugs and treatments she is receiving. Some symptoms can be expected and may be signs of approaching death.

For those of you who have never provided hands-on care before, some of the information in this section may seem a little overwhelming, even frightening. Don't underestimate your potential. You'll be surprised with how much you can do to help your friend. Listen to your friend, and work with him to find the best approach to relieve his discomfort.

Not every symptom or comfort measure known to health-care science is discussed in this section. We have focused on those things most common in AIDS palliative care. There are numerous complementary therapies that have provided a great deal of comfort to many persons in care. Your friend may be using some of these therapies already or might want to look into them. Contact your local AIDS organization for information on complementary therapies available in your area.

SOME BASIC ASSESSMENT SKILLS

The first step to helping your friend cope with her physical symptoms is to know what you are looking for. Then you must determine whether the problem is a new one or ongoing, and learn what does and doesn't work to relieve the

THIS SECTION WILL COVER:

- ◆ How to assess your friend's physical symptoms.
- ◆ Basic comfort measures.
- ◆ How to assist your friend with personal hygiene.

discomfort.

What's Going On?

Using the power of observation and asking questions are two of the most effective ways to find out what is going on with your friend in terms of physical discomfort.

Noticing any changes in your friend's condition will give you important clues as to whether the symptoms are new or part of ongoing problems. For example, you might notice that your friend is vomiting more often than the last time you cared for him, or that he is having difficulty breathing, which was never a problem before. Reading the care team log will help in determining whether any change has taken place.

Asking your friend if anything is wrong is critical to understanding her physical symptoms. Simply asking, "How are you?" is a good start, but it may be necessary to be a little more specific. Encouraging your friend to tell you about her physical problems is important. Explain that you are there to help make things better. Remember; people use different terms to describe their feelings and sensations, so make sure you understand what your friend is telling you. Be careful not to badger or nag him. Be gentle with your questions, and offer solutions, so that your friend remains in control of his care. The kinds of questions you ask will depend on the problem. We will give you many examples later in this section.

There is a Problem. Now What?

Once you and your friend have determined a physical symptom is causing discomfort, you'll need to decide what to do. Check the care team log and other charts to see if any comfort measures have already been recorded. Ask your friend what she believes might bring some relief. Review the comfort measures in this section and give them a try.

When you are confronted with a new problem, it is very important that you report it to the Home Care nurse or the doctor. They need this information to plan their care, and they can make very useful suggestions about what you should do next.

- ◆ When did the problem start?
- ◆ How long has it been going on?
- ◆ Does anything make it worse or better?

What if Nothing Works?

There is no one right way of providing comfort measures. Each person in care will respond differently. And some symptoms may persist regardless of your attempts to relieve them. Make sure you report this to the doctor or nurse.

In some cases, the doctor may want to have your friend admitted to hospital for intensive symptom control. Let your friend decide whether this is a good idea. If he wants to go to the hospital, it is important for you to understand that this is not a sign of the care team's failure to do its job. Some severe symptoms are better managed in very controlled environments with lots of available resources. And remember: the care team can go

wherever your friend needs it. In other words, if your friend goes to the hospital, the care team can go, too, and care for him there. The care team can then return home with him again if he is discharged or decides to leave.

Make Sure the Team's Caregiving is Consistent.

One of the most frustrating experiences for someone who is ill is to be subjected to a series of different comfort measures that may or may not solve the problem. Your friend needs to trust the care team and feel safe with the care the team is giving. Being consistent with your care will help build and maintain trust.

Once you have found a solution to a problem, it is very important that you record it in the care team log and that you pass the information on to the next care team member. Be specific with your instructions so other caregivers know what you are talking about. For example, recording words "back rub" is not as helpful as describing the massage in terms of exactly where, how hard, how long, in what position, and so on.

BASIC COMFORT MEASURES

Here are some of the most common symptoms experienced by people with AIDS. Basic comfort measures are described for each symptom.

Breathing Problems

Dyspnea is the medical term for difficulty with breathing. The most common symptom related to dyspnea is shortness of breath, which can be very frightening, both to experience and to observe. Breathing problems are often associated with illnesses such as PCP (pneumocystis carinii pneumonia) and other pneumonia's, lung tumors, excess secretions (fluids) in the lungs, asthma, weakness and anxiety.

WHAT TO DO:

Make sure your friend rests before and after an activity (including eating). Plan the activity and rehearse what you will do should your friend become short of breath. Help her move slowly and pace her activities according to her breathing tolerance.

- ◆ If your friend has difficulty breathing during an activity, stop the activity. Stay calm and offer quiet reassurance while he gradually slows the rate of his breathing. Encourage him not to hold his breath during difficult movements.
- ◆ Ask your friend what position helps improve her breathing. Generally, a sitting position works best, so provide support with pillows behind her back, or raise the head of the bed. You can help increase your friend's lung expansion by elevating her arms, supporting them with pillows.
- ◆ Help your friend get to know his breathing patterns, especially when difficulty starts up. Concentrate on slowing down the breathing by taking breaths in through the nose and out through the mouth.
- ◆ If the room is dry, consider using a humidifier, but keep the room warm.

- ◆ Consider using a fan to move air about the room or to bring in fresh air from an open window. A fan blowing directly onto the side of your friend's face may also help decrease his sensation of breathlessness.
- ◆ Be aware of how anxiety or pain affects your friend's breathing. Some anti-anxiety drugs and narcotics will provide good relief. Ask the doctor about these drugs.
- ◆ In some cases, you or your friend may feel that oxygen is required. Oxygen can help decrease shortness of breath in those people whose lungs can no longer move enough oxygen into the bloodstream. When the doctor orders oxygen, make sure you are instructed by a Home Care nurse on how to use the equipment and on when and how to order a new tank of oxygen. Oxygen is considered a drug and should only be given as directed. Never increase or decrease the amount of oxygen being given unless instructed by the doctor or nurse.
- ◆ Oxygen is administered through a mask or through nasal prongs, two little tubes that rest inside the nostrils. Make sure the mask fits snugly around the mouth and nose, but not too tight. Frequently check the skin under the straps that hold the mask in place looking for signs of irritation. The same applies for the area around the nostrils when using nasal prongs

Vomiting

Vomiting is often caused by the same things that cause nausea. Certain foods may induce vomiting: pressure on the stomach from blocked intestines might also cause it. Some people may feel they need to vomit at least once a day to relieve this pressure or to relieve the symptoms of nausea. Regular vomiting may be necessary. Make sure your friend does not become dehydrated or malnourished because of regular vomiting. If your friend is vomiting all the time, the doctor should be notified.

WHAT TO DO:

Many of the drugs used to relieve nausea will also help to decrease vomiting. If your friend is vomiting fairly frequently, these drugs can be given rectally in a suppository form.

- ◆ Stay close to your friend while she is vomiting and offer whatever assistance she may need. If she is vomiting all the time, have a small kidney dish or a bowl in reach at all times. When she is very weak and vomiting, keep her on her side to prevent choking. Remove any soiled linens or bowls quickly, as the smell of vomit may prolong or induce vomiting.
- ◆ Your friend may find it helpful if you support his forehead during vomiting. Wipe his face with a cool, damp cloth during and after an episode of vomiting. Once the vomiting has stopped, help your friend to rinse out his mouth. Keeping the mouth clean is very important. Stomach juices are very acidic and will cause irritation to the mouth, gums, tongue and lips. If your friend vomits while eating, rinse out his mouth and ask him to wait fifteen to twenty minutes before eating again.
- ◆ Offer lots of **clear** fluids (not milk) to replace those that are lost with vomiting. Gatorade® is a good choice.
- ◆ Ask your friend to sip fluids through a straw. (This helps to avoid gulping which can make a person feel full.)

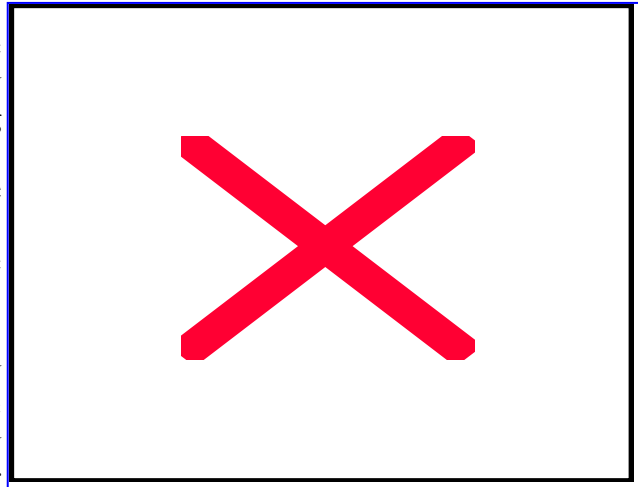
Fever or Chills

A healthy body functions best when its temperature is maintained at a normal level. Although this level may vary slightly from person to person, normal body temperature is considered to be 37 degrees Celsius (98.6 degrees Fahrenheit). A fever is a body temperature above 38 degrees Celsius (100 degrees Fahrenheit).

When the body's metabolic rate (use of energy) increases, (for example, during exercise) so will the body temperature. When a person is fighting an infection, the metabolic rate increases to do the work of getting rid of the infection. As a result, people fighting infections will have fevers. Since people with AIDS are often fighting infections, fever is a very common symptom.

Some bugs that cause infection are destroyed with an increase in body temperature. However, people living with AIDS often have prolonged periods of fevers that can get too high. These fevers exhaust the body and deplete its stores of energy, which need to be replenished with food and drink.

When a fever starts, your friend may complain of chills or shivering. As the fever progresses, he may feel hot and may have flushed skin, which is warm or moist to the touch. Fevers can last a few hours or even a few days. Some people will "spike" a fever; that is, develop a high temperature in a short period of time. When this happens (often at night) or when the fever breaks, your friend may sweat a great deal.



WHAT TO DO:

The first thing you should do is ask to take your friend's temperature. You can do this one of three ways: by the mouth with an oral thermometer; in the armpit with an oral thermometer; or rectally with a rectal thermometer.

Oral Temperature:

Place the thermometer under your friend's tongue and ask her to keep her mouth closed and to breathe through her nose. Keep the thermometer in place for three minutes. Remove the thermometer, read the temperature then clean the thermometer before returning it to its storage place. Do not use this method if your friend has difficulty breathing, is too weak to hold the thermometer in place or is prone to seizures.

Under the Arm:

Make sure that your friend's armpit is dry. Place the tip of the thermometer in the middle of his armpit and press his arm close to his body. Leave the thermometer in

place for five minutes. Open the arm, remove the thermometer and read it. Then clean and store it.

Rectal Temperature:

Explain to your friend what you plan to do and ask her to lie on her side. Lubricate the tip of the thermometer with a little bit of Vaseline® or K-Y Jelly® so it enters the rectum easily. Gently insert about an inch of the thermometer, read it then wipe it clean.

All Temperatures:

Whenever you take your friend's temperature, make sure to record the reading (including the date and time) in the care team log.

- ◆ Chills can be relieved by covering your friend with warm blankets. Once the chills are gone, remove any extra blankets to prevent unnecessary warming.
- ◆ Fevers can be controlled with aspirin or Tylenol. Aspirin should be avoided if your friend has a sensitive stomach or has problems with ulcers or bleeding. Make sure to follow the directions on the medication chart and to make a record whenever you give your friend one of these drugs.
- ◆ Fevers can be reduced with tepid or lukewarm sponge baths. The use of cold water or ice water is very uncomfortable and unnecessary. When giving your friend a sponge bath, make sure the room is warm. Some people like to use rubbing alcohol on the skin as a method for reducing fever, but alcohol has a tendency to dry the skin, which can lead to irritation.
- ◆ When your friend has a high fever, her body will release heat through the skin. A fan will circulate the air and help her skin release heat.
- ◆ Encourage your friend to drink as much as possible.

If your friend is sweating a great deal, make sure to change his clothing and bed linens so the skin is kept dry. You can place a towel behind his head or neck to absorb sweat.

Nausea

Nausea is a nagging feeling in the stomach, which makes you feel like you want to throw up. However, not everyone who feels nauseated will vomit. Nausea can be caused by particular illnesses, drugs, a sensitive stomach, constipation, the smell of certain foods or odours, sudden jerky movements during repositioning, emotional responses to fear, or anxiety.

WHAT TO DO:

There are several anti-nausea drugs available that work in different ways. You may want to ask the doctor to prescribe one of these drugs. If your friend is already taking an anti-nausea medication and it isn't working, check with the doctor to see if another drug might be more effective. Give medications for nausea thirty minutes before giving food, or give as directed by the pharmacist.

- ◆ Keep your friend quiet and free from unnecessary movement. Try reducing external stimuli. For example, close the blinds, turn off any music or TV, or ask visitors not to talk.

- ◆ Try placing washcloths soaked in cool water behind the neck or on the forehead.
- ◆ Breathing exercises such as slow deep breaths (in through the nose and out through the mouth) may help to alleviate nausea.
- ◆ Keep the stomach from being empty by offering several snacks throughout the day.
- ◆ Offer a couple of crackers to nibble on first thing in the morning.
- ◆ If the smell of food triggers nausea, offer your friend cold food or food at room temperature. (Hot food has a stronger smell.) Your friend may want to avoid being present while the food is being prepared. Use kitchen fans if you have them.
- ◆ Avoid liquid with meals. Save them for one hour before or after the meal.
- ◆ Avoid sweet or greasy foods. Increase the intake of salty foods unless your friend is having a problem with water retention.
- ◆ Encourage your friend not to lie down flat for at least thirty minutes after eating.

Diarrhea

Diarrhea (liquid or liquid-like stool) is the body's way of getting rid of something it doesn't want in a hurry. Sometimes it is a response to stress. Many people with AIDS have problems with diarrhea because of intestinal infections or because of drugs they are taking. In cases where diarrhea is severe, a person can become dehydrated in a short period of time. It's important to keep accurate records of how many times per day your friend has diarrhea and approximately how much fluid was lost. Help her replace her lost fluids by giving her lots to drink. Little squirts of diarrhea may be a sign of constipation.

WHAT TO DO:

Several drugs are available to help with diarrhea. Give them to your friend as directed and let the doctor know when the drug doesn't seem to be working. In some cases, drugs will help, although they may not provide complete relief.

- ◆ Listen to your friend and respond quickly. Diarrhea can come on quite suddenly. Offer whatever assistance, such as a commode or bedpan, he may require, and provide as much privacy as possible.
- ◆ After each bout of diarrhea, make sure you help wash your friend with warm water, and make sure her skin is thoroughly dried. Diarrhea is very irritating to the skin and can cause skin breakdown. If your friend is using adult diapers, change them as soon as they are soiled. If stool has dried onto the skin, use Vaseline® to soften the stool before gently wiping it away. You can protect the skin from stool by applying lots of Vaseline® or zinc oxide (available at the pharmacy) every time you help clean your friend. Do not use soap when cleaning your friend, as it will dry and irritate fragile skin.
- ◆ Make sure your friend drinks lots of clear fluids to replace those that are lost with severe diarrhea. Gatorade® is a good way to replace fluid and electrolytes. (Electrolytes are vital chemicals such as sodium and potassium that are necessary for many biological functions.) Decreased levels of electrolytes can result in serious physical and neurological problems.
- ◆ Avoid milk and milk products.

- ◆ Reduce the intake of fibre but don't stop it all together. Serve only cooked fruits and vegetables. Cooked bananas and applesauce may help to lessen diarrhea as well as replace important electrolytes.
- ◆ Go easy on the caffeine: reduce coffee, tea, cola, and chocolate intake.
- ◆ Some kinds of diarrhea will smell very bad, even offensive. This may make your friend feel embarrassed or ashamed. Be sensitive about this and avoid dwelling on the stench. Room deodorizers may help increase everyone's comfort level.

Constipation

Constipation is the blockage of the bowel with stool. It may be caused by illness, long-term use of narcotics, lack of activity, weakness, decreased fluid intake, or poor diet. Stress can also induce constipation. For example, your friend may be hesitant to ask for help with toileting or embarrassed about having someone present during toileting. Constipation can be very painful and sometimes will cause nausea and a decreased appetite. If left unattended, constipation can be life threatening.

WHAT TO DO:

Don't let constipation persist. The best way to treat it is with prevention. Keep track of your friend's bowel movements. If he is eating and hasn't had a bowel movement in two days, contact the doctor or Home Care nurse.

- ◆ If constipation is a problem, the doctor may want to prescribe a stool softener or a laxative. These drugs may come in the form of a pill or a suppository (given rectally) and should be given only as directed. Don't use drugs unnecessarily, as they can be very harmful.
- ◆ Some people with constipation do not respond to drugs or diet change. They might become very weak and may need an enema. An enema should be done by the Home Care nurse.
- ◆ When possible, try to get your friend to walk, exercise, or move about in bed. This might help move stool through the bowel.
- ◆ Try gradually increasing the intake of whole grains: cereals, breads, and baked products.
- ◆ Offer a variety of fruits (including prunes), vegetables and fruit juices (including prune juice) once a day.
- ◆ Increase fluid intake and try a hot drink with caffeine in the morning to wake up the bowels.
- ◆ If your friend is a smoker, having a cigarette may help to induce a bowel movement.

Problems with Sleep (Insomnia)

At some time or another, most people living with dying have difficulty falling asleep or getting enough rest. Insomnia can be caused by anxiety, fear, depression or other psychological or spiritual concerns. Physical problems such as pain, nausea, vomiting, coughing and diarrhea may well keep your friend awake.

WHAT TO DO:

Help your friend to pace her activities, with room for a natural slowing down at the end of the day. For example, avoid increased activity in the evening.

- ◆ Spend quiet times with your friend, listening and talking. Giving him the opportunity to express his feelings will do much to relieve his psychological concerns. If these concerns are related to practical issues such as financial matters, offer suggestions aimed to resolve your friend's concerns. Explain that difficulties with sleep are not unusual for a very sick person.
- ◆ Back rubs, massage, relaxation techniques, and mental imagery and warm baths are all ways of helping someone relax and eventually fall asleep.
- ◆ You can try gently stroking the hair and scalp while encouraging your friend to let all her thoughts float away, leaving the head spacious and empty. Make sure she is in a comfortable position and that she is not too cold or warm.
- ◆ Herbal tea or warm milk might help. From late afternoon onwards, avoid coffee, black tea, or colas, which contain caffeine.
- ◆ If insomnia is related to physical symptoms, do all you can to relieve them? Discuss the problem with the Home Care nurse or the doctor. Ask your friend what she thinks might help.
- ◆ Some people may need medication to help them sleep or to reduce anxiety. If your friend wants sleeping medication, make sure the doctor is aware of all other medications he is taking so the appropriate medication can be ordered.
- ◆ Confusion and agitation can cause restlessness and insomnia. Although both may occur throughout the day and night, frequently these problems are more pronounced at night. Certain medications other than sleeping pills may be required to help your friend with these problems.
- ◆ Remember it's okay for your friend not to go to sleep when you think she should. She may want to read, write, listen to music or watch TV for awhile. Sometimes, people who are dying or who are very ill become nocturnal; that is, they sleep through most of the day and stay awake through most of the night. Unless this change in your friend's biological rhythm is bothering her, you'll need to go along with it. Follow your friend's lead.

Skin Care

Helping your friend look after his skin is probably one of the most important comfort measures you can provide. The skin is the body's first line of defense against injury and infection. Once the skin is weakened, irritated or broken, pressure sores (bed sores) can develop. These cause great discomfort, and could become a serious threat to your friend's health.

Who is at risk for developing pressure sores? People who are bedridden or unable to move themselves, no longer able to control their bladder or bowels, underweight or overweight, undernourished, or experiencing more than one illness at a time. Many people with AIDS fall into more than one of these categories. And because their immune systems are so weak and fragile, any new infection related to a pressure sore could be life-threatening.

Pressure sores are caused when a part of the body is pressed continuously against a hard surface, such as a mattress or a chair. The bony parts of the body that support it when it is lying or sitting press harder against the surface than other parts of the body. Continued pressure cuts off the circulation of blood to these sites. Without blood to nourish them, skin cells will die.

WHAT TO DO:

The first sign of a pressure sore is redness on the skin. Relieving the pressure and rubbing around the site (not directly on it) with lotion will help stimulate blood circulation, and eventually the redness should go away.

If the redness does not go away, then there has been some damage inside the skin and it will take more time for the redness to disappear. You need to keep pressure off this site. Apply a simple protective dressing: a Home Care nurse will do this for you and will instruct you how to change the dressing if and when necessary.

When you do not tend to these reddened areas, the skin can deteriorate further until there is an open wound. In extreme cases, the skin can break down to the point where muscle and bone are exposed. These pressure sores will be very painful and will require complex wound dressings. A Home Care nurse will look after these dressings. When the nurse is not there, you will need to make sure the dressings are kept dry and clean.

Relieving pressure can be as simple as helping your friend reposition herself in bed every two hours. Each time you position her, check the skin, especially the pressure sites, for signs of skin breakdown. It is also a good idea to give the skin a gentle but firm rub each time you change her position. Using lotion or moisturizer helps to decrease friction on the skin. Your friend may not want you to rub her skin. Negotiate for as many rubs as possible; they are important.

- ◆ When you're moving your friend to a new position, make sure not to drag him across his bed or chair. Dragging causes friction, which will tear fragile skin. Make sure his new position does not put any pressure on red or open areas.
- ◆ Using special mattresses, for example air or foam, on the bed or chair can also help protect the pressure points of the body. Make sure the linens closest to your friend's skin are free of wrinkles and crumbs.
- ◆ Skin needs food to stay healthy. If the skin is already broken, your friend may need extra calories, protein, vitamins or liquids to help her body heal. When eating is difficult for your friend, liquid nutritional supplements such as Ensure® or Boost® may help (these are available at the pharmacy).
- ◆ Urine and stool irritate the skin and cause it to deteriorate very quickly. If your friend is having difficulty controlling her bladder or bowel, it is especially important to keep her skin clean and dry. The same applies to the person who has a fever and is sweating.

Another problem to watch out for is edema. Edema is the medical term for swelling due to an accumulation of fluid in the tissues of the body. As fluid builds up in the tissues, the skin is stretched and therefore becomes fragile and prone to break down. Sometimes

fluid may see through the skin. People with certain kinds of cancer (lymphoma, Kaposi's sarcoma) may have severe problems with edema. Take care to handle swollen areas gently, keep them elevated, and report any open areas or seeping of fluid to the Home Care nurse and the doctor. Always use two hands to move a swollen limb.

- ◆ Prevention is the key to managing pressure sores. Give your friend good and consistent skin care, and report any problems to the doctor or Home Care nurse.

Mouth Care

Your friend may get mouth problems: infections that won't go away, like thrush, cold sores, or "dry mouth." Dry mouth be a side effect of drugs or dehydration or the result of breathing through the mouth.

Careful attention to your friend's oral hygiene will help reduce the discomfort of oral symptoms and may increase his/her ability and desire to eat and drink.

WHAT TO DO:

Encourage your friend to brush his teeth twice a day or after every meal. If brushing is too painful then rinsing the mouth several times a day is very important.

- ◆ When your friend can no longer manage her oral hygiene, you will have to do it. If your friend is very weak and bedridden, mouth care should be done every two hours when you reposition your friend.
- ◆ Good mouth care involves cleaning the teeth or dentures, rinsing the mouth thoroughly, and when necessary applying Vaseline® or lip balm to the lips to prevent cracking. Each time you give mouth care, inspect the mouth for signs of irritation (redness) or new mouth sores. If you notice any irritation or mouth sores, report them to the Home Care nurse.
- ◆ When you use a toothbrush, make sure the bristles are very soft. You could use a baby toothbrush, or soften the bristles by pouring very hot water over them. Brush the teeth using gentle downward strokes starting at the gum-line. Don't forget to clean the back teeth! Keep a towel under your friend's chin to keep his clothes dry. A small kidney dish or basin can be used to collect your friend's spit.
- ◆ If rinsing is all your friend can manage, make sure that she is sitting up or lying on her side. Give small amounts of water and ask your friend to swish and spit.
- ◆ If your friend is unable to swallow or is unconscious, you can use moistened toothettes to give oral care. Toothettes are little swab sticks with a small piece of sponge on the end. The swab sticks are dipped into a rinsing solution then gently rubbed along the teeth, inside the mouth and between the gums and cheeks. If your friend bites down on the toothette, don't try to yank it out. Your friend's mouth will relax in a few moments and you can then remove the toothette. Some people use glycerin swabs, which are swab sticks packaged in a glycerin solution. However, many people complain about the awful taste.
- ◆ Depending on the condition of your friend's mouth, the doctor or dentist may have ordered special medications or rinsing solutions. Be sure to follow the medication instructions. Some preparations are meant to be swished in the mouth

then swallowed, others should be spit out, and some applied directly to a sore or tender area. Topical solutions to relieve pain can be applied before eating to prevent discomfort with chewing.

- ◆ Home-prepared rinsing solutions include one cup of water mixed with a teaspoon of either baking soda or salt. Mouthwashes that contain alcohol should be avoided, as they have a tendency to dry the mouth.
- ◆ If dry mouth persists after regular rinsing, sucking hard, sugarless candy can help to stimulate saliva production. When there is no saliva, the inside of the mouth can be lubricated with a little bit of K-Y jelly® or with artificial saliva preparations. (These are available at most pharmacies.) Lubricating the mouth before a meal is also a good idea.
- ◆ People with sore mouths should be encouraged to drink fluids or suck on ice chips or Popsicles and should avoid smoking and alcohol, both of which can irritate the mouth and throat. However, if your friend wants a cigarette or a drink, let him have it.

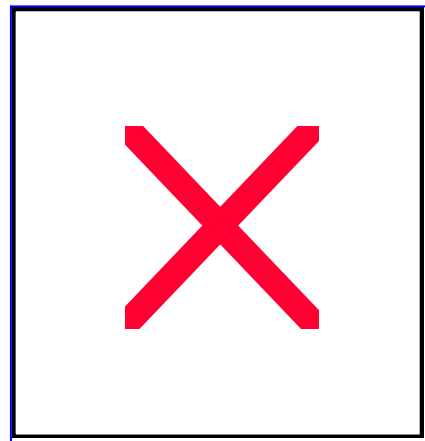
PERSONAL HYGIENE

Looking after personal hygiene is something your friend has managed all her life. The fact that she might need help with this can be difficult for her to accept and a serious blow to her self-esteem. Understanding this and being sensitive to her need for privacy and dignity are very important.

In most cases, your friend will not need a full bath every day, but the eyes, mouth and genital areas should be kept very clean.

Bathing

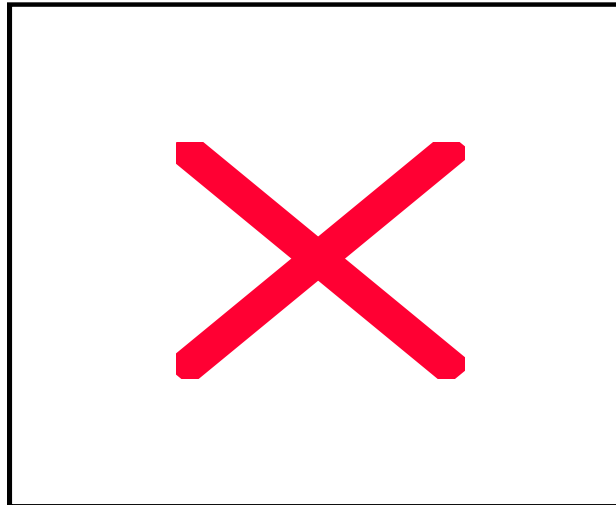
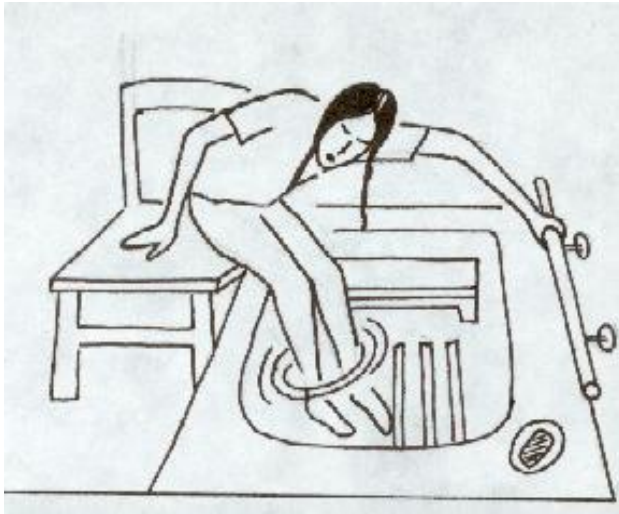
If your friend is able to move and is strong enough, he should be encouraged to bathe in the tub or shower. If getting in and out of the tub or standing for long periods of time is difficult, put a chair on a non-slip mat in the tub or shower for your friend to sit on. Having your friend sit in front of the sink is also a good idea. An Occupational Therapist can suggest some ideas for equipment, such as grab bars, which make using the bathroom a great deal safer.



Make sure to check the water temperature! Get your friend to test it first. If your friend has lost some of his ability to sense temperature, test the water yourself. Also, if there are other people in the home, let them know your friend is in the bath or shower. We all know what happens when someone flushes the toilet or runs a tap in the kitchen while the shower is running.

When you're assisting your friend with bathing, pay attention to fragile skin, any lesions (Kaposi's sarcoma), and the feet which may be extremely tender. A rule of thumb is to wash from head to toe. Make sure all soap or shampoo is thoroughly rinsed away. Soap left

behind can irritate and dry the skin. Using bath oils can help to prevent the skin from drying out.



If it is necessary, you can wash your friend in bed with water from a basin. It is better to wash a small area at a time while keeping other parts of the body covered with a flannel sheet or a large towel. The room should be warm and free of drafts. Every once in a while ask your friend if she is cold. Start at the head and work your way down changing your water as necessary. Make sure you dry each part of the body very well as you go. Use a fresh basin of water when you wash the genital area and dry it thoroughly.

Help your friend onto his side to wash the back and rectal area. (Once the back is washed and dried, your friend may like a back rub, with lotion. This is a great opportunity to give skin care.) A fresh basin of water should be used to wash the rectal area. Stroke gently towards the back, away from the genital area. Be careful when washing around the anus, as this area may be very tender due to hemorrhoids or diarrhea. Dry the area thoroughly.

- ◆ Once the bath is finished, ask your friend if she would like to use deodorant, powder, or a moisturizer. Then help her put on a clean set of clothes.

- ◆ Assist your friend to a comfortable position. He will probably be very tired and may want to rest after the bath.

Eye Care

Special care must be given to the eyes of people who are immuno-compromised. Eye infections can be very painful and are often highly contagious; wash your hands! Washing your friend's eyes daily will help prevent infections. And encourage your friend to wash her hands to avoid spreading infections to her eyes.

Each eye should be washed separately, with a different part of the washcloth, to prevent moving any infection from one eye to the other. Never use soap, only warm water. Each stroke should start from the nose side and move toward the ear side. Sometimes discharge from the eye will dry up and form a crust, so much so that the eyelid will be shut tight. Never try to pry the eyelid open. You can soften the crust by placing a cloth soaked in warm water on the eye for a few minutes. Then gently stroke the crust away and dry the eye thoroughly. Makeup can be removed from the eyes by using a small amount of moisturizer or baby oil.

If medications have been ordered by the doctor, make sure you give them as directed. Some medications are used to help fight infection; others to relieve pain and discomfort.

Tears keep the eyeball moist at all times. However, some people who are seriously ill can no longer produce tears and need to have artificial tears dropped into their eyes. This also applies to people who are unconscious or who sleep with their eyes half open.

Shaving

Shaving can be an important part of your friend's hygiene routine and his self-image. However, shaving may not be appropriate if he has open sores on his face.

- ◆ Using an electric shaver is much easier than using a razor blade, so we recommend it. If you use a razor blade be very careful not to nick or cut your friend's skin, which leaves an open area for infection. Razor blades should be disposed of in a sharps container. Electric shavers should be cleaned after every use.
- ◆ Moisturizing the skin after shaving is a good idea. Avoid using aftershaves that contain alcohol which will dry the skin.

Hearing Aids and Glasses

If your friend normally wears glasses encourage her to keep wearing them. Seeing the world clearly can help to keep someone oriented to the here and now. Make sure the glasses are clean before helping your friend put them on. Wearing contact lenses should be avoided by people who are seriously ill or have eye infections. The Home Care nurse will be able to assist you with the removal of contact lenses.

As with glasses, encourage your friend to wear his hearing aid. Have him instruct you on how it works and how it fits into the ear. If you have any difficulty with the aid, tell the

Home Care nurse, or get advice from a health hearing professional. Remember, hearing aids magnify all sounds, not just speech.

CONCLUSION

Now that you have some basic information on comfort measures, you're ready to help your friend relieve the pain and suffering of many physical symptoms related to serious illness. Take your time when you're providing care. Rushing to alleviate discomfort can sometimes result in more pain instead of relief. Listen to your friend and work with her when you're planning and providing care. Talk to other members on the care team, and record your caregiving in the care team log. When in doubt, ask for help from a health-care professional or from someone who's been part of a care team.

No matter how difficult or impossible a situation may seem, there is always something you can do to make things better. And remember, you can do it!

References

Marilyn Deachman and Doris Howell. [Supportive Care at Home: A Guide for Terminally Ill Patients and their Families.](#) Markham, Ontario: Knoll Pharmaceuticals Canada, 1991.

Christine Fegan et al. [AIDS Patient Handbook: A Manual for Families and Caregivers of AIDS Patients in the Home.](#) San Diego, California. 1989.

Susan Golden. [Nursing a loved one at home: A caregiver's guide.](#) Philadelphia: Running Press. 1988.

Diane Krasner. [The Treatment and Prevention of Pressure Sores.](#) Baltimore: Sinai Hospital. 1988.

Marg Raynard. [Providing Home-Centered Care to People with AIDS.](#) Toronto: The Canadian Council on Homemaker Services. 1990.

MEDICATIONS

**This entire chapter has been taken, with permission, from Andrew S. Johnson's "Living with Dying, Dying at Home." AIDS Committee of Toronto, (Canadian Cataloguing in Publication Data.)*

INTRODUCTION

Drugs are powerful. They can do good, and they can also do harm when poorly understood or misused. Many of us have a certain fear of drugs. They can cause unwanted side effects. They can be abused, and abuse can lead to addiction. It is important to treat drugs and the use of drugs with care and respect.

As you read through this section, you will see that drugs can be an ally in helping you provide excellent care for your friend. Many drugs are a critical part of the care of people with HIV and AIDS. And when someone is dying, drugs can play a pivotal role in relieving symptoms, easing pain and promoting quality of life.

The purpose of this section is to give you a better idea about drugs and how they work, and to reduce any fears you might have about helping your friend use them. This section has a medication chart to help you keep track of the drugs your friend takes. Make copies of this chart, keep it in a place that's easy to find, and make sure everyone uses it to record what drugs are taken and when they are taken.

This Section Will Cover:

- ◆ The categories of drugs
- ◆ Recording, storing and disposing of drugs
- ◆ The golden rules for giving drugs
- ◆ Giving medications
- ◆ The effects of drugs

THE CATEGORIES OF DRUGS

There are thousands of different drugs, and they're used in many different ways. However, you do not have to be a pharmacist to know enough about drugs to help your friend use them. You do need to know some of the basic categories of drugs, how you can get them and how to make sure they are used properly.

Prescription Drugs

A prescription is an order given by a doctor that allows a person to buy a certain amount of a specific drug and tells how to use it. Prescriptions are meant to control drugs that might be dangerous if misused.

A prescription drug will always have a label giving the name and dose of the drug, the doctor who prescribed it, the name of the person it is for and instructions about how it should be taken. It may have other warnings about how the drug should be used. (Some examples: “Avoid milk products,” “Finish all this medication unless otherwise directed.”) Here are three points to remember about prescription drugs.

1. Give them only to the person who is meant to get them. That’s the person whose name is on the label. Never give them to anyone but the person who is supposed to take them. And never take them yourself.
2. Follow the instructions. Specific doses and times are very important to make a drug work the way it should. Warning labels, such as “Take with food,” are often meant to help reduce the side effects of a drug, so pay attention to them.
3. Don’t run out. You need a doctor to write a prescription or place an order with a pharmacist. This can take time. So you should watch for supplies getting low. When there are only three or four days’ worth of a drug left, check with the doctor to see if the prescription is supposed to be refilled.

Over the Counter Drugs

Drugs you can buy without a prescription are called over the counter drugs (OTC’s). Aspirin, cold remedies and products for indigestion are all OTC’s.

The use of over the counter drugs is not controlled by prescription, but it is still possible to misuse these drugs. Your friend may use many OTC’s, and that’s all right. But here are some things to remember about them:

- ◆ Make sure the doctor knows about them. Some over the counter drugs should not be taken with drugs a doctor might prescribe to cure infection or relieve symptoms. Some OTC’s can make a prescribed drug work less well, or make side effects worse.
- ◆ Read the instructions and warnings. Over the counter drugs always have notes on the package to tell you the recommended dose, to warn about side effects and to say that people with particular conditions or illnesses shouldn’t take the drug. Make sure the drug is all right for your friend and that she isn’t taking too much.

Natural Preparations

Many people are very concerned about pumping their bodies full of chemicals such as drugs. Natural preparations have become increasingly popular as alternatives to traditional drug therapies.

Most natural preparations are derived from plants, roots and herbs. Responses to natural preparations vary from person to person, but for many people these preparations cause fewer side effects and can be more effective than other drugs. Some people have had great success using only natural preparations. But most experience to date suggests that a combination of both traditional and natural drug treatments is what works best.

You can find out more about natural preparations from naturopaths, homeopaths and specialists in (Native and) Chinese medicines. They will need to know what traditional drugs your friend is taking. And the doctor should be given a list of any natural preparations your friend decides to use.

Alcohol and Recreational Drugs

We use alcohol and other recreational drugs to affect our moods. This may be an important need for someone who is dying. The person you are caring for may have used alcohol or other drugs before, and may want to now.

REMEMBER:

The goal is to improve quality of life, and it is up to your friend to decide what that means. Some recreational drugs may be helpful. But, like any drug, some might react badly with prescription medication, cause serious side effects or keep the medicine from doing its job. This is especially true of alcohol, which can be dangerous when taken with many prescription drugs.

Encourage honesty about recreational drug use between your friend and her doctor. Your friend wants to feel better. The doctor can advise on what might help that happen, and what might hurt.

RECORDING, STORING & DISPOSING DRUGS

The Medication Chart

Keeping records of medications is very important, especially when regular doses of pain medication are being given. A medication chart is included to help you with this important task. Note that, for each medication your friend is taking, there is a space provided to write the name of the drug, the dose, times it should be given and what the drug's purpose is. Important notes about a drug (example: take with food) should be written in red. Write the date under each day of the week and the times the drug should be taken in each box for each day. When a drug is taken, circle the time (or write it in if different than scheduled) so other care team members know that the drug was given. Side effects can be written in by a nurse, doctor or pharmacist.

Storage

Here are some things to consider when deciding where and how to store drugs:

SAFETY

- ◆ Drugs should be kept in a safe place out of the reach of children or anyone who might take them accidentally. This includes your friend, if he can no longer control or record his own use of these drugs.

MAINTAINING DRUG QUALITY

- ◆ Heat and light can change the chemical composition of some medicines, so most drugs are best stored in a cool, dark place. Some drugs need to be kept in the refrigerator. Make sure they won't freeze and that children can't get at them. Many drugs also have an expiry date. If a drug is too old to use, throw it away and get a fresh supply.

MAKING SURE YOU HAVE WHAT YOU NEED

- ◆ Remember, it might take a few days to get a new supply of a prescription drug. You always need to know how much you have left of any drug and how long it will last – ***so keep all your stock of each drug in one place.*** Make sure someone is in charge of keeping inventory supplies.

STAYING ORGANIZED

- ◆ It is very easy to mix up drugs, especially when someone has to take many different ones. Try to organize the way you store drugs so it's easy to tell which is which. Keep the medication chart nearby for quick checking. You might try colour coding: mark each label with a coloured dot, then put a matching dot beside the drug's name on the medication chart. This will help you be sure you're giving the right drug. Many pharmacies sell medication dispensers, which can help to organize a long list of medications to be taken. These dispensers include a series of small compartments in which you can organize medications for each day of the week. Some dispensers will have, for each day, several compartments for different times of the day. Others come with alarms that go off when a medication should be taken. Check these dispensers out and find the one that suits your friend best. Whatever storage or labeling system you set up, make sure everyone who has to give drugs knows about it. They all have to make sure everyone who has to give drugs knows about it. They all have to be able to find drugs quickly, tell which is which, and keep them organized.

Disposal

Expired or unneeded medications should be flushed down the toilet.

- ◆ If you have to throw any drugs in the trash, make sure they are securely contained so children or animals can't get at them.

THE GOLDEN RULES FOR GIVING DRUGS

There are five golden rules that need to be followed when you give any medication:

- ◆ **THE RIGHT DRUG**
- ◆ **THE RIGHT DOSE**
- ◆ **THE RIGHT PERSON**
- ◆ **THE RIGHT ROUTE**
- ◆ **THE RIGHT TIME**

1) The Right Drug

Many people with AIDS take a lot of drugs, and many of those drugs have similar names. So it is very important when you are giving someone a medication to make sure it is the right drug. Check the entire name carefully.

Read the medication chart and the drug label carefully. Make sure the drug names match. Over time, many drugs become weaker or stronger, so check the expiry date to make sure it's still all right to give this drug.

- ◆ Never give any drug; even an over the counter drug; that is not on the medication chart without checking first with a nurse or the doctor.

2) The Right Dose

Many drugs are available in different doses, that is, different amounts or strengths. When giving medication, make sure you are giving the amount prescribed on the medication chart. For instance, the prescribed dose may be 500 mg, but the label on the drug you have might say the tablets are 250 mg. You have to give your friend two tablets to give the right dose.

- ◆ Giving more than the prescribed dose of a drug will not necessarily make it work better or faster. Never increase or decrease the dose of a drug unless instructed to by a doctor or nurse.

3) The Right Person

The rule is important in settings where more than one person is being taken care of. Nurses in hospitals, for example, must always make sure they are giving the right drug to the right person.

Your care team is probably taking care of only one person at home. But if you are caring for more than one person, always make sure to check the person's name on the label of the drug you are about to give.

4) The Right Route

Drugs come in different forms: pills, liquids, ointments, drops, injectables. (We will discuss all these later in this section). A drug's form usually dictates the route by which the drug gets into the body.

Most drugs can only be given by one route. Usually the right route is obvious – but sometimes it is not. Some pills are meant to be put under the tongue, not swallowed. Some ointments are dabbed inside the eyelid, not rubbed on the skin. Drops may go in the nose or eyes or ears. Make sure you know the right route for the drug you are giving.

Sometimes the usual route for a drug can't be used, but the drug the person needs may be available in a different form that can be given by a different route. For example, a person in a coma cannot swallow pills, but there may be a liquid form of the same drug that can be given under the tongue, in the cheek, rectally or, as a last resort, by injection.

5) The Right Time

Most prescription drugs are meant to be given on a regular schedule or at a specific time, for example: every two hours, twice a day, with meals. These instructions will appear on the drug's label, but should be written on the medication chart too.

- ◆ The safest thing to do is to give the drug as scheduled. However, when that can't happen or when a dose has been missed, it is all right to give a drug up to a half-hour before or after the time it was scheduled to be given.

This rule can change when it comes to certain drugs:

PAIN MEDICATIONS.

The section on pain will tell you more about drugs meant to relieve pain and how they are given. **

PRN MEDICATIONS.

Some drugs are prescribed "PRN." These initials stand for *pro re nata*, a Latin term used on prescription forms that means, "for something when it begins"; in other words, "take when necessary." These drugs are usually used to treat specific symptoms as they happen, such as fever, vomiting or anxiety.

PRN drugs must be used carefully. They have the greatest potential for being misused or abused. Most PRN medications will come with instructions that limit how much of the drug can be taken in a twenty-four hour period. Excessive use can have serious side effects.

Any PRN medications your friend is taking should be listed on the medication chart, even though they are not given on a regular schedule. Don't forget to record on the chart the time your friend took any PRN drug, how much and what effect it had.

The Sixth Right

Your friend's right.

- ◆ Anyone asked to take a drug has the right to know what the drug is, what it is supposed to do and what the possible side effects might be.

It is the responsibility of doctors, nurses and pharmacists to provide this information. It is *your* responsibility to tell these things to your friend if he doesn't know about them already. You should always do this when a new drug is prescribed. And even when you are giving your friend a drug used before, always say what the drug is. If you think you need to, say again what it is for.

Any person has the right to refuse any or all drugs. Never force anyone to take any medication. Remember that it is your friend's body, your friend's life, and your friend is in charge. You can remind someone what a drug is for, you can suggest what may happen if it's not taken – but you *cannot* force it.

The best thing to do if someone refuses a drug is try to find out *why*. Perhaps it makes your friend feel sick. If it's a pill, maybe it is too hard to swallow. If it's an ointment or injection, maybe it hurts too much. Try to find out. Record the reasons on the medication chart and in the care team log, and let the doctor or nurse know. There may be another drug, or another form of the same drug given in a different way, that could be used instead.

GIVING MEDICATIONS

Here are different forms medications can come in; how they work and some helpful hints on how to give them.

Oral Medications

Oral medications include anything that goes in the mouth and is swallowed: pills, capsules, tablets, lozenges, syrups and elixirs. Most of these are meant to be swallowed right away. However, some oral medications, such as lozenges, are sucked or chewed. Lozenges should not be swallowed whole.

Oral medications are absorbed in the stomach or intestines, then circulated through the bloodstream to the rest of the body. Some oral medications will act quickly, but not for long. Others are absorbed more slowly, take longer to act and last longer. Generally, a pill will take effect in fifteen to thirty minutes. But remember: how quickly any drug acts and how long it works will vary from person to person.

HOW TO GIVE THEM

Giving medication by mouth is the safest and easiest way to get a drug into the body. Here are the things to remember:

- ◆ Wash your hands before you handle the drug.
- ◆ For pills, capsules, or tablets, offer a glass of water or juice to help your friend swallow. Suggest she take a sip of fluid before taking the pill. This

will lubricate her mouth and help her swallow. Avoid milk unless you're told the drug should be taken with milk.

- ◆ Some pills and capsules can be very small and slippery and may be difficult for your friend to handle. Try putting them in an eggcup (available in the kitchen section of most stores). This will make it easier for your friend to see the drugs and get them into his mouth.
- ◆ Help your friend sit up, or raise her head, to make swallowing easier. Never give an oral medication to someone who is lying down. A person who tries to swallow while lying might choke.
- ◆ If your friend cannot swallow pills, try to get the medication in a liquid form. If a liquid form isn't available, you can crush the pill between two spoons, then mix it with liquid, pudding or apple sauce.
- ◆ If your friend spits out the drug or vomits, try to give it again in fifteen minutes. If that doesn't work, ask the doctor if there is another form of the drug, or if there is something your friend can take to help prevent vomiting.
- ◆ Some drugs are hard on the stomach. Don't give oral medications on an empty stomach unless that's what the instructions say to do. Check the labels on the package or bottle and do what they say.
- ◆ Before you record on the medication chart that an oral medication has been taken, ***make sure your friend has swallowed it.***
- ◆ ***Never*** try to give oral medications to someone asleep, unconscious or in a coma.

Sublingual Medications

“Sublingual” means “under the tongue.” Some medications are not meant to get as far as the stomach. They are put under the tongue, where they dissolve and are absorbed into the bloodstream. Many sublingual medications act very quickly. **Buccal** medications are medications that are placed in the inside pocket of the cheek.

HOW TO GIVE THEM

- ◆ Wash your hands first.
- ◆ If possible, ask your friend to rinse out his mouth before giving these medications. The drug will be absorbed better in a clean mouth.
- ◆ Put the pill under your friend's tongue or in the inside pocket of the cheek. Explain that it should not be chewed, and that it has to stay under the tongue until it is completely dissolved.
- ◆ Don't give any fluids or food until the pill is gone.

Nosedrops

Nosedrops go directly inside the nose, where they act on the mucous membranes to loosen nasal congestion, reduce irritation and swelling or relieve allergy symptoms.

HOW TO GIVE THEM

- ◆ Gather the medication you need, then wash your hands.

- ◆ Help your friend lean her head back. If she's lying down, a pillow under her shoulders can help.
- ◆ Push up the tip of the nose and place the dropper a third of an inch into one nostril. Squeeze the medication in. Make sure you give the right amount. Then do the same for the other nostril.
- ◆ Ask your friend to leave her head back for a few minutes.
- ◆ Nosedrops may cause some throat irritation, so offer your friend a sip of a fluid.
- ◆ Wash your hands.

Eyedrops and Ointments

Some medication in liquid or ointment form go inside the eyelid to act directly on the eyeball or be absorbed into the bloodstream. Eyedrops come in a small bottle with an eyedropper attached to the lid, or in plastic bottles with a tip for squeezing drops out of. Eye ointments usually come in small, squeezable tubes.

Eyedrops and ointments are used to soothe irritation, relieve pain, fight infections, lubricate the eye or dilate the pupils.

HOW TO GIVE THEM

- ◆ Get the right bottle or tube and some tissues. Wash your hands.
- ◆ Ask your friend to sit or lie with her head leaning back.
- ◆ You may need to clean her eye of any crust or discharge. Using a clean, moistened tissue, wipe gently from the inside of the eye, near the nose, to the outside. To avoid spreading infection, use a different part of the tissue for each stroke; never use the same tissue for both eyes.
- ◆ Ask your friend to look away from you. Gently pull down her lower eyelid with the fingers of one hand. If you are right-handed, use your left hand to do this. If you are left-handed, use the right. You want your best hand free to squeeze in the medication.

For Drops:

Gently squeeze the prescribed number of drops into the lower eyelid. Do not let the eyedropper or the tip of the bottle touch the eyelid. Ask your friend to blink once.

For Ointments:

Squeeze a thin line of ointment from the inside to the outside of the eyelid. Ask your friend to squeeze her eye shut for a second. If necessary, you can help with this by gently squeezing her eyelids together.

- ◆ Do not put eyedrops or ointments directly into the tear duct. That's the small pore on the edge of the lower eyelid nearest the nose.
- ◆ Wash your hands when you are done.

Eardrops

Eardrops are put directly into the ear canal, where they help to treat infections, relieve pain, or dissolve wax.

HOW TO GIVE THEM:

Get the medication you need, and some cotton swabs or Q-tips. Warm the medication by rubbing the tube or bottle between your hands or by putting it in warm water for a few minutes.

- ◆ Wash your hands.
- ◆ Ask your friend to lie flat, on his back and turn his head so the ear you need to treat is facing upwards. You need to get at the ear canal easily. For a child younger than three, gently pull the earlobe down and toward the back. For anyone older, pull the side of the ear up and back.
- ◆ If there is any discharge, wipe it out with a cotton swab. Do not push the swab into the ear canal.
- ◆ Squeeze the prescribed number of drops directly into the ear canal. Do not let the dropper touch the ear canal.
- ◆ Ask you friend to stay still for about ten minutes; you can then treat the other ear.
- ◆ Wash your hands when you are finished.

Suppositories

A suppository is a medication moulded into a small solid shape that can be put into the rectum or vagina. The drug dissolves and is absorbed into the bloodstream through the rectal or vaginal lining. This route is a useful alternative when medications cannot be given orally.

- ◆ Suppositories are most often used to relieve pain, constipation, nausea, vomiting or fever, or to treat infection.

HOW TO GIVE THEM:

Most suppositories are kept in the refrigerator. But you shouldn't use one right out of the fridge; it will be cold, and that could be uncomfortable for your friend. Let it warm up first. To give a suppository, you will need latex gloves and some lubricant. Collect everything you need.

- ◆ Wash your hands.
- ◆ Help your friend get into a position that will make it easy to insert the suppository. For a rectal suppository, the best position is lying on the side, with the upper leg bent forward. For a vaginal suppository, it may be more comfortable for your friend to lie on her back with her knees pulled up and spread apart.
- ◆ Put on the gloves, lubricate the suppository, and tell your friend what you are doing. Make sure he is ready before you insert the suppository.

If it is a rectal suppository

Ask your friend to take a deep breath and try to relax the muscles around the anus. (Slow, rhythmic deep breathing will help to relax the muscles). Spread the buttocks with one hand to expose the anus. Then, with the other hand, slide the suppository inside about two inches. This may give your friend the urge to defecate. Ask him to hold on: the suppository needs about ten to fifteen minutes to dissolve.

If it is a vaginal suppository:

Ask your friend to urinate first. Spread the lips of the vagina with one hand. Use the forefinger of your other hand to insert the suppository about two inches into the vagina. Use a sanitary pad for any drainage or discharge.

- ◆ Ask your friend to lie still for 10 – 15 minutes while the suppository dissolves.
- ◆ When you are finished, throw away your gloves and wash your hands.

Topical (Skin) Medications

Topical medications, usually in the form of creams or ointments, are applied directly to the skin. They act where they are applied, to treat itching, rashes, irritation or burns, or to fight infection. But they are also absorbed through the skin into the bloodstream, so they can affect the entire body.

Some topical medications are used when a drug needs to be absorbed over a long period of time. These medications come in patches, which are applied directly to the skin and left there for a prescribed period of time. A new patch should never be applied before the first patch is removed.

Some people may be allergic to some topical medications. When a topical cream is used for the first time, try a little bit on a small spot to see if it causes a reaction, such as redness or swelling. Sometimes a smaller dose may help. This does not mean using less of the cream, but getting a new prescription that has less of the drug in it. The actual amount of the drug in a cream or ointment may be very small, maybe only one or two percent. But even small differences can have a big effect.

Because they can be absorbed through the skin, you should always wear latex gloves when applying topical medications. A drug that is meant to help your friend may not be for you.

HOW TO GIVE THEM:

- ◆ Wash your hands and put on gloves. There may be excess medication on the skin from a previous application. Sometimes this should be wiped away before you apply the next dose. Use a clean tissue, and then change your gloves before putting on new medication.
- ◆ Rub on the cream or ointment using smooth, gentle strokes in the direction of hair growth. Make sure to put the cream only where it's supposed to go. Some topical medications can irritate skin that doesn't need to be treated with the drug.

- ◆ Try to keep the medication off clothes or bedding. Some creams will stain fabrics.
- ◆ When you are done, remove your gloves, throw them away, and wash your hands thoroughly.

Inhalants

Inhalants are medication breathed directly into the lungs. They can be given with hand held inhalers (the puffers some people use to relieve an asthma attack) or with special vaporizing machines called nebulizers. Many people with AIDS will know about nebulizers because they receive aerosolized pentamidine, a drug commonly used to prevent PCP pneumonia.

Drugs given by inhalation are absorbed almost right away in the lungs, and can work quickly. But some inhalant drugs have serious side effects. They should only be used as directed.

HOW TO GIVE THEM:

If your friend is using a nebulizer to take an inhalant drug and needs your help, make sure you understand how the machine works. (A nurse can show you). To use a hand held inhaler, your friend must be alert and able to understand and help you.

- ◆ When your friend is ready, shake the inhaler, remove the mouthpiece cover, and ask your friend to exhale.
- ◆ Hold the inhaler with the tube pointing upwards, and place the mouthpiece one or two inches away from your friend's mouth.
- ◆ With his mouth wide open; ask your friend to take a deep breath in while you push down quickly on the inhaler tube. This shoots a mist of the drug into the lungs with each inhaled breath. Repeat as directed in the instructions.
- ◆ Replace the mouthpiece cover and put the inhaler away.

Injectables

Injectable drugs are given by injection, a shot with a needle tipped syringe. Injections are given at different places on the body, depending on the drug and what it is meant to do. The drug is absorbed into the bloodstream from the muscle or fat tissues where the injection is done. Injections are used when drugs cannot be taken by mouth, when a particular drug is only available in an injection form or when the drug has to get into the bloodstream fast.

HOW TO GIVE THEM:

In most cases, injections will be given by a doctor or nurse. But your friend may need injections often, or when a medical professional is not there.

You can learn how to give injections correctly – but the point is, you must learn. **NEVER GIVE AN INJECTION UNLESS YOU HAVE BEEN TAUGHT HOW TO DO IT.** You must be confident that you know what you are doing, and your friend must share your confidence. If you're not confident, you risk injuring the trust you and your friend share. You could injure your friend with a bad injection or injure yourself by accidentally sticking yourself with the needle.

The safest way to learn how to give an injection is to have a doctor, pharmacist or nurse teach you. Nurses are generally the best. They have the most experience in giving injections. If you have to give injections, talk with the nurse about it, and make time to learn how. Once you have been taught, you will see how easy it is.

Intravenous Medications

Intravenous (IV) medications are given directly into the bloodstream, using a needle or catheter (a tiny tube) that is put into a vein and left there. The needle or catheter is attached to an IV set-up; a longer tube leading to a hanging plastic bag that holds the medication. There may be special ports along the tubing where other drugs can be injected into the IV tube. An IV set-up might include a small electronic pump to monitor and control the flow of the drug.

An intravenous set-up is used when medications must get into the bloodstream fast, when a large amount of the medication is needed, or to avoid repeated injections. IV set-ups can also be used to give people fluids, extra nutrition or blood transfusions.

You will **not** have to know how to connect your friend to an intravenous set-up. A doctor or nurse must do this, and must check the set-up regularly to make sure everything is working. You may need to know how to tell when an IV bag is running out and how to change it. A nurse can give you instructions on this procedure. Mostly, you will need to check that your friend is comfortable.

The place on the body (usually the arm) where an IV needle or catheter goes into a vein can get irritated, so this area should be securely covered by a sterile dressing to keep it clean and to make sure that movement doesn't disturb the tube. Check for swelling, redness or other signs of infection frequently. Let the nurse know if anything looks wrong. The needle or catheter may have to be put somewhere else.

Movement can cause an IV tube to get tangled around an arm or leg. This may be uncomfortable and frightening. If it happens, calm your friend and gently help her get untangled and comfortably settled again.

If an electronic pump is attached to your friend's IV set-up it may sometimes beep or buzz. This can be alarming; it sounds like something is wrong. Make sure you know what these sounds mean so you can reassure your friend about them, and so you can respond to the machine's signal. A nurse can explain this to you.

When you bathe your friend, make sure the dressing used to protect the IV needle or catheter is well covered with either Saran Wrap® or a plastic bag. It's important to keep the dressing dry.

Some people with AIDS have had a special IV catheter surgically implanted into a large vein through the chest wall. These devices are used for specific reasons and must be treated with great care. Either a portion of the catheter will extend out of the chest wall (Hickman catheter) or a small injection port will be left under the skin (Portacath). In either case, the catheter or port site must be kept very clean. Because these set-ups are connected very close

to the heart, you will need to practice excellent infection control. Make sure you get the nurse to explain how to take care of one of these devices.

THE EFFECTS OF DRUGS

Drugs have many possible effects, both physical and emotional. You should always watch for any effects medications have on your friend, and record significant effects on the medication chart.

Desired Action

The desired action of a drug is the normal, predictable effect it is supposed to have. But other factors about us or our environment may affect the desired action. For example, when we take aspirin for a headache, the headache is supposed to go away. But if I am working a jackhammer and have an ulcer, aspirin may not be enough to get rid of my headache, and it may upset my stomach. The most important thing to remember about desired action is that different people may respond differently to the same drug.

Side Effects

Many drugs will cause effects other than their desired effect. As with desired action, side effects can differ from person to person. The side effects of some drugs are very common, but can be reduced with other drugs or with non-drug therapies. Some drugs are used especially for their side effects. For example, Scopolamine is an anti-nausea drug with a side effect of drying up excess secretions.

Side effects may be minor, or they may be serious enough that they outweigh the benefit of the drug. Make sure you always record side effects of any drug on the medication chart and report them to the doctor or nurse. They will decide whether to stop the drug, reduce its dose, or replace it with something else.

Toxic Effects

Prolonged use of a drug at high doses can have toxic effects. Usually the liver and kidneys help clean drugs out of the body, but when they are not working well a drug may build up in the body. Too much of any foreign chemical in the body can become poisonous and can sometimes cause death.

Drugs that are particularly toxic, such as those used in chemotherapy for cancer, are monitored by regular blood tests that show the level of drug in the body. These tests can tell if the dose of a drug should be reduced or increased.

Make sure your list of important phone numbers includes the number of your local poison control centre. If you have to call, use the medication chart to tell the centre which drugs the person you are caring for is taking.

Drug Reactions

Some drugs react with each other, canceling out desired effects or creating serious side effects called drug reactions.

People with HIV and AIDS often take many different drugs at the same time. The doctor must always know about all the drugs your friend is taking. You should never give drugs the doctor has not prescribed without the doctor's approval. If more than one doctor is treating your friend, make sure *all* of them have a list of *all* the drugs being used.

Allergic Reactions

We can be allergic to many things, including some drugs. People with AIDS may be particularly prone to allergic reactions because their immune systems are weakened. Substances that might not have bothered them when they were completely healthy might now have serious side effects.

Allergic reactions to drugs can vary, depending on the person and the drug. Mild reactions include itchiness and redness of the skin, swelling of the nasal mucous membranes (making a person feel stuffed up) and nasal drip. More severe reactions include rashes or hives. The most serious allergic reaction is called an anaphylactic reaction. This is the sudden swelling and constriction of the air passages in the throat. Anaphylactic reaction is very dangerous. Air to the lungs may be choked off completely, and the blood pressure may drop, causing anaphylactic shock. Special drugs can correct this, but a fast trip to a hospital emergency will be necessary.

Allergic reactions to drugs can happen very quickly. The moment you suspect an allergic reaction, call the doctor. If you suspect an anaphylactic reaction, call an ambulance first. A few minutes can make all the difference.

Where to Find out More

A detailed list of all the medications used in palliative care would take volumes. You do not need to know about all of these drugs. But you may want to find out more about the ones your friend is taking.

Your best source of information about medications is your pharmacist. Few people realize how helpful pharmacists can be, and how much more they know about drugs and drug reactions than some doctors or nurses.

As a care team, gather the information you need and record it in the care team log or in notes you can attach to the most appropriate sections of this manual. Share what you found out. You will be making the care team stronger; and that will help the team provide the best possible care and quality of life for your friend.

References

Susan Golden. [Nursing a Loved One at Home: a Caregiver's Guide](#). Philadelphia: Running Press. 1988.

Nashine Ginwenimawazawin

Maryanne Wagner (Editor). [Drugs](#). Revised. Springhouse, PA: Intermed Communications, Inc. 1983.

ANTIVIRAL DRUGS

INTRODUCTION

This section will outline the drugs (called anti-retrovirals, combination drugs or protease inhibitors) available, how they work, the side effects and some of the issues to consider. For more detailed and updated information, please refer to your doctor, the Resources section or call CATIE (Community AIDS Treatment Information Exchange) 1-800-263-1638.

To understand how the new drugs work, a more detailed description about HIV/AIDS is necessary.

How HIV Reproduces:

HIV enters white blood cells and forces them to begin producing more HIV. This is a process; it takes a number of steps for the conversion to happen. At each step, there is the possibility of disrupting the conversion process.

1. HIV attaches to receptors on a host cell, releasing its genetic material as RNA.
2. An enzyme called *reverse transcriptase* converts the viral RNA into DNA. Drugs called RT inhibitors can interrupt this process.
3. An enzyme called *integrase* splices the viral DNA into the host cell's chromosomes. Scientists hope to develop a new class of drugs called integrase inhibitors, which will add another obstacle.
4. The infected cell now produces viral RNA, which generates proteins and other virus constituents.
5. The protease enzyme cuts the viral proteins into shorter pieces. Protease inhibitors foil replication by neutralizing the enzyme. They're even more effective when combined with RT inhibitors.
6. The newly milled proteins fold together to form new HIV capsules.
7. Completed HIV capsules bud away to infect other cells.

How quickly the immune system fails and the vulnerability to opportunistic infections and other illnesses is associated with the rate of decline in CD4 and T-cell levels. The rate of CD4 and T-cell decline varies between each person and isn't consistent throughout the different stages of the progression of the disease.

HIV needs the enzyme protease to replicate. Antiretrovirals attack a different enzyme. There is question as to when to start therapy and which combinations to use. Viral load testing is very valuable because it gauges very clearly when to consider starting and whether or not therapy is working.

The drugs may not work in other areas where HIV can hide, such as in the lymph nodes, the brain, and also in tissue.

T-4 and CD4 Cell Counts

This is a laboratory measurement that can show what the status of the immune system is. It can also reflect how effective treatments are. If the T-4 cell count increases, it probably means treatment is working. If the T-4 cell count is decreasing, it may mean other choices have to be thought about, with the help of a doctor. A lower T-4 cell count is better, because that means there are less particles of HIV. In a CD4 count, the higher the count, the healthier the immune system is.

Viral Load Testing

Viral load shows if the antiviral therapy is working or if changes should be made. Viral load:

- ◆ Measures how many particles of HIV are in the blood.
- ◆ Helps in making decisions about therapy, such as when to start and whether the therapy is working.
- ◆ Does not measure how much HIV is in the lymph nodes, organs, brain and tissue.

What the Drug Treatments Try to Do:

HIV is called a retrovirus, made up of two strands of RNA that are wrapped in a protein coat. Drugs that are used to fight HIV are called antiretrovirals. They are often called antivirals for short. Antivirals slow down or temporarily stop the virus from reproducing itself. When antivirals are able to slow replication, there are fewer viruses in the blood and the T4 cell count increases. Antivirals are being studied for what kind of side effects and long term effects they cause.

3TC became introduced in. Oh gee, let me think, probably the latter part of 1995. I believe that's when it came into effect. It was looking really promising. It was attacking a different portion of the disease, (unlike) AZT (that) would attack the cell, replicate, and leave. 3TC was attacking the virus before it was getting into the cell.

It was attacking so only half of the virus was getting into the T-cell, that's what 3TC did. AZT basically confused it as it went inside and brought it out so it couldn't replicate half the time.

Saquinavir became available in June, in 1996, and they were saying that this is the miracle drug. That's what they were calling it. With a combination of the three (AZT, 3TC, and Saquinavir), they were calling this the miracle drug.

It was a protease inhibitor. What it was doing was attacking another side of the virus. When the virus entered the T-cell, the virus would replicate, but the Saquinavir removed a certain protein from the cell that the virus needed to survive. So, when it replicated itself, this protein was missing, it couldn't live without it, so it would die.

Nashine Ginwenimawazawin

So, this is exactly what is happening now. The AZT is attacking it as it's coming toward them and it's killing off half of them. The AZT is confusing it, as it goes in. The 3TC is standing guard and attacking it as it comes forward. The Saquinavir is built to remove a protein that AIDS and HIV needs to survive. So, when it's leaving and it's replicated, it can't survive, so it dies. Which, of course, means that it's not killing off as many white blood cells anymore, and they're able to replicate themselves.

It's like a big army, right? It's like the army's not dying off anymore. The army's staying alive; they found a way to stay alive.

That's how they used to put it to us. They used to see it as an army and this army (HIV) was attacking this army (T-cells) and killing everybody off. Well, now, this army (T-cells) has gotten smart and they found a way to keep alive, and what they're doing is killing these guys (HIV) off, so this army's (T-cells) actually doubled.

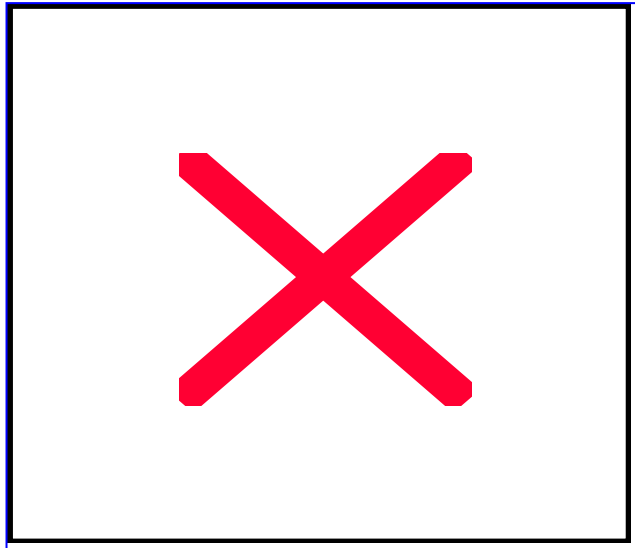
They're in a battle; it's like a constant battle, twenty-four hours a day, three hundred and sixty-five days a year. It's like a war going on inside that's what it is. The only difference is now, there's been so many years that they've been studying this thing that they've now found something that... they've found some control, finally. They've found something to control it finally after all this money and after all these years.

So, everyone is basically happy that there is something to control the disease but they're lost in which direction to go now. I guess I'm the same as everyone else.

Of course, they have no proof as of yet, whether or not these drugs are going to work for us. They do their tests and the terms between doing the tests on the new drugs and releasing them have become much shorter. They used to test them for two, three years; now, they're testing them for six months and releasing them. So, we don't know what kind of toxicity these drugs are releasing into our body. We have no idea what kind of long-term effects will happen from these drugs.

It's the stomach, the liver, things like that. These are all the things that we need to keep our engines running. If those parts of the engine have deteriorated to the point where these things can no longer filter blood...they have deteriorated to the point where they're worthless, these drugs would be pointless for these people because it just can't filter the drug through the body.

You can't bring a liver back to life. You can't bring back your stomach lining. With your immune system trying to fight all these things off and at the same time putting new pills in, it comes to a point where it's just going to have to give up. There's just too much for it to deal with. It just can't deal with everything. It has to give something up to deal with something else.



So, if it's dealing with your liver, then it's not dealing with the HIV. This is why there are still people dying. They have deteriorated too far. There's no coming back.

- an Aboriginal person living with HIV/AIDS

Antivirals may have only short-term effects if HIV can find ways to protect itself from the drug. HIV can produce copies of itself that makes antiviral drugs unable to work. When HIV begins to protect itself and the drugs no longer work, it is called developing resistance. When resistance is developed to one drug, it is possible that resistance to other drugs may also happen.

Taking two or more anti-HIV drugs is called combination therapy. One of the benefits of combination therapy is that it is harder for HIV to develop resistance to antiviral drugs.

Antiviral Drugs

There are three general types of antiviral drugs:

- ◆ nucleoside reverse transcriptase inhibitors,
- ◆ non-nucleoside reverse transcriptase inhibitors (NNRTIs)
- ◆ protease inhibitors

Nucleoside Analogues

Are a class of drugs that include AZT, ddI, ddC, d4T, and 3TC. HIV needs to change its genetic material (RNA) to match the genetic material of the cells (DNA). Nucleoside analogue drugs work by interfering with the process, where the HIV changes to match the cell. RNA and DNA are genetic material and both are made up of nucleosides. An analogue is a chemical compound that is similar to another. Nucleoside analogues are compounds that are almost the same as the basic components of genetic material. As the viral RNA is being turned into DNA, nucleoside analogues bind to the DNA and block the conversion process.

SIDE EFFECTS OF NUCLEOSIDE ANALOGUES

- ◆ nausea, vomiting, headaches, diarrhea, chills, anorexia, dizziness, confusion, fatigue, rash, muscle pain and fever. Not everyone experiences them.
- ◆ Some people can adjust to the side effects over time. Some people may drop the dose and then gradually increase the dosage to the recommended level. Others may not be able to take them at all.

EXAMPLES:

- AZT** - (azidothymidine, zidovudine, ZDV, or Retrovir)
- ddI** - (didanosine, dideoxyinosine, or Videx)
- ddC** - (dideoxycytidine, zalcitabine, or Hivid).
- d4T** - (stavudine, or Zerit)

3TC - (Lamivudine, or Epivir)

Non-Nucleoside Reverse Transcriptase Inhibitors or (NNRTIs)

This is a class of drugs that works against reverse transcriptase (it has a different chemical structure). There isn't much known about the effects and side effects of the drugs. They are being used in clinical trials. Only **Nevirapine** is available in Canada.

Nevirapine (Viramune) may be used when someone has developed resistance to AZT. It is currently being studied. What is currently known about it is that it may be able to cross the blood/brain barrier, which would benefit people who have developed dementia. In addition, it may also cross the placental barrier and lower the chance of a pregnant woman from transmitting it to her baby.

Protease Inhibitors (or Proteinase)

An inhibitor is a substance that stops a chemical reaction. HIV has a reproductive cycle with different stages. Chemical messengers called enzymes help HIV reproduce. There are drugs that can slow down the actions of these enzymes, which will stop the virus from reproducing as quickly. One of the enzymes that HIV needs is called reverse transcriptase (RT). RT inhibitors work early in the HIV's life cycle, when it has just infected the cell.

Protease is an enzyme HIV needs during the later stage of the reproductive cycle. Protease inhibitors slow down or stop the action of this enzyme. When it can't do its work, HIV makes defective copies that can't infect cells. Protease inhibitors may reduce the amount of HIV that can be measured in the blood, increase T4 cell counts and protect against the development of opportunistic infections.

They work best when combined with one or two reverse transcriptase inhibitors.

Side effects, benefits, and the best combinations of Proteinase inhibitors are currently being studied.

EXAMPLES:

Saquinavir	(Invirase)
Indinavir	(Crixivan)
Ritonavir	(Norvir)
Nelfinavir	(Viracept)

Experimental Drugs

New drugs take a long time to become available. It can take up to ten years to develop, test, evaluate, and then approve drugs. Experimental drugs may be the only hope for people that are close to death. The risks that come along with taking non-approved drugs are extreme side effects and an earlier death.

Drugs that have been developed still take time to become approved. The Drugs Directorate has a faster approval process for drugs that treat terminal diseases.

New drugs and combinations are being tested, with hopes that they:

- ◆ Will be more potent.
- ◆ Have less side effects.
- ◆ Don't require a strict meal regimen.
- ◆ Don't become useless if HIV mutates.

How do you take them?

They (doctors/researchers) would like to believe that I'm taking them eight hours apart. Realistically, it doesn't happen. I can't do it. I mean, I don't know too many people who are dedicated to having their watch alarm go off and go, "I have to take pills now."

Basically, what I do is take them when I eat. It's like I get up in the morning, have breakfast, take my pills. In the afternoon, when I'm having something to eat, take my pills. Before I go to bed, have something to eat or have my dinner.

I can take my pills up to two hours after I eat. That's what they tell me. So basically what I'm doing is eating and taking my pills. I never forget because it's just something I do. I eat three times a day and I take my pills three times a day.

The only difficult part is remembering to take Septra because I only take it on Monday, Wednesday, and Friday. That's the only problem I have with the drugs. I haven't seemed to (have) forgotten so far.

- an Aboriginal person living with HIV/AIDS

I started taking AZT in 1989, and I took it for two years. I decided that I wanted to clean out my system a bit. I had been told this drug was very toxic. They said it becomes useless after a while.

- an Aboriginal person living with HIV/AIDS

Combinations

- ◆ Each drug may have a side effect.
- ◆ Each drug combination may have a side effect.
- ◆ A drug may affect another drug in an extreme way, making it very potent, toxic or weaken the effect.

Some drugs produce the same side effects, so they aren't used together. For example, both ddI and ddC can cause peripheral neuropathy. Other drugs should not be used together because HIV can mutate to resist both of them.

Some people can't tolerate the side effects that are produced from combination therapy. When there are risks of developing peripheral neuropathy and pancreatitis as well as other complications, these can contribute to the decline of someone's quality of life, which makes

it difficult to decide when to begin taking the therapy. An additional drawback is that someone's drug schedule can be very complex. There are a lot of pills, some may be taken with meals or not, some at very specific times of the day, etc.

To make decisions about combination therapy, the benefits, risks, and possibility of improvement should be considered.

What we don't know:

- ◆ Which combinations work the best.
- ◆ Which order to use them in.
- ◆ When the best time to begin using them is.
- ◆ When the best time to change them is.
- ◆ What the long-term effects will be.

Why don't they work:

- ◆ The drugs can be toxic.
- ◆ HIV can mutate and then the drugs won't work anymore.
- ◆ CMV Retinitis may happen with people that begin taking protease inhibitors.
- ◆ The body does not absorb the drugs.
- ◆ If the regimen of how to take the drugs isn't followed, an HIV-resistant form will emerge and that particular treatment will be useless.

Potential benefits of combination therapy include:

- ◆ A greater survival rate.
- ◆ Slowing of the disease progression.
- ◆ A better T4 count than *monotherapy* (single drug treatment).

What we know:

- ◆ Treatments can reduce the damage caused by HIV.
- ◆ Treatments can help the immune system partially repair the damage caused by HIV.
- ◆ Treatments can extend the life of people with HIV/AIDS.

I believe that all the drugs that they have pumped into him has, sort of, imbalanced his thinking sometimes. He can be very angry and he can be very withdrawn; he can treat you quite rude sometimes. We all understand it's the effect of the drugs, because he's had so many drugs. Who knows how these drugs are going to effect him? They don't know how the reaction is going to be from one drug to this drug.

If he's taking twenty drugs, and they know that with these three drugs you're going to get this reaction, but what (happens) when you add this drug? What kind of reaction will it leave? For what kind of reaction will it make? What kind of side effect will it give you?

Nashine Ginwenimawazawin

Well, they didn't know. He got to the point where he was healthy. He had brought his health back up, but he was intolerable to be with at times. All you could do was detach yourself from him for a while until it went away.

- an Aboriginal person living with HIV/AIDS

I don't know if this is a part of the drugs or not, but I've been feeling like (something is wrong with) my nervous system, I have numbness and pain in my body. I have to move my hands or feet to get the blood circulation going.

- an Aboriginal person living with HIV/AIDS

My drugs go right to the jail; the nurse makes sure I get them.

It's the time thing. That's what's stressing me out. It has to be right on time. It has to be, like, every six hours. Every six hours for AZT. Every twelve hours for ddI. Then there's the 3TC.

- an Aboriginal person living with HIV/AIDS

If I take the drugs without any food, I feel that nausea right away. The drugs are really powerful. I feel this nausea in my stomach and it comes up close to my throat. I feel like I could gag or vomit. It comes and goes. It stays for a little while and then it goes away if I eat something with it; if I do that then I don't feel the nausea.

- an Aboriginal person living with HIV/AIDS

I'm involved in a cocktail right now. I'm taking AZT, 3TC, (and) Saquinavir, and on Mondays, Wednesdays and Fridays I take Septra. Septra is to guard against PCP and pneumonia and things like that.

On average, every day, I'm taking fifteen pills. I'm taking three Saquinavir, one 3TC and two AZT in the morning and at night. In the afternoon, I'm taking three more Saquinavir.

I feel that is too much. My friends and I, we have this belief that all these toxic drugs aren't good for you. They still don't know enough about the drugs. I feel that they're giving me too strong a dose.

I think they're overdosing because they don't know yet, they've only been out since last June. They're still reading everyone to see how they're reacting to it. I must say, they're reacting very well, but the fact is, they just don't know everything right now.

Like before, they didn't know 1,800 mgs of AZT was toxic to a person's body. This (AZT) was a cancer drug in the '50's and they cut it out because it was too toxic. Now, they're giving it to us.

- an Aboriginal person living with HIV/AIDS

Patients that started on protease inhibitors and were in their end stages, they were so sick (that) they vomited and couldn't eat. They got terrible diarrhea and really bad cramps. One patient, he said it's just awful, and his lasted for two months.

Now, if someone is palliative, they are not going to stand that for two months. They're just going to say, 'O.K., off the stuff.' That is their choice. If they want to come off it, then they come off it.

You will see them decline very quickly once they are off (it) because I think it puts the virus into a remission. Once there is nothing there, it just goes full blown and it attacks everything.

The patient who was on them was on them for four weeks. He died in six weeks, which was quite fast. He had diarrhea before he was put on these drugs, but it was really gross after he had been put on them. They are not easy drugs for people to tolerate.

They seem to be able to cope with some of the diarrhea, but the nausea, they can't. They have to eat so frequently and take small amounts frequently that they are constantly nauseated. The thought of food puts them off, let alone the smell of food.

- a support person

ACCESS TO DRUG THERAPIES

Non-insured Health Benefits (Sunnybrook List)

- ◆ Is run by the Sunnybrook Hospital, through other hospitals. They are available for free, to anyone that they are prescribed to regardless of income.

Ontario Drug Benefits

- ◆ You have to be on FBA or be a senior. It does not pay for drugs that are experimental. The drugs must be approved/released by Health Canada.

Trillium Drug Program

- ◆ Is an income-based program you have to apply for once a year. It is to help out people who are not eligible for the Ontario Drug Program or FBA and who have to pay a lot of money for their drugs.

Expanded Access Program or Compassionate Access

- ◆ Is a program that allows people to use drugs that are usually in the experimental stage. When the drugs are approved, the drug company may continue to provide the drug without charge. Your doctor would be able to send in an application.

Issues to Consider with Drug Treatments:

Not everyone can take the new medications because of the side effects or because they do not respond to them. People with a long exposure to AZT seem to have limited success with combination therapy. Others that began combination therapy during the late stages of AIDS may see the benefits of the drugs wearing off. They may not have enough of an immune system for the drugs to benefit. "Crashing" is what some people are calling it when the drugs wear off. There is unpredictability about this "crashing" effect happening.

Nashine Ginwenimawazawin

Research has not concluded how long the effect of the drugs will be. The drugs are very expensive.

Combination therapy also requires a strict regimen. Sometimes people have to take as many as 30 to 40 pills a day and they are on a very structured timetable. There is also the fact that some of the drugs have to be taken with food and some without. If there is a dose missed, a strain of the virus could develop that is resistant to that particular combination and possibly others. This is a big concern when considering that IV drug users and street people live transient lives. Others who are living in poverty may have problems obtaining food. Ritonavir needs to be refrigerated, which may be a problem for communities that don't have hydro or refrigerators. People that rely on meals at soup lines don't have control over when they eat. This can also be a problem because you can't control what kind of food you're getting and one of the drugs requires that you have a low fat diet.

My doctor says, 'I might have to put you on the cocktail.' But I can't go on the cocktail yet until we have food. I need to eat good solid foods to take the pills. But right now, I can't eat solid food. This month has been rough on me because I had to help pay off a bill.

Plus, I am afraid, in case if I get sick with the pill with some of the side effects, I would have no money there to help me. Plus, this co-op wants me to do some chores around there. How about if I get sick with medication?

They said, "Then we can't help you, you still have to do some work."

They don't really understand about the illness. I told them the truth, I could vomit on the medication. I showed them the pill, what it does, it gets you sick, you go through diarrhea, headaches, numbness.

They said, "We can't help you, it's not our fault, you have to do something. You made a promise."

I says, "Yeah, but I never thought I was going to get this sick."

My doctor knows, but he told me to stay on right now, stay on the AZT and 3TC until you're ready and then start the other one. I got all the cocktail drugs and he said to keep it in the fridge

- an Aboriginal person living with HIV/AIDS

Safer practices (safe sex, cleaning needles, etc.) are still important because someone on combination therapy could infect someone with a drug-resistant strain of HIV.

BODY MECHANICS: LIFTS & TRANSFERS

*This entire chapter has been taken, with permission, from Andrew S. Johnson's "Living with Dying, Dying at Home." AIDS Committee of Toronto, (Canadian Cataloguing in Publication Data.)

INTRODUCTION

Body mechanics is the coordinated effort of muscles, bones and nervous system to balance, posture and body alignment during movement (lifting, bending, walking). Paying attention to how these systems work will help to prevent injury.

The most common injuries associated with hands-on care are back injuries, particularly the lower back. There are many factors related to these injuries, but the two most common causes are poor use of body mechanics and a belief that care for the caregiver comes second to care for others.

This section provides you with some direction in how to lift and transfer your friend safely. You can also benefit from the expertise of physical and occupational therapists, who are skilled in the theory and use of body mechanics. Seek out their advice and have them visit you to teach you and other caregivers about lifting and transferring.

The importance of using proper body mechanics when you are lifting or transferring someone or something cannot be stressed enough. There is no room for taking risks that could result in injury. You must consider your own safety before you attempt to lift or move your friend.

This Section Will Cover:

- ◆ The basics of body mechanics
- ◆ Moving someone in bed
- ◆ Moving someone from bed to chair, chair to chair and so on
- ◆ Walking
- ◆ Dealing with falls
- ◆ Fire safety

BASIC BODY MECHANICS

There are two important principles associated with understanding the basics of body mechanics: Know your body, and take your time.

Know Your Body

The first and most important aspect of body mechanics is knowing your own body and how it works with and against the force of gravity. You are the best judge of your body's capabilities. Muscles and bones work together every day to support and create movement. Listen to your body and respect its limitations.

There are three basic points you need to understand: centre of gravity, line of balance and base of support.

CENTRE OF GRAVITY:

- ◆ This point is located at the middle of your body, in the pelvic region.

LINE OF BALANCE:

- ◆ This is an imaginary line, from head to foot, that divides your body into two equal parts.

BASE OF SUPPORT:

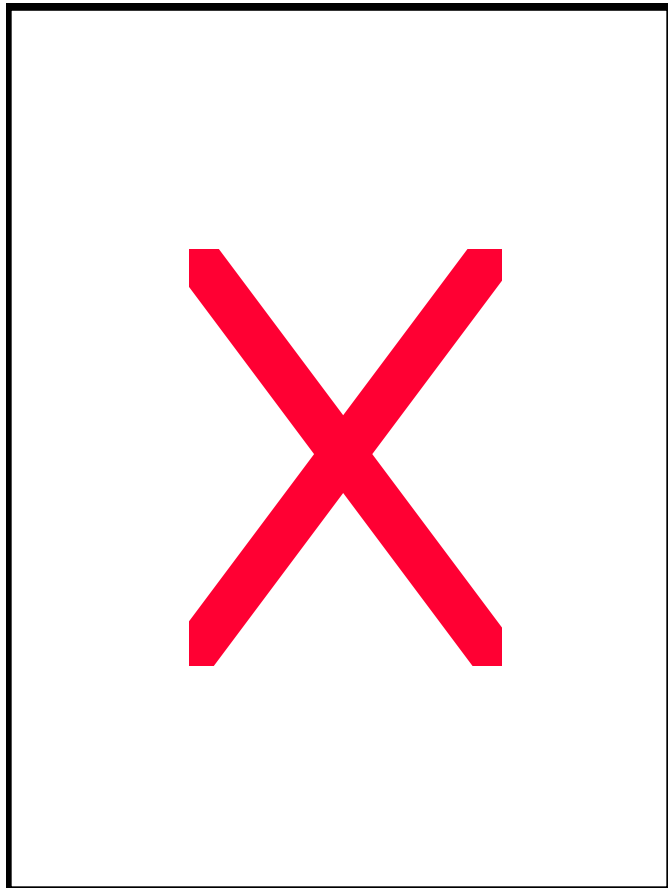
- ◆ This is the space between your feet that bears the weight of your body.
- ◆ When moving or lifting a heavy object, you can reduce the strain on your back by keeping your line of balance close to your centre of gravity. You can do this by bending your knees instead of your back. This keeps you from leaning forward or backward. (Leaning moves your line of balance away from your centre of gravity.)
- ◆ Open the distance between your feet to broaden your base of support. This distributes the extra weight you're bearing or lifting and decreases the strain on your back muscles.
- ◆ Get close to the object you are moving. Make sure your centre of gravity is as close to the object as possible. This keeps your centre of gravity in your line of balance, and gives you the greatest potential for using muscle power.
- ◆ Use your arm and leg muscles to do the work. These are nature's mechanical levers, and if you use them you can prevent unnecessary back injuries. When you're using your arms, keep the load close to your body: short levers require the least amount of work. Your greatest lift power comes with pushing rather than pulling. Use your legs and arms, not your back, to move the object.



*Incorrect
lifting
technique.*



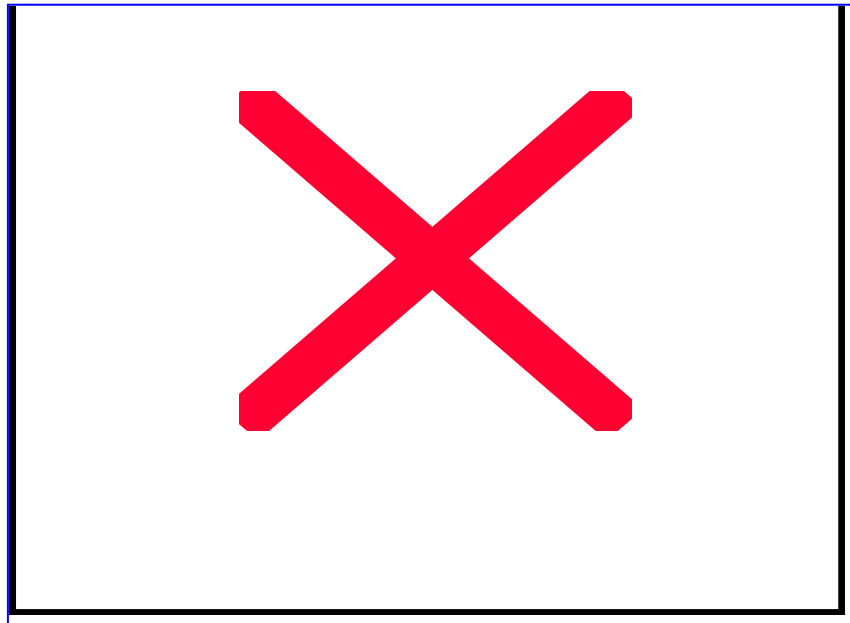
*Correct lifting
technique.*



Take Your Time

Never rush into moving or lifting someone or something. Always take a few moments to think about the movement before you start. Look at where you are and where you want to go. Imagine the movement before you proceed.

- ◆ Never attempt to lift or transfer that you think you can't do alone. Two people are almost always better than one. If you know your back is weak or injured, do not attempt to lift or transfer. You must think of yourself and your back first.



Avoiding Back Injury

- ◆ Make sure everyone involved in the lift or transfer understands the direction and purpose of the movement. Talk it out step by step. Everyone should count to three before the movement begins, so everyone moves at the same time.
- ◆ Make sure any obstacles or barriers are moved out of the way. You want a clear path during the move. Your destination should be in clear view.
- ◆ Turn with your feet, pivot, or step, and avoid twisting your body.
- ◆ **Always do the least amount of work to achieve your move. Have your friend help you as much as possible.**
- ◆ If the load starts to slip, go with it gently. Don't try to save the load by pulling on it or holding it up. If the load is your friend, let him gently fall to the floor. Bend your knees, keep your back straight and go with the fall, protecting your friend's head at all times.
- ◆ If you do injure yourself, seek professional help right away. Don't wait until it is convenient or until the injury is so painful you can no longer

function properly. Back injuries need attention. The longer you wait to take care of yourself, the greater potential for chronic back problems.

MOVING SOMEONE IN BED

Preparation

Make sure the bed is secure and won't move around while you are lifting or transferring. If the bed has wheels, check to make sure the brakes are on.

- ◆ If you can, raise the bed to about your waist level. If the bed cannot be raised, remember to bend your **knees**, not your back.
- ◆ If the bed has side rails, lower the side rail closest to you.
- ◆ Fold an extra sheet in half twice, to use as a turning sheet. Place the sheet under your friend so it goes from mid-thigh to shoulder.
- ◆ Before any move, check to see that any tubes or urine bags will not be pulled with the move.

Using One Person

If you're moving your friend up in bed, place a pillow against the headboard.

1. Face the direction of the move. Your feet should be wide apart, toes pointing in the direction of the move. You can also place one knee on the bed to get close to your friend.
2. Place one hand flat under her shoulders, the other hand flat under her thighs.
3. Have your friend bend her knees and tuck her chin to her chest.
4. On the count of three, shift your weight from the back foot and knee to the front foot, and as you shift, move your friend up in bed.

WITH A TURNING SHEET:

- ◆ Grasp the turning sheet under his shoulders.
- ◆ Ask him to bend his knees and tuck in his chin.
- ◆ On the count of three, shift your weight from your knee to your back leg. Your friend's head and shoulders will come to rest on your thigh near the top of the bed.

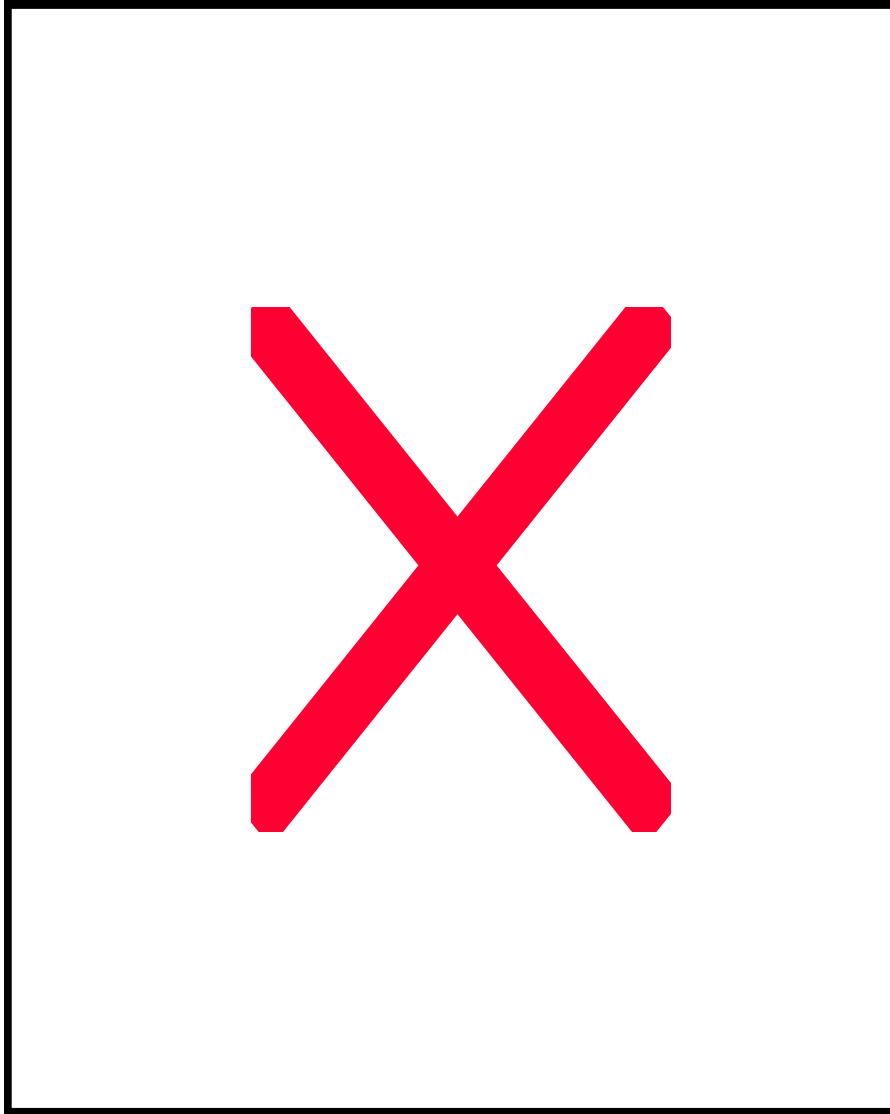
Using Two People:

Both people face the direction of the move. You can be on the same side of the bed, or on opposite sides.

1. If you're on opposite sides of the bed: each person places their hands at the shoulders and waist. If you're on the same side: one person places their hands at shoulders and waist, the other at waist and hips.
2. Ask your friend to bend her knees and tuck in her chin. On the count of three, both care team members shift weight from back foot and knee to front foot.

WITH A TURNING SHEET:

Facing the direction of the move, stand on opposite sides of the bed.



- ◆ Grasp the turning sheet close to your friend at his shoulders and hips.
- ◆ Ask your friend to bend his knees and tuck in his chin. At the count of three, caregivers shift their weight from back foot and knee to front foot.

Pull and Turn to Side Position: One Person

1. Help your friend move from the centre of the bed to one side. If she wants to face to the right, she should move to the left side of the bed. This will ensure that she ends up in the centre of the bed.

2. Facing the bed, with feet wide apart, lean well over your friend, or place one knee on the bed. Grasp your friend's far shoulder and hip (or reach across your friend and grasp the turning sheet at the shoulder and hip.)
3. Have your friend cross her far leg, with knee bent, over her near leg. Then ask her to cross her arms on her chest.
4. On the count of three, shift your body weight from the front leg and knee to the back leg, and as you do, gently pull your friend onto her side. Make sure her bottom shoulder is pulled out a bit, to maintain blood flow and prevent cramping.

Sitting Up on the Side of the Bed: One Person

1. With the bed flat, help your friend move to the side of the bed where he wants to sit.
2. If you are using a hospital bed, raise the head of the bed or prop your friend with pillows.
3. Face your friend and place one knee on the bed. This should be the knee closest to his head.
4. Lean forward, reach across your friend and place your hand (the one closest to the foot of the bed) on his hip. Place your other hand behind both shoulders.
5. Gently rock your friend while counting to three, then pivot him to a sitting position by lowering his legs over the side of the bed and lifting his head and shoulders.
6. Stay close to your friend, using your knees against his to prevent slipping.
7. Take a few moments to let your friend adjust to the sitting position. Some people might feel dizzy after sitting up.

MOVING FROM BED TO CHAIR OR FROM ONE CHAIR TO ANOTHER

Preparation

Have all your equipment ready for the transfer. Bed brakes are on and the height of the bed is lowered to that of the chair (when possible). Place the chair at the head of the bed, parallel to the bed, facing the foot.

- ◆ If using a wheelchair, make sure the brakes are on and (when possible) remove armrest and foot pedal close to the bed.
- ◆ Have your friend wear nonslip socks or slippers. Check to see that any tubes and urine bags will not be pulled with the movement.
- ◆ Make sure your own footwear is non-skid to avoid slipping.

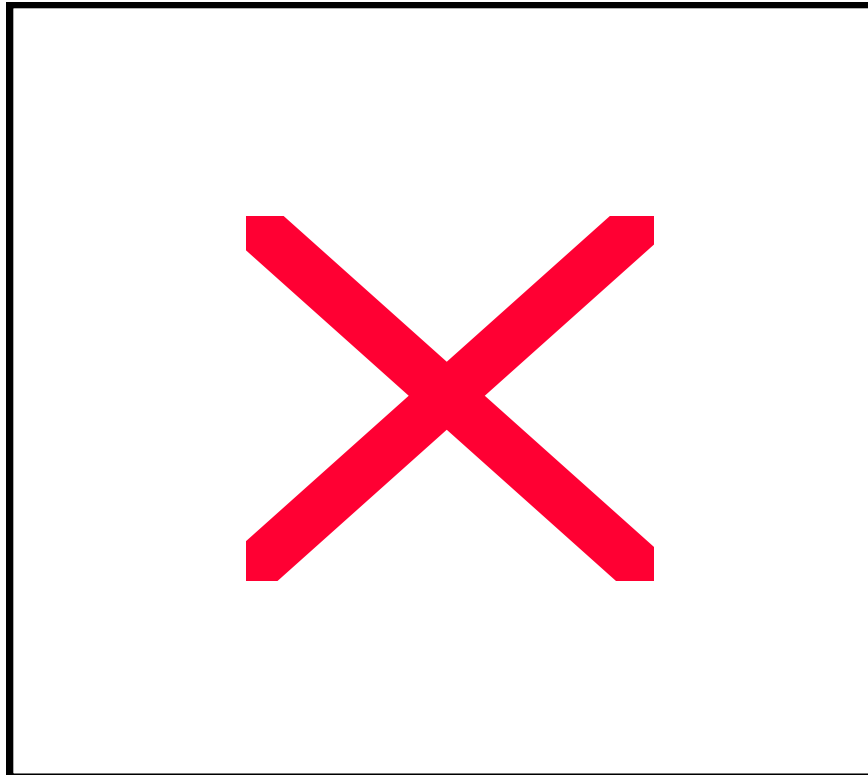
Transfer from Bed to Chair: One Person

Help your friend sit up with feet hanging over the side of the bed. Make sure her bottom is as close to the side of the bed as possible. You want to reduce the distance between the two positions. When possible, have your friend's feet resting on the floor.

1. Stand in front of your friend, with one foot between her feet. Use your feet or knees to block your friend's feet and knees, to prevent slipping.

2. With your back straight, bend your knees and lean towards your friend. Place your arms around her lower back or you can grasp her waist band, or use a turning sheet or towel as a transfer belt.
3. Have your friend wrap her arms around your back and trunk, not around your neck. If your friend is too weak to grasp, place her arms over your shoulders. Her head should rest on your far shoulder.
4. Gently rock for momentum and count to three. In one movement, stand, pivot toward the chair, and gently lower your friend (bending your knees) into the chair.
5. Replace armrest and foot pedal.

Transfer from bed to chair: one person.



Transfer from Chair to Chair or Chair to Bed: One Person

You will use the same procedure as described for a transfer from bed to chair. Keep in mind the following:

1. Chairs should be placed at right angles to each other. This may be difficult when you're transferring someone to a toilet, so make sure you have enough room to pivot your friend safely.

2. Minimize the distance between the two positions. Make sure your friend's bottom is at the edge of the chair with her feet as far back (under her bottom) as possible.
3. When moving from chair to bed, make sure you lower the height of the bed, and check to see that all brakes are on.

Transfer with Front and Back Lift: Two People

When transferring from bed to chair, chair to chair, or chair to bed, you may want to use a two-person front-and-back lift.

1. Designate one person to coordinate the transfer. Prepare equipment and your friend as described above.
2. One person stands behind your friend, with arms wrapped under the armpits, grasping your friend's forearms. The other person squats close to your friend, with one arm under her thighs and the other under her lower legs. Hold her legs close to her body.
3. On the count, and together, the upper lifter moves the upper body and the lower lifter moves the legs.

You can use one of these methods to help your friend in and out of a bathtub or car. Think about the move before you do it, and make sure everyone involved is clear about the move. Bathtubs are very slippery and should be set up with hand grips with the help of an occupational therapist. Have the therapist visit the home and teach you how to move safely in and out of the bathroom.

Moving from Bed to Stretcher

(This move usually takes three people to perform safely.)

The stretcher should be placed at right angles to the end of the bed. Make sure the brakes are on for both the bed and the stretcher. The height of the stretcher should be the same as the height of the bed or at about the height of the lifters' waists.

1. Remove any obstacles between the bed and the stretcher. You must have a clear path to perform this transfer, as you will not be able to see your feet.
2. Check to see that any tubes will be able to move with you.
3. The tallest person stands at your friend's shoulders, the second tallest at the waist and the third person at the lower limbs. Each person takes a wide stance facing the bed.
4. Each person places their hands and arms well under your friend's body.
5. Position your friend on the side of the bed with his arms well under your friend's body.
6. Position your friend on the side of the bed with his arms crossed on his chest and his chin tucked in.
7. The tallest person leads the movement, but all count together.
8. On the count, lifters rock your friend towards their shoulders, bringing him onto his side wrapped in lifters' arms.
9. Shifting weight from front to back leg, lifters take one step back, turn and walk towards the stretcher.

10. On the count, all lifters bend their knees and lower your friend onto the stretcher.

NOTE:

Another option is to place the bed and stretcher side by side and touching. Two or three people get on the far side of the stretcher, and with a draw sheet, gently pull your friend onto the stretcher on the count of three while keeping in mind the principles of body mechanics.

FALLS TO THE FLOOR



Falls may occur as the result of a transfer. Your friend might try to move on her own when she is too weak.

- ◆ If your friend begins to fall while you are transferring her, do not resist the fall. Go with it gently, and protect both of you from injury. Make sure to protect your friend's head from hitting the floor.
- ◆ Once you reach the floor, take a few moments to calm down. Reassure your and check to see that she is okay.
- ◆ Once you both have had a good laugh, collect yourselves. Then prepare to return to the bed or chair. It is usually easier to go from the floor to a chair first, and then from the chair to the bed.
- ◆ If you find your friend on the floor, check first to see she is okay. If you suspect she is hurt, call the doctor or an ambulance.

When your Friend can Help

METHOD ONE:

Bring a chair to where your friend is on the floor. Place the chair so that an armrest is in your friend's reach, then kneel beside your friend.

1. Supporting his hips, help your friend push himself, using the chair armrest for support, into a kneeling position, facing the chair.
2. Help him place his forearms on the chair. Then lift one of his knees and place one foot on the floor.
3. On the count, help your friend to push up, stand and pivot into the chair while holding onto the armrests.
4. Have your friend rest and check to see that he is okay.

METHOD TWO:

You will probably need two people to get your friend back into a chair or into bed.

1. Use the front-and-back lift, paying special attention to bending your knees and using your legs.
2. If you are alone and cannot lift your friend by yourself, call a care team member or the fire department to get some help.
3. Until help comes, stay with your friend and keep her comfortable with a blanket and pillows.

WALKING

Although your friend may be able to bear weight and walk, he may also need assistance so he doesn't fall. Some people will be able to use a cane or walking device; others will simply need assistance and support.

- ◆ Make sure all obstacles are out of your path. Have a chair nearby should your friend need a rest station as he walks from one room to another. Make sure he is wearing nonskid slippers or shoes.
- ◆ Always provide your assistance on his weaker side. You want him to use his stronger side as much as possible.
- ◆ If he is using a cane or walking device, make sure your friend holds the cane on the stronger side. This will keep the weight on the side that can support it.
- ◆ To help your friend to walk, stand beside and slightly behind him, facing the same direction he is. When necessary, remind your friend to stand tall and to look ahead, not down at the floor.
- ◆ Your arm closest to your friend can be used to support his back at the waist. Your other hand can stabilize his shoulder or armpit for extra support.
- ◆ Avoid having your friend hold your hand or wrap himself around you. This will make it difficult for you to support him should his knees buckle.
- ◆ If you have any doubt about assisting your friend alone, get another person to help you. One person stands on either side of your friend, supporting him as described above.

FIRE SAFETY

In the event of a fire, your main concern is to remove everyone away from danger. Stay calm, and move quickly and assertively.

- ◆ Call the emergency number to alert the fire department. (In many parts of Canada, the emergency number is 911.)
- ◆ If the fire is at the bedside, remove your friend immediately. If there's a fire on the bed, smother it with a blanket.
- ◆ Once you have moved your friend and know that she is safe, then call the fire department.
- ◆ If the oxygen is being used, turn it OFF if you have the opportunity. (Do not risk going near the fire to turn off oxygen. Oxygen is not flammable, nor will it explode. It does, however, feed a fire and help it to burn.)

When You are Alone

Some people with AIDS are so thin and light that they can be carried, cradled in your arms or wrapped on your back with their arms over your shoulders.

1. When your friend is too heavy to be carried, and if you have no time to wait for assistance, you will need to drag your friend away from danger.
 2. Grab a blanket or sheet and place it on the floor beside the bed or the chair. Or use the bottom sheets on the bed.
 3. Move your friend to the side of the bed or to the edge of the chair.
 4. Get behind her, place your arms under her armpits and grab her forearms. Lower her onto the blanket or bottom sheet, taking care of her head. Her legs will follow.
 5. Wrap her in the blanket. Grab the blanket at the shoulders and drag your friend to safety.
 6. If necessary, you may have to drag her down a staircase. It will be a bumpy ride but far better than dealing with burns or smoke inhalation.
 7. Once you are both safe, stay with your friend until help arrives.
-

Reference

Fran Caruth and Flora Thompson. **Transfer and Lifting Techniques for Extended Care**. Second Edition. Vancouver: Authors. 1985.

* THIS CHAPTER IS TAKEN FROM:

AIDS Committee of Toronto (Andrew S. Johnson). **Living with Dying, Dying at Home: An AIDS Care Team Resource Manual**. Toronto, ON, 1994. (Canadian Cataloguing in Publication Data.

INFECTION CONTROL

**This entire chapter has been taken, with permission, from Andrew S. Johnson's "Living with Dying, Dying at Home." AIDS Committee of Toronto, (Canadian Cataloguing in Publication Data.)*

INTRODUCTION

Infection control is a term that describes of preventing infections. It protects all of us from infectious agents, for example bacteria and viruses that can make us ill. This section will give you some basic guidelines on how to provide care that is geared towards preventing infection. Although our goal is to protect both the receiver and the provider of care, our main concern is with preventing the person in care from coming in contact with any infectious agents.

Caregivers must protect themselves from coming in contact with blood or body fluids. We can do this in a number of ways. The most important thing to remember is to always follow the basic rules.

Before we look at the basic rules, let's quickly review how the HIV virus can be transmitted.

HIV Transmission

There are four ways the virus can be transmitted:

- ◆ Through unprotected sexual contact with an infected person.
- ◆ By sharing needles with an infected person.
- ◆ From mother to fetus in the womb.
- ◆ Through a blood transfusion that occurred before November 1985 (in Canada).

All other forms of casual contact with an infected person, such as touching, drinking from the same glass or using the same toilet are not ways in which HIV can be transmitted.

Remember, the ways in which HIV is transmitted are very limited. There are other bugs (bacteria or viruses), such as Hepatitis B, that are much easier to transmit. The message here is that **ALL** bugs, not just HIV, are the target of prevention when you are practicing infection control.

UNIVERSAL PRECAUTIONS

Very simply, the idea behind Universal Precautions is that all individuals are potential carriers of any number of infectious agents. Therefore, the rules of precaution apply to everyone, regardless of HIV status. We must be careful when handling blood or body fluids (semen, vaginal secretions, urine, feces, vomit, saliva, sweat, tears and other internal body juices such as drainage from wounds and open sores).

Handwashing

Washing your hands is the most effective way of preventing transmission of infections. You should wash your hands before and after every contact with the person you are caring for. Wash your hands with warm, soapy water. Keep your hands in good shape by preventing dryness and chapping with hand-lotion, and keep your nails trimmed and clean.

Gloves, Masks and Protective Aprons

Wearing gloves is necessary whenever you are handling blood or big spills of body fluids (changing diapers or cleaning up vomit). Gloves are like condoms; they act as a protective barrier for both persons involved. Don't use them more than once; throw them out when you are finished the job, then wash your hands. If you are not sure whether gloves are necessary, it's better to use them. (You don't need to wear gloves when giving a backrub or a massage or for holding hands).

- ◆ You should wear a mask when you have a cold or when the person you are caring for is coughing a lot. Use your judgement: it might be best just to stay away.
- ◆ When you are cleaning up large spills of blood or body fluids, you may want to protect yourself with a plastic apron.

Protecting the Person with AIDS from Infection

We know that the number of times a person has an infection may affect the person's immune system. We must take great care not to infect the person who is immunocompromised by HIV. The same applies to the caregiver. Maintaining your general health with proper nutrition and adequate rest will help to prevent illness. Take care of yourself. If you get sick, use your judgement to decide whether you should be providing care or back at home in bed.

Open Wounds

Always wear gloves when you might come in contact with open wound or when you're changing dressings or menstruation pads. Be sure to properly dispose of any materials used in the care of open wounds; that is, use double garbage bags. Wash your hands when you are finished.

Laundry

Wash sheets, towels and clothing in hot water with laundry detergent. Unless it is necessary, you do not need to use bleach every time you do laundry. (You should use

bleach on laundry that has blood stains or body fluid stains). If you prefer to use cold water, that's okay; the heat of the dryer will kill any bugs in your laundry. Make sure you have one designated location for the laundry basket or bin. Try to keep it away from where your friend spends most of her time; dirty laundry often smells. Being organized with your laundry is good infection control.

Garbage Disposal

Always try to have a good supply of heavy-duty garbage bags. If you find you have a lot of wet garbage (for example: used diapers), double bag it to prevent leakage. Try to have two bins for garbage collection: one for wet or infected garbage in a double bag and one for regular garbage. When the bags are full, tie securely and dispose of the garbage as you would normally. As with your laundry bin, try to keep garbage away from where your friend spends most of her time. And don't keep the garbage and laundry bins together. Too often, laundry gets thrown out with the garbage.

Spills

Clean up any spills of urine, vomit, or feces as soon as they happen. You should wear gloves, especially if there is blood involved. Using warm soapy water to wash the area is fine. If a large amount of blood is involved, a weak dilution of bleach and water (one part bleach to ten parts water) should be used. (Be careful: you don't want to bleach out the carpet). Soak the area well before scrubbing. Take care not to splash the solution into your face or eyes as soap and chlorine are very irritating.

Food Preparation

Raw foods are prime carriers of infectious agents. Meats and eggs should be cooked thoroughly. Fruit and vegetables should always be washed before you cook or eat them. Wash dishes, glassware and cooking utensils in hot, soapy water. If you use a cutting board to prepare raw meat, always wash the board in hot water before you use it again.

Pregnant Caregivers

Pregnant caregivers are at no greater risk of HIV transmission than any other care team member. However, pregnant women should avoid direct contact with someone who is infected with CMV, Toxoplasmosis or with Herpes. These infections can be harmful to the developing fetus.

Sharps and Needles

You may have to give an injection. Make sure that after you've given the needle you do not recap the needle or try to remove it from the syringe. Dispose of the needle in a heavy container that is carefully marked. I usually write "sharps" on mine. These containers might be provided by Home Care, or try calling your local public health unit. You'll find the number in the blue pages of your telephone book.

When the container is full, seal it securely and call your local public health unit to arrange for disposal.

Be very careful not to stick yourself with the needle after giving the injection. In the unlikely event that you do stick yourself, safely dispose of the needle in the sharps container, then wash the stick site with warm soapy water. You should then notify your family doctor of what happened.

Pets

Since animals can carry disease, it is important to make sure that your friend's pets are healthy. It may be the job of the care team to take animals to the vet for checkups or shots. You'll probably also be taking care of them from day to day; changing the cat litter, feeding the dog and so on. Make sure you wash your hands thoroughly after you clean the cat's litter box or the bird's cage. Your friend's pet is a cherished family member, and a very important part of the care team.

CONCLUSION

Caring for someone with AIDS is the same as caring for anyone else who may be ill. Good infection control will help you maintain the health and well being of all individuals involved. Universal Precautions can help you protect against and prevent infection. They do not discriminate against or isolate people. Universal Precautions take some time getting used to, but you will be surprised how quickly they become just another of your many habits.

Reference

Health and Welfare Canada. **Infection control guidelines for isolation and precaution techniques**. Revised. Ottawa, Ontario, 1992. (Supply and Services Canada, Catalogue No. H30-11-6-1E).

FOOD & FOOD SAFETY

Avoid:

- ◆ Raw fish, raw shell fish such as oysters, shrimp, clams, mussels
- ◆ **Never eat:** raw eggs, unpasteurized milk, or meat that isn't cooked all the way through.
- ◆ **Never eat:** raw dough that contains eggs (ex. raw cookie dough).
- ◆ Don't buy or use cracked eggs

I don't go for milkshakes made with raw eggs in them. I say just make them with ice cream and fruit. Heaven knows what bacteria you can get from the eggs.

- a support person

Cleaning:

- ◆ If you are cutting meat, be sure to clean your hands, knives, and the cutting board with warm, soapy water before using them to prepare other foods.
- ◆ If you use a cloth to clean up spillage from raw meat, throw it into the laundry before using it again.
- ◆ Use diluted bleach to clean surfaces that raw meat has touched.
- ◆ Clean cutting boards with anti-bacterial detergent.
- ◆ If there is raw blood left over, dispose of it to avoid contact with other food.

Preparing Food:

- ◆ Use one cutting board designated only for meat to avoid spreading bacteria from raw meat to other foods. If you have two cutting boards (the other for vegetables, breads, etc.), label the meat board, so the boards don't get mixed up.
- ◆ Always make sure meat is well cooked.

Storing:

Parasites and bacteria can form in spoiled food; therefore, use the following tips when storing food.

- ◆ Airtight containers are ideal for storage.
- ◆ Don't leave food at room temperature.
- ◆ When re-heating, heat food all the way through.
- ◆ If you're not sure whether food has spoiled, don't take chances. Throw it out.

Thawing:

- ◆ Thaw food out in the fridge, instead of on the counter.

DIETARY NEEDS:

Speak to the doctor, nurse or dietician about helping you to design a menu that is specific to their needs. If they have symptoms such as diarrhea, wasting, or vomiting, the health care workers can offer advice on food that can help.

An excellent resource is Healthy Eating Makes a Difference by Sheila Murphy. Copies are available at any chapter of the Canadian Hemophilia Society or at the National AIDS Clearinghouse. Another great resource for nutritional information, Living with Dying, Dying at Home is also available through the National AIDS Clearinghouse or at the AIDS Committee of Toronto.

TRADITIONAL ABORIGINAL FOODS

Meat:

- ◆ caribou, goose, duck, pheasant, grouse, deer, moose, buffalo, bear, organs (liver, kidney), eggs, Indian steak, rabbit, fish, muskrat

Berries:

- ◆ raspberries, strawberries, blueberries, blackberries, cranberries, crab apples, currants

Vegetables:

- ◆ dandelion greens, Indian corn, tomatoes, squash, potatoes, turnips, various roots, parsnip

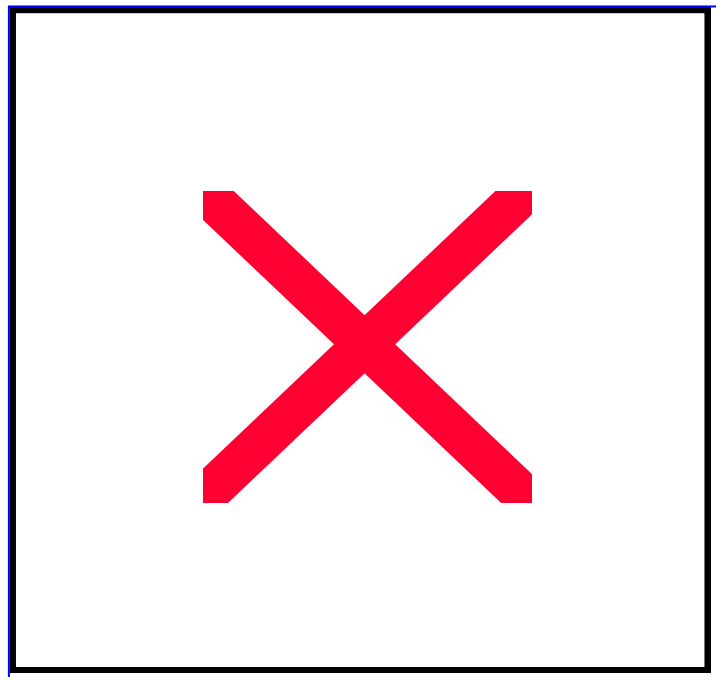
Grains:

- ◆ bannock, cornbread, mush, wild rice, seeds, nuts

Legumes:

- ◆ beans

Various herbal teas



NUTRITION

The following quotes talk about the importance of knowing the food preferences of the person you are caring for. The experiences that care team members have had with Aboriginal people are also talked about.

Elders talk about a compromise between Aboriginal and Euro-western food. They discuss the connection between food, spirit; eating foods within a natural geographical region; as well as people making responsible choices about the food they eat.

I give them a few drops frequently. You can give it in a feeding cup, like one of those baby cups with the holes in the spout thing. Whatever they can manage. Some people are too weak to take (a drink) through a straw. Obviously, they are not going to be able to hold a cup either. You can give it with a syringe. Sit them up. When it comes to the very, very palliative stage, it is an effort to get fluids in. Some doctors will start an IV and hydrate them that way.

- a support person

This life has been given to us. When they can believe in it, then they know they have to do this. That's when things can work well for them. They take the responsibility of this so-called illness. They take the responsibility of what they're to eat. Everything that is put into the system, it has to come out somewhere. If you put a hamburger in there, it takes ten days for it to come out.

Understanding and knowing our own foods, I call it bioregional. Bioregional means eating what is natural for us in the environment. Three of the main things that are not natural for us as Native people in this environment, number one is the cows and the pigs. We never had them. That's the most terrible meat and diet you can be on, even if you don't have a(n) illness. Number two is the milk. That's foreign to us. It's been proved that a lot of Native children are lactose intolerant. So, we have to go back to the natural, which is breast milk. Number three is all the imported plants. We don't have oranges here, orange trees. We don't have kiwi. You go into the markets nowadays and some of it, I don't even know what it is.

It's not that we shouldn't understand it and can eat it. It's not that we can't have it. But, in the bioregional teaching, it's that everything is here for us. It's a belief coming from our tradition and culture that the Creator has put that there for us. The medicines and the foods have been put there for us.

The Creator isn't that stupid that he's going to put us in an environment that we can't survive in. It's the same with the animals. The Creator wouldn't put the animals in an environment, like take that cat and put it out in the ocean. He put the fish in the ocean. It's the same with us, as humans. The Creator put us in this environment. We're Native people. He didn't put us in Africa. Look at the Inuit people, how they eat. They eat totally within their environment.

People that I meet that are taken out of their environment, they can't survive. I met people in jail; I've met people in Healing Lodges from way up there. The first thing they tell me, "Oh, I'm hungry for my food."

Nashine Ginwenimawazawin

It's the same as me when I was in Europe. I couldn't handle it there because I was too hungry for my environment, my own foods, fish and corn and everything that is in our environment.

They have to look at what they're eating. That's another part of the treatment plan that I work with. How they're feeling. Their spiritual belief. What they're eating, what they're putting in there.

The first thing that I tell them is don't eat any beef and pork and sugar. Anything that's not part of your environment, anything that isn't from here. They have to understand that what they eat, what they put in, it's like a machine.

- an Aboriginal Elder

There's a lot of people preparing wild game, now. You can go buy it. There's a lot of people making different teas and different foods. Naturally, people can't get a lot of it. But, they can compromise. I tell them what wild game or some of their own traditional foods are in their family.

Within nutrition, that links within the spiritual and it links to the consciousness. That can be like a comfort food for them. That's healing for them.

Maybe I'm going to eat toast constantly and it's going to cure my cold. If I tell you to eat toast and you say, "That doesn't help me."

Then I can't tell you, "Toast is the best for you. Eat toast." But, I can't push toast on you.

That's what's being done to us. We're being pushed, these foods are being pushed on us. For instance, they're telling us vitamin C is so good for us. Vitamin C, you have to have it. It builds the immune system. When we're getting these foods pushed on us, we have to look where did we get vitamin C from? Which plants? Squash, we had and it has lots of vitamin C. We've got wild plants. Up north there, the Indians, they get Labrador tea. In a green pepper you get ten times the amount of vitamin C, which has nothing to do with the colour orange, than you do an orange. There are all these foods that are bioregional.

- an Aboriginal Elder

His appetite was really poor because when he was healthy, he used to like rich food. You know, like, gravy, fries, fried food, chicken. He still tried to eat that stuff but the smell was so strong and greasy that it would turn him off. He didn't like my cooking because I'm no whiz in the kitchen, so he was ordering food in. He would get this sixteen-dollar order, have one bite of it, gag, and then throw it out. He was going through his money pretty fast, ordering food in.

Home Care food, it was Meals on Wheels, once a day for lunch. It was like soup and stuff. But, like I said, he didn't like their food. He would pick at it. He would take a bit of this and a bit of that. He didn't like that, either. It was hospital-type food.

So, he was dropping weight rapidly. I was trying to read up on materials, like what to have in the house, but when you have chronic diarrhea or constant nausea, you're supposed to eat bland foods. Crackers, clear broth and stuff like that. I couldn't get him to switch over to that because he's a creature of habit. He was very much set in his ways, real, real stubborn. He

Nashine Ginwenimawazawin

wouldn't take my advice, as far as what to eat. That was really difficult. I was dealing with a person who was very, very adamant that things were done his way. His way, or hit the highway!

- an Aboriginal support person

A woman who is in the palliative stage, her Moontime usually stops because she's very weak, very malnourished.

- an Aboriginal support person

At Casey House, he had the meals that they serve for everybody. He liked the food there. It was very well prepared. It was a very gay, well-presented menu.

They had a fridge that had snacks in there, so he could go eat anytime he wanted. He could get up and have juice. There'd be three good meals a day.

It was real home cooking. I think they went to all the people and got input for what they liked. It was good, he ate mostly everything. It was your typical Canadian meals, chicken, stews and vegetables.

- an Aboriginal support person

The only thing that is important is if they fancy something, get it for them. If you give somebody three crackers and this liver pate stuff, they've had a good little meal. Loads of calories. Adding extra dried milk gives added calories to people, to build up some body mass. It also to give you the calories because you need quite a number of calories, believe it or not, to breathe, let alone move any extremities and walk around. Just the effort of breathing, you can burn a lot up.

- a support person

He needed his meals prepared for him. It was liquids, you know, ice cream, Mr. Freeze, cold coffee, anything he could get down. I talked to the others about that, you have to be creative.

It was getting close to the end. Whatever he needed, you know, don't deprive him of whatever he wants. By the end, he had dropped down to about one hundred pounds.

- a support person

You need to get the likes and the dislikes of the patient to begin with. Work around that because not everybody likes to eat porridge in the morning or cereal or toast. Work around that. If they like to have a decent breakfast, allow them to have a decent breakfast. Some of the patients say, "Yes, I want an omelet for breakfast and toast." An omelet is quite nutritious, depending on what they put in. They may put onions in, mushrooms in, cheese in.

They may not want very much for lunchtime. I'm personally not going to worry if they don't have much lunch, because they've had a good breakfast. In the evening they may enjoy a reasonable sized meal.

If somebody can't tolerate three meals a day, then the idea is to give them frequent, small, nutritious amounts during the day. Something they can snack on. It could be cheese and

Nashine Ginwenimawazawin

crackers, it could be salmon, it could be tuna, whatever they want. It's better for them to eat food in that manner as opposed to taking it in Ensure or Boost because one of the side effects is diarrhea and you don't get the same nutrition out of it that you do out of a well balanced diet.

- a support person

TRADITIONAL CARE

The following quotes talk about Elders encouraging Aboriginal people to use the healing gifts of both Aboriginal and Euro-western ways. Some of the healing ways are spoken about by Elders. One Elder speaks of caring for people with AIDS when it was an unknown disease. Some of the First Nations medicines that can help people with AIDS are described, although this is done generally. The Elder your careteam is working with can explain the specifics around medicines and treatment.

Symptoms management from a First Nations perspective is in the second half of this chapter. Insight from the Euro-western perspective on symptom management is also shared. When using both approaches, the care team can create a balance that provides the best of both worlds.

Some of them just prescribe drugs, drugs, drugs. They drug you but they don't do anything with it! I have a strong belief in natural medicine, but I would not tell anyone, except maybe my own family, to try it first.

- an Aboriginal Elder

TRADITIONAL TREATMENTS

If it was my family, I would say use both traditional and western. Whatever works for the way you want to live, then let's go try these out.

Some of them just prescribe drugs, drugs, drugs. They drug you but they don't do anything with it! I have a strong belief in natural medicine, but I would not tell anyone, except maybe my own family, to try it first.

One of my Elders said he would live long enough to see another sickness come to our people. He knew how it would affect us. Then, AIDS started to show up. He said it was really going to hurt us.

- an Aboriginal Elder

When you go and talk to people who are really sick and dying, I asked them what have they seen, what are they dreaming? Who is coming to talk to them? There's different levels in the spiritual where people will go if they're dying.

I would get called to different places like San Francisco, Santa Cruz, all around this area. Then, I started seeing this illness in different stages. They didn't have a name for it. They were calling it lupus, cancer, pneumonia.

Some of the first cases that I saw were really serious cases of people dying. One was a Native woman. She was in a hospital in San Francisco. She was dying, they said, from pneumonia. They had operated and cut part of her arm and hand off. She also had black spots on her. So I knew right away that this was something coming from this strange illness that they were looking for names for.

Nashine Ginwenimawazawin

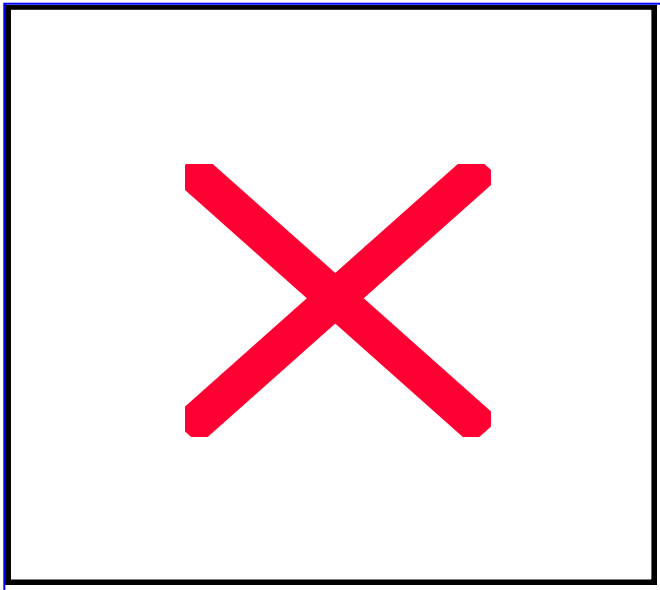
Then other cases came up. There were two cases in Santa Cruz with non-Native people. One man was in his house when they called me, so I had to go and see him. I went down there to do a lecture on plants and the work that I was doing.

This man, when I went in there, he was on the respirator. He was really fading quick. He had the pneumonia and he had the markings, the KS. He told me that he had been sick for quite a while.

Then, they came up with this name, this HIV/AIDS. Then they started talking about the stages of it. The different stages of where it was coming from and they didn't understand it, so they were asking me.

When I treat people, I start right from the old way, which means we treat their blood only.

This doctor I knew, he called me into the hospital. I had to go in to comfort this woman. She was a Native woman. She was asking to see a Medicine Person.



She wanted the Medicine Person to burn tobacco for her and say prayers. She wanted the Medicine Person to tell her children that she loved them and that she knew where she was going.

She was still conscious when I got there. I held her hand. They said she had been sick and in and out of the hospital for quite a while and there was nothing more that they could do with her. There was no place that they could send her because she didn't want to go back to the reserve. She had just these messages that she was saying and sending.

I talked with her, I burned the tobacco and sweetgrass. I talked with her and I said prayers. I asked her then, I said, "Where are you going? Do you know where you're going?"

She said, "Yes."

I said, "Tell me what you see. Tell me your dreams."

She said she saw her mother, who had died, and she said she saw her sister, who had died.

I said, "Are they happy?"

She said, "Yes."

I said, "Are they waiting for you?"

Nashine Ginwenimawazawin

She said, "Yes."

This gives me an indication that she has passed over in her dreams because I've died twice in my lifetime, too. So, I know the stairway. I call it the three stages of death, that Native people go through. We go through these three stages, so I know which stage people are in, spiritually, when I go to treat them when they are dying. She was in the second stage. I told her, I talked to her, I said, "Do you know where you're going?"

She said, "Yes."

I said, "Have you been there before?"

She said, "Yes."

I asked her what happened to her. She told me that she got sick from living on the street. I sat with her for maybe two hours and we talked off and on, saying different things. She was conscious most of the time. Then, she started to cry. She said that soon, she was going to be leaving and that she would miss her family, her children. I think she had four children.

There was no problem with me going in and burning offerings and burning tobacco. They let everything go, they allowed everything.

After that, I think it was only four days later when I called the hospital and she had passed away. She had left. She was gone.

- an Aboriginal Elder

What happens is, number one, the medical profession, they put this name on it and it's scary for people, they get afraid. Their business is to take care of you, number one. Their business is also to make money. I mean, this is what it's about.

Any individual not knowing that, they're putting their hands, their life in that person's hands, saying, "Do what you have to do with me."

Any person that knows an alternative, they know that their responsibility is to take care of themselves.

- an Aboriginal Elder

I've seen people that have taken specific kinds of drugs. What happens to them seven, eight, ten years later is all of that has to surface. If you take something inside, it'll go inside your system, in your bone, in your blood. It's going to happen with these drugs and this medicine that they're experimenting on and researching with people. That's why there are different break-downs of the system.

I don't want to sound as though I'm totally against the medical profession. They have to have their space, too. But, that isn't what we came with. That isn't what Native people here were taught. We came with a belief, number one, that the Creator put everything there for us, which are the natural plants. We came with the belief that it's our responsibility, because the Creator gave us this life.

Nashine Ginwenimawazawin

I always ask the people, "What are you going to give back to the Creator for this life and the responsibility you have for it?"

It's a big responsibility to the individual with this illness.

I call it the Medicine Triangle. They're all in relationship. Where it's the blood, the physical, the next one is the spiritual and the next one is the consciousness, the mind.

How strong is it? If your mind isn't strong, you're believing all this that people are telling you. The doctor may tell you, "You're going to die in eight months." So naturally, they're going to say they'll die.

It's a big responsibility for people, especially when it comes to palliative care, caring for people who are dying. Because again, we live in this Circle, this Medicine Circle. They teach us that we're born and we die or we die and we're born.

A lot of the cases that came to see me were when the doctors gave up and told them to go home and die. A lot of them did die. That's the point where doctors will come to me.

The first thing I do with them is ask them who sent them. I do this because it helps me to know and understand if they're serious about what they're doing and what they're involved with. Usually it works on referral. One person will be getting treatment and then they'll refer their friend. Sometimes doctors will refer them.

The next thing I do is I ask them where they're from and how many in their family. I do a taped session with them, so that they can hear their answers and they can understand what I've asked them. Everything I do with every individual is a taped conversation. I give them the tape, and I say, "Here, you keep the tape so that you'll understand what we're saying. You listen to it three or four times. Every time you listen to it, you're going to understand more."

I ask them three major questions. I ask them what they want to do. This is their health and this is their body. I ask them what they're eating, what their lifestyle is, if they're taking any medications or medicines. The third thing I ask them is to describe it and tell me how they got this illness and what it is.

To me, it's a spirit. So, describe this illness. Draw it, if you have to. I've even had children come and children will draw it or make it. I've had children make it in the form of paper mache and clay. I've had them gather up sticks and stones and make a figure. This is what the illness is to them.

I tell them, "Don't tell me it's AIDS. Don't tell me it's cancer. Let's not put a name on it. Just describe it to me and tell me."

So then they tell me all about this illness. The next thing I do is I tell them, I'm only going to work with you for so long. I'm only going to work with you three months, five months at the longest. The responsibility of this is yours. That's part of me working with you is helping to teach you this process and these steps.

Nashine Ginwenimawazawin

After we do that I tell them that they have to eat like this. They should take these different medicines. While we're doing the consultation, different medicines will come to me. I'll write them down.

After the consultation when I'm doing the preparation for medicines, my husband helps me prepare them. We pick a lot of the medicines ourselves.

Of the different names, I only start them with two medicines. It's the medicines that will start clearing the blood. If they have any pain, if they have any discomfort then I'll give them the medicines for that.

We make the medicines. They take them and they also learn how to make them. I teach them. I'll take them right in my kitchen and I teach them right here. This is when I know that they're going to stay with it and be serious about it.

She told me that she got sick from living on the street. I sat with her for maybe two hours and we talked off and on, saying different things. She was conscious most of the time. Then, she started to cry. She said that soon, she was going to be leaving and that she would miss her family, her children. I think she had four children.

- an Aboriginal Elder

The person I worked with in Vancouver, he was taking the medicines for almost two years. He would come and see me or send people. He took the medicines and stayed with taking the doctor's medicines. His condition was the same. He had KS.

I also put them on a strict diet. Most of them explain to me that they've never cooked. A lot of them will say, "I've never cooked. I don't know how to cook."

I said, "Well, that's part of the process. You have to take the responsibility. That's why it's there, the teaching. Taking responsibility of ourselves."

- an Aboriginal Elder

I mentioned that belief is most important. I call it the belief in the spiritual. Belief is spiritual. Belief is most important because it's inherited to us. It came with us from our people. Our people told us if you dream about this, if you believe in something, it will happen. Belief is

To me, it's a spirit. So, describe this illness. Draw it, if you have to. I've even had children come and children will draw it or make it. I've had children make it in the form of paper maché and clay. I've had them gather up sticks and stones and make a figure. This is what the illness is to them.

I tell them, "Don't tell me it's AIDS. Don't tell me it's cancer. Let's not put a name on it. Just describe it to me and tell me.

- an Aboriginal Elder

most important when it comes to what is going to help us and make us well and keep us strong.

That's something that's been pushed down. They brought it to us in the forms of foreign religion. They brought it to us in a belief system of education. They brought it in a form of money. They put all these different belief systems which are foreign to us as Native people, that we have to learn about. I call it walking in a two-row Wampum. It's harder for us as Native people because we

have to learn their way. I had to go to school, university. I had to learn how to read and write. I had to learn not only theirs and I had to learn my own, too.

Nashine Ginwenimawazawin

The system of belief, everyone has to have. If they don't have this, they walk with fear and anger. When this fear and anger comes in, anger is the emotional expression of fear. Fear takes over on all of us. It's there within our children right now. That's what's important to me right now, the suicide rate of our Native children. They're seeing that it's not a good place, they're seeing that there's not good people. That's why they're not loved. We believe that. We always say there's a belief in love. That the child has to be loved and have a home and be safe. When they're not, that really throws their consciousness off, their thinking.

Believing helps the consciousness be strong and not be afraid. If you're told, you have this and you're going to die, then they just say, "Oh, O.K. I have this and I'm going to die." They don't have the will and they don't have the belief. A belief system is most important. That's why I call it the Medicine Triangle. You have to have those three things in balance, spirit, mind, and blood.

Believing in something, believing in the plants, that's going to help you. What can help you can't help me. It can't help someone else. What can help someone else can't help you or me. It's their own belief.

It's more like I'm putting people on the spot and introducing them and helping them think about what they need to give back and be responsible for. When I say, "Give back," I mean, "Give back to the Creator."

The Creator has given us this life. We don't go out and buy it at Sears or Eaton's. The Creator gave it to us. We can't go there for new blood or a new heart for nineteen bucks.

I say to them, "The Creator gave this to you. So what are you going to do to give back to the Creator? Are you going to give back the Creator a broken-down old car or broken-down old canoe?"

You need to use and develop and understand what all of this is for, this body. The Creator gave us this body, this life and this spirit. That's why I ask them, "What are you going to give back for this?"

If you're given a gift, the first thing in a gift-giving ceremony is people will say, "Well, what do they want back from me? What is it they want from me?" That's what we're taught, even in university. If someone gives you something, that's not right. They want something from you.

In Native culture, we believe that gift-giving is so important, that the Creator gave us everything. The Creator gave us this environment. We didn't pay him a thousand dollars. The Creator gave us this life, gave us this water. So, in Native culture, what is given to us is an important issue.

In tribes, with people, if you admired something of theirs, it was totally their belief that they give it to you. If you admired their barrette or if you admired their shirt, they'd give it to you. That comes with us. It's imbedded in us. That's the differences with us and the non-Native. The gift-giving came to us from the Creator because he taught us that. Everything that the Creator has given to us, plus life.

So, I'll put people on the spot and say, "What are you going to give back?" That's quite a responsibility, taking care of the life. Being responsible for it.

- an Aboriginal Elder

There is a profound truth around the ability of your mind to help you be healthy and strong. When, physically, mentally, emotionally and spiritually you are in tune, you are then having a good time. When you do not believe in something it is highly unlikely it is going to work for you. That has been proven in all sorts of situations where people are ill, that their mental state is extremely important. It goes in line with the view that we have of holistic healing that deals with all aspect of a person, emotional, spiritual, mental and physical.

Now while that is true, a disturbing thing that I have heard is that Elders and people quoting Elders say that they have treatments but that people have to believe and commit themselves to it, otherwise it won't work. If you really believe in them and do everything that you can and yet you still die, then what happens? The obvious suggestion is that the person didn't believe strongly enough or it would have worked. It lets the healer and the healer's promises off the hook. That is really dangerous. I've seen people running to healers hoping that it would help and feeling better and then get sick again. So they believe and they still get sick. So what happens to that trust and belief? When you make promises like that, then the person says, "I didn't have enough belief." It's really quite simple. Don't make promises you can't keep.

- an Aboriginal support person

I'd like people to understand and respect the alternative methods. I don't know why they call it alternative. It's natural for us. It's the method. I look at western medicine as an alternative for us, as Native people.

It's the same as death. We were here first. We were here first with a culture, with a tradition, with a people, with a knowledge, with our medicines. Then came in these alternatives, the religions, the doctors, the lawyers, the government.

So, if we can help people to understand our people, Native people, help them to understand and gain back the belief system. That's what the genocide was all about and the residential school abuse, was to remove us from our culture and traditions because that's the strongest of points that we have as Native people. They took us out of that to dispel it and take it away from us. So, now we're going back to that and quickly, too. I see a lot of people coming back quickly. They want know it, they want to understand it. So, it's important, these writings in these books.

- an Aboriginal Elder

The medicines are sacred to us. They come from the plants, from the trees, from the roots. Each one of those has its purpose, as created by the Creator. It has a spirit the same way we have a spirit. It has a right to live.

Our medicines that our Elders gather when they're asked for help, they use a particular protocol to gather and harvest that medicine. As well, to make that medicine.

Nashine Ginwenimawazawin

The one that's receiving that medicine, that's asking for it, must open their spirit and themselves up and believe in that medicine. Our Elders tell us we can make the best medicine to cure your sickness. But if you do not believe in it, it's not going to work for you. You have to believe in your own self, in your own spirit. It is your spirit that's going to help you heal.

When our spirit is at a low key, what we tend to do in our life is smother our spirit. We pick all of those things up in our life, those negative things and we wrap it around us like a coat. Or in the Ojibway language, biskawagen, we're wearing a coat. And we smother that fire. The fire is not blazing in a good, healthy way at the center of us, or it's not glowing real bright. It may have gone down to just a smoulder.

When that happens, we begin to feel that physical sickness, we get physically sick, but as well, mentally sick and spiritually sick. Because we began to let our mind carry things away from our belief in the Creator.

- an Aboriginal Elder

There is only one Creator. There are many paths to travel and ways to communicate with the Creator. There is no wrong way. Those that follow religion, that is their way to speak with the Creator. We must respect that, that is their way. But we must understand the original way that was given to us in the beginning by Creator. That is our way. We must understand that and we must be willing to learn about that.

Our people are having a hard time. We need a lot of healing in our communities. Mind, body, spirit. We must begin someplace. We must look at those ways that we've been using that have not totally helped us. Some of those medicines are good, we must understand that.

The drugs, we can safely say that, probably 98% of them are made from those natural plants and herbs that come from our Mother the Earth. But they're not natural anymore. Any medicine has two sides to it. It has the good side and it has the bad side. It's just like life. We have the good side and we have the bad side of life. The key is balance in our life. We must have balance of both. So that we're not walking a straight road, we're walking a little on this side and a little on the other side, a little on this side and a little on the other side. But we're staying on the main road. That's what we call balance. If we have too much of one or the other, then we get sick.

A belief system is most important. That's why I call it the Medicine Triangle. You have to have those three things in balance, spirit, mind, and blood.

Believing in something, believing in the plants, that's going to help you. What can help you can't help me. It can't help someone else. What can help someone else can't help you or me. It's their own belief system.

- an Aboriginal Elder

We must be able to understand that we have a choice in the medicines that we use. There is no guarantee for a cure with those medicines. The reason for that is the Creator is the one that controls life, not man. We may be able to help comfort ourselves or take away pain and prolong our life a little bit. But when it's our time to go on our journey, it will be our time.

When we talk about mixing drugs or mixing medicines, whether it's Euro-western with Anishnawbe medicines, we can do that. It can give comfort to the individual that's sick. It may help them. But we must also believe in those medicines, that they are going to heal us.

You can have the best medicine from the drug store, but if you don't believe in it, it's not going to help you. You can have the best medicines, traditionally, from our Medicine People, but if you don't believe in it, it's not going to help. Our Elders tell us that.

- an Aboriginal Elder

SYMPTOM MANAGEMENT

The following quotes, Aboriginal people with AIDS share their experiences with various symptoms. Elders talk about some of the traditional ways that symptoms are understood and how to care for them. Euro-western friends, family and health-care workers talk about the support they provided for Aboriginal people on palliative care teams.

Fatigue

I do a lot of walking and when I am walking really fast, my lower calves get really tight and I get muscle cramps. They get really tired, to the point where I have to stop and allow the blood circulation to go through my legs again. I feel very weak and as though I could trip very easily. I lost the sensitivity in my legs. I have to slow down, stop and take a rest.

- an Aboriginal person living with HIV/AIDS

He didn't have much energy at all. He would get up and go to the bathroom. He would spend a lot of his time in bed, watching TV

Once in a while, he would take a bunch of pills and go out shopping. One day I ran into him and he was carrying this great big 25 lb. turkey and all this stuff.

I was going, like, "Where are you going?"

He was like, babbling away about how he was going to cook this big meal.

Once in a while he would get this burst of energy and go out and do stuff. He would collapse into bed when he got home.

- an Aboriginal support person

They wanted to extend his work but he just couldn't do it. He was sleeping a lot, a lot, a lot, a lot. He was up every night, either playing cards or trying to finish this book, which he did get finished about a month before he died.

- a support person

Dementia

It comes to that stage where their mind is affected. I see it as a stage of any illness that people go through. It's a particular stage, where they start envisioning things, where they're starting to talk about spirits. They're starting to talk about things out of place, they start losing things, losing their memory.

It's a part of a stage because, again, treating the blood. The blood is everywhere in your system. The blood's in your brain.

Nashine Ginwenimawazawin

Usually, I try to work along with them. Whatever they're seeing and saying. I tell them that I understand and I believe it. They are seeing it spiritually and mentally. We can't sit there and say, no, you're lying. We have it in our old people, too. They are actually seeing it, their mind is going over things.

I look at the mind as, it grows and fills up with all this information over the years. Before we die, we have to go over that and go backwards with it. It brings back a lot of things. It's completing the full circle.

- an Aboriginal Elder

When it comes to dementia, most doctors are really hesitant to put that label on somebody. It's hard to prove that it's dementia because the only way you can test is by taking a brain sample. The only way they can make that diagnosis for sure is when they're dead.

- an Aboriginal support person

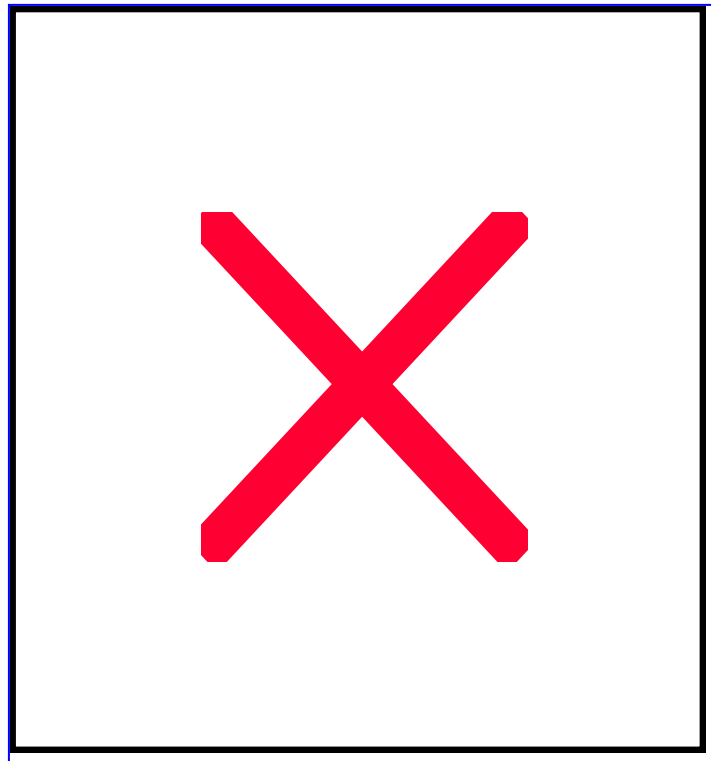
You have to give them constant companionship because you just never know what they are going to do. They could make two boiled eggs for supper or breakfast. They put the pan on, they put the eggs on, they forget all about it and when it all boils dry, you've got a fire. They might take the pan off and still leave the burner on.

I had one client who thought he would get down to work and wash his floor. Well, he did try to wash his floor but it was with the earth out of his plants. There he was scrubbing earth into his floor. The homemaker walked in on him, with all the earth out of his plants. He did not have one plant pot on the floor, it was all of them. So, there was mounds of earth everywhere and there he was with his scrub brush, scrubbing this earth into the floor.

The homemaker, he said, "Oh, I see you're trying to wash your floor."

He said, "Yes, do you think I'm doing a good job?"

He said "Well, maybe if you do it much more, you'll get too tired. Maybe you should leave it to me." He got around it that way.



Nashine Ginwenimawazawin

The patient said, "Yeah, I shouldn't probably be doing all this." He went, had a bath, got rested and went to sleep. Then the homemaker got all the earth cleaned up.

You can't scold anybody or cut them down. I mean, they're going back to childhood. We probably scrubbed floors with mud when we were kids, too. We certainly didn't do it the way our parents showed us how to do it.

You know you've just got to keep an eye on them, there's unfortunately no treatment. Just try and get a team together that will look after them in their home.

There are not many places for placement. You can get some patients into Riverdale hospital, their palliative unit. Casey House is basically our only option. There's not many places to go, which is the hard thing. It's hard on their friends and their families looking after them 24 hours a day, when they have dementia.

- a support person

People that have dementia, if they don't have 24-hour care, they may take their own medications. Even if you have a bubble pack, they could open up all the packages and take maybe, all the blue ones. You may have to keep all that stuff out of reach.

If you can't do 24 hour care (which is usually the case even if that person needs it), then there's one person who takes it upon themselves. It's usually a partner. They may call the person and say, "You have to take your drugs now. Take the pink one, take the white one."

- an Aboriginal support person

They would call the rest of us to be with him during the evening when he was awake. We would go sit with him in his room, and talk about his favorite movies and all the famous people that he had met. It was like he was giving us the history of his life.

He made his wishes explicitly known, that he wanted me to be his caregiver and he appointed me as his alternative decision maker or whatever you want to call that. That's not an easy job. Think twice about it if somebody asks you to do it. Because of his dementia, he was always changing his mind.

- a support person

I think the big reason was his dementia. It was getting to the point where he couldn't be left alone because he was falling down. He was wandering around and was totally disoriented. He started to wander, he was sleepwalking, and he was falling down.

He was double-dosing his medication or forgetting when he took it. He was stubborn, he wouldn't let me near his pills or administer them to him. It was too much for him. It was like treating him like a child or an affront to his dignity. He wouldn't let me handle that, so he was popping them and stoned out of his tree. Plus, he had dementia on top of it.

He kept sitting on the end of his bed, he'd fall on the floor and then he'd be sleeping. He'd fall asleep and then wake-up. I don't know what was going on there. He was very restless, yet he was bombed out of his tree on all these pills and disoriented. He'd fall asleep sitting-up and then would fall on the floor.

Nashine Ginwenimawazawin

He would start crying or he'd be laying on the floor crying. I was like, "Oh My God, this is terrible. What am I going to do?"

I'd get into a big dither about it. I'd pick him up and put him in the bed.

Another time, he cut his head. He was bleeding all over the place and he was crying and crawling on the floor. We couldn't stop the bleeding, so I phoned the emergency, 911. They came and took him to the hospital, patched him up and sent him home the next day.

When he was finally admitted into Casey House, he had a 24 hr nurse at his door.

- an Aboriginal support person

I went over to the hospital and went into the room to talk to him. He was so confused he had no idea where he was. He had to go to the bathroom, so I ran to the john and I got the urinal for him. And he peed all over me. He didn't even know what happened and he says "OK, I'll see you in an hour." He laid down and sort of went back to sleep for lack of a better expression. He was sort of in an out of consciousness because of the fever and the pain from the travel and everything.

- a support person

Pressure sores

I use medicine you can use externally and I give them a bit of it to take, internally.

After this weakness takes over, again, it's the strength of this illness. I call it the weakness side that causes the system to do that. The illness is building, getting stronger and stronger. That's why that comes when you're lying in bed and the breakdown of the body, the system. It's not only just happening on the outside, it's happening on the inside, too. The breakdown is coming more predominant on the inside.

It's a medicine I pick here. It treats the blood. What it works with is the system: the cells, the nervous system and the lymph system. You can find it in different foods. To give it in the medicine form, that's when it will deal with the system.

Usually in that stage, the mind comes in play, where their mind is at. If they've given up. They're bed-ridden. Their body has taken over. Again, the spirit has jumped out of the body. Again, I try to work with them to bring the spirit back to the body. Unless they tell me they can't do this, then I start helping them through to process of dying.

People don't know how to die. That's what is most important. Their journey and where they're going, they'll be safe and they're going to be with their family again. Their spirit is leaving the body and going back to a space where it came from. That's happening all through them.

- an Aboriginal Elder

He didn't get pressure sores. We were pretty good about keeping him moisturized and he had padding on. When he was in hospital they had special padding for him to lie on. He was still

Nashine Ginwenimawazawin

pretty mobile, he was never, ever bed-ridden. He could always get up and sit up. He could always go and walk around. So, he got air to those areas.

It was a plastic air mattress. It was pretty good. I can't remember where it came from, maybe the nurse brought it in or somebody donated it. He was mobile, so we didn't have to turn him around or change the bed with him in it.

- an Aboriginal support person

I had this one fellow. You can't just turn him on his back, he's got sores. Tip him on his sides. As soon as he started to get sores, okay, stomach. He was more comfortable on his stomach, I guess he'd been lying like that for the longest time. I mean that was his position of choice. I had never thought about it because the last thing you want to do is stick someone on their stomach with the head on their side. It just doesn't look very comfortable. He was really comfortable, well positioned pillows under him.

- a support person

Hopefully the pressure sore hasn't got the skin really badly broken down to the fatty layer. If it's redness we're seeing, like a first-degree bed sore, keep them off it. Don't let them sit on it.

This does happen, unfortunately, when they are so dehydrated and malnourished. The skin breaks down very quickly.

Elders and people quoting Elders say that they have treatments but that people have to believe and commit themselves to it, otherwise it won't work. If you really believe in them and do everything you can and yet you still die, then what happens? The obvious suggestion is that the person didn't believe strongly enough or it would have worked. It lets the healer's promises off the hook.

- an Aboriginal support person

It's important patients get turned every two hours at least. Never let them be on any spot for longer than two hours. You'll just see a blister develop.

At one time we used to rub pressure sores to get the circulation going. Now the opinion is that you don't rub a pressure sore. They say you can cause more necrotic (dead) tissue with a massage. I've never had that happen. I've never seen that happen with the massage but there again I insist these people are turned every two hours.

If it is just a superficial one, I will massage the area where the sore is, just around, to get the circulation going in. Put heat on as well which will also open up the blood vessels and get the circulation going.

Pressure sores are when blood vessels have collapsed and no nutrition is going to the tissue. That's what causes the pressure sore to form, that's the wound. There are various treatments for the pressure sores, but I think the basic thing is keep the person off the area that's sore. It's going to break down or has broken down.

I'd like people to understand and respect the alternative methods. I don't know why they call it alternative. It's natural for us. It's the method. I look at western medicine as an alternative for us, as Native people.

- an Aboriginal Elder

You can get alternating mattresses, which are plastic things where air fluctuates underneath different areas. It's hooked to a machine. You may get pressure on one spot and one of these things deflates, another inflates and you get pressure

Nashine Ginwenimawazawin

moved around the body. That can be very effective if you've got superficial wounds.

If they're really deep wounds, you are not really going to be gaining anything from it. You've got to go then to a very expensive bed that costs around \$1500 a day. We have to usually call in the nurse who suggests this is the way to go. She'll contact Home Care and get this special bed.

There are all sorts of treatments for pressure sores. Casey House will come out and do treatment on them. It heals up very nicely. You can put medication on. They have a thing called Hydrogel, which I usually use on AIDS patients, providing the wound isn't oozing a lot. You can take it off, do whatever you need to do to that wound and then put this Hydrogel back on again. So it's re-appliable.

We don't usually ask the volunteers to treat pressure sores. We do say to them if the bandage is coming off, either remove completely. Don't leave it all wrinkled and turned up at the end and that kind of thing because that is going to cause another pressure sore, wherever it is wrinkled up and turned back.

They can phone us and we'll tell them how to proceed. There's always that kind of stuff in the home if you've got sores. It's not really in their job description for the volunteer to do that kind of thing. It needs more expertise than that.

What I'll do is make up a plan in the home to turn them, "From to the left to the back to the stomach."

Whichever way they're going to do it. If you've got really bright people in, they're going to mark down when they turn them so you know what they've done. For example, the patient has been turned and I got there half an hour later. If they left and this patient was on his own, I wouldn't probably know what the positions had been. I need to know that so I'm not going to be turning him back onto the side he's just been turned on.

- a support person

Night sweats

To a point it's good that they have night sweats. That's a fever, the release of infection.

When it's too much, there's a medicine I give them for that. Again, when the spirit takes over, the spirit of the illness, it's fighting your system, your spirit. That's the fight that's going on there. It's the spirit from the illness Vs your spirit. In plain language, it's just trying to kick it out. That's the fight that's going on. Mentally, physically, spiritually. Again, trying to keep that balance.

That weakness, it's coming from your own body. The illness is trying to take over, the spiritual illness. All illnesses are spiritual.

- an Aboriginal Elder

Fever

In some cases, fever is good. That's an expression of the system, the hot and cold. Fever inside the system is the infection that you have to get rid of.

Some people do Sweats. They make them Sweat, so that the toxins will come out. A lot of people won't do that. A lot of people won't make themselves Sweat. And then the system will just house this fever and it won't release it.

- an Aboriginal Elder

Vision Loss

I treat it from the blood and it's the spirit. The spiritual side of the person is leaving and their vision loss comes from the weaknesses. Also, them getting so weak that their eyes are fragile. Each one of us, our eyes are fragile.

They can say that they're seeing things consciously or subconsciously. It's visions they're having. A lot of people that I've been with that have died right there in my arms or in the same room. These are things that we talk about. It's the last stage, the vision goes, the hearing, all of that.

When they're not near death, again, it's been affected from the blood. It's the trauma they're going through, the fear. I treat it as a fear when someone loses their hearing or their seeing.

- an Aboriginal Elder

Yeast Infections

The only thing I've had so far has been major yeast infections. It was an ongoing. I was put on medication, one pill a day of fluconazole.

- an Aboriginal person living with HIV/AIDS

The Lungs

That's a place that is affected. Each one of us has a weakness. It could be my heart or it could be your lungs or it could be someone else's brain. That's the part that's affected the most. It's a particular stage of the person themselves, how they're affected from it.

It's a battle. It depends on the individual and how they're affected. There's a big difference between us and western. That's why it's important that we do this work. Again, they're mainstreaming us, "Oh, you're supposed to be like this or this isn't supposed to be happening."

- an Aboriginal Elder

No Appetite

It has to do with the medicines. There's medicines you can give to them that'll help with their appetite.

And then, asking them, what is it we can give you to eat? They'll tell you themselves, their system. They'll tell you what they want.

Usually, you can put the medicines, how I work with them, is only in the form of teas. You can give them these medicines to drink.

When their appetite is gone, again, that is part of that spirit. That spirit is taking over again. I explain to them that it's important that "You take over. It's your responsibility. You have to

Nashine Ginwenimawazawin

feed this body. That's how you were born, that's your responsibility, feeding it, taking care of it." So, why let this spirit take over your appetite.

In severe cases, it has to do with the stomach and the stomach lining. Sometimes it'll create a big pain for them.

Usually, loss of appetite, to me, indicates that they have loss of spirit, loss of soul. You know, their heart. They've given up. You have to do ceremony, to try and bring them back to that place where they can start eating. We make special ceremony food that will help them. We make a special kind of oatmeal, or mush. Then we make a special bread for them.

- an Aboriginal Elder

Constipation

Usually I find that if they've suffered sexual abuse, women will have that problem. Women will have cancer of the uterus or they'll have constipation or they'll have some problem with that area of their body. There's something, some trauma that's happened with them earlier in life that will indicate that.

Constipation will come when they don't want to release things. It can stem from abuse. Everything tightens up, everything's in a state like that. There are medicines I can give them to help the to relax, relax the bowel.

It can also come from different foods that they're not digesting. There are medicines I give again, in the form of tea.

If they're really constipated, we have to use an enema. They can use an enema that will help them to release.

- an Aboriginal Elder

Incontinence and Diarrhea

Each time someone's been incontinent, whether it's stool or urine, they should wash the skin, that keeps the skin in good condition. You're not going to be burning it. The urine is very strong and acidic and burns. Stool, if you've got diarrhea that can be acidic and burn. So, you need to get all that off the skin to keep it healthy and breathing properly.

It gives a sense of worth, too. They're not going to be lying there, incontinent for a long time. How can they say they are being taken care of if they are lying in poop for a long time?

I usually tell them about and show them a condom catheter. We don't usually get volunteers to put them on. If it comes off, I usually try to tell people to pad the patient up with a diaper or an incontinence pad. Failing that, just get a big towel and a pad around where they are going to be peeing.

- a support person

If you're incontinent, you're incontinent. You have to deal with it, whether you're transgendered or not. If you're transsexual and you're not operated on and you're a male-to-female transsexual, you still have a penis. If you have urinary incontinence then you would have to put a catheter into the penis. Of course, the argument is that it's disrespectful. On

Nashine Ginwenimawazawin

one hand, you're keeping the body safe from deteriorating. If you do it in the most respectful way, still respecting the individual as who they represent and identify, to me you've done everything.

I can't tell you that a person is aware or not. By the time you've put a catheter in, they're pretty far-gone. I think those are issues that should be discussed with the client and the beginning, when they're assessed. When they're seeing a counselor.

"In the event that you would go on this road, what kind of care would you like? How do you want me to treat you if you're incontinent?"

I think by asking them, you have more choices in order to advocate for them when they're there.

- an Aboriginal support worker

Incontinence pads can protect the bed mattress from stool. They cost money. You could make your own incontinence pad by sewing two pieces of flannel sheets together with plastic, like a plastic table cloth, in between. You can use homemade incontinence pads many times because you can wash them. Make sure the plastic doesn't touch the patient's body because it will create moisture or cause chafing.

- a support person

Something could have happened. There's something in the system, usually that will happen from fear; from fear of the illness, from fear of themselves.

Fear is the biggest thing. It can start things, stop things. Everything can come from fear.

It's the same when you die. The final movement, the final thing is your bowel and everything empties. It all comes out of you and the trauma with people works different. Every individual is different. You could have constipation, where me, I could have diarrhea.

- an Aboriginal Elder

The diapers, we got some donated. I couldn't handle doing that, so the other care team member would change them.

You would have to bath him afterwards, every time, because he was so emaciated. We got this donut for him to sit on in the bathtub. Sometimes, he would get stuck in the donut, because it was suctioned. So, when he had an accident, it was a disaster. That only went on for a couple of weeks because that was at the point where we were going, "Oh my God, this is too much, we can't handle this."

When he became incontinent, that was one of the hardest things you have to deal with.

Some of the Home Care helped him with that, too. We had rubber gloves. We had a special thing to dispose the dirty Depends, a special garbage can. It was only once or twice a day he had that problem.

Nashine Ginwenimawazawin

When he was living at home, he was never totally bed-ridden. Sometimes, he could make it to the toilet. Sometimes he would even change it himself. It wasn't too often I had to change him.

I just wasn't used to that, dealing with people's excrement and the smell and stuff like that. It was really disgusting, I found. I had to, well, I did, a few times, out of necessity. He needed to be changed, he needed help. So, I did...I'd get it over with as fast as I could.

Well, he'd tell me, "I need some help in here! I just shit myself." Bluntly. He's tell you exactly what was going on.

We would go in and put plastic down underneath him, a plastic sheet. Have the rubber gloves on. Then, he would take off the Depends. Wash his bum and put on a fresh one. Sometimes he would put on powder or cream. It was just like changing a baby.

There is only one Creator. There are many paths to travel and ways to communicate with the Creator. There is no wrong way.

- an Aboriginal Elder

We used soapy water to wash him. Our bathroom was just down the hallway. We would fill the sink and run back with a facecloth. Sometimes, if there was a real mess we would fill up the tub or he would say, "I want a bath."

We would use baby oil, so that he wouldn't get a rash. You have to be really careful. It's just like a baby, they can get diaper rash. You have to be really careful to keep that area clean because it could get infected. He could develop cracks in the skin.

We got the supplies from Home Care. He had a plastic covering there to protect the mattress. That came from Home Care. We got the Depends from Anishnawbe Health. Also, we had this thing for needles, when they changed his IV. Then, there was a garbage can where you throw his Depends in.

It was a major operation. Fortunately, he was still strong enough that he could still walk around and make it to the bathroom. Once in a while, he'd be lying in bed and he'd take off the Depends to air out because they were bothering him and he felt kind of damp. Then, he'd shit all over the bed. That was a big hassle because you'd have to get him up, clean him, clean the bed, change the sheets. It was a big production. That was a major disaster when that happened.

- an Aboriginal support person

Anger, he was mostly frustrated with that. He was never body-conscious or shy around his body, he was very comfortable. He was more pissed off that he had these accidents. A couple of times it was so frustrating that he broke down crying. He would just get changed and get comfortable and then it would happen all over again. He would cry because it was like he would have to go through this whole rigmarole. It was like he couldn't relax.

- an Aboriginal support person

We gave him bed baths, sponge baths. We had to make sure he was dry, especially around the genital area and the bum. You powdered so that it would soak up any moisture. You had to make sure there was no chafing or rashes. You had to watch for pressure sores. You also had

Nashine Ginwenimawazawin

to use baby oil to keep the skin moisturized. Massages are important. Keeping the body dry but also supple because of his dehydration, he had a lot of problems with dry skin.

Keeping the bed clean. Keeping the room clean, keeping the dust down. It was a lot of work but in the long run, it's better because you don't want bigger problems with sores developing from infections.

- an Aboriginal support person

We used those gloves they have in emergency rooms. Those one(s) that you can get at the drug store, too. If I was in the emergency and I saw a big pile of them there, I'd scoop some up. They're like, fifty cents a pair. I'd be stuffing them in my pocket! You go through a lot of them. The Home Care nurse would bring a lot of them. They would bring a lot of supplies in because they were there every day, changing dressings and changing IV needles and changing bags.

For some Aboriginal people, they're very, very private about their body. Another person I was on a careteam for, they mentioned if they were being changed, "Don't laugh at me."

He was embarrassed. I think you have to be really conscious of that person's privacy. It may be when you're doing that, look away when you're changing or else they may want a sheet over them. You just can't go in there and strip them naked and not be concerned with their dignity.

He also used that jug. He would just sit on the bed and urinate and I would go and spill it out.

- an Aboriginal support person

Vomiting

Usually I give them medicine to make them vomit, so that everything comes out. If it doesn't stop, then I have to give them a medicine they can swallow so it can stop.

Usually when people are vomiting, it's better for them because they're bringing out any toxins that the system is discharging. It's like diarrhea, sometimes it's good for you, then everything can come out.

If you're holding it in, then you can get real sick if it goes into the system. I have medicines that I can give them.

Especially in cases of people with AIDS and the final stages, their system breaks down or something is going on with the stomach.

- an Aboriginal Elder

Mouth Sores

They started out like a cold sore. Usually a cold sore lasts for a couple of days and then it's gone. This time it didn't. It just stayed longer and it went on and on. It just kept getting bigger and bigger. It became very sore. My tongue would also get them. It would be like little red dots on my tongue. It was very painful. I wasn't able to talk clearly. I had to be very careful of what I ate. It was very painful to swallow anything solid.

- an Aboriginal person living with HIV/AIDS

He called me to come over and see him. I went over and he was all curled up in his bed. He was having trouble eating and all this kind of stuff. So, we go through all the trying to find something that he can swallow. I gave him some medication, it's good for the sores in his mouth, so that he could at least get something down. That worked for a while.

- a support person

Nausea

Well, it feels like you're ready to vomit. What happens is I have a problem digesting food. I feel this nausea, and it's always there. It takes a while for a meal to be digested. I'm always burping and feeling that nausea in my stomach.

- an Aboriginal person living with HIV/AIDS

He was also smoking up (smoking marijuana), too, to help him with his nausea. It relaxed him.

- an Aboriginal support person

Wasting

Well, it was weight loss. He was a big man, 260 lbs. At first, he dropped down to about 200 lbs. the first time, after he got diagnosed. He was having chronic diarrhea. He plateaued there for a while. He was actually happy to lose the weight.

When he got Hepatitis, it dropped even faster. From around Christmas to the summer, he lost around 90 lbs. He was around 120, 115 lbs. He was around 6'3".

The skin was just hanging off him. His bum, it was like, in folds of skin hanging down. His muscle tone was non-existent. His face was like, so gaunt. I have before and after pictures, it looks like two different people. It was the chronic diarrhea that did it.

I think it was also that everybody carries parasites. When you've got a healthy immune system, it's no problem. As soon as your immune system is compromised, well the parasites take over and you've got problems.

It was that and a lot of drinking, too. You get diarrhea the next day, when you've been drinking. He was a heavy drinker.

His nerves, too, he was very high strung. Even when he was healthy, in the morning he would get sick. He would throw up because he was so tense and wound up. That's how he would start his day.

- an Aboriginal support person

He basically administered the drugs himself. He was also on morphine and percodans. He was pretty good about taking them. He didn't really abuse them. It was for the pain from the wasting. He had no padding, no muscle tone or fat. He had body-ache. He was sore because he was always lying down and he wasn't getting any exercise.

It was mostly pain medication but he was also on Imodium, an anti-diarrhea medication. That stopped working after a while.

Nashine Ginwenimawazawin

He didn't start getting dementia until a week or so before he went into hospital. I think at that point he was so anorexic, I think it started to affect his brain. He was probably starting to lose brain tissue because he was cannibalizing himself.

- an Aboriginal support person

The devastation to the body is something that I will never forget as long as I live. I have seen many, many people die of cancer and I have never seen anybody as reduced and emaciated. He was just skin over bone. You could see even the joints in his jaw. You could see every joint, there was not an ounce of flesh left to him. Skin, there was left. But there was absolutely nothing under the skin. It was unbelievable. I really don't want to see it again, but I know that I will. I had never seen anything that horrifying in my entire life. The indignity of it all.

- a support person

SPIRITUALITY

There are different cultures, different tribes, different nations, different traditions.

- an Aboriginal person living with HIV/AIDS

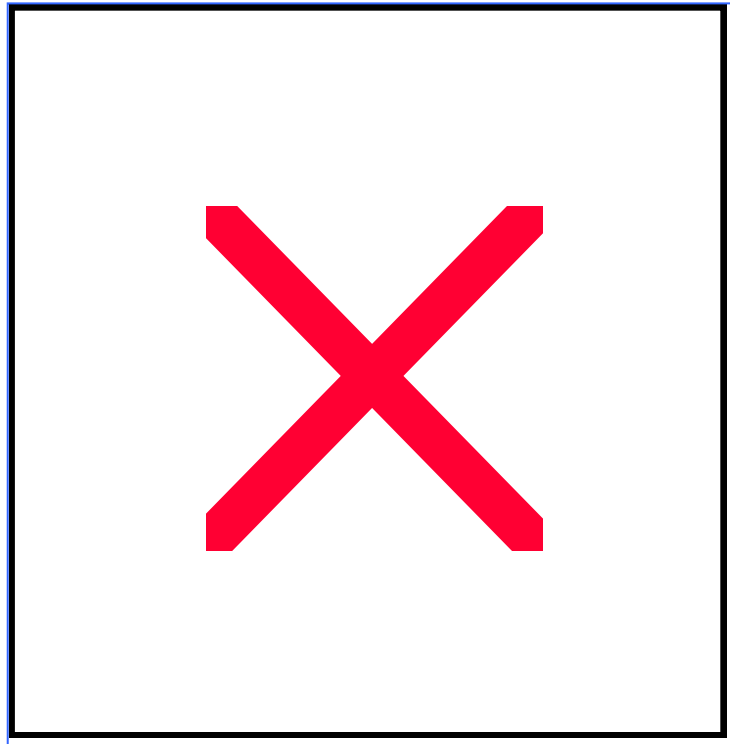
I can't speak for all traditional people because there are so many nations, there are so many ways and so many different views about the same things.

- an Aboriginal Elder

As the above quotations observe, spirituality is very individual. Each and every person has a different understanding of what spirituality is and how he or she wants to express it. This diversity has caused many people to celebrate spiritual differences; it has also caused countless disputes.

The person you are caring for may be very spiritual. She may have many ways of expressing this. She also may have little or no involvement in spirituality. Other people are very spiritual for a time and then drift away from it.

It is important for your care team to recognize that not all Aboriginal people have experienced spirituality in a way that helped them. It is unfortunate, but there are people who use spirituality for power, control, and abuse. The community and family she comes from may have been negatively influenced by the residential school system and churches. There are Aboriginal people who use spirituality to hurt their own people. If she was adopted or fostered, she may not know the ways of Aboriginal spirituality.



As with any of her decisions, it is important for care team members to respect her wishes regarding spirituality. You may be tempted to encourage her to turn to spirituality because you recognize that it may give her peace of mind. It is essential to realize that while you can make suggestions, it is her decision.

Nashine Ginwenimawazawin

The frustrations that people have with spirituality are also discussed. As a care team member, you will want to be certain that she is treated with kindness, and given space to feel comfortable as she learns and makes mistakes. What do you need to recognize judgmental behavior displayed by an Elder or Traditional person? It may be helpful for your care team to know there are people who have proclaimed themselves as spiritual leaders, who haven't learned the traditions and don't live a spiritual life. An awareness that some people use spirituality to attack, control, and abuse vulnerable people may help your care team ensure that this does not occur. There are people who claim to be spiritual leaders who aren't even Aboriginal.

I was self-taught. I did a lot of my own research. I studied a lot of major individuals like Chief Dan George and Sitting Bull. Some of these major historical Native figures from our community. There are certain figures that stood out in the Native population and they had a lot to tell us historically, spiritually and how to relate to nature. I did a lot of research into their biographies and teachings. They were Elders that gave teachings through books, videos, and movies.

- an Aboriginal person living with HIV/AIDS

The following quotations talk about the many wonderful ways that Aboriginal spirituality can enrich your life. Elders, your clan, your traditional name, understanding what happens to your spirit after you die, celebrating your relationships with others, speaking your language, praying, using sacred medicines, and taking part in ceremonies are just a few of the ways in which you can follow this path. These quotes also have stories to show the person you are caring for as well as for you, the care team member, the ways to explore, understand, and express spirituality during one of the most crucial times in her life.

Some people embrace religion as they know they're dying. Other people reject all religion altogether. If you're someone who embraces it then all the more power to you.

- an Aboriginal person living with HIV/AIDS

I was raised by my traditional Grandmother in her style of living and carrying on with life. That is something you're not taught, you just live it. I lived it with her. I learned a lot of the teachings and stories. I learned about the different meanings and power within the Four Directions, the Sweatlodge. I learned about the spiritual side of the elements that we use to relate to the Spirit World. I turn to my Traditional ways of relating to the spiritual world.

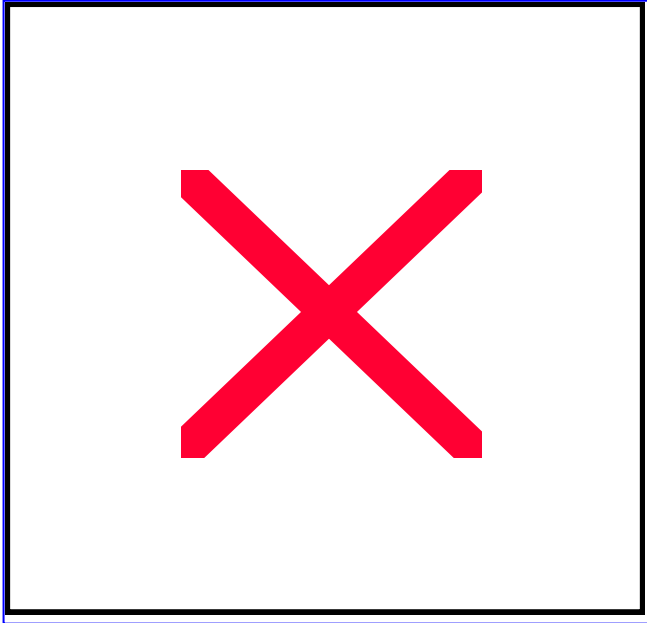
This is going to a lot of Sweats. When I was growing up, I did Sweats on a regular basis. I do a lot of praying on my own, to relate to the Spiritual World. I've always felt I was connected one way or another. I carry those practices that I learn in the community.

- an Aboriginal person living with HIV/AIDS

The first couple of years, I started to get involved in ceremonies and traditions. I went to Sweats up in (the) Sudbury area. I went down to Toronto, there was a women's conference that I went down to. It was for Native women. It was really nice.

Sometimes I really miss it. I always try and take care of myself. One of those things is trying to do ceremonies. I never give myself time to do that. It's really important for anyone to participate in anything like that. It's a learning experience for everyone.

- an Aboriginal person living with HIV/AIDS



I've never been somebody that has been into my culture. It was only after I was diagnosed. I had a lot of support from our Elder and he was able to help me understand about our culture and how important it is to have our name. He helped me prepare for the ceremony.

It made me realize who I am as a person. Just knowing that I have my Traditional name, it helps me out, especially when I'm praying or going to ceremonies. It makes me feel special.

I thought I was a Fish Clan but, as it turns out, I may not be. So, I'm

kind of struggling with that because I always thought I was a Fish Clan. Now that I'm not sure if I am or not, I feel kind of lost, a little bit. I'm trying to find out exactly what Clan I'm from. It's been a struggle. It'll take time before I actually go down the line in our family to find out what Clan my father is.

- an Aboriginal person living with HIV/AIDS

All these tools that are given to us, a Drum, a Rattle, a fan, a feather, a Smudge bowl, the Medicines from the earth. All these tools that are given to you are tools. They are tools that reflect who you are in your walk in life and where you're at.

I talk about this in my Sweatlodge. A lot of people say, "Oh, thank you, Creator for the honour of this feather." They revere the feather.

What I say to people is, "It's easy to get a feather. What's not easy is to walk in the honour of that feather. It's not easy to keep the honour of it."

So, all these tools are given to you because they reflect you and they reflect a portion of who you are and where you're at in your walk. They also help you focus on what you've already got inside of you. Everybody has a pipe, everybody has a feather because **we are the most sacred Medicine. Women, men, two-spirit, whoever. We are the sacred Medicine. People forget that. We walk between the earth and the sky.**

It's easy to get a feather. What's not easy is to walk in the honour of that feather. It's not easy to keep the honour of it.

- an Aboriginal Elder

I tell them, "The Creator knows who you are. You smudge every day. You're part of Creation. You walk the earth. You eat the medicines of the earth, you've fed yourself, sheltered yourself. The Creator, whoever the Creator is, He, She. What ever language, the Creator knows."

You go in a Sweatlodge for three hours, you humble yourself, you pray hard, you sing beautiful songs, you cry, you walk out of the sacred Sweatlodge ceremony and you start

Nashine Ginwenimawazawin

swearing and you become judgmental. You think the Creator doesn't know that? It actually makes you more of a hypocrite. If you're not striving to change that and you just go in, you pray and you go, "Good enough." And you carry on the same behavior.

The walk is yours. **You are the Sacred Medicine. It's already been given to you. It's keeping it.**
- an Aboriginal support person

When I was on the reserve growing up, I never knew that traditional part. I was never taught that. I guess you could say we lost our tradition long ago. There was no such thing as Elders or anything like that. My grandpa never taught me anything. Even Pow Wows, that's so amazing to me. When I came down to Winnipeg, I wasn't involved in it but when I came to Toronto, I couldn't believe there was so much tradition. It was totally shocking to me. I didn't want...I don't want to be like, traditional. In my time, I guess. I can speak my language, but ...

- an Aboriginal person living with HIV/AIDS

I never realized there were so many traditions. I don't know if it was ignorance or just plain stupid. It doesn't bother me. I'm glad I'm starting to learn. Right now, I have to like, straighten out my life and all that. Right now I'm having too much fun! Somebody slap me!

- an Aboriginal person living with HIV/AIDS

Where do you look, when you want to find your culture? So many Elders want you to go to them and find them. Well, these pretend Traditional people stand out. There are all of these instant Elders too. They learn a few things and all of a sudden they have a little group around them and they are being proclaimed as traditional healers. An Elder is someone chosen by the community to be that. They do not choose themselves to be Elders. The members of the

Everybody has a pipe, everybody has a feather because we are the sacred Medicine. Women, men, two-spirit, whoever. We are the sacred Medicine. People forget that. We walk between the earth and the sky....The walk is yours. You are the Sacred Medicine. It's already been given to you. It's keeping it.

- an Aboriginal support person

community recognize the qualities: the wisdom, the ability to heal, the ability to read people, help people, etc.

Now, we have these people who decide to quit drinking, drugs and maybe they quit fooling around on their mate. They establish

themselves as a "clean living" person, they go to a few ceremonies and next thing we know they are being touted as an Elder. Who said being clean and sober is the only requirement to be an Elder?

Meanwhile, you have a lot of these people running around and they are judgmental, gossips, destructive, cruel and set people off against each other. They have little groupies they like and people they don't like. They like to set up factions in our communities. Toronto is a very fractious Aboriginal community. We are all from different backgrounds, different cities, towns, reserves and communities. We don't need more problems separating us. We need to be brought together.

When our young people are looking for role models and help in living properly, it is very dangerous to have instant Elders running around, whose main qualification is they don't drink or do drugs. What other qualifications do they have? Not drinking or doing drugs is

Nashine Ginwenimawazawin

admirable but it doesn't mean these people are caring, knowledgeable, wise or a good community member.

We also have Aboriginal people who are into a pan-Indian thing. We have Crees learning Lakota traditions and ceremonies, Mohawks learning Ojibway ceremonies and Ojibways learning Mohawk traditions. Then they go out and proclaim themselves as healers in the tradition they just took up. Now I know why some of our societies are so secret because we have these "beliefs in a blender" healers. I don't see a lot of these people demonstrating true traditional values, and by that, I mean not judging people, sharing, having respect for all things, honesty, giving to the community, a commitment to excellence and taking care of each other.

The better every individual is, the more they contribute to the community and the stronger the community. What I do see is a lot of rejection of people: people in prison, two-spirited people, people with HIV and AIDS, people who drink or do drugs because they have been so damaged by the world that we live in. These people didn't get the culture, the language, the community support because everyone else around them was damaged. We are blaming them for the symptoms of the illness we all have, which is loss.

- an Aboriginal support person

I know that I have my Eagle Feather. I have my Sage and all my medicines there that are available when I need it. Sometimes I forget about those things.

I know my Elder is there when I need him. I pray when things are tough.

I like to go out with my friends and have a good time. Going out, whether it's to bingo or wherever. As long as I'm out with my friends and we're all having fun. That's one of the things that I do, I make sure that I'm around people that want to have fun.

- an Aboriginal person living with HIV/AIDS

I don't believe in blind faith. I don't believe that just because you're a Native person and this is your history and your culture, that you're supposedly handed this on a platter and said, "Believe" and that's it. That's not how I see the world. I believe in what I believe because I tested it and I found it to be true for me. I think that everybody has their own responsibility to do that. I don't think you're supposed to listen to all this stuff and never say, "How come?" or "Why?".

I think if you're going to really believe in something, you've got to really buy into it, and I don't mean buy into it in a bad way. You do. It's got to make sense to you. You've got to understand it. You've got to be able to say, "Yeah, I agree or I don't."

- an Aboriginal support person

I would say that I always pray. I've gone to various religions. As I was growing up I went to a Catholic Church, then I went to Baptist, then my Aunt was Jehovah Witness. From there, I went onto Christianity. That was basically the last major institution that I was a part of in mainstream society. I realized that all of the religions are inter-related. They have one final goal and it's that the Great Spirit or God is the ultimate and the all. There are various different teachings and how they are taught is different within each religion.

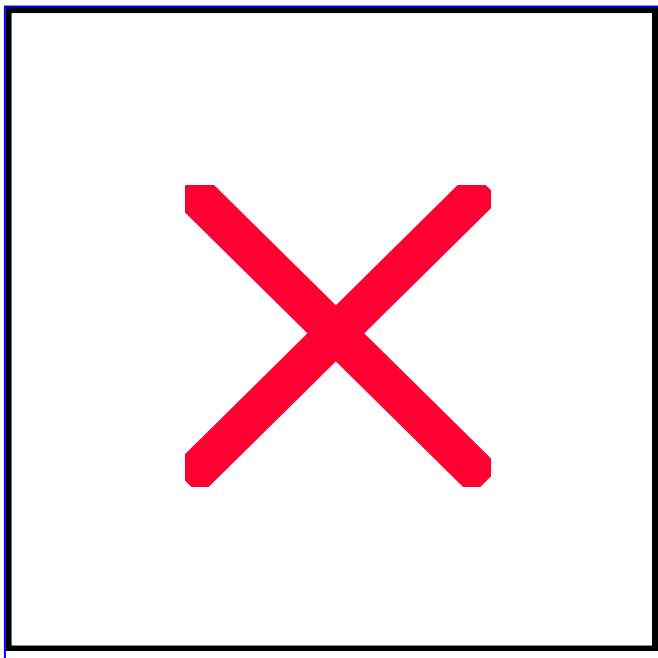
- an Aboriginal person living with HIV/AIDS

Nashine Ginwenimawazawin

I remember when I was first learning, what I appreciated was those little things, so that I wouldn't do something whereby I would feel like, "Oh my God, am I ever an idiot". That's what people need to hear.

Do all those things with kindness. It irks me when we make mistakes and sometimes it's the Elder or teacher or just other people participating. They act as though it's the end of the world because you started walking right instead left. You didn't know. It's all part of the learning process. We make mistakes and then we learn from those mistakes. If you're really going to have a fit on somebody because they made a mistake, well then they probably won't be back.

- an Aboriginal support person



When people ask about living a traditional way in a contemporary society, I say that it's absolutely available. Although we may not be living in a traditional environment, everything is a teaching.

With our day to day life, if we use it as such, it means we're constantly moving and developing on that path of awareness. That is what this whole journey is about. Everything, the vehicle you travel in. The road, the experiences, it's real.

These things that we often think of as modern

technology. There are teachings in there because inevitably, everything here, in some form, came from the earth. Whether this was made from petroleum by-products, the metal in there may be tin. It is coming from the earth in some way. So, we can have a relationship with that, the same as if it were a bird or an animal. You just use it as a way of learning. That's why we pay so much attention to the symbols like the trickster. Those teachings are all around.

- an Aboriginal Elder

Those non-Native people that pretend they are Aboriginal? We call these people culture vultures or culture shoppers. They are so desperate for culture, they will go and adopt someone else's. We always hope it comes out of respect, caring and appreciation of the values of our culture. That is not how it often translates. What happens is that we have these little Grey Foxes running around, who pretend to know more about our culture and tradition than we do.

When you grow up in another culture, you look at everything through the lens of that culture. If you are raised as a Christian, you go to the Sweatlodge and observe the ceremonies, you are likely to interpret them through a Christianized lens. I don't truly believe that a

person from another culture will really get it. These people come in and they become little white Indians. They really don't get it and they don't understand it completely. There is more to our culture than you can observe through attending Ceremonies, Sweatlodges and language classes.

There is a danger in these people going out and becoming beacons for our young people. Unfortunately, a lot of our people have had drummed into them that white people are better and if there is a chance of following a white person, they will do it. They will particularly follow someone who claims to have power through their observance of our traditions.

Truly powerful people in our communities never show their power and never claim to have it. Elders do not express their gifts in terms of power. So, we have these frauds running around, attracting desperate people who have been rejected by their family or communities and may not know much about their own traditions. These people will hate themselves and will follow these gurus of Indian culture. It is dangerous for these young minds who need something to hang on to.

It is really hard because you wonder what kind of damage someone has suffered in their life to want to be an Indian. Very few of our communities have anywhere near what they need to sustain an economy or employ their members.

Think about all of the stereotypes. Why would a non-Native person want to be one of us? One of the things they do is capitalize on other people's guilt and they capitalize on the noble savage stereotype.

They go out and say, "I am a victim of an oppressive white culture and I won't stand for it anymore."

We are desperate for leadership. We will follow people like that. People won't even question who they are, so long as they claim to be Aboriginal people. They go off and observe our ceremonies and start talking in the language of the tradish-Nish and people believe and follow them.

Those people are dangerous. They found a way of coming people and maybe finding and respect they could never get from their own community. They are not doing this for us, they are doing it for their own selfish reasons.

- an Aboriginal support person

APPROACHING AN ELDER

The person you are caring for could already have a relationship with an Elder, if he doesn't, and asks to see an Elder, a member of your careteam may have to approach an Elder for help. Your search may begin through word of mouth, or his partner or family might know an Elder. Aboriginal organizations, such as Friendship Centers, might be able to provide a referral. You will find listings of Aboriginal organizations in the Resources section.

Nashine Ginwenimawazawin

An Elder may be a vital support for the person you are caring for by offering guidance to help him cope with issues such as grief, anger, and dying. The spiritual knowledge, life-time of experience, and many other gifts that Elders have to share, can provide him with indispensable healing. Many Elders will address issues in a holistic way, considering his physical, mental, emotional, and spiritual needs.

Depending on the availability of the Elder, he or she could assist the care team as well. The Elder may be able to hold Healing or Talking Circles or provide guidance regarding medicines or ceremonies that could aid your team.

There are certain protocols to use when you approach an Elder for guidance. The best way to find out the appropriate protocol is to ask him or her. Each Elder will likely have a unique way that they prefer a request to be presented to them.

The following quotes talk briefly about the role of an Elder. There is discussion on the practical needs and considerations that the care team needs to think about if they are going to be working with an Elder.

An Elder will definitely appreciate your care team spending time with them to explain the details of the situation. The Elder may not know a great deal about AIDS and he or she isn't going to know his specific palliative care needs. For an Elder to offer the most appropriate kind of help, educating, and sharing of information will have to occur. **This information is confidential and can only be spoken about with the permission of the person you are caring for.**

Another reason for explaining background information is because some Elders have prejudices and fears. Some Elders may be homophobic or afraid of AIDS. While many Elders have traditional teachings about death and dying, they may not be at a point where they choose to offer them. Others may not have the capacity to cope with the anger and fear that comes up from the person you are caring for. These are very important considerations to examine before inviting an Elder to meet him.

The Elder in the community is a person who has earned respect through his life. An Elder is not recognized by just their age. They are recognized by the knowledge they carry. They are recognized by how they are a role model. They are recognized by the people and the gifts they have been able to become, about our original way of life. Learning the teachings that are thousands of years old, to be able to understand that. To be able to orate that. To be able to practice that on a daily basis.

An Elder is someone chosen by the community to be that. They do not choose themselves to be Elders. The members of the community recognize the qualities: the wisdom, the ability to heal, the ability to read people, help people, etc.

Now we have these people who decide to quit drinking, drugs and maybe they quit fooling around on their mate. They establish themselves as a "clean living" person, they go to a few ceremonies and new thing we know they are being touted as an Elder. Who said being clean and sober is the only requirement to be an Elder.

- an Aboriginal support person

Nashine Ginwenimawazawin

But as well, to be able to perform those ceremonies that are sacred to our people. To be able to help our people understand who they are, where they belong and what their belief originally was, prior to contact of the newcomers. So that our people are able to learn.

We do not call ourselves Elders. It's the people that call us Elders. That recognition of respect has to be earned. You have to work for it.

But as well, it's being able to share life's experience. To be able to share that life, even before our spirit left the Creator. How it travelled and the experience that it had in that journey. How it came from that realm to this realm here, on our Mother, the Earth. To be able to know those teachings and to be able to understand that it is the spirit that walks this life.

- an Aboriginal Elder

Again, it depends who it is. You usually take tobacco. Don't be stingy with the tobacco. Some people, they put it in tobacco ties. I don't know where that comes from but that's not how I was taught. You need enough tobacco for a pipe.

You don't open the tobacco and just give them that much. You hold the tobacco while you talk to them. It needs to be your energy that goes into that tobacco. I find people make these tobacco ties and leave them. You have done nothing to earn that. When you take tobacco to an Elder, your energy goes into that tobacco. You hold it while you are talking and you're asking. You talk to them about what you're asking for, when you give that to them. You offer it to them and just leave it there.

Sometimes they don't take it because they can't help you, for whatever reason. So, if they don't pick it up, if they don't take it from you then you just hold it. You keep it. The tobacco is for spirit because that's what we put in our pipe and we use that smoke. The tobacco always goes ahead.

How you pay the Elder is how ever you pay the Elder. At one time, it was blankets or materials. Today, most Elders need gas money. You can offer money, although I've known Elders to refuse it. So, you offer the tobacco and you give them a gift as well. You don't just offer money as though that's what they're after. I've heard so many rumors about, "Somebody charges this for a Sweat." The reality is today we use money. You have that as part of it. If they give it back to you, then you take it back.

- an Aboriginal Elder

They just bring tobacco. I like to go by my Native name, my Mohawk name that was given to me. When they approach me, they come with the protocol of bringing tobacco. Tobacco is a known protocol amongst Native people. That means we're to burn tobacco and pray for you, that you want help. That you want some knowledge, that you want the attention. That's when I give them the attention and the methods of practice. That gives me an indication that they know what they're coming for and that they want to be here.

- an Aboriginal Elder

Elders are shown respect for a lot of reasons. They have lived a long life during which they experienced a lifetime of lessons. They take those lessons and offer them as teachings to our

Nashine Ginwenimawazawin

people. They learn about sacred ways and they share them with our communities. They have knowledge of ceremonies and medicines.

Some people confuse respect with reverence when it comes to Elders. Elders themselves can even get carried away, desiring an image of being looked up to. Look for an Elder that "walks the talk." This is one that lives the same way that they talk about. They aren't hypocritical and they don't put themselves on a pedestal.

Elders that get caught up with an image-thing are human beings, just like everybody else. Our Elders went through a lot of really awful experiences. They were the ones that went through generations of residential school systems. Imagine, being grabbed out of your home as a little kid and taken to a cold, abusive place that removed your culture, language and pride? Then, thrown back to the world, damaged. Then to make matters worse, their kids were stolen by adoption and fostering.

The survival of our culture is a testament to their strength of our Elders. They carried on our ways, despite so much damage from schools, churches, and government. Our Elders were once little kids who used survival skills and a strong spirit to refuse admitting defeat during a terror-filled time.

If your care team is requesting the help of an Elder, simply use common sense to treat him or her with respect. You don't have to fall all over yourself to run errands for them. It's just thinking of the small things, like what transportation needs do they have? Money doesn't materialize on trees for Elders. Is there a collection of money to help them with gas if they have to travel to get to your care team? Can someone go pick them up if they don't have a car? Is there cash set aside to pay an honorarium for their time, wisdom and work? Can you find out what kind of tea or juice they like to drink? If they're going to be working with the person who has AIDS for hours, what kind of food do they like? Are there any preparations the Elder needs you to do ahead of time? Does the Elder have any mobility needs, like maybe they need help up the stairs? Can someone from your care team be designated as a helper for the Elder while they are there? If they're traveling really far, do they need a place to stay overnight?

The teachings that Elders can share will be very helpful to your care team. Maybe they'll be able to teach the people on the care team how to smudge the person with AIDS, so this is available to them when they need it. There are teachings and instructions on how to do this and the Elder may explain these things.

Truly powerful people in our communities never show their power and never claim to have it. Elders do not express their gifts in terms of power.

- an Aboriginal support person

There are the physical things that an Elder can help with. They know sacred and herbal medicines that will help. They can take care of the physical part.

The person with AIDS may be very scared about the changes that are taking place from having AIDS. Maybe they're scared about going to the Spirit World. There may be emotions or questions that they don't know how to put into words. Some fears emerge because they don't understand these things or else they've been brainwashed and scared out of their minds from hell-filled teachings of various churches. Elders can offer (to) help alleviate some of these fears because they know teachings to help the

person make preparations to transition to the Spirit World. The Elder will probably recognize that the spiritual part of the person needs care and attention. The Elder can probably explain reasons for this sickness and dying. There are answers for what everybody can expect for our spirits when we die. Elders can make sense out of it and give meaning and purpose.

This isn't to say that all Elders are going to be able to answer every question. An Elder isn't a walking encyclopedia that just recites words. They don't have an answer for everything. They may even offer remarks that don't seem to make sense right away. They do this because the Creator gave us a mind and we're supposed to use it, to figure things out for ourselves, even during a time before going to the Spirit World. A lot of people expect the Elder to provide all the work. We have to work as well. This includes using our brains.

Another thing the care team has to consider is whether or not they need to explain what AIDS is to the Elder. They may also have to explain the specific needs of the person who is dying. Are they having a hard time sleeping? Are they depressed about shitting the bed all the time? Are they pissed off at the Creator because they are being called to the Spirit World at such a young age? Maybe they really need a fix and they're too weak to do anything about it? Of course, all of this sharing has to be done with the permission of the person with AIDS because it's confidential information. When you have permission, give the Elder the details of situation, so that they don't go in blind. Like I said, treating an Elder with respect just boils down to common sense.

It irks me when we make mistakes and sometimes it's the Elder or teacher or just other people participating. They act as though it's the end of the world because you started walking right instead (of) left. You didn't know. It's all part of the learning process. We make mistakes. If you're really going to have a fit on somebody because they made a mistake, well then they probably won't be back.

- an Aboriginal support person

The person who is dying decides whether or not they want an Elder to help them, just like with any other decision. Some Aboriginal people would rather go with the church. The person with AIDS may be two-spirited and have experienced homophobia from Elders before, so they may be too hurt to trust another Elder. Internalized racism may stop a person from considering the help of an Elder. This would be a shame because Elders have so much to offer and teach.

If the care team is really lucky, the Elder will be able to provide some time and attention for the care team itself. Most Elders have the kind of vision where they'll recognize the emotional issues coming up for everybody who is helping the person with AIDS. Everybody involved, the friends, the family, the partner, care team volunteers, the medical professionals, they all have to cope with emotions such as grief, anger and pain. Maybe the Elder can educate them about the Spirit World, so that they aren't so traumatized about this person dying. The Elder may even be able to do a Sweatlodge Ceremony to provide holistic support for the care team.

The work that the care team is doing can be really difficult. An Elder just might be able to provide them with guidance on how to regenerate their own spirits, so that they care take care of themselves while they provide help to the person with AIDS. They don't want to allow the

Nashine Ginwenimawazawin

work to consume them, emotionally. Having an Elder around with all that time and energy is kind of like a best-case-scenario. That's the kind of scenario that I pray for, for any care team that comes together for an Aboriginal person with AIDS.

- an Aboriginal support person

I think it's based on your own experience with that particular Elder. It's based on the experiences of the people close to you, with that Elder. It's being able to talk with the Elder about some of the issues that you think would be issues. Finding out from this Elder, what is their position on working with two-spirited people? How do they see that whole thing? What are their thoughts and feelings? What is their experience in working with people who have HIV or have AIDS? How do they feel about that particular illness?

Our assumption that our Elders are these...everything, in one person. It's just not true. As

An Elder is not recognized by just their age. They are recognized by the knowledge they carry. They are recognized by how they are a role model. They are recognized by people and the gifts they have been able to become, about our original way of life.

- an Aboriginal Elder

individual people, we all have strengths, we all have challenges. We're all good at some things, we're all shitty at other things. They're just like us in that respect. They have feelings. They have opinions. They have biases. They may have prejudices. They're just like everybody else.

A lot of it has to start with us, as well, in terms of the assumptions that we make about people. We put them on a pedestal. Then, we're all upset when they make mistakes or they mess up. Well, geez, yeah, they're going to make mistakes. They're going to mess up sometimes. So, part of it has to come from us and part of it has to come from them, in terms of, what is it that they want to do? What can they do? Where are they coming from? It's talking with them. Spending time with them and finding these things. Watching them. It's that old thing about not just putting blind faith in. How do you choose people?

Me, I'm just very choosy about the people that I have in my life. There are very, very few people that I go to for anything. I'm very careful about that. Over about twelve years, since I started learning, there's lots of Elders and teachers that I've come into contact with. I've had conversations with them, but there is only a couple that I've stuck with all this time. That's what's best for me. I know where they're at, I know I can talk to them, they provide me with the guidance and direction that I need. There's a whole slew of other ones that I really have no interest whatsoever in having anything to do with them. It's almost like this trial and error thing.

The survival of our culture is a testament to their strength of our Elders. They carried on our ways, despite so much damage from schools, churches, and government. Our Elders were once little kids who used survival skills and a strong spirit to refuse admitting defeat during a terror-filled time.

- an Aboriginal support person

Why would we make an assumption that an Elder knows anything about AIDS? They're going to have to learn about it, too, just like the rest of us. So, yeah. Teach them! Somebody, take some kind of responsibility to teach them, to answer their questions.

I think the other part of this is looking beyond the illness. Sometimes, it isn't about what we're dying from, it's the fact that we're dying. People who are dying, regardless of the illness,

are going to have a whole lot of questions and concerns. Where are they going? Does the Elder have a good understanding? Can they talk and teach about that? Can that Elder look beyond the illness and help that person with their questions? They don't have to know everything there is to know. Maybe they can learn a part of it.

- an Aboriginal support person

In our teachings the proper protocol for approaching an Elder is to bring your tobacco. For whatever it is we look for, tobacco is always ahead of us when we travel in life. When we ask for knowledge or wisdom of an Elder or ask for medicines or ask for help in any way, we always put our tobacco ahead of us. The reason for this is that is the first gift that was given to us in the beginning.

We offer tobacco in prayer. The smoke that comes is our visible prayer to the Creator. The Creator understands our communication through that tobacco. Whenever we ask the Creator for help, we always ask those to hold that tobacco. Whether that be for emotional help, physical help or spiritual help, the tobacco is always used. The tobacco is one of our four gifts. We use it to smudge with.

- an Aboriginal Elder

THE SWEATLODGE

The Sweatlodge is a sacred ceremony practiced by some First Nations; not all Nations practice the Sweatlodge. A Sweatlodge may or may not be something the person you are caring for chooses to take part in.

The unpredictable nature of AIDS is such that she may have a rebound to temporary health that allows her to go into a Sweatlodge. She may be in need of palliative care but isn't confined to her bed and may choose to express her spirituality by going to a Sweatlodge.

If she is very sick, it may not be easy to determine if she can go into a Sweat. Physical weakness or severe symptoms may prevent her from taking part in the ceremony. She can speak to her Elder and doctor to collect all the information she needs to make a decision. In order to make an informed assessment, an examination of all the benefits and risks is crucial. If she decides not to go to a ceremony, the Elder may hold a Sweatlodge in her honour.

A Sweatlodge is difficult to describe because each ceremony is unique and original. Different Nations hold Sweatlodges in ways that are specific to their traditions. Even two Sweatlodges, held by the same Elder with the same people present, will be very different from each other. While the following quotes can give you an idea of what occurs, the only way to really understand a Sweatlodge is to attend one.

The teaching and healing from a Sweatlodge can help her come to terms with the issues and emotions that may arise from knowing she is dying. She may find comfort physically, emotionally, spiritually, and mentally from the Sweatlodge, it can give her peace of mind and strength to cope with the extreme difficulties that AIDS can present.

Nashine Ginwenimawazawin

A Sweatlodge can be of great benefit to the care team as well. A Sweatlodge can raise awareness throughout the care team and allow for holistic healing to occur. It can also help you cope with the many emotions that will emerge after her death.

The teachings of the Sweatlodge are very powerful and healing. Many of the benefits of a Sweatlodge ceremony are discussed in the following quotes. If she decides to take part in a Sweatlodge, the care team may need to do some work to make this possible. If she is already involved in the Aboriginal community, making these arrangements may come together easily. If the care team consists of people who aren't familiar with the Sweat, contact someone to help you. A Native organization listed in the Resources section may refer you to someone who can help honour her request to take part in a Sweatlodge ceremony.

Culture changes. Sweatlodge is something that happens in this area. There are different versions of where the Sweatlodge originated from. Now, it seems to be something practiced by almost all the tribes.

The thing is, different rituals and different ceremonies exist. You can't do a "how-to" when it comes to incorporating Native spirituality into the healing process of somebody who is dying, or anyone in general. It changes, varies from place to place. Culture changes and evolves.

- an Aboriginal person living with HIV/AIDS

A Sweatlodge is a purification ceremony. It's prayer. It's about sacrifice and identity. You're asking yourself, "Who am I?" It helps you to define that in yourself. It helps with your identity. It has therapeutic value, medicinal value and helps you physically, emotionally. It helps you get stuff off your chest. It helps you work through issues. It purifies you, by sweating. It also teaches you about physical suffering. It helps you develop understanding about life and death.

The benefit to someone that is HIV positive, it all depends on what teachings are provided. There are teachings on everything, grief and bereavement, death, life, darkness, negativity, light, illumination. There are different teachings within each direction of the Medicine Wheel.

As for the entire team, if you look at the care team as an entity, it's a commitment that fringes those people together. It's a focus on giving care. There's a start point and there's an end point. It's the latter stage of the cycle, of many cycles. It's the cycle of life, the cycle of AIDS.

By having a Sweatlodge or Circles of some kind to watch over that group or people, it can provide the spiritual support they need. It can also provide the emotional support. At the end, it can provide some healthy closure on the whole experience.

If the group is willing to do that, the more power to them. It is important to recognize that it's up to the person being cared for whether or not it's something important. Not everybody lives like that. Not everybody values that way of doing things. That's O.K., too. As long as they have something to provide the supports they need because people that give care have to look after themselves.

- an Aboriginal person living with HIV/AIDS

I've had people come to me who tell me, "Well, I'd really like to go in a Sweat but because I've got asthma, my doctor says there's no way I can do a Sweat."

Nashine Ginwenimawazawin

All I can do is present my experience and my understanding of what it is. Then, it's up to the person. If they want to try it or if they want to go by what the doctor says. That's where you have to let people make their own decisions. Yeah, the doctors will tell you if you go into something like that, you're going to have an asthma attack.

- an Aboriginal support person

A Sweatlodge is like, it's one of those holistic kind of healing things. By holistic, I just mean that it's designed to address all four of those parts. You know, the spiritual, psychological, physical and emotional. You could do a lot of work in there in a couple of hours!

I think that's why they're really good. You learn a whole lot because there are so many teachings that go along with just that one ceremony.

I think it can be really comfortable for some people because there's a certain sense of being anonymous in the sweat. It's pitch dark, nobody can see you and you can't see the other people. Even though you're in there with people there's a sense of, kind of being by yourself, kind of being in your own little world. I think for some people it makes it easier to say things and to release some of the sadness that may be a little bit harder to do with everybody looking at them or whatever it is that makes them nervous.

Certainly on a physical level, you're in there, sweating it out. That's got to be good for you. We've been doing it since the beginning of time. Those ancient ways, to me, are always the better ways in terms of healing. It's that whole thing about doing things naturally, with what we were born with.

On a spiritual level, you...you're inviting that other world in. A big part of going into the Sweatlodge is about those spirits that come in through the doorway. I think for people who are actually going to be going through that doorway at some point in the not too distant future, that this can bring them much more in touch with that spiritual part of them. What we can actually come to see, you can start seeing those spirits that come in. To be able to do that is a real gift because, again, where do you learn how to do that? Where are you ever given that opportunity? I don't know of religions that really do that, make an effort at connection to the Spirit World.

I think that for people who are going there, there's so much wanting to know what it is they're going to. Again, we've been bombarded with a lot of stuff about where we're going to that maybe is frightening, that isn't going to be nice, that is based on what we did here, for God's sake! As opposed to, you had a spirit that's pure, regardless of what you did in your life here. I think we get so much of that and it makes that whole thing, that other side scary to a lot of people.

When you go into ceremonies like the Sweatlodge is, you get to face that fear because you're in a place where those spirits are and these things are talked about. You can start seeing them, you're feeling them for yourself.

I think that it can be a really helpful thing in a lot of ways, but I think it also alleviates a whole lot of fear about where you're going and that kind of acceptance. On that level, I think it's

Nashine Ginwenimawazawin

really good. It's one of those ceremonies that covers everything that might need to be done. I think it's really helpful for people, if they choose that they want to do it.

- an Aboriginal AIDS worker

I think they're going to expect that it's really, really hot. I think it can be frightening for some people when you talk about being in the pitch dark and closed in. That's scary for some people. When you talk about a Sweat, that you go in and sweat, people get concerned about the level of how hot is it going to be and are they going to be able to breathe.

Some people, when they talk about what they've heard of people's experiences in the Sweat, they talk like all these weird things are going to happen in there. Like, a Sweat moving or being touched by something or seeing things in there. I think it's because those things are unknown and the reaction is to be afraid of them. They may have heard all of these stories. I don't know if they're true or not. Sometimes things just get really exaggerated.

You do see things, things do happen in there. You might get a little scared at first because it's something new but again, it's like, nobody ever gets hurt in the Sweatlodge. It is your own fear. If you go in, what you'll be doing is facing that fear and seeing for yourself. Lots of times, you don't see anything and you don't feel anything, it's kind of whoop-de-do! People have such funny ideas about what's going to happen or what's supposed to happen and if it doesn't happen then something's wrong.

- an Aboriginal support person

That can differ from nation to nation in terms of how exactly they conduct their Sweats and also from teacher to teacher. What I can tell you is what my experience is but that's only mine. I follow a society of Ojibway teachings, those are the Sweats that I go to. I can talk about how those are conducted.

We usually have a couple of Firekeepers. Firekeepers are always men because it's the male that takes care of the fire. That's what they do.

In terms of tobacco, it kind of depends. When I host Sweats, what we do is just give tobacco to the Elder on behalf of the people going into the Sweatlodge. I know some Elders want each person to give them tobacco, so you kind of have to check that out. But, that's how we do it, is we give them tobacco from everybody that's going in.

Women wear a long night-gown or long T-shirt or a sheet. Men, they usually wear shorts and a big towel.

After the Sweat, we'll have a feast, so we're bringing the food. I guess the way I like to do it is that you just show up with whatever you're going to wear into the Sweat. You don't worry about doing anything. Like, we're hosting it and it's for you so we'll take care of things. I think I like to do it that way because again, people, especially if they're new to it, they get all freaked out. If you give them too much to do, there's enough anxiety already. So, it's just, "Don't worry, everything'll be taken care of."

What we also do is, unless everybody's done the Sweat already, the Elder will do the teachings around sort of the practical things about how we go into the Sweat and where everybody will sit. Also, they tell spiritual teachings around why we have a Sweatlodge. What is it for, how

Nashine Ginwenimawazawin

did it come to be, what's the purpose. I don't think you should take people and just shove them into the Lodge without any kind of sense of why they're doing this. So, all those teaching are usually done with them as well.

The whole thing around the four directions. Who sits there? Why? Why does she put certain people in those doorways? What do those doorways represent?

It's little things. How come we crawl in there? Why don't we just walk in? All those things need to be done. When you take that time with people and you address all the reasons why things are done the way they're done, then they come to understand it for themselves why they're going in there, why they want to do it. I think it alleviates a whole lot of anxiety, especially if they've never been in before.

It's down to a whole lot of little things about telling people that you don't wear your earrings and jewelry in there. Part of the reason for that is because we're going in there as close to being new-born as possible, so we don't have all this artificial stuff. It's also because if you're wearing a ring in there, it gets hot and that ring is going to get real hot on your hand. So, there's another reason. There's kind of a spiritual one but there's also the practical thing. Like, "No, don't wear your contacts lenses." There's a reason for that...they'll be implanted on your head.

There's a lot of practical little things that nobody thinks to tell people about. There's so much pressure, "I'm a Native person and I don't know anything about this, this is embarrassing." Hell, none of us do! We've got several generations that didn't grow up with this. We all had to learn.

- an Aboriginal support person

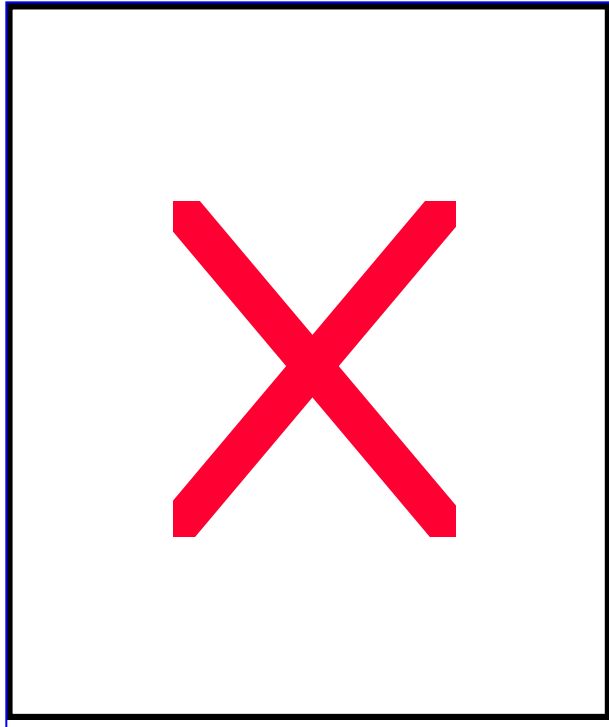
PAIN

I could just say that on the other side there is no pain. Sometimes we learn from pain. Why are you suffering, what understanding are you getting from the pain? Sometimes with the pain, the learning comes.

In terms of physical, just find whatever you need. Smudge, to clean the aura.

- an Aboriginal Elder

I think some of the western pain management works. Again, they're only dealing with the physical. They're not taking care of the spiritual.



At night time when you're working with people that are ill, it's a really hard time for them to go through. It's like the same system of the seasons changing. The seasons have an effect on our system and how we feel and how our health is. It's the same with people dealing with this illness.

Comfort measures are good for the people. They'll tell you themselves what's good for them. Maybe they only want a cold washcloth. Maybe they want to get submerged in water.

A lot of times with fever, you can't touch them because they're hurting. Their whole body's hurting, they're in pain.

It just depends, again, on the individual. What's good for you isn't necessarily good for me and visa versa.

The person that works with the individual would know them and know what they like and be able to help them. They know they're going through this process of death.

- an Aboriginal Elder

Many more people are becoming aware of the fact that pain is holistic. Previously, it was widely assumed that pain was only a physical thing. Our Elders have always said that everything about us, as beings of Creation, makes us holistic. Whether or not we take care of ourselves according to that understanding is a different story.

Nashine Ginwenimawazawin

We have our teachings of the Medicine Wheel. They tell us that someone can be in spiritual agony and we know the ceremonies and practices that can help that sort of thing. Our Elders can tell when someone is detached from their spirit and can bring that spirit and the person back into harmony.

We know how emotions can manifest in the body, such as fear. A physical response to fear is to stop breathing. If someone has always had to live with shallow breathing, since the time they were a kid, then it will show up later in the lungs that never got to work properly. That same pain also gets stored in a variety of places throughout the body. We know that anger is stored in the back and jaw. Sexual abuse often shows up (in) a very tense digestive system.

I think that is why it is so important that First Nations take care of their own people. Really, what will it take to light a fire under people? Every time someone, whether (it be) an individual or a band, ignores the need of a First Nations person it is such a tragedy. Who better to recognize and understand the holistic pain of a person? Who better to provide the best possible kind of help for them? Whether it is through prayer, smudge, listening and sharing. Everything that we need in order to die a good death is there. It is a matter of whether or not it is available to us.

- an Aboriginal support person

First he was on Percodans and he didn't really like them. Then, the doctor prescribed morphine. He took mostly morphine and once in a while Percodan if he was in a lot of pain. They would give him a burst of energy, like a high.

I think he was on tranquilizers, as well because of his stress level. I think Percodans have a sedative affect. The tranquilizers were for his nerves, the anxiety. They calmed him down. I think it was Oxipan, Diazepam or something like that. It was also to help him sleep.

- an Aboriginal support person

I went to an Elder once. I started talking, going backwards in time. When I told her I was adopted, she stopped me. She explained how, when you're inside your mom, you hear her voice. She feeds you. From being inside her, you are so much a part of her life, as she gives you life. When you're born and you're a little baby, you're absolutely dependent on her.

Your vulnerability as an infant means that if you're taken away from her, it is the equivalent of death. She fed you while you were inside of her and all your young spirit knows is her. No one else can provide that kind of comfort. Since you're a baby, you don't have the capacity to deal with the pain in any way, except to store it physically.

All those kids that were adopted out and fostered out, they all have that first pain, that first loss. After generations of residential school and everything else, no wonder our past generations were vulnerable to having their kids scooped. The result is that there are a lot of kids that were taken from their moms.

Thinking in terms of community, it is definitely everybody's responsibility to make sure that families are healthy. We have to start now, so that (no) more of our children are going to raised carrying a lot of pain. The dads have to be healed and loving, so that their presence in the family creates harmony. The moms have to have a lot of balance, strength and creativity.

Nashine Ginwenimawazawin

Those ones that are out there right now, those adoptees and fosterees, they needs so much support to heal that first pain. If they are also dealing with palliative care needs, rejection, loss and identity, well, that is so much to deal with. The isolation of that person can be tremendous. They may not believe that the Elder's healing is something they deserve because they were given away to begin with. A care team has to be sensitive to all this stuff. It's a lot of work.

That Elder, she talked to me until I started to cry. I was crying about that first pain. She asked permission to touch it. She began to heal it as I continued to cry. She facilitated a physical release of some of that emotional pain. That kind of healing is every bit as important as the physical pain. Only that Elder could have done that. I couldn't go to my doctor and get a prescription for that kind of help.

- an Aboriginal support person

If a health care worker won't refer to a transsexual as "she", I explain to them the person has assumed another identity. The health care worker is there to care for the person. While the person is in their transition to dying, they must endeavor to ensure that the person dies pain-free. Pain-free, for me, is emotional and physical. I would really impress upon that.

What is pain-free? It's according to every individual. It's individualistic. You can't address it in a general format. Each individual must be treated separately and not as a bunch of numbers or a group of people. Every individual is an individual! They all have different needs!

I try to address it that way, that your role as a health care provider is to ensure that that person dies pain-free. Pain-free includes emotional.

That's individualistic, whether or not to take hormones at the palliative stage. There are no post-market studies on long-term hormonal therapy on women that are post-menopausal, let alone transsexuals. We need post-market longitudinal studies on hormonal therapy.

There are no studies on hormonal interaction between different types of medications. There are no longitudinal studies on transsexuals on bone density, whether you're on hormones or you're off hormones. There are no longitudinal studies on post surgery and hormonal therapies, either. We need those types of studies.

Once someone is diagnosed with full-blown AIDS, they take you off the hormones. That's a problem because then it forces people to buy hormones on the black market. They can overdose themselves. They can have secondary side-effects. If you're taking hormones for a long time, one of the things that can happen is a fungus under your nail bed. You have to monitor that. If you're full-blown AIDS, that fungus could really affect you.

Some hormones, estrogen, progesterone, and others affect the nails. They increase chipping, cracking and breaking. This is due to sub-clinical yeast or candiditis that long-term hormonal therapy can create.

Long-term use of estrogens can diminish muscle mass and diminish strength. It can increase fat in the muscles. It can increase water retention, mood swings, edema and phlebitis. There is sometimes a diminished sexual activity interest. The globe of the eyes will change, which will affect the vision. The surface veins will become more prominent. You could see some tumor

develop in the nipples. All this compounded with someone who is palliative, there's a lot of pros and cons to hormones.

- an Aboriginal support person

What is Pain?

Basically, any palliative patient, the goal is to keep them comfortable and pain free in whatever state they may be in. Some people have a lot of pain, even prior to becoming palliative. Our goal, again, is to keep them comfortable and pain free.

There is plenty of medication on the market now, no one should have pain with the combinations that we have available to us. The majority of them are available through prescription.

- a support person

Pain is when someone is feeling discomfort, distress or suffering.

If the person you are caring for is feeling pain, their description of that pain will be unique and personal. They are the only one who can describe and express their pain, whether physical, mental, emotional or spiritual.

It is not possible to tell someone that their pain is not as bad as they think it is. Two people will experience the same pain in a different way. It is important to always listen to someone when they say they are in pain and more important to believe what they are saying.

Pain could come from a wide number of sources. It could be a result of an opportunistic infection, or a side effect of medication.

Acute Pain

Acute pain is a concentrated, stabbing, shooting feeling. The person can identify a specific area where they are feeling the pain. Acute pain can range from mild to excruciating. Examples of pain could be: a headache, a broken limb, a sore back, an open lesion or stomach cramps.

Some people may not feel comfortable expressing that they are in pain. This may be because they believe it is important to "be strong." If the person feels they are depending too much on the care team, they may also feel bad expressing that they are in pain.

Chronic Pain

Chronic pain is long-term and persistent. It is characterized by an aching, dull feeling, and it may not be possible to describe where the pain is located.

Chronic pain can last for long periods of time during which the body may become accustomed to it.

Chronic pain can affect many areas. The person may feel depressed, or frustrated. He may not want to engage in activities because the on-going pain has drained him. He may have a smaller appetite or no appetite at all.

Not only my chest ached, but my body. It felt like somebody had stabbed me and it went right through my rib cage.

- an Aboriginal person living with HIV/AIDS

He had a couple of admissions to the hospital when he got dehydrated. They would pump him up with IV and bring him home. We were having a harder and harder time bringing him into the house because of the stairs getting down into his room. This room was down in the basement, you had to get him upstairs in the door and then downstairs. It was getting very difficult to move him, because he was so light and he was in so much pain.

- a support person

Some Signs of Pain

- ◆ Touching, rubbing, holding or protecting where it hurts.
- ◆ Increased pulse
- ◆ Fast, shallow breathing, holding the breath or sudden gasps.
- ◆ Bracing, tensing or stiffening of muscle tension.
- ◆ A sudden change in the voice to a tense, high voice or a low whisper.
- ◆ Speaking quickly or in a slow, halting manner
- ◆ Insomnia
- ◆ Changes in facial expression, such as clamping the jaw, frowning, squeezing the eyes shut, tensing the facial or neck muscles
- ◆ Crying, groaning or screaming
- ◆ Stillness, to avoid increasing or experiencing the pain
- ◆ Rocking or holding the stomach.

PAIN MANAGEMENT

The goal of pain management is reducing or stopping pain. The person you are caring for may tell you she is in pain. Some people may not express to you that they are in pain. If you recognize any of the signs of pain in someone, ask them about it.

Managing pain is an on-going, consistent process. It is ideal to stop pain before it starts or as soon as it begins.

Pain Assessment

Finding as many details about the pain itself is called a pain assessment. Collecting information about the pain will help the doctor determine what to do about it. Write down the information of a pain assessment in the care team log.

PAIN INFORMATION CHECKLIST

- ◆ LOCATION, ASK THE PERSON: **WHERE** IS THE PAIN?
 - ◆ Is it inside the body or outside?
 - ◆ Is it in one area or many areas?
 - ◆ Could you point to the area or areas where you are feeling pain?

- ◆ QUALITY, ASK THE PERSON: **WHAT** THE PAIN FEELS LIKE IS IT:
 - stabbing
 - burning
 - shooting
 - tender
 - migraine
 - stinging
 - throbbing
 - aching
 - swollen
 - spasms
 - sharp
 - tingling
 - pins and needles
 - nausea

- ◆ INTENSITY, ASK THE PERSON: **HOW** SEVERE IS THE PAIN?
 - ◆ On a scale of 1 to 10, what degree of intensity is your pain?

No pain											Intense pain
0	1	2	3	4	5	6	7	8	9	10	

- ◆ TIMING, ASK THE PERSON: **WHEN** DID THE PAIN BEGIN?
 - ◆ Does the pain come and go?
 - ◆ How long does it last?
 - ◆ Does it come during a certain time of day?

- ◆ CAUSE, ASK THE PERSON: WHAT **CAUSES** THE PAIN?
 - ◆ Is there anything that makes the pain worse?
 - ◆ Eating, moving, pressure, breathing, sitting or walking?

- ◆ WHAT **HELPS**?
 - ◆ What medications, treatments or complimentary therapies help relieve the pain?

There are many pain relieving drugs. There are different forms the drugs could take, such as pill, liquid or IV. The doctor who prescribes the drug will know what the side effects of the drug are.

Some people will need stronger pain medication doses as time goes on. The body can become used to the drug, so it needs a higher dose to control the pain.

BREAKTHROUGH PAIN

What I do is give them medication, whether by mouth, injection or I will give them an extra dose by the pain pump. If it is a pain pump, it'll work in ten minutes. Orally, it'll take half an hour. Then, I will be able to turn them onto a different side.

- a support person

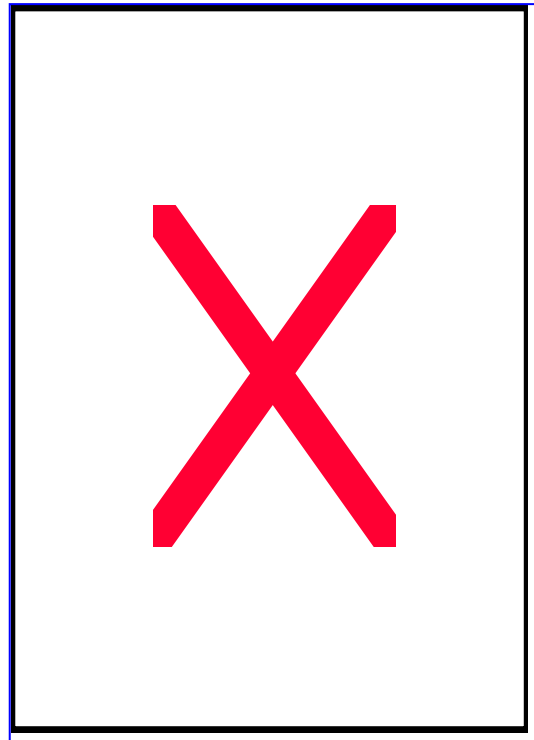
Breakthrough pain is when someone still has pain even though they are taking pain medication.

The doctor may prescribe medication for breakthrough pain. (It is important to follow the directions because giving more may produce more side effects).

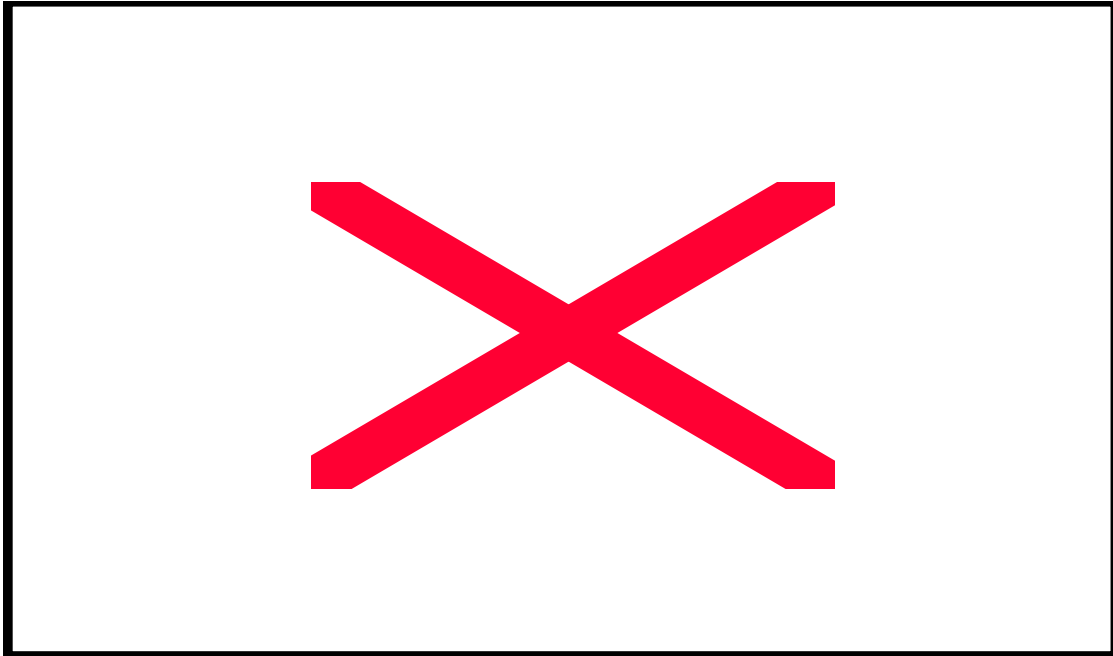
Pain medications prescribed for breakthrough pain are given on an as-needed basis (called PRN dosing).

Movements that cause pain, such as sitting, walking, eating, changing a dressing, changing a person's sheets or diapers can be done right after the pain medication has started to work. It is a good idea to plan movements shortly after the dose has taken effect.

As with all medication, it is important to give pain medication according to the instructions of the doctor or pharmacist. If you increase medication, it may cause dangerous side effects.



LIVES WITH HIGH STRESS



PRISONS

The many issues that affect Aboriginal people who are living with HIV/AIDS become even more complex when they are in prison.

Having him released from prison would be the most beneficial to his health, but sadly, like many others, he will probably die inside (the prison). There are many difficulties in trying to get him released before his full sentence has been carried out. One way of obtaining an early release is through a “compassionate release.” In attempting to obtain an early release in this manner, Correctional Services first considers whether or not someone is an “undue risk to society.” It doesn’t matter how sick he is, if he is considered a risk, no matter what his health status, he will be kept in the prison until he dies.

To my knowledge, there has never been an individual released for compassionate grounds from prison, even though they may have been at the palliative stage of their illness.

- support person

In order to get a compassionate release the person has to have a residence to go to. If he has become estranged from his home community, he may not be able to make these

arrangements. Unfortunately, some reserves have been known to pass Band Council Resolutions to not allow people back onto the reserve.

One of the complications of someone living with HIV/AIDS in prison is that not all the

It depends on whether they like the prisoner; whether they trust him; whether they think that prisoner has drug-seeking behaviour before, and some of them have without a doubt. Some of these people are drug addicts and it is not easy. It usually means a battle; and sometimes I win and sometimes I lose. Sometimes there is an uncomfortable compromise, which means less than adequate pain medication.

doctors working within the system are knowledgeable about the disease. If the person in prison has a history of IV drug use, the staff may refuse or hesitate to give him pain medication because they think it will be encouraging his addiction. If a dying person needs pain medication and are refused it or given less than they should, then it has nothing to do with addiction prevention and everything to do with cruelty.

- a support person

In terms of Aboriginal people who need palliative care in prison, there are many concerns about the quality of treatment that they will receive there. The hope is that they will do what they can to treat the people who are dying with humanity and allow them to be surrounded by their support people from the outside.

If you are on a care team for someone who has been released from prison, it will be helpful for you to know his story; however, he may not want to talk about his prison experience. The following stories provide insight into the difficulties found in a prison environment.

The Aboriginal men and women that are in prisons are too often judged harshly and dismissed as valuable human beings because of their crime(s). Their existence as part of Creation often becomes minimized to focus only on their crime and they are treated like they are less than human. While there is a place for responsibility on their part, **it is not a reflection on their value as a human being and there is a place for them in our communities.** In a lot of cases, the circumstances that led up to the occurrence of the crime probably stemmed from the community in the first place. Therefore, communities also have a responsibility in acknowledging their part in contributing to the crime.

In many prison environments, courageous Aboriginal people are supporting one another, forming strong groups such as the Native Brotherhood, the Native Sons, the Native Sisterhood, and the Native Daughters. There is also support from home communities in the form of Elders and Native Liaison Workers in addition to the partners, families and friends who provide support through socials, letters, and phone calls.

The following quotations talk about the concerns that Aboriginal men and women are faced with in prisons.

The prisons have strictly their own system. They're just now opening up to Native culture and traditions. Their own system includes the medical profession.

The biggest challenge that I see for us as Native people is to assist our own people. We know our culture is important, our traditions are important, and these beliefs are important. They've

Nashine Ginwenimawazawin

proved to us in the last 500 years that theirs is not. They've proved to us (that) their culture, (and their) belief system(s) and practices aren't good for us. So now, they're putting it back in our hands. They're saying, "If your culture is so good, and your traditions and your beliefs, then do it with your own people."

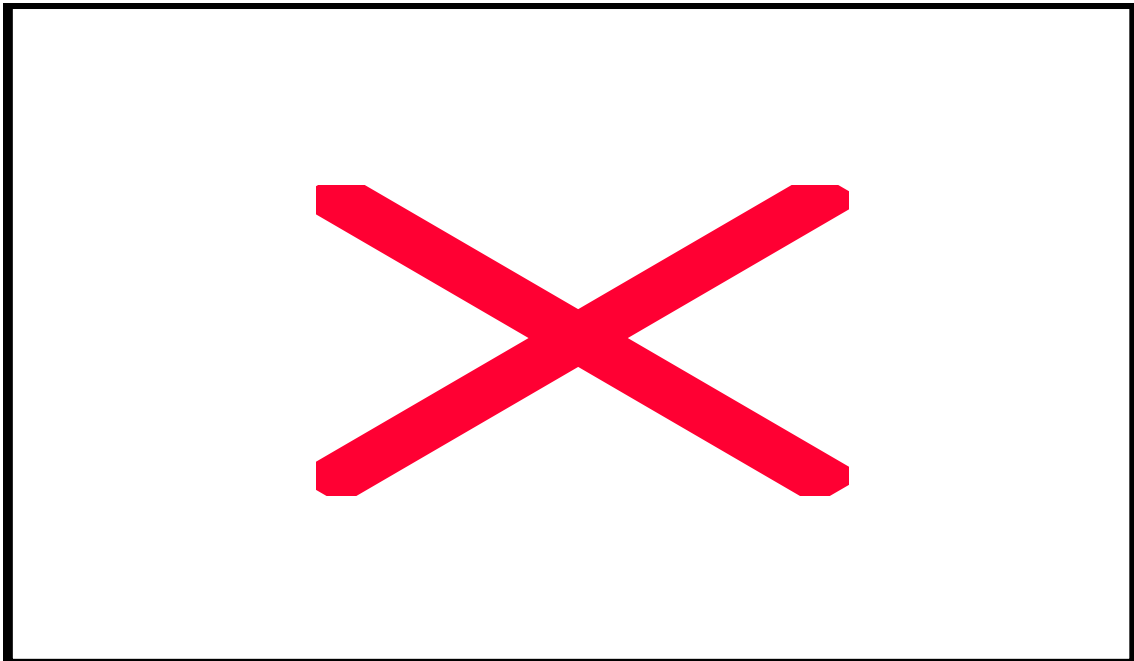
So, that's the job we have. That's the job all of us have. We have to take responsibility of caring for ourselves and our culture and tradition. If we don't, then it's going to be lost.

- An Aboriginal Elder

The biggest issue is trying to get people released on what is called "compassionate release." It is really an accelerated form of parole, which is called "parole by exception."

There is the bureaucracy and the difficulties persuading people that someone they are looking at, who is still walking around, is going to be dead in three months. It is very difficult to do this. I have been successful in two or three cases of getting people out before they are literally moribund (very close to death). The problem is that when people are moribund, they are going to die within the next week or two. It is very difficult to get someone to look after them, unless they have a very supportive family. And not everybody has a supportive family. That is the biggest problem facing people.

- a support person



Pain medication is not readily distributed within the framework of Corrections. If you want Tylenol you are required to buy it from the Canteen. I had a client who had very serious medical issues and who was not given any kind of pain medication (for his pain), such as Tylenol for headaches and so forth, that was (caused by) the side effects of the medications he was taking for his primary illness. He was told that he would have to purchase this medication through the Canteen. So there he is, being required to purchase through the Canteen the medicines that at the very least he should have had prescribed because of his condition.

Nashine Ginwenimawazawin

Recommendations from community based practitioners are not being followed by the institutional staff, who take it upon themselves to determine that the doctor (has) over-prescribed medication for individuals who have been hospitalized or have seen an outside doctor for some other reason. I've had more problems with Aboriginal staff, trying to work with them in this environment, than I've had with inmates or non-Native staff. Non-Native staff are more open.

You can look at where they're working, how they were trained. Again, we're walking in this two-row Wampum. A lot of people, they're not coming directly from their culture. They've been removed. Their thinking is structured into their work environment. They have a job description.

When you work with people in Corrections, or you work with people in the medical profession, they've been specifically trained. They can only do this; they can only do that.

When Native people come in and there are other programs and practices that we can teach and introduce, they're afraid of it. They're afraid of anything that is from the tradition and culture.

- an Aboriginal Elder

To my knowledge, there has never been an individual released for compassionate grounds from prison, even though they may have been at the palliative stage of their illness. In fact, there have been people who have applied under those conditions and they have been denied release and they have ended up passing on inside the prison.

In light of the fact that Aboriginal offenders get out on parole or early releases at a much lower percentage than non-Aboriginal offenders, you can see that even if Corrections let out a few people, the likelihood of Aboriginal offenders getting out is very slim.

They did place this criteria for release in the Conditional Release Act very specifically for people who were at the palliative stage of their illnesses, whether it be HIV or other illnesses. It has not been a process that has been implemented or utilized in the way it was envisioned in the first place.

- support person

I don't think you can talk about palliation and prison in the same breath. Palliation implies that you are doing your very best to make the death as comfortable as possible, both in the physical and the emotional sense. The circumstances in prison certainly don't deal very well with the emotional side of things.

They may be adequate in terms of dealing with physical pain. That in itself is a problem with prisoners, particularly prisoners with HIV, because most prisoners with HIV have acquired it by way of drug use. The general feeling is that you can't really give these people a lot of morphine because they might be abusing it.

- a support person

They put me in population. It was stressful the first time I went to population. They were all teasing me, saying, "Suck me off. Come to the shower with me." Just a bunch of garbage.

Nashine Ginwenimawazawin

I've gotten to know everybody in the years that go by. They keep coming in, coming in. It's like, "Oh, you were here last year." Now, I own the jail.

I could go to PC (Protective Custody Unit) but I can't go down there with them. The reason is (that) I was raped by my dad when I was little. I can't hang around the same people that rape kids. I'd just literally lose it, because I'm on hormones and stuff.

The hormones are the only thing(s) that keep me balanced. Especially with the stress level, being in there.

You have to argue with the doctor to get them. I have to have my doctor on the outside say, "O.K., we have to get them for her because she needs them." It takes about three weeks.

- an Aboriginal person living with HIV/AIDS

You are probably aware of the inquest which took place in one of the prisons recently. It was suggested that the prisoner, who was in quite a lot of pain and who was dead within one month of the particular incident, was accused of dissolving his M.S. Contin (morphine) in his mouth in a sponge to wring out so that other prisoners could use it. I am not going to sit around and try to dissolve M.S. Contin (morphine) in my mouth to prove that you can't, but I don't think that you can.

They do now get visits from their relatives. There was a time when this was not easy to do. It is certainly not possible for a relative to sit there for hours on end and hold their hand. At the inquest that just finished, the guy was alone when he died and he had been alone for many hours.

- a support person

- a support person

I go to the Don Jail. I went to the West (Detention Centre) and they threw me in PC (Protective Custody). I was not impressed.

I told them, "I want a transfer, now."

The guard goes, "Who do you think you are?"

I said, "I want a transfer out of here. I'm not PC. I'm population. I want to go to population and if you can't put me in general population here, then put me back at the Don (Jail)."

He said, "I give the orders here."

"Oh, do you? (I said.) Watch."

They were saying, "No access to the phones for her."

I had a friend and said to him, "Call my lawyer. I'm stuck in my cell and I want a transfer to the Don (Jail)."

My lawyer is quick. Half an hour later they were putting in a transfer. They weren't ready!

- an Aboriginal person living with HIV/AIDS

Nashine Ginwenimawazawin

At the inquest, the prison staff said that it is a very pleasant hospital penitentiary. I don't know where they get their standards from. The prison is a prison. By definition, you cannot have a prison that is nice. The general public think it is nice, particularly some of the farms and camps. Some of them are nice and nicer than a prisoner would get in his own home circumstances. But it is not nice. It doesn't compare with a hospital or a hospice or home.

- a support person

If they were in the general population, I have doubts whether they would get visits. It would be said that if this person is that sick and he wants visits, he has to be in the hospital for our convenience. They do now get visits from their relatives. There was a time when this was not easy to do. It is certainly not possible for a relative to sit there for hours on end and hold their hand. At the inquest that just finished, the guy was alone when he died and he had been alone for many hours.

That now has changed, and I think that CSC (Correctional Services Canada) is trying as best (as) it can, and CSC isn't very good at anything other than keeping prisoners inside, which is what its mandate is. There is a lot of obstruction. The guards have a lot of power. The unions have a lot of power over the guards and therefore the guards have a lot of power on their own. Whenever you want to change anything, they say: "Oh no (we can't). Security problem".

-a support person

I'm a Federal Inmate, two and a half years. I literally beat this guy, when I was little. He raped me and I just lost it because I was drunk. I literally lost it.

He's still alive. But, I went off. Like, he was on top of me. I grabbed his hair. I threw him against the wall, just bang, bang, bang, until he started bleeding. I wouldn't let him go.

- an Aboriginal person living with HIV/AIDS

On one occasion, when a guy was at his mandatory supervision date he got gated. I had written letters saying that he had a combination of HIV and Hepatitis C and was going to be dead within six months to a year and that he should be let out because he had severe liver damage and was showing signs of brain failure as a result of the liver damage.

I had to go to court in Toronto when the guy's lawyer appealed the decision. The Crown's lawyer harassed me so badly that the Judge said, "this has got to stop. I will cite you with contempt of court if you harass her anymore." Anyway, the guy got out and he stayed with his family for a little over three months before he died. I believe he was very content. It is one of the few things I feel really good about because I did go to Toronto and put my name on the line. You have to do that from time to time.

He was Cree and French. He was one of those people who had been abused in a Catholic school. He didn't have any contact with Elders and he had no faith in the Catholic church. He was a very disillusioned man. He had been in prison a long time for some very serious offences.

He said to me once, "I don't do corner stores. I don't frighten the life out of women whose jobs are on the line if they lose the cash out of the till. I don't do banks because I know some of those women never go back to work because they are so scared. I do Brink's trucks because

those guys are armed and expecting it." This is an honourable man. They are the kind who are very respected in the prison. Someone who does security vans is high in the pecking order.

- a support person

Several of the people I have cared for have organic brain syndromes, an HIV-related dementia. Sometimes it is difficult to determine the difference between organic brain syndromes that are caused by HIV and those that are caused by drug use. It is probable that the combination is worse than either would be alone. They are synergistic.

It becomes very difficult to manage people in prisons because as soon as an organic brain syndrome appears and the patient starts acting differently, it is assumed that they are acting out rather than that they are having some organic problem. The response that I get from them when I make this diagnosis is that they had better sedate him and then he gets large doses of Haldol. It is a major tranquilizer and is no good for dementia. It just makes things worse. Their idea is, if he is demented, we should chemically restrain him so that he cannot get into any trouble.

- a support person

Someone who is in the latter stages of the disease, or who has an X-ray or physical signs of severe pain, then I quote to them (CSC) the World Health Organization's recommendations on the treatment of severe pain in people whose life expectancy is limited. That is that you take the person's word for it, and give them as much morphine as they need.

It depends on whether they like the prisoner; whether they trust him; whether they think that the prisoner has had drug seeking behavior before, and some of them have without a doubt. Some of these people are drug addicts and it is not easy. It usually means a battle; and sometimes I win and sometimes I lose. Sometimes there is an uncomfortable compromise, which means less than adequate pain medication.

With a severely immuno-suppressed patient, whose CD4 count is below 200, they generally didn't argue too much. In April of 1996, I said that they were being unethical and (that) they had to abide by the guidelines of the World Health Organization. They took that fairly seriously and things have been better since then.

- a support person

In prison, there is not a lot you can take control over, apart from your health. A lot of prisoners use this as a way of exerting control. People do need to exert control. That is the biggest fault that exists within the prison system. There is not much of an attempt made to allow prisoners to develop a sense of control (of their own lives).

When they try to give the guys a sense of control and responsibility by giving them their medications and making them responsible for advising us when they need new orders, it may be beyond their responsibility to do that and they are not given support to do it. For example, they may be demented. It becomes a sort of punishment. They give them a task that they are bound to fail at. It is true whether they have HIV or not. It is a kind of punitive attitude, which says, "I am going to believe you (only) as a last resort,"

Nashine Ginwenimawazawin

People think it is okay for me because I am out of the prison most of the time, and I don't have to deal with it. I would agree. I think it is very stressful. I don't know if the prison nurses are adequately trained to deal with that. I realize the difficulties they face and I am very sympathetic, but it is not something that is being addressed. It is something that goes on and on and on.

- a support person

The institutions do allow family members to visit in the hospital unit and are fairly generous about the visiting process and times (are) allowed for families (to visit) people who are critically ill. That is not to say that I have known them to make any kind of arrangements for families to travel to institutions to visit their loved ones when they are critically ill.

I can tell you that there is no money available for family members to come to visit people from out of province or out of the immediate area. There are also no facilities available for (family members to stay at while visiting), except for Bridge House, which is available for female family members and children. Bridge House is in part funded by Corrections. Women and children who are family members of prisoners can come and spend the night for a reasonable cost when they are visiting an institution. It is only available for women, and male children under the age of thirteen. It does have some significant limitations.

- a support person

There are individuals in the system who are committed (to) and who recognize the value of Elders and teachers coming in, (but) this is not always the case.

There was a man who was critically ill and he came from one institution to the hospital. There was a helper, a liaison at his parent institution, who cared for this individual and had been an incredible support for him. The liaison had made a personal commitment to be there for him throughout his illness. He left his home telephone number, his cell phone number and his work number at the hospital. He made them totally aware of his role and that he would be willing to be there throughout this man's illness.

He was not advised for two days that the man passed away, let alone advised to come in before the man's passing so that he could be there to support him. That tells me how (our roles in the prisons) are perceived.

- a support person

If anyone is critically ill and requires twenty-four hour care or if they are in isolation and require constant care, (then) they must be shipped to an institution which is not where they live.

For example, if one of the brothers (a male Aboriginal prisoner) is in Bath and he gets very sick and needs twenty-four hour care, he must go to the hospital unit. That is where he will stay throughout the duration of his illness. This means that the brothers who are his support system (and) the Elder who is his support system are not there and readily available for him. He is totally isolated from the people and the support network that he has in his home institution. Those kinds of things are fairly critical.

- a support person

Nashine Ginwenimawazawin

If someone goes to an outside hospital and is being cared for by the prison unit in an outside hospital, there is little likelihood that the person will see a loved one while they are there. It is equally unlikely that they will see an Elder or traditional person. It is incredibly difficult to get people in. They are set up right in the hospital and depending on the security level of the person who is ill, you have a difficult time finding out that they have even been sent to an outside hospital and if they are staying there. Information about their locations and the opportunity for visits just does not happen.

If someone goes out for surgery, the prisoner can tell their loved ones that they will be gone for a few days sometime in the next weeks. They cannot even tell them when because it might cause a security breach. Some people are in those outside hospitals for a significant amount of time. There are people who go to outside hospital and stay there under armed guard for weeks at a time. It is difficult to put normal visiting processes in place for people in that circumstance.

- a support person

This ostracizing saddens me. This attitude is not restricted to mainstream society and that is unfortunate. It is happening in our own communities to our own men and women who are being alienated and disregarded.

Currently, I am living on a reserve which is 45 minutes from a large penitentiary which houses 700 Aboriginal men and there is no one who is on a volunteer visiting program at that institution. I know that from this reserve alone there are probably ten men living in that institution.

The bottom line is that we cannot disregard the fact that prisons and prisoners are part of our community. The community does not end at the wall. Many of those men and women are going to come home to the communities. It is not our place to judge. The Creator takes care of all of us. That is entirely what the world is about.

We have a responsibility and need to heal the people in the prisons, and to acknowledge that they are there largely because of circumstances that took place before they ever got there. There was a problem, issues, dysfunction, violence, alcoholism, drugs and addiction. There was oppression and alienation and separation and homophobia.

When they go to prisons and when they are sick in prison, we have a responsibility to be taking care of them and acknowledge them as the Creator's children and as valuable resources. They have walked a walk which has been very painful and all of us have left them. We really do ourselves a disservice by not embracing that responsibility.

We need to care for them so that they can teach us the things they know and teach us how not to take the steps that they have taken. There are opportunities for us to embrace people and bring them back into the communities, to be part of their healing process and part of their passing so that there can be closure for everyone and things can be put to rest. Sometime that means bringing someone into the community who has hurt people in the community. That is hard for people to recognize that as a positive thing but it is positive. Its not about

forgiveness. It is about acknowledgment that each of us needs to be able to die with dignity and respect. Certainly that is not the case in mainstream society for prisoners who are left behind the walls.

- a support person

We have a section of the Conditional Release Act, called section 81 that is very specifically focusing on releasing people into communities. There is nothing in the world to stop Aboriginal communities from taking on this responsibility of bringing people into facilities in the community.

The extended family suffers through this passing as well. They suffer more because that man or that woman is behind a wall, and they feel helpless and unable to be engaging in anything or taking responsibility for lessening the pain of that man or woman's passing.

We can facilitate that empowerment of family members and that opportunity for families to resolve issues by engaging in processes where palliative care facilities are set up under Section 81 of the Conditional Release Act. In order to facilitate bringing back people into the communities where families can better engage and interact in a more compassionate and less threatening environment. Making an environment that is peaceful and recognizing that the man or woman is part of a larger picture. They are part of their biological family and their extended family, and also part of their community.

- a support person

STRESS

For people in the palliative stage, stress is a big concern. Financial instability (or poverty), addictions, family conflict, and children are just some of the stresses someone who is dying may have to face, making the task more difficult for care providers. In addition to current problems, historically, some people may have pasts that were extremely dysfunctional and that in turn affects how they are (emotions, behaviours, etc.) today.

Life on the streets for him may have involved being surrounded by violence. In order to survive, he may have become a sex-trade worker. As stressful as life on the streets is to begin with, working the streets would only add to this dilemma, with harassment and risks coming from many sources. Attempts he made to leave his life on the street, such as trying to find housing may have proved to be extremely difficult. As if the above problems weren't enough, he may also have addiction issues.

An awareness of the pain he has been through may help you understand his incredible strength to even attempt to quit using substances. He may have tried many times to turn his life around but hasn't gained

The family ostracization is one of the biggest things. If you don't have a family base, without a family base, your whole core values are vacant. A lot of street kids, one of the main things we're preoccupied with is getting love by our mother or our father. So we spend half our lives trying to get that, to realize we'll never get it. So now, we'll have to spend the other half of our lives building our own values. It's a pretty fucked-up world out there.

- an Aboriginal support person

the tools that he needs to achieve that goal.

Often, you will hear one of our best ways of coping with difficult times is through our sense of humor. In finding out her story, you may be amazed to hear a lot of laughter. These are great moments for you both to share and enjoy.

She may be in a situation where there isn't any communication or contact between her and her family. Maybe she really wants them to support her, but past experiences keep her from contacting them. Deep down, her family may truly want to support her but they don't know how to make the offer. They may not understand what her life is like on the street, but if they knew they might attempt to learn the skills they need to give her the love and support she needs.

This is the hope most of us wish for; however, there are many barriers in the way and sometimes the people involved can't get past their pain to reach out to offer, or ask for support. The hope lies in our traditional teachings, which provide us with the guidance to heal and to relate to each other with love and respect. Those teachings provide the necessary tools needed to mend the gap and build the bridge that is needed for caring to occur.

You may be part of her chosen family. You may already understand a lot about where she comes from and the type of help that she needs. In opening up the lines of communication with her, you will be able to provide her with an environment in which she is comfortable enough to speak freely without the fear of being judged. You may be someone she knew while she was inside the prison; you could be from the streets; you may be a service provider or someone from the medical profession. Regardless of where you come from, the support you give her is an important and necessary part of her care.

Many street-involved people have become infected with HIV and they, as anyone else who is HIV+, will all reach the stage of their disease where they will need palliative care. Yet, as with many issues, their needs are often forgotten. While their lifestyles might make providing care difficult, it is still the responsibility of family and community to take the initiative in making this care available. In mainstream society, knowledge about the kind of life that someone leads while on the streets is limited. The harsh brutality, as well as the sense of community that occurs on the street are either downplayed or brushed aside. The following are some of their stories.

I have five children. They're all nice kids. They're well brought up. They have a lot of respect for me, for each other and other people.

I nursed my baby for four months. I didn't find out I was positive until my baby was about ten months old. That's when I found out my ex-boyfriend had HIV. My youngest got tested three times. His test turned out negative.

- an Aboriginal person living with HIV/AIDS

Lately, they've been harassing us about where we stand. They've been pulling our tricks over and giving them tickets. In between nine o'clock at night until about eleven, they block off

Nashine Ginwenimawazawin

the street and any car that goes down the street gets a ticket, even though you're just driving by.

One time, I was standing there. I turned around a guy grabbed me by the hair and threw me down. The Task Force came running from all over.

He goes, "Where's the bank money?"

I go, "Bank money?! Please, do you think I'd be on this corner if I'd robbed a bank!? Give me a break, put two and two together."

They literally smashed my face on the ground. They took me down to the station and they said, "Oh, that's not her."

I called my lawyer and I said, "I was just smashed by the police."

He wasn't impressed. The Sergeant wasn't impressed either, because he's my regular. I had a big bruise on the side of my face.

- an Aboriginal person living with HIV/AIDS

There are two cops that harass everybody. They call them Batman and Catwoman. Seriously, they'll hide in a tree. Literally, these cops do that.

One time I was high. This guy's going, "Pssst. Pssst. I'm watching you. I'm watching you."

I knew who it was right away. They were saying it to my friend; "I'm watching you."

He jumped down right on her. Her whole wig fell off and everything. She wasn't ready!

I said, "Oh, that's Batman." Catwoman came running around the corner, all flashlights, and everything. They're idiots.

- an Aboriginal person living with HIV/AIDS

I am a transsexual and I've lived my life on the streets for years and years. I'm in recovery.

In our community there's what you call the primary transgendered people and the secondary transgendered people.

The primary transgendered people are usually the people who, at a very early age, like puberty, will come out of the closet. They have come out of their closet and have exposed themselves and said, "Hey, I don't fit what you're saying I am. I don't endear to that. That's not who I am."

In most of those cases, if we're looking back, fifteen, twenty years ago, there was nothing existing for those people. So, they ended up on the streets. They ended up being ostracized and pushed out of their home.

The secondary transgendered individuals are the ones that have lived most of their lives in their gender of birth, their sexual gender of birth. They assumed that gender identity and lived a

Nashine Ginwenimawazawin

"normal life." They kept a job, were middle-class and all that. At a later time in life, they went and asserted their other identity.

That's the difference between a primary and a secondary, the same issues are faced by both groups at various levels. For example, discrimination, and ostracizing, we can't judge the intensity of the experience for each individual. We do know that it may be for longer periods of time.

If you're in the primary group, you've come out at an early age. Your road of ostracizing, discrimination, and social isolation, the emotional battering that goes on and the bashing that impedes on the self-esteem; all this goes on for a longer period of time (then) it would have (if it) happened with the secondary transsexual.

On the other hand, the secondary transsexual will have a fight with their inner self for a longer period of time because they keep their secret for a longer time.

There's two different groups, and although the intensity can be equal, there's different aspects to that. For example, my own life. My dad had this idea of what men are and I was a man. I was thirteen years old and I had to go and work. When he was thirteen, he earned a living and brought bread on the table for his mother because his dad killed himself.

Being Metis back in the '70's, it was totally different than what it is today. Today, there's a lot of wanna-be Natives. Those types of social issues are different in this tone, today, than they were in the '70's.

My life experience in the '70's was quite awful. I used to get beaten up just because I was an effeminate man. I was ostracized by my family by the age of thirteen. My dad told me I was a man and this was what I was supposed to do. I wrote him a five page letter saying, "I not a man. I'm a woman and I'm going to grow up to get married and be a nurse."

He beat the living shit out of me. It was all my fault and he didn't know what he did wrong and his genes were good genes, his mom raised a good family and all that kind of shit.

By the time I had worked up enough courage to let them know I was not a man, I had been drinking for four years. I had been turning tricks for a year. I had been a survivor of severe emotional and physical abuse in my own family because of our family dysfunction.

I can remember, from the age of five to the age of nine, where my dad screamed and yelled and beat the shit out of us every day. Prior to that I have some images where my dad sexually abused me. So, we suffered that part as well as being from a low socioeconomic group. My dad was also on social services when he was not working. He worked maybe twenty-five percent of the time.

All those things compounded with my gender dysphoria (depression, anxiety) feelings, that's kind of the intensity...do you kind of get a picture?

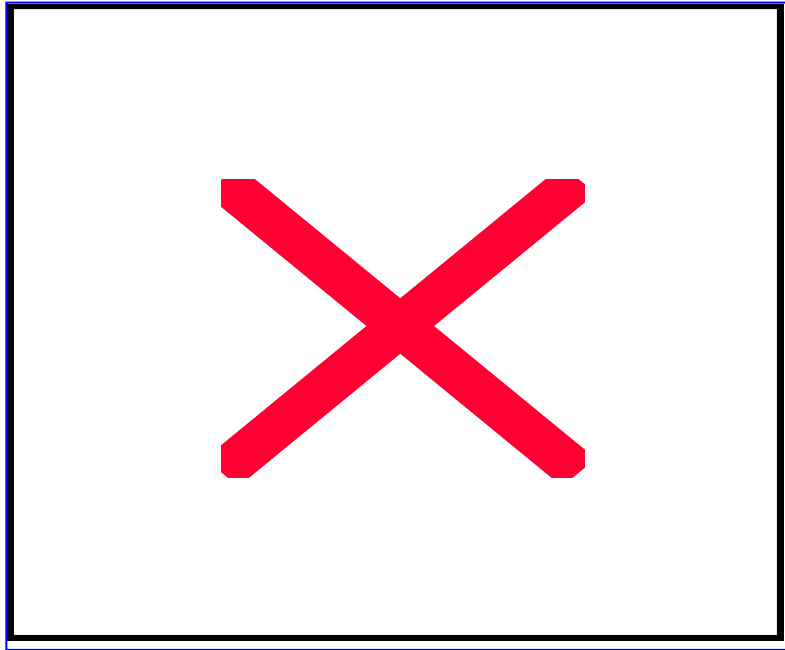
When you're a primary transsexual, most of the time, if you look at transsexuals today that are 34 years old, they're passable, they're comfortable, and they've adjusted to their life. Our primary transsexuals have been in the field and identified as and lived as for 15 or 20 years.

Nashine Ginwenimawazawin

Now the new kids on the block that are coming up today, they have it good. Although there still is a lot of discrimination and there still is a lot of ostracization, there is a lot of support groups for transsexuals and transgendered people. There's a lot of places they can go and be safe. There's a lot of acceptance compared to back then. There's a whole lot less bashing.

- an Aboriginal support person

It's a big building. As soon as you walk in, it's like an old garage. There's little compartments that they made into apartments. The kitchens are downstairs.



Everybody I know from the streets are there. It's more security. Everybody I know from the street are more like my family than going home to my family.

Having a roof right now, it's different. I'm so used to going from hotel to hotel to hotel. I'm not used to having just one residency. I have my own living area.

First, they offer you a hostel part. They give you a hostel part for two

weeks. Then, if you fit in to that clique, then they make you a resident.

Basically who lives there are prostitutes, people getting off the street. We have a few older ladies, in their sixties and seventies. Other than that, the rest are kids.

- an Aboriginal person living with HIV/AIDS

Getting into that house was a lot of stress. They said, "Oh, we don't just take anybody off the street."

I said, "Stick your house up your ass!"

I was being sarcastic, but I was also being straightforward. I was their first challenge, where they picked somebody off the street.

With the attitude that I have, "This is what I have to say. If you don't like it, look the other way. If you're going to give me the fucking room, I'll take it. If not, then get out of my face because I don't need no long story."

They gave me the room. I had two roommates. My first roommate, he moved to away, but he moved back. When he moved back, he died two days later.

Nashine Ginwenimawazawin

My other roommate (was a) stress Queen. I'm telling you, you dirty a glass, she goes off! She does. Literally. I drank a cup of water and she comes in, (freaking out), and I said, "Here, take the damn glass!" (I threw it on the floor).

She chased me around the house once with a broom. I came in one day and there were leaves stuck on my heels, so I just took them off and left them by the door. She went off! She hit me with the broom.

One time, we had roast. You know how there are two different kinds of knives: a meat knife and then a table knife. I took a table knife and cut the roast. Ahh! She went off!

She goes, "Oh, what are you doing? What are you doing, cutting a roast with a table knife?"

I said, "Here, take your roast!" Bang! Didn't that thing just bounce across the floor and hit her right in the lap! She wasn't ready! I'm telling you.

- an Aboriginal person living with HIV/AIDS

We were sitting there, talking. Then, (before) he fell asleep he (asked) me to wake him up (in an hour).

I said, "Sure, no problem."

That was it. He was stiff.

It's better to have your own place. You can say "Hi" in the hallway (or) "Oh, you're dying." But to stay in the same house or be roommates, watching, you get so attached. When they go, you're lost.

It was great, but it wasn't. I couldn't watch anyone die in front of me again. I couldn't look because I know it's going to happen to me one day. I couldn't just see somebody keel over in front of me again.

- an Aboriginal person living with HIV/AIDS

They had meetings. I never joined them, though. I was in my own world. I just do what I want to do when I want to do it!

- an Aboriginal person living with HIV/AIDS

My mother's coming on the 15th. I've got court on the 10th. Watch them throw me in.

I'll say, "Hi mom, how are you?" Talking through the glass!

Yeah, that's all I need, talking to my mom in jail.

- an Aboriginal person living with HIV/AIDS

I was on the highway at twelve. I put on my first pair of heels. I walked around this one street and this guy stopped me. He goes, "I've got a hundred dollars."

That bought me lots of candies back then! So, I took his hundred dollars and he just wanted to feel me up.

He goes, "Oh, you're a young one, eh?" He grabbed me.

I thought, you dirty motherfucker!

Back then my tricks, the ones that drank, I couldn't stand, because it reminded me of my father. I could just smell his booze on top of me.

It was like, "Oh, I can't do this."

They would say, "Why not, why not? I'll give you more money." That's when they started grabbing me. It took me on a spin. I'll never forget that hotel. I kicked so many tricks down the stairs.

- an Aboriginal person living with HIV/AIDS

SUBSTANCE ABUSE

Substance use continues to be a challenge for First Nation's communities. Injection drug use (or IV drug use) and alcohol abuse are very much a part of not only street life, but also on reserves. When abuse of substances such as heroin, cocaine, alcohol, inhalants, and other drugs take over and begin to dominate someone's life, it can be very difficult to provide constant care.

Oh yeah, I'm an alcoholic. I've dealt with that since I picked up the bottle when I was twelve. I knew I became an alcoholic then.

- an Aboriginal person living with HIV/AIDS

Many people both practice and encourage abstinence (not using substances at all). Other people favor Harm Reduction, a model that involves providing the person with all information about a problem/issue and then allowing them to make their own, informed, decisions. An example of Harm Reduction is, for IV drug users, to educate them about safer practices, such as bleach kits to clean dirty needles and needle exchanges. This method has several benefits. It gives people the opportunity to become fully educated and aware of issues; it places responsibility for their actions directly on their shoulders. Also, people are more likely to follow through on decisions they have made for themselves, and it allows people to feel like they have control in their lives at a time when they may feel they have none.

Despite all the programs that are in place, some people are not willing to take advantage of them. Even though they would like to quit, there are many obstacles in attempting a clean and sober life. Low self-esteem, no support system or simply feeling undeserving of a clean and healthy lifestyle may make achieving this goal seem impossible.

When the person you are caring for has an on-going problem with substance abuse, there are often challenges in providing care. Inconsistent moods or mood swings, low tolerance for pain, low priority of treatment and/or appointments are all possible side effects of substance abuse, all of which can interfere with care.

Learning his story, his history, his experiences, can help you to provide him with support. It is likely that he has many issues in his past that propel him to try and forget. Creating a

Nashine Ginwenimawazawin

caring, open, trusting, and non-judgmental atmosphere, that allows him to feel safe enough to share his stories, is one of the care team's most important jobs.

Oh yeah, I'm an alcoholic. I've dealt with that since I picked up the bottle when I was twelve. I knew I became an alcoholic right then. The reason why, is because I knew my mother is an alcoholic and my father is an alcoholic. With myself, I knew once I picked that bottle up, (that) there was no turning back. I've been able to deal with that.

My partner and I have been sober. I've always believed once you're an alcoholic, you're always an alcoholic, it's one of the things that I have to deal with.

I wasn't so much into drugs, it was more alcohol. I went into treatment, came back out, and started drinking again. There are days that go by that I (still) have the urge to (drink). I think it goes for a lot of people.

- an Aboriginal person living with HIV/AIDS

He couldn't handle alcohol. When he was really sick, one drink would be enough to knock the wind out of his sails. It would make him real tired and sick to his stomach.

So, he chose alcohol over retrovirals. It was AZT and ddI; he had a bad reaction to both because he mixed alcohol with them. He had a lot of pain, nausea, and backaches. So, he threw the pills out. In his measures of quality of life, it was to be able to go and drink, party and get high.

- an Aboriginal support person

He used to go out, one of his friends would take him down to the bar, and he'd have maybe one drink. He'd get tired and come back home. He still liked to go out because he used to get so bored. Plus, he was a real barfly anyway.

He tried anti-viral drugs, but he quickly quit them because it meant he couldn't drink. His attitude was "If I can't drink, I'd rather be dead, anyway."

- an Aboriginal support person

I go to bingo! I dropped the bottle and picked up a bingo dabber! That's what they say, you drop one addiction and you pick up another one.

- an Aboriginal person living with HIV/AIDS

There is so much effort to prove that we're not alcoholics that anyone who drinks and (who) contributes to the community is open for attack. It's internalized racism.

Just because you're an Aboriginal person and you drink doesn't mean that you're an alcoholic. It also doesn't mean that you don't contribute to your community; it also doesn't mean you can't manage yourself and drink.

There is definitely an implication that you're a bad person. It's just another judgement. Some dry drunks hate themselves a lot and are very full of rage. Whether they're twelve-steppin' or tradish-Nish, they feel their sobriety has to be everyone's sobriety. When they are judging people that drink, they do some really cruel, mean, judgmental things.

People will say, "Well, you're not a good role model." If the kids, teenagers, and adults had wonderful, happy lives then they wouldn't need external role models. It's about time that we

Nashine Ginwenimawazawin

started looking underneath, to find out the root of the problem. Alcohol is only the symptom.

When it comes to palliative care, alcohol is a problem if you let it be a problem. If you can manage it, then you can manage it.

There are people who say no one can manage it (drinking), because it's a progressive disease. I don't buy that. If you say it's a disease, then that means you don't have to take responsibility because, of course, you can't control a disease. It is easy to describe alcoholism as a disease when someone has no control over their impulses, this is because they've not looked at their own issues and they're in pain. If someone explained these impulses as a disease, well it lets them off the hook from having to look at whatever is underneath.

Not everyone has that stuff underneath to deal with. Some people have dealt with it and are still dealing with it. If you are using the brain the Creator gave you, then you can make your own decisions.

- an Aboriginal support person

He was part Cree. His mother was Cree, but she was adopted. He didn't really follow the beliefs. He actually had a lot of negative attitudes towards Native people. It was the community he grew up in.

I would describe him as a self-destructive person. He grew up with a lot of shame and a lot of negative attitudes about his sexuality, being gay. He just internalized all of that. I don't think he was a happy person.

He used all sorts of substances to numb himself, to numb his emotions. I doubt he wanted to grow old, anyway. He was self-destructive and he had attempted suicide before. He had a lot of emotional problems, and he never sought any help for it, either. His solution was to party.

He was raised in a working-class, white neighborhood. There is stereotyping against all different types of races across Canada. I'm not saying that it's only working class Canadians that are prejudiced, but it is prevalent there.

He had racist attitudes towards Black people, Asian people, and Native people. He had all sorts of prejudices. It was the era he grew up in, the '50's, and '60's. They were a little more up front about their racism and their homophobia. Now, it's more hidden - everybody's trying to be politically correct.

- an Aboriginal support person

I think it was my health and the well-being of other people. You know, getting drunk, you do things you don't normally do. You wake up the next morning, wondering what happened the night before.

I did it for myself; then I did it for other people. Mainly, I thought about myself and my family. It wasn't very good for my health. It was putting more problems onto me than anything (was).

Nashine Ginwenimawazawin

I've been trying to quit since I've had my son. I still struggle with it today. With the support that I have, it's going O.K.

- an Aboriginal person living with HIV/AIDS

When I was learning the teachings, there was lots of times I felt like an idiot. There was lots of times when there were people teaching me who were harsh with me. Fortunately, I had the stamina not to give up.

Well, what did I learn from that? I learned that when I get there, I'll be firm, but I'm not going to be harsh with anybody, because I know that sends people away. Then, people can see, "Well yeah, look at the hell-life she had. If she can do it, I can."

It's not putting a whole lot of expectations on people either, it's like, "Do as much as you want."

Remember that it's your choice to do as much or as little as you want. Just take your time with it and find out for your own self if this is good for you or not. Take what you want, you don't have to take it all.

All these things around judgments, the way people go on and on and on about, "If you want to be a Traditional person, you can't drink."

I remember when I started out, too. I told everybody, "Yeah, I drink and I do drugs, but I'm alright about who I am."

They told me, "O.K., this is what we want you to do. Four days before you go to the ceremony, don't do drugs or alcohol."

I did that for years. If I knew I was going to go to a ceremony, for four days I wouldn't drink or do drugs. I'd go to the ceremony and a couple of days (later) I was out drinking again. Nobody was dinging me on the head or telling me I was a terrible person. I was doing both for a long time and nobody told me, "You have to stop drinking." I decided when I was damn-well good and ready, that, yeah, these are the reasons why I decided I'm not going to drink anymore. Nobody made me do it.

- an Aboriginal support worker

I think a lot (of) people don't get involved in a traditional lifestyle because they're using alcohol or drugs. It's not really an important issue with them.

There's no acceptance for people who are at different points in their lives. Maybe they need to use alcohol or drugs at that point.

It's too high. They put people on pedestals, and it's too high to get up there for some people. When they just need acceptance and support, maybe they would stop using. Because there's that standard that's impossible to meet, they don't try it.

I think there are people that have a lot of bad experiences because of that, because of people that are so rigid in their thinking that they turn people off culture. It's like they're supposed to

be perfect and leading life on the Red Road. Well, they're not going to go back to get shit on again.

- an Aboriginal support person

There are a lot of people out there who have problems other than HIV and AIDS. There are a lot of people who were sexually abused - a lot of people who were sexually abused. Child abuse (too).

All this shit from their past. It's never been dealt with and at some levels, they're still like little kids. They have no control over impulses. If they need a drink, they take it. They don't think of the consequences. It's like a Band-Aid, a quick fix, because the pain is just so overwhelming that they don't know what to do with it.

Then, on top of that, "Oh my God, I have HIV. I have AIDS."

- an Aboriginal support person

I think when they first get diagnosed, that's the first thought that comes into their head, "Oh, my God, I've just been handed a death sentence. I'm going to die."

As they get more information, if they do, then some people will go, "O.K. I've seen people live ten years."

Other people, it's like, "I've been handed a death sentence. I'm just going to drink and drug because it doesn't matter."

Some people are already on that path where it doesn't matter, because people have treated them like shit all their lives. They don't know that they deserve to be treated better.

Then, you have Elders who are saying, "Well, I would help you but you're drinking."

They're not saying, "Oh, I see you're really hurting. Right now, you're using, but that's O.K., I still accept you and I'll still help you. When you're ready to quit, I'll still be there for you."

It has to be unconditional, not putting all these conditions on being an Indian and accessing your spiritual side.

On top of that, the two-spirited people have these Elders who are homophobic and (who) have their own sexual orientation issues. They condemn people because they don't know, and they don't understand. It's so threatening to them (that) they have to put other people down and not accept them.

It can be like, "Oh, you're sick because two-spiritedness isn't a real thing."

Some Elders have their own shit that they haven't even begun to deal with. Just because they've been handed the title or they've assumed it. They don't have the skills. They didn't

Nashine Ginwenimawazawin

earn that title; they just gave it to themselves. They're doing a lot more damage than they are good.

No one is supposed to be on a pedestal. No one. It's a power imbalance. Elders are supposed to be teaching us and we're supposed to learn from them, not because they're better than us; or smarter than us; or more wise than us; or more spiritual than us. They have wisdom and so do we. It's a two-way street.

It's a power and control thing. It's like, "Well, people abused me, now I'm an Elder and I feel good about myself because people look up to me. I have a title, and I'm so spiritual, and I have all these things."

When really, deep down inside they're the same hurting little kids that our clients are.

It's too high. They put people on pedestals, and it's too high to get up there for some people. When they just need acceptance and support, maybe they would stop using. Because there's that standard that's impossible to meet.

Get off your high horse! If you truly are walking the Red Road, and you're talking the talk, then you get off your high horse and you walk the walk.

- an Aboriginal support person

I'm not going to listen to you, and clients aren't going to listen to someone who's going off about being loving to all people and turning around and saying, "Oh, except for two-spirited people. That's wrong, that's bad." or "Except for if you drink."

It's like it becomes organized religion. If you want people to listen, you have to show respect. If you want respect, you show it. Treat people on equal ground.

The best workers are those that are really quiet and anonymous. They don't do all this blabbing, they just go out, and they do it. It's like, be human.

We put them there, but some people also manipulate and they make it so you're nothing without them. It's bullshit. It's total bullshit.

I would say find the quiet little groups who are actually doing things. Seek them out. Ask them who they respect and who they would suggest you go see. Go from there.

It's not the people that are out there getting their picture in the papers and being the so called "speaker of the whole nation". They're the ones that are all talk.

- an Aboriginal support person

I don't believe in substance abuse in any way, I have a hard time saying they can't use it. But if that's what that person has done, why should they sober up when they're dying?

The teachings I have, and the understanding I have, are that if you die drunk, you wander. It's like suicide. You can have the rituals in your funeral and whatnot, but you wander.

I know that (the) Creator, in his infinite love for us, does not let them stay there forever. There is time they spend, walking back and forth until they come to whatever realization they need to, in order to go across.

Nashine Ginwenimawazawin

I know from some of the work I have done, that when you get in touch with the spirits, you can send them on. There are some Elders that can do that. You can get in touch (with) and talk to those spirits.

- an Aboriginal Elder

Everybody has to have their medication under direct observation. It is very difficult to give breakthrough pain medication to someone who is still ambulatory (not in emergency care). It is a very difficult concept for the prison authorities to believe that you can be at the stage where you need to have breakthrough morphine and still be out in your own house.

Prisoners like to be in their own house. They don't like to be in the prison hospital because the prison hospital has limited freedom. They can only go out when it is convenient for the guards to take them out for exercise or for smoking, and many of these people are smokers. They have no occupation (anything to do), and it is very difficult to find anything for them to do.

- a support person

That's how I am with people. I say to people who come to my circles, "Don't come to my Circle if you're drinking. I can't do anything with you. This isn't a judgement, it's just that I can't sit and do counseling with somebody who is drunk. It's too aggravating. If you're going to miss sometimes because you're drinking, so, miss."

If they say, "I didn't come last week because I was drinking."

O.K. What am I supposed to say? Have a big fit? Why? It doesn't make any sense.

All I'm asking you (to do is) just give me this little bit of respect. Our agreement is, I can't do anything with you, and I can't let you be around the medicines if you're drinking. So, you don't come.

Don't think that I'm not going to like you anymore; or (that) I don't even want to be around you; or I don't want to work with you because you drink. This is crazy. To me it is, anyway. Again, there are people who disagree.

- an Aboriginal support worker

There is very little acceptance of injection drug use. It does not matter what category of individual. People are certainly judgmental. It is clearly stated by people that there are innocent victims of HIV, like babies born with it, and (that) there are guilty victims like IV drug users. That is not the truth. The truth is that all people with this disease are innocent and no one deserves to be infected. It is not punishment. It is (a) tragedy.

- a support person

I'm going to treatment for crack; I used to be into cocaine, I used to shoot up. That's how I was diagnosed. I smoke some pot every now and then. I was more into the harsher drugs because it took my problems away. When I came down, the problem was still there.

Nashine Ginwenimawazawin

I'm quitting for my mother's sake and my sake. I left home straight (not using drugs), and I'm convinced (that) when I'm going home with my mother I'm going to go straight.

- an Aboriginal person living with HIV/AIDS

If they're in sex trade work, there (is) still a poverty aspect. A lot of times, most of the individuals, and I don't say (this) for everybody, are in the sex trade work to keep up an addiction.

The medical model is really one of, "You've got to stop using, you've got to stop drinking, in order to be healthy." I'm not for that.

- an Aboriginal support worker

I met a man, fell in love, and got married. We started hanging around with the wrong people and got into coke addiction, alcohol, and smoking pot. I was turning in (to) a real bad addict in a lot of ways. I'm not too proud of that, but it's something I've experienced.

Before I moved away from home I was chubby. When I was going back I was real skinny because I was snorting coke, basing coke, cocoa puff and it eventually turned into IV use. It was really bad. We had to have it all night and every day.

It ruined my marriage. My husband wasn't treating me like a wife; he was verbally abusing me, big time. I lost a lot of stuff I had in storage.

I almost lost my life a couple of times. I did too much and my body, my heart, my mind, everything was just racing. The cold water that I put in my hands and the cold towel around my neck, nothing could slow it down. It was scary. I think (that) if I didn't have that towel around my neck and put my hands in the sink, I probably would have O.D.'d (overdosed) right there. It was scary.

That part of my life I used to have a hard time talking about. Big time. Now, I find it easy to talk about. Even now, I have dreams about doing coke. Sometimes I get some kind of flashback, where I'm actually getting high on coke. I'm like, whoa! I feel that rush, and it really... sometimes, it makes me want to have it again.

About a year ago, I did go experiment with it again, IV (drugs). It wasn't the same as before. It scares me now. The past two times, I've actually said no, and walked away from it. Hopefully I can keep doing that.

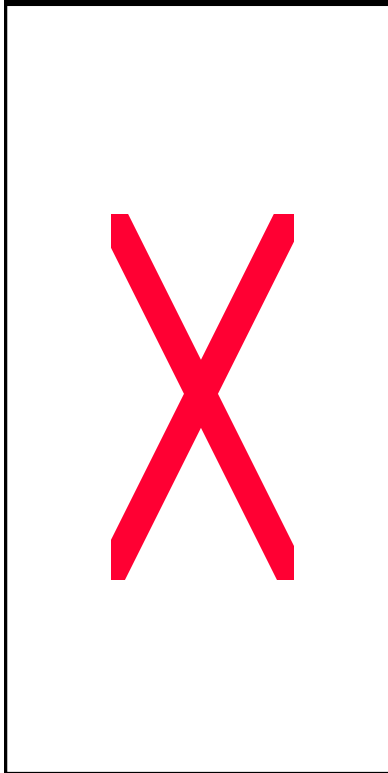
It's pretty hard. A lot of my friends that are still into heavy using, IV drugs like cocaine, they're asking me, "How are you doing this?" They know not to bother me.

I had to experiment with a lot of things. I went through all kinds of things by the time I found out I was HIV positive. Some things I wish never happened, some of them I'm glad. I think I'm accepting myself for going through the coke addiction. I know a lot of people in this city that have the same problem and they're looking up to me now. I'm a role model, I guess.

- an Aboriginal person living with HIV/AIDS

CARING & SHARING

In the section entitled, “Lives with High Stress,” we discussed some of the problems that come up when the person you are caring for wants to contact their family. She may have lived on the streets for many years; or in a city; or perhaps in prison. She may have had little or no contact with her family for quite some time.



The lives of many Aboriginal people who are living with AIDS have not always been easy; how they cope today can often be attributed to the difficulty they faced in the past. From a traumatic time growing up to tough times on the streets, she might have learned to be very defensive when dealing with people. In order to survive, it was necessary for her to have these defenses.

If her life has not allowed her much control, the use of intimidation, coercion or silence may be her way to gain control. If she has been hurt a lot, it is likely that she will defend herself by lashing out first, because she believes that others will attack and judge her. When she expects to get hurt by everyone, defense mechanisms protect her and allow her to observe whether or not you can be trusted.

It could seem like she has a tough personality to work with; anyone who has done work with people on the streets or in prisons knows that a relationship formed with her could be very fragile. She may not want anything to do with her family because of a painful history. It may be difficult seeing someone, who has been through such a tough life, go through the battles they must face in the palliative stages and without the support of her family. The sad reality is, she may die lonely and afraid.

However, if she does not want any contact with her family, this is something that must be respected. It is her choice, and to her, her reasons are valid.

She may really want to see her family and go home to be with them. This may not be possible. Her family could be too afraid of and uninformed about her illness to be with her because she is dying. They may come to see her in the hospital or a hospice, but providing her with care in a home setting could be something that they don't have the capacity to deal with.

In some cases, the family may have to be the ones to take the first steps to reach out to her. If you are a family member, encourage the rest of your family to take the initiative. Often, breaking down these barriers takes time and effort on both sides. She may be too close to death and not have the strength to begin the communication process or she may have

Nashine Ginwenimawazawin

difficulties with pain or discomfort from her illness. She could be terrified of dying and really need her family to be there for support.

The traditions of sharing and caring can be used to break down silences. If you consider the tragedy of a family member dying alone, it may not seem like such a big effort.

When you look at your relationship with her, it may or may not be something that can be repaired; some families have too big a gap to build a bridge over it.

You will find in the stories the reasons why some Aboriginal people are estranged from their biological families. People that have been adopted or fostered may be estranged from both their biological and adopted/foster family.

Family is who they define it to be.
Their chosen family is family because
they have been the ones there
providing love and support.

Some people have a chosen family because their biological/adopted family has rejected or hurt them too much. Their chosen family could be the friends they have on the street, in prison or helpers from service organizations. Family is who they define it to be. Their chosen family is family because they have been the ones providing love and support.

If you are on her care team, it will be helpful to recognize the isolation she may feel without a relationship with her family. You may also see the joy and strength she gets from her chosen family, you and others.

I haven't talked to my family in ten years. I grew up on the reserve until they found out I was gay. I was twelve.

I used to have long hair and I used to braid it to look like a little Indian boy. Little did they know!

When I was twelve, I took my father to court for rape. I lost. So, they threw me in child welfare, they kept me in child welfare for two hours after court in this room.

They were saying, "We're taking you to a group home for boys."

I said, "Well, I want to go home."

They said, "No, you can't. Your dad doesn't want you there."

I said, "Sure, no problem."

I went to this room. There was a little window about this big. The ground was like....it was a good drop. I jumped out and that was it.

- an Aboriginal person living with HIV/AIDS

Nashine Ginwenimawazawin

She may ask you to play a part in contacting her family, to see if there is a way that they can become involved in her life. On the other hand, she may not choose to do this because it would only create more trauma for her.

His sister was supportive. He was estranged from the rest of his family. He was very angry at them for the rejection he received because of his sexuality. His sister was the person he felt closest to, so she was supportive.

We did approach the AIDS Committee of Toronto for a buddy to help him. They couldn't match him because he had such very narrow guidelines, a very narrow criteria for who he wanted around him. He didn't trust a lot of people. He was very sick and as a result, he was very angry.

I wasn't ready to phone home. It was like taking a burden off my shoulders just to say, "Hello, I'm alive."

But to phone home and say, "Hello Mother. I'm dying of AIDS."

It's a different story. I'd rather see them in person. I see my father last month. I wore my best dress!!! He was not impressed. But he's over it now. I guess. He left me here.

He expected me just to get up and leave, after all these years. I told him about all the suffering and the things I've been through by myself.

I expected him just to say, "Hi, how are you? This is where you live, it looks good. I hope one day, you can come home."

Not just to come here and say, "Pack your shit. We're going home." It doesn't work that way.

He saw my high heels on my rack. He goes, "Who wears these?"

I said, "I do."

He goes, "What did you say?"

I said, "I wear those shoes. I wear those shoes and I wear make-up and a skirt."

He said, "I'm not hearing this, I'm not hearing this."

I said, "I guess you're not. There's the door."

He said, "Come back to my hotel and see me later."

I said, "Yeah, when I've got time."

He said, "You don't even have time for your father?"

I said, "If you're paying me, I've got lots of time for."

He went off, again! He didn't know I was soliciting. He just thought I was a fag that does it for free. Wrong.

I went to the hotel, dressed to the nines. He opens the door, "Hi, can I help you?"

I said, "I'm here!!!"

He went off! He goes, "Get in here!" He looks out the hotel door to make sure nobody saw.

He made me feel so small. I told him, "Okay when you were on top of me, when I was twelve years old, I was free. And, I was a boy. Now, I'm twenty-five years old, I look like a woman, I'm not free no more. It costs money."

He just didn't know what to say.

I said, "What? The truth hurts? When I leave this room, I'm not coming back. It was just nice seeing you. I'm sorry we didn't make amends, if that's what you wanted to call it. It's never going to happen."

And I walked out.

- an Aboriginal person living with HIV/AIDS

My Mom is fabulous. She's jealous of me because I'm beautiful!"

She goes, "What's this?"

I said, "Those are earrings." It was those big hoops I used to wear. I sent her pictures of (me in) my black patented leather outfit and my red one.

She goes, "Where's the rest of your clothes?!"

I said, "Mom, I can wear what I want to wear."

I miss her a lot.

- an Aboriginal person living with HIV/AIDS

COMMUNICATION IN EMOTIONAL TIMES

For some people, expressing emotions can be very difficult. When overwhelming emotions are involved, they can either help or hinder the communication process. People constantly get messages telling them not to express healthy emotions. In the movies, men are admired for being "strong" by not showing emotions; women are expected to be "nice" and not get mad about anything.

The person you are caring for may have a hard time expressing his emotions and you may too have difficulties expressing your emotions. When this is the case, communication can become confusing or even be explosive and that can make the care team environment a difficult one.

No one is perfect. Many people have been through painful, violent or lonely experiences and you, as a care team member, will have your own hurt and pain. For the best possible care, you are both going to have to work to get past these difficulties and establish an environment in which positive communication is present.

Good communication skills are learned; bad ones can be unlearned. Remember, when emotions get very intense, base your communication on caring and love. If you can maintain a caring way of communicating, it will contribute in a positive way to his environment. It might seem as though he isn't responding to your kindness and he may even reject you. Maybe, in his life, no one ever treated him with kindness, so be patient, building trust takes time.

Internalization plays a big part in the problems we, as a people, have with communication. There needs to be more awareness and strategies for dealing with internalized racism, sexism and homophobia. As First Nations people, we have to explore the things we do to destroy our own health. In the context of the care team, he may have his own internalized racism, etc.; more importantly, the Aboriginal members of his care team may also have internalized issues that could hinder care. This is especially true if family is allowing that internalization to stop them from offering any support at all.

I have this belief that if you are an Aboriginal person, the Spirit of your ancestors is in you and does not go away. No matter where you have been brought up, you will always question your difference and always try to find out where you come from. You will always look different from other people and from your adoptive or foster family.

If you are lucky, your first experience of Aboriginal people is the noble savage; or the man crying because of pollution; or you will hear about Sitting Bull, Chief Joseph or Seattle.

Usually though, your first experience will probably be the guy on the street; drunk, beaten up, and he is the only Indian you get to see.

- an Aboriginal support person

If he was adopted or fostered, it may not be easy to "rejoin the circle" or become involved with the Native community. In a non-Native environment, he may only have seen stereotypes about First Nation's people. When he hears people negatively attack or negatively stereotype First Nation's people, it may contribute to him internalizing this hatred. If this happens, it may be hard for him to embrace his culture.

Memories from the past and his feelings about death and dying may make it difficult for him to express himself. Using sensitivity, compassion, kindness and patience can create a solid foundation of trust and open communication that not even the most emotional of times can destroy.

Well, it's always fear. Fear is at the bottom of that. It's also the result of their history, if they've been put down or never given those skills. Many kids are not given those skills to say,

Nashine Ginwenimawazawin

"I'm hurting," or "I'm feeling this at this time." They don't have those skills so they're not able to express it.

Then again, the overriding feeling or context is (that) they can still read the manner of the members of the care team. They can still read the love of the care, even if they cannot personally express it.

Who knows? One of the gifts that come with that is they are able to express something. Most of all, we are able to model for them, to show them our vulnerable side, to be able to say, "I'm feeling this today" or "This is what's happening for me." Give them the words so that maybe, after a while, they may start finding (the words) you're teaching them.

You're teaching them the verbal skills (they) can use to express these emotions. It's difficult because they don't have those skills; they don't have the practice in doing it, so they just stuff everything down and leave it there.

I taught parenting skills to a young woman who ran a daycare on a reserve. She told me a story about this little three-year-old girl. They would be talking about feelings and she used to get them to put their hand over their heart and say, "Feelings live here."

The girl went home one day and her father; he was having some difficulties with substances and so on; he was screaming at the little girl.

She looked at him and she said, "You're not being very kind. You're hurting my feelings."

She had found the words. It just stopped him dead. That little girl had done something that maybe he hadn't learned to do, which was (to) identify the feelings of hurt.

She was doing it perfectly, assertively. "When you do that, I feel this." Nobody can argue with that. Nobody in their right mind can argue with you about your feelings.

- an Aboriginal Elder

I have this belief that if you are an Aboriginal person, the Spirit of your ancestors is in you and does not go away. No matter where you have been brought up, you will always question your difference and always try to find out where you come from. You will always look different from other people and from your adoptive or foster family.

If you are lucky, your first experience of Aboriginal people is the noble savage; or the man crying because of pollution; or you will hear about Sitting Bull, Chief Joseph or Seattle.

Usually though, your first experience will probably be the guy on the street; drunk, beaten up, and he is the only Indian you get to see. You know you are different. If you are lucky, your adoptive or foster parents will have told you something or you will remember something about your life before and know you are an Aboriginal person. You may know nothing about the language or the culture; however, you look different and you experience the racism that comes along with that.

When you come in contact with the school system, they tell you lies about Indians; (that we) were savages who killed priests; we scalped people; we carried off white women to use as slaves;

Nashine Ginwenimawazawin

and we were horrible evil people who contributed nothing to North America. So you grew up with enormous internalized racism.

You reach a period in your life when you have to find out who you are and you have to deal with that internalized racism. You have to fight all of the stereotypical images and the complete lack of good quality information, which reflects positively on your culture in school, the media, movies and television. You are dealing with a completely negative view of what you are.

Once you are (done) fighting the negative images in the mainstream you then have to deal with your own community. Are you brown enough? Are you Native enough? Do you speak the language? Do you know your culture?

We have adopted this whole class system in the Aboriginal community, in urban and First Nations, around who is more Indian than the other. Are you a tradish-Nish? Do you have a status card? It is some kind of class system we have adopted, and it makes no sense because it doesn't belong to us.

The racism you face from the Aboriginal community doesn't belong to us either and we have very few people who can help us get through that. If you can get through that without killing yourself, or without seriously getting into drugs or alcohol, then there is another hierarchy you have to get through. That is, how traditional you live. How do you live? Who do you hang around with, etc. So you go to sweats, Pow wows, you observe the traditions.

You have to take a lot of shit to get through this and then maybe you (can) make it. You can't make it too well, because if you do anything that is excellent people will jump up, and drag you down and stomp on you.

If you are two-spirited look out, because not only are you dealing with internalized racism and general racism, you are dealing with homophobia and internalized homophobia in the two-spirited community. It's the same thing that happens in mainstream society: the judgement; the rules; making you conform to what someone else thinks is important.

You survive sometimes by rejecting your own community. Sometimes you find a few close people who behave in a traditional way and follow the fundamental values, they have respect; they share; they give to the community, despite what the community does. They have the qualities we have been told are traditional to Aboriginal peoples.

You often end up creating your own family and community. Part of it is becoming your own person, and not listening to people when they tell you how you have to live and about all of the rules (you have) to follow to be accepted. You have to find your own way and find out where there are resources to help you get through this stuff. Sometimes you have to pick and choose between the things being offered. You have to sort through (a lot of) garbage and it takes a really strong person.

The best thing to do is to learn to think for yourself and not be trapped into these little group excursions where you have no individuality. It is a clue, the minute people start telling you, "You have to do this to belong." They are telling you how to live, and that is not a traditional value.

Nashine Ginwenimawazawin

The community has to turn inward and look at what there is. There has to be a community healing process for urban centers and First Nations and rural communities. There has to be a turning inward and a review of where we have come from. Are these our values or aren't they? Who are we kicking out here? Who do we want in (and who don't we), and why not? What does it mean?

We can eradicate alcohol, drugs, HIV/AIDS, diabetes and high blood pressure. (But,) unless we have that fundamental respect for ourselves and that caring for each other, something else will be killing us. Other symptoms will be taking us over until we deal with the real problems and that is that we hate ourselves because we have been taught to hate ourselves. We have to believe we are good and of value and that we (have) contributed to this land. It comes to loving yourself. Once you do that you have energy to contribute to your community and family. If you don't, all you are contributing is your own self-hatred.

- an Aboriginal support person

Anger

The person you are caring for could have a long list of reasons, either in the present or the past, for being angry. Here are a few.

- ◆ They feel afraid, helpless or out of control.
- ◆ Have feelings of shame or guilt.
- ◆ Have experienced sexual, physical, emotional or mental abuse.
- ◆ They are feeling physical pain.
- ◆ We're taught that anger is a "bad" thing and received no skills for expressing anger in a healthy and constructive way.
- ◆ They were dislocated from traditional lands and forced to live elsewhere.
- ◆ They have experienced multiple losses in their lives (from AIDS, accidents, violence, etc.).
- ◆ They have experienced a loss of freedom from residential schools, adoption/fostering, prisons, reserves, etc.
- ◆ Their children have been lost through death, residential schools, adoption/fostering, or running away.
- ◆ They live in poverty and are dealing with poor housing, poor nutrition, poor health, etc.
- ◆ No one takes the time to visit.
- ◆ They are feeling cheated for dying at a young age.
- ◆ Is humiliated because she is incontinent and needs someone to change her diapers.

All these reasons of lost physical abilities, pride, culture and family may be why she is angry; however, she may not always express her anger when she is feeling this way. She may keep it all bottled up inside and sometimes it may explode.

Encourage Healthy Expressions of Anger

Nashine Ginwenimawazawin

1. Try to maintain your patience, understanding and listening skills.
2. Yelling and screaming are healthy expressions of anger. Violence is not healthy. Don't stay in a situation where you may get hurt.
3. Allow her the time to express her thoughts and feelings, an Elder or counsellor may be able to help.
4. Instead of becoming silent, withdrawn, or confrontational, keep healthy lines of communication open. When she is angry, remind her support people how important it is that they be there for her at this time. Care team meetings and Talking Circles can help them support each other and cope with any issues that come up.
5. She may feel bad after an angry outburst; she may change her mind about something later, gently accept any apologies.
6. If you get angry and feel you might hurt the person you are caring for (physically, emotionally, etc.), remove yourself from the situation immediately. Find someone to cover your shift and go talk to someone; write out your frustrations in a journal; go for a run; work out; do whatever works for you until you calm down.
7. Seek support from your care team to decide if you need some time off from the care team.

The following are the words of care team members and support people that describe how they deal with anger that comes from the person they are caring for.

There are people that are using other narcotics, you know, the self-medicating kind. They suddenly don't want to take their medication, the medication that is keeping them healthy. They don't want people in their house. There will be a care team set up and they'll be like, "Piss off! I don't want anybody in my house!" They may not answer the buzzer for their apartment.

That's when the leader of the care team usually goes in. When they've sobered up, you say, "Look, we're here for you. If you want to drink, fine but we're worried about you. You need to let people in. Or, you can call and say, "I'm okay, but don't come." These people are donating their time.

People will be like, "Oh my God, they're dying, we have to be nice."

That's not helping them either. Keeping on track and being consistent will take care of your volunteers, if you let them be treated like shit, then they're not going to come back.

- an Aboriginal support person

You are going to come across that. You'll come across people who are very difficult. I think the thing is not to take it personally. I know it's very hard, especially if there's already a history between you and the person, (but) it's about not getting personal about these things.

If they're really difficult, get help. There's all these agencies. That's what they're there for. Get the help that's out there. Access as much as you can. Be persistent and aggressive. Get more educated and learn how the system works. Plan ahead when you realize someone's getting symptomatic or that they may need palliative care in the next year or two. Start doing some

Nashine Ginwenimawazawin

research on it. Phone your local AIDS committee of 2-Spirited People. Planning ahead will save you a lot of hassle, instead of trying to put it all together at the last minute when everything is happening all at once.

- an Aboriginal support person

Sometimes, that's the personality of the person who is dying. They're just difficult, cranky. That's the time when you need to talk to them and say, "Okay. I know you're grouchy. You're allowed to be."

They're dying! Of course, you're going to be grouchy. Maybe they're just very sad that they don't have anyone to talk to; maybe they're in pain.

Sometimes they don't want to see a counsellor. You can suggest it. Usually, it would be a very good thing to have a counsellor on board but sometimes they just don't want that structured appointment thing.

It's treating them like a human being. We all have grouchy days. It's trying to be kind and understanding but also not taking bullshit from people.

Saying, "It's okay for you to be grouchy, but you can't talk to me like that. That's not okay. Let's talk about how you're feeling."

- an Aboriginal support person

A lot of people in my area are angry Aboriginal people, for a million reasons. There are still a lot of racist attitudes in the town because of what has gone on before. I think that it is hard for a lot of Aboriginal people to let go of it.

There was a huge amount of dislocation; a lot of the communities are not the peoples' traditional communities.

There are a lot of social problems in the communities and culturally there is a lot of confusion. I see a lot of mixed forces like churches and traditional cultural viewpoints being (a) conflict for young people. I don't see a lot of choices for young people on the reserves. There are a lot of chronic problems like family violence, sexual abuse, alcohol abuse, poor housing, poverty, lack of nourishing food options, overcrowding in the houses, and a lack of recreational activities. There is a lot of unhappiness and illness and imbalance all the way round in some of those communities.

For me, sometimes it seems that in communities where the cultural devastation has been more profound, we can see the effects even more. Some of these communities had profound cultural devastation; genocide, dislocation and they are (still) trying to recover from that.

- an Aboriginal support person

Denial

Denial is when someone refuses to accept something. The person living with AIDS may be "in denial" that they are going to die. A partner may be "in denial" that anything is wrong.

It is important to respect that someone is in denial. People go into a state of denial because the emotional toll of accepting something is too much. Don't feel that you have to bring the

person out of their denial. Forcing someone to look at something that they are not ready to see is cruel and often times disastrous, as denial is their only coping method.

Denial can make difficult the work the care team is trying to do. If the person who is dying is “in denial”, they may refuse help that would make them feel better. If it is a partner, family member or friend, they may try to interfere with care.

If the person you are caring for is “in denial”, you may wonder how to proceed with certain decisions, for example a will. The following stories talk about ways that you can

Presumably there's a relationship built up between the team and the person who is in denial. It's communication in addressing something as you go along, "Have you considered....?" or "Is this something that you want to deal with?"

Always be very respectful. If you were to say, "Have you considered a living will?"

If the person is in denial, they could say, "No and leave me alone. I don't want to talk about it."

Okay. But, you've offered. That's all you can do. There can be no pressure. Bring it to their attention that if these things aren't done, it's their loved ones who are going to have to deal with it.

- an Aboriginal Elder

communicate with him about a will; yet still respect where he is at if he doesn't want to talk about it.

If the person “in denial” is a family member, partner or anyone else surrounding him, then there are ways or working with them to help make the environment less tense.

Denial is always built on fear. I would suggest that the care team leader respectfully address that fear and the root of it.

"Tell me." You've got to hear their story. Rather than them going on a position and saying, "No" and becoming an obstruction, speak to that. Behind it, there is some desire to do good for the person.

First of all, you've got to get them to tell their story, "What is it?"

I can see a scenario where someone who believes in the Natural Healing methods doesn't want the person to take chemical drugs. In a scenario like that, one of the things I always remind people is that a lot of drugs are coming from the natural world in some form. The whole thing is, if your focus is the spirit and Creator, you can take that drug and offer it to the Creator, and say, "Make this the agent of my healing or my comfort."

I think the leader would have to find a way to hear that person's story because in there, you're going to get clues as to why they're in that place of denial and what they believe they're accomplishing by putting a break in there somewhere.

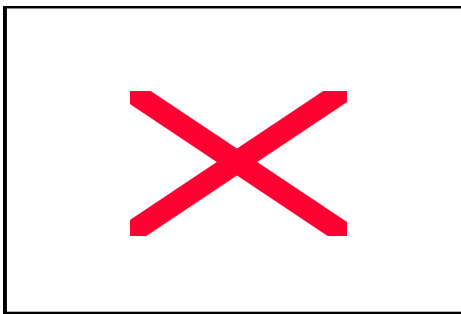
If the patient wanted the medication and somebody in the family didn't, I would like to find a way to remind the family member that this is the carriage of their own case. That we should allow that person to have some sense of carriage, of power, to deal with their own life.

- an Aboriginal Elder

CONFIDENTIALITY AND GOSSIP

Breaking confidentiality occurs when someone who has privileged information (for example, a care team member, health care worker) and they tell that information outside of the care team group.

Gossip occurs when someone who is not privileged to the information begins spreading things around. They could be saying cruel things based on fact, or things they made up, or a combination of the two.



Some of the following quotations talk about strategies for ensuring that confidentiality is kept within the members of the care team. There can be regular reminders in care team meetings. If you refresh everyone's memory, it could prevent the breaking of confidentiality before it even happens.

There are also suggestions on dealing with broken confidentiality. This may be with an individual or the entire care team. There are ideas on how to address broken confidentiality, even if you don't know who broke it.

Broken confidentiality and gossip is likely to upset her. She is already dealing with the effects of AIDS. If she hears of vicious talk about her going around, this is added stress that she doesn't need. On days where she may be well enough to go for a walk, seeing unwanted stares or having people come up and say stupid things is going to take away her opportunity to enjoy getting out of the house.

At the moment, it would seem that within small communities that a lot of talk goes on. Within large cities, especially in our Aboriginal community, there is still a lot of gossip and broken confidentiality. In larger communities, she may have a choice to stop accessing services where there is no confidentiality. This may mean going to non-Native service providers. In a smaller community, she may not have this choice available to her.

In any small community, it's going to get out sooner or later. I'm not saying, you know, send a flyer to every household saying what you got and what you need. For someone in palliative care, I don't think they would want everyone to know how many times they shit the bed that day or anything like that.

It's going to become common knowledge that this person is sick and that they're home and

they're dying. I think that is all people really need to know, unless they're going to help and want to know how they can help.

- an Aboriginal person living with HIV/AIDS

I have friends who had been through the mill working with multiple care providers at this place. My impression was that the majority of Aboriginal people living with HIV and AIDS no longer went to that place for care. One of the big issues was continuity of care. Other issues were homophobia and judgement about people's substance use and traditional healing.

Another issue is confidentiality. Because there are such small communities, it might be that your aunt works in the health field. Even in an urban area there are huge concerns about confidentiality and breaches of confidentiality.

- an Aboriginal support person

There's always going to be gossip and there's always going to be talk. That's just reality when it comes to confidentiality, it's going to get out because you're going to need help.

- an Aboriginal person living with HIV/AIDS

One of the ladies from here had gone to the doctors and she had just found out she was pregnant. Her doctor told her that somebody from the reserve has AIDS, so she should be tested. To me, obviously, something was happening there. Obviously all of the doctors must have found out. That's basically the only time I had any trouble with that.

- an Aboriginal person living with HIV/AIDS

I wonder if people realize the damage that is inflicted by gossip. Gossip affects the person who is dying and the team surrounding them. If that person who is gossiping came into the person's room and hit them, well, something would surely be done. Gossip is less obvious. There aren't any visible bruises, but the pain is very much the same.

My definition of confidentiality would be if you're talking in a room about the client, it should be staying in that room.

Gossip is like being a sniper. You fire off your mouth and then hide like a coward as the damage is being done. Some people enjoy planting little seeds that grow into nasty rumors.

If, however, some people want to go out to a restaurant afterwards and discuss what's going on with them, personally, "Oh, I'm getting really stressed out. You know, my partner's getting pissed off because I'm never home. My laundry's piling up."

If people that incessantly blab about others knew that their time and energy spent on gossip is a

I don't have any problem with that, as long as they do not discuss what other people have said in that room.

- an Aboriginal support person

reflection of how insecure they are, they might think twice about being so yappy. They are only gossiping because they're afraid the attention is going to turn to their own life, which they feel is useless and pathetic.

- an Aboriginal support person

Nashine Ginwenimawazawin

I know a lot of people are talking, but through my eyes, I see something totally different. To me, he's the most beautiful human being that I've ever met in my whole life. He's courageous and he cares about other people's feelings.

Someone asked me, "Why do you want to hang around him? Some day he's going to die and you're going to hurt all over again."

We almost stopped being friends because of all the small town crap, but we talked about it and came to the conclusion that no matter what, people will always talk.

- a support worker

If the client says to the care team person, "Oh, don't talk to the leader, but let's go to a bar and get drunk." That goes over certain boundaries. You're going to have to tell somebody about it.

If they want to tell you old stories about their families and they don't want anybody to know these secrets, that's fine. When it comes to specific care of that person, then, you're going to have to say something. If somebody's banging up needles, somebody needs to know. You have to set it straight, right from the beginning.

Other groups I've been involved in have just been, "It stays in this room and goes no further."

Sometimes it's been, "Well, it doesn't matter who you tell, just as long as the person who said it doesn't find out." That's not confidential at all!! It's wicked, wicked gossip!

That's another thing you have to look (at), "Are you able to handle it? Can you be confidential? Can you do that, have you done that in the past? Do you have experience with keeping your mouth shut?"

- an Aboriginal support person

I would ask that person to come in for a meeting. I would sit down with them and say, "Look, this and this is what happened, these are the facts. I'm not saying you either have or you haven't. What I'm doing is asking you directly if you have broken confidentiality."

If they say "Yes", explain to them they're just going to have to go and the reason being you can't have that risk out there. It's a major risk. You have to think about it this way. That's really hurting a person directly. You might as well go in there and rob them. That's what you're doing, you're robbing them of their thoughts and their words.

I wouldn't sit them down and preach to them, "Oh, you're such a bad person!" Just ask them, "Did you say it?"

If they did not say it, leave it at that. If there's another incident, bring it up again.

In the beginning of your training, let them know. This is what happens when you break confidentiality.

Whoever tells you they know confidentiality has been broken, ask them to write it down on paper. Get them to put their name to it. Have them fill out an incident report. Put your

Nashine Ginwenimawazawin

name to it so I'll have it documented. It would be much better to have it on paper. When you bring it up with the volunteer, you can say, "Look, I have this report, this is what I was told. What's your reply to this?"

Ask more than once, if they say "No", just make sure.

Then say, "Well, that's all I wanted to know, I'm really sorry if I put you under pressure. I needed to find out. Do you understand why? Okay, thanks, see you later."

- an Aboriginal support person

I would have the group come together in their weekly meeting. Express the concern, "This is what's been going on."

Express your disappointment with the group, "I really thought at the training we made boundaries clear and issues regarding confidentiality clear. You know what, guys, I'm going to go through it again with you."

Just go over it again. Ask them if they have any questions. "Maybe you were not clear by what I meant when I said confidentiality, that means, 'tell no one.'"

They may have forgotten. Maybe they think, "Well, it's been six months since I had my training. I don't think that's as strong of a point anymore." Stress it over, stress the basics.

- an Aboriginal support person

I have a kind of vague idea that within small communities, that it was a way of keeping certain people in line. You didn't behave in a certain way that was hurting your family or hurting the community or hurting your children or else people are going to talk about you.

In my own personal experience within my community it was very important to keep up appearances. I don't know whether that's an Aboriginal thing or whether that's just a small town thing. It was an "Everybody knows everybody else's business" type of attitude. I think that goes for most societies, not only Aboriginal people. There are certain standards of behaviour and it varies from community to community. I think there are certain limits to anti-social behaviour. I think that maintaining your family's dignity and pride is a good thing. We behave in a way that's respectful to your parents and your community. You don't put them in a bad light.

When you do the meetings, bring it up, "Confidentiality. Remember, everything in here is confidential."

It also kind of reassures people, "Okay, I can tell them that I had a crappy day with my client."

- an Aboriginal support person

No, gossiping has become almost like a pastime. It's more like a recreation or spectator sport. People use it, not so much to help the community or to maintain community standards of behaviour, but to oppress people. That's where vicious gossip, slandering people and maligning the reputation has gotten out of hand.

A lot of Native communities, because of internalized racism, if they perceive someone as succeeding or doing better than them, then they have to shoot holes in that whole theory. They say, "Oh yeah but, did you hear that they are this way." or "Well, maybe he went to

university and maybe he's got a good job but he's a fag." or "She's a director of this organization but you should have seen her at the bar. She was just falling down drunk."

It's like we're almost afraid to create role models. We talk about racism and yet we trot out these stereotypes about our own people. Calling them drunks. Calling them this and calling them that, "Well, you're not needed if you take a drink." or "You're not walking the right path if you're gay or you're a lesbian. You're out of balance, you're sick."

- an Aboriginal support person

CONFLICT

Conflict comes in many forms. There may be a family member or community member who has prejudices, whether it is AIDSphobia, homophobia, sexism or internalized racism. Family members may feel obligated to be present for the care team, yet still have many unresolved issues. The conflict could be between people on the care team or with people in the health care field.

Conflict can be over how to care for him. When each care team member wants to do the best possible thing for him, this can lead to conflict if they have different points of view on how this is done.

You need preparation around what to expect. If your partner doesn't respect your family members or vice versa. If your family members don't respect your partner, what is going to be done about that?

Especially if you're going to be dying at home. You know, the family's going to get into your home and stay in your home until you die, no matter what your partner says. You'll have to think those things through.

- an Aboriginal person living with HIV/AIDS

Often, someone really wants to help but their issues get in the way and they end up judging someone harshly. There are a lot of potential benefits if you can work with this person, instead of turning them away because of their attitude.

The person with an unresolved issue is probably someone very close to the person you are caring for. It may be their partner or a family member. If they are there as part of the care team, they are someone very important to the person who is dying. If they are treated badly, it is not going to improve his environment. More than that, it is not going to take care of the people that are in his life and are important to him. In having disputes with a member of his support system, it is taking away from him. It isn't honouring him.

Generally, people that do this kind of work are open people. If this person isn't, I wouldn't want them around.

The chief or council could do the advocacy and political work to make sure services are provided in a culturally sensitive manner.

- an Aboriginal person living with HIV/AIDS

Conflict Resolution

A care team provides many wonderful things to the person who is dying and the surrounding people. This is also a very emotional time. Naturally, some very strong emotions will also emerge. Occasionally, these emotions result in conflict. It may be when you are advocating for health services. Perhaps it is a dispute between the family and the partner. It could be between just about anyone around the person who is dying.

There are people who resolve conflict by taking a stance. They may become very threatened when they think someone is trying to impose something on them or they see something that they don't agree with. The stance they take may be a very firm one. It may be hard to keep your patience with the whole thing, yet there are still ways to work with that person.

Ideally, you would like to deal with each conflict as it comes up to avoid having it build into something that seems impossible to work out. Having conflict takes up a lot of energy. When that happens, there is less energy for yourself and the person you are caring for. When conflict gets out of control, gaps become formed between people. It turns attention and care away from the person that is dying.

In the event that you have to address an issue with someone, they may become very defensive, for example, missing shifts or coming in late. You can talk to the care team member in such a way that there won't be conflict. One of the following quotations talks about working with a care team member to address unreliability. A gentle way of communicating makes sure that the person isn't going to feel alienated for coming in late, yet is very straightforward about defining responsibility.

The following ideas and strategies provide constructive methods of approaching conflict resolution. They are a reminder that you are working with another human being. In the middle of conflict, it is quite easy to see someone as a threatening adversary instead of another human being.

Regardless of what the conflict is, if your approach to resolution includes honoring each other instead of challenging each other, the end result will be constructive. The importance of this is simply about caring and sharing. It also has to do with honouring each other, for the sake of the person that everyone is there to care for, the person that is dying.

That's what you would have to ask. You would have to hear their story. It's only in the telling of that story that you're going to have the chance to make a shift.

If two people go on position, nothing will happen. If you can ask directly, "Do you know what it is that scares you about this? Do you know what it is that turns you off?"

It's to try and get the person experiencing this negativity to find out what the source of it is. This is where the possibility of shift will happen, in being able to speak to that.

It may be something that takes time. That has to be recognized. It's not an instant "go" from the unconverted to the converted. Somewhere, there is the opportunity for education, but most of all finding out why this person is afraid.

Nashine Ginwenimawazawin

It's usually the result of something happening, some training that came out of the home. Plus, the stuff that comes out of the media.

A person who is putting an objection there, their normal condition of Spirit is to want to help that brother or sister. But, because of all the crap that's gone into the mental realm, of conditioning or hurt in a situation, forms a prejudice. In that prejudice is where the block is.

In order to find the prejudice, we have to hear the story. It's the only way we have to start to make a shift. By our questioning or by our exchanging something with that person.

The source of all pain and suffering is ignorance and prejudice. Prejudice, meaning to pre-judge. This is something I do every day. I will admit to prejudice. Only then can I deal with it.

Many people will say, "No, I'm not prejudiced." They think of that current definition of prejudice about racial prejudice and so on.

Prejudice is in all forms of our lives. We tend to take one experience and put it in a box and say, "This is the truth."

That's why the traditional teachings always left it incomplete because that's all we can know. You see, if I were truly following all traditions, I would be completely open to every moment instead of bringing my past history into it. But, I have to use some of my past history to make decisions.

We at least allow for a place where, **we don't know**. That's why I say in my workshops, "I don't know the truth. I can only tell you where I'm at, at this moment."

- an Aboriginal Elder

They're going to have to look at their own anger because the underlying fear is fear of death in some way. We face what I call many deaths every day. Life is full of little deaths. But we detach ourselves from it. Look at it and say, "This is what we have to do."

The person will have to look at their own fears. That's where the answer is. So, they will have to look and see how they feel about death.

I would extrapolate that if they're afraid of homosexuality, if they're afraid of disease, what was the ultimate part of that? It has to do with separation and death.

So they have to look at their own fear, their own conditioning about it. It's really interesting that even if a person had that kind of conditioning, yet they're putting themselves on a care team or being around a relative. So, you've got two forces there, the willingness to help, and then the fear that is getting in the way.

- an Aboriginal Elder

Always sit down and talk to the care team member. Try and get them away from the situation, i.e. don't start talking to them while they're at the clients' home.

Close the door to talk to them, "You know, I'm really concerned why you didn't show up. I really need two people there at the same time, it's impossible with one person. If you're

Nashine Ginwenimawazawin

having a hard time, call. Tell us you're going to be late, or if you're not coming at all. That way I can arrange something."

Set a time limit. "Call me the day before. Give me at least a day to try and find somebody else to fill that position."

- an Aboriginal support person

Lateral violence has to do with Native people within the workplace. It's about how we're jealous of one another. How we backstab. How we created such an environment that is so violent that we're coming up to a point where we're destroying one another.

We've been trained that way. It has to do with competition. In Native culture, we have no competition. We were never brought up with this idea, format and structure. Competition is something that's taught to us within these schools. You have to strive to be the best and that's what Native people are doing. We're going 150 percent overboard trying to prove this is good and it's got to be accepted.

In lateral violence, I teach that the reason people are working so hard and striving so hard is due to this competitiveness that's been put on us. It doesn't exist in our culture.

In our systems of belief, the Triangle, no one is in competition with anyone. Man isn't in competition with woman because we're totally different. We're female, they're male. They think different and we think different.

- an Aboriginal Elder

You get the person to tell you his story as to why he was in that position. Just taking a position never helps anything. You have to get that story out. The story is where the clues are, where the possibility of shift is.

I believe that each individual situation could be dealt with as it comes along. If a scenario came along, I would work with the person in a way that doesn't polarize the situation.

It's in his telling of his story, as to why he feels this way, that you have the possibility of solution. Without that story (in a non-threatening atmosphere), he's on a position.

At that point, instead of getting angry about it, you could say, "Well, tell me more about that. Tell me more about why you're feeling that way. What's that all about?"

You see, so in a non-threatening way, try to draw him out.

Of course, he could also be adamant about, "That's it." He might be the kind of personality.

Most people, if they're that strong in a position, they've got a big story. Who knows? Maybe he grew up in a family that had certain strong beliefs and that's how it came through over here. Without giving him a doorway to express himself, you've got no possibility of knowing where there might be some opportunity to shift his attitude.

Nashine Ginwenimawazawin

You get him to shift yourself by making it a place of agreement. In some way, assuring this person that you respect their point of view, "How would it be if we did it this way? How would it be for you if the family was able to do this?"

It depends on the content that's coming from the person. Quite often, when someone gets a chance to express their story (which obviously has a strong hold on them), even in the telling of it, they're softening up a bit because they're allowed to put it out.

There's a history there of hurt. Maybe, this is just one way of "getting back." It's in the process of finding out where that strong position came from. It's usually connected to a hurt of some kind. So, getting him to talk about the hurt, it could supply the opening that you're looking for.

So, it has to be that kind of skill. It's finding ways to getting the person to do what I call "clothes-line" their story. To put it out here. It's only when you do that, can you have some idea of where it's possible to work with it. If you close the door yourself then there's no possibility. Both people take position and stay on that.

It's putting a question to the person about their own situation, "How would it be for you if you were in the other shoes? If you're family was on the other side, how would you like to be honoured?"

How to honour him because both parties care for that guy. If he wants his relationship with the patient to be honoured, is it not possible to honour the patient's relationship with his family? Honouring one person in a good way also honours the other. It goes both ways.

It's making it available for someone to see that he would actually be taking care of his partner by honouring the family. It would be taking care of himself as well. It goes both ways.

Then again, it's our own hurt that teaches us from finding out the story. "I've been hurt by someone there. I don't want to give them a chance to tell their story. I've got my anger connected up to my old experience. It's my story!"

In this case, we have to at least get our story out of the way in order to make a shift with that person. I'm not saying it's simple or easy. It does give us a tool for any form of prejudice.

A lot of stuff is old, grown-out prejudices. It's worn-out ways of doing things or thinking about things. Over and over again. Western culture is one of the worse ones for that.

A lot of Indigenous cultures live close to the earth. They have that ability because they lived in immediacy. They had the ability to live right there and not pre-judge, because they were living in a natural world. They would keep that immediacy of response to something.

This is why we honour the animals. There was no way of putting the animals in a box. You couldn't know how the animal would act at this particular time. We could know if it was foaling season, the animal might act in a certain way. But we always allowed it respect for the moment.

Nashine Ginwenimawazawin

So, you live closer to that kind of time, rather than having a preconceived idea about something. That's why the Indigenous cultures who lived close to that land were able to stay much more open. They were dealing with the natural world.

But now, we've got everything enclosed in buildings and in little boxes. It takes us away from dealing in a spontaneous way. This is where prejudice comes in. Everything is guided by what happened before. We use that as a way to say, "Is this going to happen", and we respond to the moment with that.

But, it's the extra baggage that comes with it, "What if I caught this disease from this person?" Then, it presses the moralizing.

All that old baggage, "This person is a terrible person, they deserve it, blah, blah, blah."

That's all old prejudging. If they can learn the power of clear thinking, to put the situation in exactly what is happening here and now, "How can I respond to that situation?"

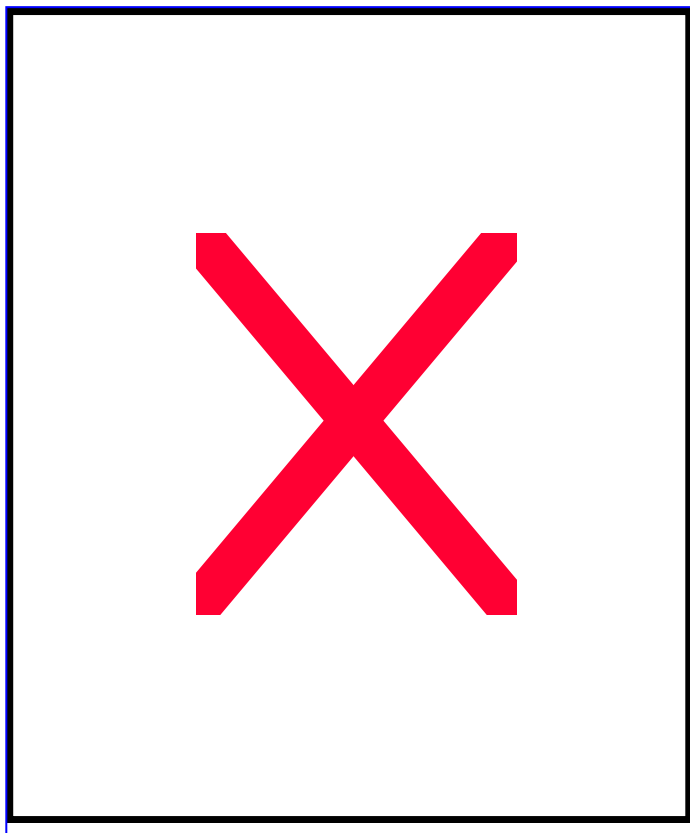
If that person who is having difficulty with the sick person, the here-and-now is, here is someone who is dying and in need of help. Period!

- an Aboriginal Elder

DEATH & DYING

Thinking or reading about death may bring up some very strong emotions for you. Be gentle with yourself. Only read as much of this section as you are comfortable with. You may find comfort and understanding that can support you when you are coping with the death of the person you are caring for.

Aboriginal people living with AIDS share what they think and feel about death and dying.



When I did want to start dealing with it, I had a really hard time with it. I know my little boy is a big part of my life. He knows when I'm upset; he knows when I'm crabby. I always think of him as my little counselor because he always makes me sit there and tell him what's the matter with me.

I sat down and I told him what I was feeling and why I was sitting there, crying. I told him someday, I would have to go to heaven. I told him I was sick.

He laid down on the bed and he looked at me and he said, "Well, I'll still be your little boy when you're up there."

Little things like that. That really helped me because then I knew that this little boy here was dealing with this also. So, we're

going to have to deal with it together. It's a part of our lives. It's good to see that he understands that.

- an Aboriginal person living with HIV/AIDS

Caregivers talk about the way the person they were caring for faced their death.

There are practical discussions, such as the decision to take the person off of treatment drugs. A doctor answers questions of the family and loved ones regarding the death, what happens to the body in the morgue and the completion of a death certificate.

Elders talk about the natural occurrence of peoples' ability to see spirits when they are dying. There is much discussion of the celebration and ceremony about dying.

Caregivers share their experience of watching the death of the people they had been caring for. Reading about this may answer some questions you have about the death of the person you are caring for and make things less traumatic for you.

The following stories can provide suggestions on what you can do when the person you are caring for is dying. Give her permission to die. Spend time with her after her death. Call the people on the care team list, family, friends, the Elder, to tell them she has died. When you are ready, phone the doctor. After the doctor has pronounced the death, do whatever preparations you want to do. You may want to wash the body, smudge, say prayers. When you are ready, phone the funeral home. Support each other, letting everyone grieve in whatever way they choose.

Get different perspectives on it, because the hell and damnation brings terror to you. We've all done stuff that makes us have the right to go to hell. For me, common sense says that's not true, because Creator, God, however you put it, is a loving person. Look what Creator gave us. Creator gave us light, eyesight, hearing, an ability to think and to reason. Creator gave us a beautiful voice. Look at the hands at the feet that we have. How could somebody that does something so beautiful hurt us? We hurt ourselves. Creator doesn't punish.

- an Aboriginal Elder

If your attitude toward death is part of your attitude toward life, it's so much easier. You don't have to fight the differences. It's a different battle if you want to fight, struggling with pain, as opposed to struggling with being afraid to die.

My son's friend, he's dying. He has no wife, no children. His family isn't there for him. He talks to my son. Some of the things he's talking to him about, he doesn't want my son to tell people. He's going downhill and he doesn't want to talk about death and dying.

One of the things that I've found, most people do not want to die. That's the one thing they need to talk about. It can be an around-the-clock thing when it's the end, so that you're satisfied. And then you, as a caregiver, can feel good, because you did what he wanted.

- an Aboriginal Elder

I've always been taught that Heaven is the place. As I was saying, I'm just learning. This is one of the things that I don't have a full understanding of. That would be one of my next steps, to learn about that. I know, I really struggle with the thought of even thinking about death.

When I do need to talk about it, it's very hard on the whole family. We know that some day, everybody's going to die. It's hard for us to even think about that.

We just sort of say, "Okay, well, we're her today and we'll look at today. We'll worry about tomorrow when the time comes."

- an Aboriginal person living with HIV/AIDS

Nashine Ginwenimawazawin

If you are raised with the belief of hell and damnation, you're a sinner and if you don't have the last rites, all of those things have made us afraid of death. I just tell them to talk about it. Talk to somebody.

I would also find somebody that has some knowledge about different ways. If you need to

We know the Creator put us here with a purpose. And that when we serve our purpose here, the Creator will call us and we will journey on from this life to the next life. And we understand, because of teachings, that when the Creator calls us, we do not know when that's going to be. But when our work is done, our work is done. And we must be able to accept that our work is done. And now we are going to be given that forever life, where all of our relatives have gone from the beginning of Creation. They're waiting for us over there.

- an Aboriginal Elder

talk to an Elder, a priest, a minister, a man, a woman or even a Buddhist. Get different perspectives on it, because the hell and damnation brings terror to you. We've all done stuff that makes us have the right to go to hell. For me, common sense says that that's not true, because Creator, God however you put it, is a loving person. Look what Creator gave us. Creator gave us light, eyesight, hearing, an ability to think and to reason. Creator gave us a beautiful voice. Look at the hands and the feet that we have. How could

somebody that does something so beautiful hurt us? We hurt ourselves. Creator doesn't punish.

It's like getting an understanding and not being afraid to go to those places that we've never been allowed to go and talk about. Death is taboo? Well, death isn't taboo for me. Hey, that's a place I want to go. All my relatives are there and some interesting people. Those ancestors that I talk about from a long time ago, maybe I'll get to meet them over there. It's such a different principle than the Christian church. Just talk about it and work it through.

Okay, well, we're here today and we'll look at today. We'll worry about tomorrow when the time comes.

- an Aboriginal person living with HIV/AIDS

I'm not afraid of dying. I'm sure if I have the attitude where I'm willing to look at death, then it's not a bad place to go. To me, this life is hell. So, that's where hell is. If you look at our people and look at the stuff that's going on in the world, how could anyplace be any worse? Burning in hell forever, that might be better.

We need to talk about it and explore it. Creator is not going to come and "get you" because you're asking questions and wondering. I have traveled over to the Spirit World several times. I know that's the place I want to go. It's beautiful! The depth of the music is so much deeper than we have it here.

If that's where your mind is about people, that's how you'll find them if you develop different attitudes about things, you can create your own. You're able to face yourself. God doesn't judge us. We choose. We make decisions.

- an Aboriginal Elder

He was pretty stoic about it. He never mentioned he was afraid, that it was on his mind or that he really concerned about it. I think he just lived his life day-to-day. He didn't think too much about the past and the future. He was more concerned about the day-to-day life. He

Nashine Ginwenimawazawin

was doing very, very well and when he died, he was only sick for two or three days. It went quickly. Up to that point he was fairly mobile and not in any real discomfort.

Emotionally, I'm sure he talked to his other friends. He was pretty open to everybody. I never really talked to him about that. We were close, but there were certain areas that we didn't get into. We didn't get really personal about emotions. I don't know why, that's just how our friendship was. But, like I said, he was pretty stoic about the whole thing.

- an Aboriginal support person

Once I was working in the summer in a town of about five thousand people. I was staying in the hospital because I was working with a family doctor who did most of the deliveries. My room was right next to the palliative care section of the hospital. It was a small community hospital and there were three palliative care beds. It was the busiest, most social part of the hospital. Everyone was coming with their extended family.

For me, coming from a city, I saw that as a very positive thing. Most people, they don't talk about death and they are afraid of it. I will always remember that as something very positive and important.

We as Aboriginal people, have a lot to share around death and dying with mainstream communities. It can be two way. It is not only learning about medical interventions and learning what to put into place in our communities. I find that the people who are dying are the biggest caregivers. When I am doing palliative care, it seems as if the people who are dying are taking care of their friends and families. I've even had them taking care of me. I never cease to be amazed by what I have learned and how people seem to cope with illness. That is why it makes it very rewarding as a caregiver. There maybe high burnout but it is a very special time and it is an honour to be with people at that time. They have a lot to teach us.

- an Aboriginal support person

We know the Creator put us here with a purpose. And that when we serve our purpose here, the Creator will call us and we will journey on from this life to the next life. And we understand, because of our teachings, that when the Creator calls us, we do not know when that's going to be. But when our work is done, our work is done. And we must be able to accept that our work is done. And now we are going to be given that forever life, where all of our relatives have gone from the beginning of Creation. They're waiting for us over there.

- an Aboriginal Elder

As soon as you're born you're getting ready to die. Explore those things. It's okay to die, it's natural and it's normal. Death is not the end, it is a new beginning. It's in a different realm. Allow your mind to let that happen, to explore. It's terrific stuff. When you walk into that light, that spirit light, there's unconditional love. Just walk into the light. A lot of people see the light, that spirit light, but you have to walk through it and walk into it. It's love. There are no ugly things there.

I've had several visions. That helped me as I began to open my mind. To get over the terror is to explore. There are a lot of books on the market now that will give different perspectives on death.

- an Aboriginal Elder

Nashine Ginwenimawazawin

At some point there must be a death certificate. When a person is in the final stage of their life, someone should contact the family doctor and let him or her know the situation. If a nurse is available, the nurse can communicate with the doctor about where they can be reached when the person dies. If there is no nurse, when you are in a palliative care situation, there are signs of when a person is approaching the end of their life. The doctor can be notified that the end is approaching and arrangements can be made on how to reach him or her.

In remote communities where there are no doctors, this is a different issue. The funeral home is then contacted to pick up the body.

- an Aboriginal support person

For our people that have experienced a tremendous amount of abuse and hardship throughout their lives, death may very well be another source of turmoil. Fear will come in. There are traditions that provide us with positive and hopeful answers about dying.

Elders and everybody else have to realize that someone who has only known pain will have a subconscious that won't let them absorb teachings and positive understanding about dying. Their subconscious only knows what it has been programmed for, which is fear and pain. If it has only ever known abuse, suddenly hearing about the wonderful spirit world isn't going to make everything peaceful and wonderful for them. They'll still be scared and will need a whole bunch of patience, love, reinforcement of teachings and understanding when they periodically reject the teachings.

- an Aboriginal support worker

Some of the old people and some of the others, they know when they are going. Sometimes when they are sick and in the hospital and are on drugs it's hard to see that. The drugs dull things that we look at as spiritual. Sometimes they would say, "Auntie Mary came this morning" and you know that Auntie Mary has been dead for a long time. It's the preparation in the going, they see spirits and they see that other realm. Sometimes they communicate.

It is in that time, too, that they are sleeping. They're sleeping a lot before they die. Their spirit is traveling and their spirit is communicating with spirit. They're in the spirit world already, but sometimes they don't remember.

They can see light, some will see angels, some will see their old people. It's just to acknowledge that, that it's real, they are there.

- an Aboriginal Elder

I was never really afraid of death. I think it's a continuation of our spiritual being. I feel there's another place that we will be in the future and our spirits will be closer to the spiritual powers that are above us all. They're around us and totally surround us. So, I really don't fear death. There's nothing to fear, basically. There's nothing to fear because it's a continuation of our life cycle.

- an Aboriginal person living with HIV/AIDS

Nashine Ginwenimawazawin

Spirituality is important, because at some point, we all wonder whether we have a soul or a spirit and what happens after death. It's always thought about.

- an Aboriginal person living with HIV/AIDS

If somebody died in the hospital and there weren't any family or friends there, I would usually try to come in to the hospital and call the family myself.

Sometimes it might be the nurse and certainly the nurses would play a role, in terms of keeping family posted, particularly if there has been a nurse more involved in the care. My decision would be to try to find the person who knows the family best. Some people feel better if they have talked to the physician and I usually feel it is my responsibility. I try to let them know if it has been a peaceful death and if I thought the person didn't suffer much. Sometimes they're interested in how a person died and I would try and explain that in lay terms.

In the hospital in the city, they would have an option of coming in to see the body in the hospital. Usually there is a lot of co-operation of the hospital staff, and we would be able to keep the body on the hospital ward where the person died, so that the person would have time to come in and see their loved one.

Usually what happens next is that the person would go to the morgue of the hospital. The next question around the time of death is whether or not to have a post-mortem exam, an autopsy or organ donation. I would try to sort out those issues in advance because it is not very nice to have to ask the person in mourning, right at the time of death.

- an Aboriginal support person

He had dementia and other things were getting worse, his incontinence and his diarrhea. He wasn't eating at all. He was just going down hill fast. I thought he was going to die. At this point, we hadn't discussed his dying. I was still hoping, and so was he, that we could get him to the hospital. That was the point where we realized that he's not going to get better.

That's when I had to raise the topic of going to Casey House. It was hard because we were coming to the realization that he was dying. I don't think he had even thought about it. If he had thought about it, he didn't know it would be so close. At that time, once you made a decision to go into Casey House you're going in there to die. That was hard. I spoke to his sister and she talked to a worker at Casey House. I think that's where the reality really struck him.

Things started to get a bit better. I guess I had been in denial about the whole thing. That's really what led up to me getting the ball rolling about getting him into a hospital and then into Casey House.

It was like, he was going down hill and there was no chance. I couldn't see him staying at home and getting better, or the quality of life being good up until his death.

His body cavity started to fill up with fluid. All they told me was it was a natural progression. His organs were starting to fail. He was unable to excrete phlegm, so it started to fill up and it affected his breathing and clogged his lungs.

Nashine Ginwenimawazawin

He was on oxygen. They turned him on his side, so everything moved. It shifted to one side and that freed up one lung so he could breathe more comfortably. Eventually, it filled up more. Basically, he suffocated on his body fluids.

His organs just started to shut down. He was so weak, he was having a hard time getting up to go to the bathroom. It took a couple of people to get him to the toilet.

Death is not the end, it is a new beginning. It's in a different realm. Allow your mind to let that stuff to happen, to explore. It's terrific stuff. When you walk into that light, that spirit light, there's unconditional love. Just walk into the light.....it's love. There are no ugly things there.

- an Aboriginal Elder

He was pretty out of it. I think at that point, they had turned up the morphine more. He was gasping for breath. He wasn't emotional or agitated. He was struggling to breathe. It took all of his energy, to breathe. His Adam's apple started to pop out because of the strain of each breath.

He was able to speak, but very little. He was exhausted. He was pretty out of it. He was okay in the morning and then he just started to spiral down,

within 48 hours. He went into a coma on the last day and died two or three days later.

He woke up just before he died. The nurse was talking to him. The nurse saw the signs and she told him, "You're going. You can go soon." I think that right after that is when he passed away.

- an Aboriginal support person

When somebody has died, we try to get the family down so they can be with the patient. Sometimes that's a bit tricky because Medical Services only funds one escort. There is sometimes some flexibility. Ideally, if someone is trapped in hospital and is too sick to return to the home community, then you try to have as much family there as possible.

When the person dies, if they wish, they can have a priest. There's not a lot of traditional healing that I saw happening. In the hospital, some community leader would come to be with the family and the person at the time of their death.

The person, after they die, usually gets flown home and then there's a wake or a funeral in the home community. Most of the communities have a fairly strong church thing happening at least in my area, so it would be in a church.

- an Aboriginal support person

One thing about death is it can powerfully concentrate the mind, to see things as they are. That is often the gift of dying people. They can see things very clearly because they don't have to be bothered with all that old prejudice and baggage.

One of the hardest things to do is to let go of roles, the roles we have played in this life. Family roles or the community roles. Some of us hang onto that, they hang onto those roles, "Oh, I've got to do this," when we're really ailing and failing and don't have the energy for that.

Nashine Ginwenimawazawin

It's a symbol to us, if we let go of that then, "There goes my identity already." And so, they hang on but then we get to the point where we say, "enough," and there's that acceptance. Then, they get very, very clear. All those roles that take our attention and take some of our clarity, they're not there anymore, "All I have to do is focus on this carriage, on this chapter of my life."

- an Aboriginal Elder

At night, you would sit there and the nurse would come and shoot extra morphine in. All you had to do was sit and visit. So, the last night I stayed with him we watched three old movies. Oh, jeez, I can't even remember the names of them now. You'd think you wouldn't forget that would you? I can see them. They were black and white.

Anyway, the night after that, he started to go into the coma. I got to spend a last alert night with him. That was really nice. When I came at 7 o'clock in the morning, I said to him, "I have to go home and have a shower and go to work."

He said, "Oh, don't leave." Your guilt starts. "Please don't leave." I had such a struggle.

He went into a coma on the Saturday. He woke up on Sunday and organized a picnic party. He said, "You bring the booze, I'm going to bring the steaks. So and so, you can serve the drinks. So and so, you can make the salad."

He wrote it all down on a piece of paper. It was like his last hurrah. And then, he went into a coma and he didn't, he never came out. He died three days later.

- a support person

I've heard about reincarnation. I don't care for the idea of heaven. I went to church and all that, growing up. I thought of God as this big guy sitting on his big, gold throne. He was sitting there and pointing down at people. It was like, "Thou shalt do this and thou shalt not do that. If you do, I'm going to throw this thunderbolt down on you."

That was my concept of God. And, I have a problem with that. I guess I didn't like the idea of this judgemental God or this heaven or hell.

When we die, one way it was described to me that I liked, is that there's a big fire in.....Happy hunting ground! Just kidding.

I believe we have choice. How you make your choices throughout your life determines how closely you sit to that fire. I like that one a lot better than, "You're either good or you're bad." I don't like the idea of judgement. Who gave them the right to judge anyway?

- an Aboriginal person living with HIV/AIDS

I think what I would like to have mentioned is that the dying process and natural death is taking on the responsibility of life. You were born. When you take on life as a child, that's a big responsibility. When it comes to death, having the respect and belief that comes with that.

Nashine Ginwenimawazawin

I knowing where you're going and believing that you're going somewhere. Believing in reincarnation and that you've completed this learning process of yourself. It's inevitable for all of us.

What's happened in Euro-thinking. I call western thinking, is that they've made businesses on all of this. Businesses on people dying. What happens is people become afraid of it. People are conditioned for this, that death is such a big fear. Whereas, Native people, we believed in a system that death is part of life and part of the process. Everyone is going to die.

- an Aboriginal Elder

Sometimes it gets to the point where the drugs that they are giving to cure. People get to the point where it's not working. The drugs that they are giving them are so toxic that they're making them sicker. There's just a certain point where the person is not going to get any better. They just take them off all of those drugs because it's damaging the body. Then, they usually put them on morphine. It helps them deal with the pain and keep them comfortable.

One client, she was out of it. She was out of it before that, but it just put her in a little deeper. She was completely peaceful when I saw her last.

One thing about death is it can powerfully concentrate the mind, to see things as they are. That is often the gift of dying people. They can see things very clearly because they don't have to be bothered with all that old prejudice and baggage.

- an Aboriginal Elder

She had a very peaceful death. She was surrounded by family. I think that matters because she knew she had made her peace with them. She was ready to go. It had been a really, really hard life for her.

- an Aboriginal support person

It's name-calling and the name branding they've put on this. They say, "Death is the end, death is black."

In Native culture, black is a significant colour of reincarnation. It doesn't mean it's the end. That's what is happening to you, even at night when you go to sleep. Your body's resting and you're sleeping and you're in that space.

A death can occur in many different ways. A death can occur for you when you're turning twenty-one. A death can occur for you when you get married. A death can occur when you get divorced. A death can come when you have a child. A death can occur when you've got to move.

You've got to take on models or different concepts of death and it's important to define it for Native people. Go back to our culture and our teachings of it. We have no fear of death, we have no fear at all. It's a process. We have an explanation of it, a given explanation of what I call Seven Stages of Soul. Seven different teachings that we learn while we're going through this life and the final stage in each stage is birth and death. In each stage that we live here, we're learning something different. We're learning about emotions, we're learning about addictions, we're learning about illnesses, we're learning about something in every different stage.

Even the stage for suicide, why there's suicide. Why babies, why children die. What's going on with that. It's all the process of learning.

- an Aboriginal Elder

FUNERALS

You may have the instructions for what he wants at his funeral. In the following stories, Aboriginal people living with AIDS talk about expressing what they want for their funerals.

Care team members talk about following and fulfilling the wishes that were left by the person who died. There are also instances of preparing a funeral when there are no instructions.

I think what was nice about it is that the whole community came together and observed the four-day journey to the spirit world.

Some funerals may be done in a Traditional manner while others prefer the funeral to be done through a church. Some ceremonies are a mix of Traditional and Christian influences and beliefs. There are many descriptions of what happened during a funeral. One talks about having children at the funeral and allowing them to be kids, like running around and playing.

I'm not too keen on the idea of a wake. I think I'd like to be cremated and have a portrait of myself when I was young and beautiful!

I wouldn't want a big crying thing. I'm hoping I can prepare the people around me as I die to be okay. Well, of course they're going to miss me because I'm just so loveable!

- an Aboriginal person living with HIV/AIDS

Sacred ceremonies may be done during the funeral. Celebrating, having fun, drumming, sacred medicines/prayer, telling stories about his life may all be a part of the funeral. It is a time to celebrate and honour his life.

The funeral was planned after he died. All I knew he wanted was to have it at the Metropolitan Community Church of Toronto (MCCT) because that was the church he belonged to.

He really liked church. He felt very comfortable. I think he used to go there with a friend of his that died of AIDS, long before he got diagnosed. He used to go there off and on. Once he got sick, he used to go there regularly. The chaplain started to work with him, he was a volunteer at Casey House so, he looked after the arrangements.

The rest of the care team was there, too. After he died, we went and arranged the funeral.

I got to see him the morning he died. He was in a coma. Then, I went home. They phoned one of the other care team members that was on the list. He phoned me. I think Casey House sets that up right away, when you go in there. Where does your body go when you die? Which funeral home is handling it?

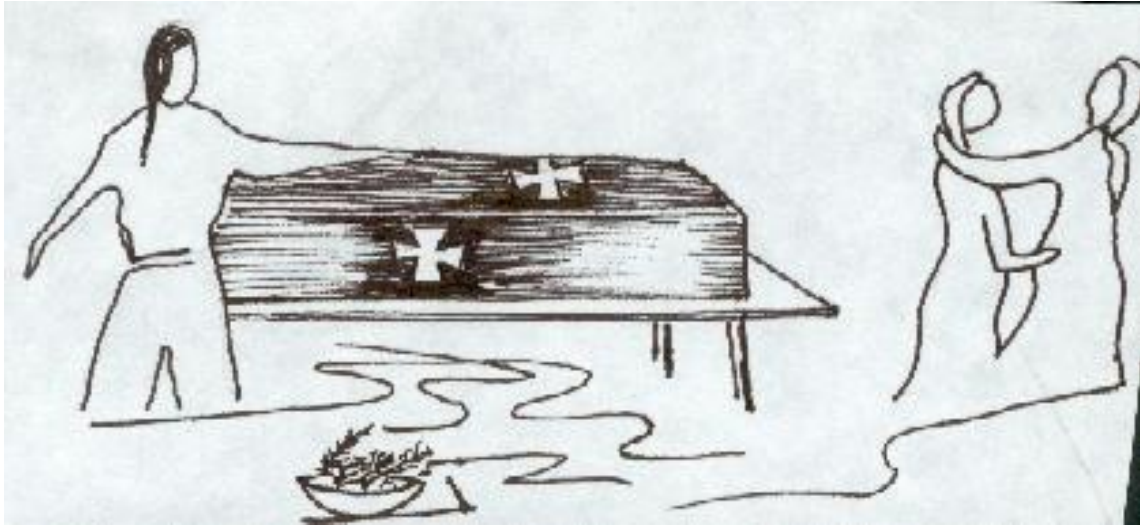
The funeral home comes to get the body. They already know ahead of time that the person is in the hospital. The day he dies, they get a call and they come pick up the body. It was all paid for, through his estate, his life insurance.

We all gathered, we went to Casey House. That's where we purified his body. We smudged him. We stayed with him for about 45 minutes.

Nashine Ginwenimawazawin

After, we sent his body to his hometown. We already had it prearranged which funeral home he would go to. His ashes were sent to Toronto for his memorial service.

The following week, the ceremony at MCCT took place. We met and arranged what we wanted to do and who was going to speak. We contacted his friends. We spoke to the MCCT and arranged what we wanted to say. I put the obituary in the paper.



At the MCCT it was Traditional mixed with Christian. They did a ceremony, a smudge. We had a picture of him. Two of the care team members did the Traditional part. They talked about grieving and where our spirit goes when you die. Then they did the Christian stuff. We invited people to come up and speak. Someone wrote a poem. We had a reception afterwards, in the back. People brought food.

His family took his ashes. I think they were going to take them up north somewhere, to the bush. It was some place near the water.

- an Aboriginal support person

Everyone says, "Oh, culture is lost, we lost our culture, I don't know anything about culture." That's not true. Everything we do in life, especially on the reserve, the way things happen, things have been happening that way for a long time. Maybe they're not rituals, but they certainly are customs. They're traditions. If somebody dies, the whole community puts aside their differences and they all come together to have a wake.

- an Aboriginal person living with HIV/AIDS

That's how I remember him. We would have to go upstairs and carry him to the bathroom. We would carry him downstairs to spend a couple of hours before he would go back to sleep. We would carry him out into the front porch.

I would stay there and I would jump in bed with him. We would sit there and cuddle and talk about what was going on in his life. We would discuss how he was feeling and what the drugs were doing to him and what kind of symptoms he was having and how his legs felt. We would just go on like this for hours and hours and hours.

Nashine Ginwenimawazawin

All his friends had a job to do for his funeral. We all had a part of the funeral. We were all good at different things and we all had our different parts to do for his funeral. He had asked us all this and he would always remind us of that.

"Okay, we know what this guy's doing and we know what this guy's doing and you know what your part is."

"Yes, I know what my part is, I'm supposed to do this and this and this."

My job basically was to ensure that his favourite music was playing at all times at the wake. And it was. And it played and it played. My partner and I had a catering company at that time. We were supposed to provide the food and supply the bar. He had set aside two thousand dollars from his money for his party afterwards.

Certain things happened at that time. I remember people walking around the casket and saying their good-byes to him. Everyone sat down and a song came on and it was kind of racy. There was a certain part of the tape where Bette Midler in *The Rose* started talking about, "Pleasing your man and staying home and washing them pots and pans."

Well, we all started to laugh because it almost sounded like he planned this part by himself.

Well, it was okay for the homosexual side, since the homosexuals were sitting on one side and the heterosexual hicks were sitting on the other side. So, we were all snickering at this point because it almost seemed like he did this, from wherever he was, on purpose. The heterosexual side didn't take to it very much. I think they thought it was kind of rude, by the looks on their faces. But we loved it.

- an Aboriginal person living with HIV/AIDS

We teach that there's a process in it, there's a ceremony. After that, for the people remaining, there's a grieving process in it. Grieving is part of that death. Grief comes from having to leave all of this, leaving life and what you've accomplished, leaving people behind you. So, if you're doing this with respect, belief and knowledge, it eliminates all this fear.

I've been in the room, like I said, many that have passed away and have died. Once they've come to the recognition that is inevitable and that's where they're going, that's the question they ask.

I worked with a young girl who was 14 and that's the question she had. She said, "The only thing I had to do in the last days that I lived was complete my studies in school because I wanted that for my parents."

I said, "Well, what do you want to do for yourself?"

She said, "I want to understand this illness and what it is. I want to understand how to die."

- an Aboriginal Elder

Nashine Ginwenimawazawin

When I did the ceremonies for those people at the crematory, I followed the method I knew of to send the spirit out and ask the Creator to be with them, so they're not afraid. There's a process, there's steps.

- an Aboriginal Elder

Death is the ultimate fear. Separation. Of course, we start off that way in being separated from our mothers. In a way, that's a form of dying, from the one environment and going into the other.

In our culture, it's taught that Native people who die in winter, they go out in the most sacred time, the most purest of time, that their spirit walks out in the snow, onto the Milky Way.

- an Aboriginal Elder

For the surviving person, because we are identifying so closely with somebody, it can be, in many ways, a wonderful time. In particular, when that person goes in a very peaceful and sort of natural way.

I can only speak from my own experience, but when I've been involved with someone who leaves like a feather, leaves in a very light and peaceful way, for me it's like being present at the birth in to the next plane. Physically, you're present at the birth of a baby. Only this time, the person's going into the Spirit World.

In many ways, it can be a celebration, particularly when that person is relieved of their pain and they are relieved of the earthly trappings. Then, they slip, literally, you see them slipping into the other world.

I had an old friend. Her mother came to see me. She, as usual, got to talking about spirit. I said something about God and she looked right at me, and this was a woman in her mid-eighties and she said, "I don't believe in God."

Okay, all right. We'll talk about something else."

Some time went by, and I had a call from the daughter saying, "Please come to the hospital. I think my mother's going."

So, I ran to the hospital and this woman was in the last part of her journey. She was breathing in the way that they do.

In the middle of it, I started to say some prayers, very special prayers. Healing prayers for this woman, asking that she be received in the Spirit World, whatever her beliefs and whoever her ancestors were. That everything go in a smooth way for her.

In the middle of the prayer, she opens her eyes and she looks right at me. They're perfectly clear. It was like, bang! And she closes her eyes. And then, her breathing goes from the harsh breathing that she's doing and it starts to get softer and softer and softer. And then, she dies.

It was so gentle, that passing, just watching. It was almost as if the other side started to claim her and the prayer was answered, that she go in a nice, soft, easy way. It's extremely powerful because of recognizing that we are in that place of watching someone go on to the Spirit World.

Nashine Ginwenimawazawin

When they are returning through the doorways, back into that other realm just leaving the shell back there. For me, it's always been a very, very moving experience. Very, very powerful. Not sad making. Just knowing what I believe to be happening. What we know.

In those cases where, like this, that particular woman said, "I don't believe in God." I believe that at some level, they are believing in Spirit. What if "God" is just a word we've made up? What does it mean? At some level there's recognition of our own spirit. When we get right down to the wire, that's what we have going for us. The other one is falling away, ceasing to function. So, we go into Spirit.

- an Aboriginal Elder

Death is a stage of life. It is an important event traditionally in the community, the family process and is kind of a spiritual milestone.

In my experience, in urban areas there are a lot of losses, dislocation, and identity issues. Any kind of important milestone is profound. In your community when you are dying, that would be a time when your house would be full of family. But for whatever the reason you are alone in the city, then that loss is something that caregivers need to be aware of.

Ideally in palliative care, you as a caregiver would be supporting a person around that and trying to re-establish some kind of community. In the city a lot of people say this is my city family, and that is why it is so important. Work to build up that kind of network and knowing.

Sometimes hospitals are not used to having lots of people around during important events like birth and death. Having people advocate at hospitals and saying that, "This is an important cultural event to have all this extended family and all these friends here." Whether it is birth family or family by choice.

If it is a palliative care hospital, there would be visiting hours but there would be more flexibility. The notion of extended families in our culture is something people aren't used to. In any kind of institution, it is kind of inconvenient to have twenty people standing around. They are not used to having kids there either. We should inform people about that. There is flexibility when people are dying. Family are called. You would coordinate that with the nurses' managers of that floor.

- an Aboriginal support person

Part of the traditional burial is that we never leave the body alone. A somber attitude doesn't have to be there. It can be a fun time. At a traditional funeral I was at, they give tobacco or cigarettes to somebody and said, "Tell us a story." Then the stories start. It would run down to the next person to tell us a story. Some of them are just hilarious. It's not always a sad time, it's celebrating this person's life.

Part of how I understand it is the songs and the prayers are alerting the relatives in the spirit world that this one is on their way. You alert those ones that are going to care for you on your way. It's a part of the process.

- an Aboriginal Elder

Nashine Ginwenimawazawin

The women would use plants and herbs to prepare the body. Along with prayers and doing a ceremony, they are preparing and cleaning the body. They make preparation with teas and singing songs. There's a different ceremony that they use.

Usually, in traditional culture of the Mohawks, they bring the body to the house because that's the final place where they lived and where they wanted to be. They lay out the body. They have the body there for three days.

At the end of three days, we say then, that the spirit is in three stages. The spirit is in the earth. The second is in the sky. The third stage is in the beyond.

So, for the first three days of death, they celebrate with the spirit. We prepare foods and people come to pay respects. People eat there with the spirit and the body.

The last evening of the second day, they prepare games and play games with the spirit. They have an empty chair there and they do these songs and games. They say, "Go on your journey. These are the last games and songs that we're going to do with you. Everyone here will be okay. Don't come back, don't look back.

Grief comes from having to leave all of this, leaving life and what you've accomplished, leaving people behind you. So, if you're doing this with respect, belief and knowledge, it eliminates all this fear.

- an Aboriginal Elder

When they go up into the second level, the sky level, that takes ten days altogether. We say that they're traveling around the earth, looking at the earth. They're paying their respects for the final days that they're here. They're looking at everything and appreciating it.

After ten days, they go into the beyond. It takes one year for that journey, from the sky to the beyond. Then, they're gone.

At this time when the spirit is leaving, what I teach is the stages of death. There's three stages of death.

What I seen in that space when I died, there were faces. Their eyes were closed and they had arms. Your spirit had to walk through this space. They touched you, briefly and you had to go through it.

In the next spiritual stage is our ancestors, where they are. I seen my Grandfather and my father and people in that stage.

Then there's the stage where we come to the spiritual state of the Creator. They say the spirit stays on the wing of the eagle. They say that's a state where we are, that we're flying constantly. When we decide to reincarnate, we'll come back and birth again.

There's these three stages of spirit that they need to learn and talk about. There's these three times that people who are living celebrate with this spirit.

At no time are we supposed to stop them. We have a given time of three days to celebrate with the spirit because we bring the body there. We have a given time of ten days that the spirit is in the sky, travelling. Then, the spirit passes to the beyond.

Nashine Ginwenimawazawin

There's a ceremony that women perform. We feed the entire communities and the earth. They sing a song and dance all evening. They're paying tribute to all the people that have passed on and died in communities and non-Native communities.

It's a time we go eat and spend time with the spirit. We call the spirit back. That's the only time that I know of that we interrupt that journey. They come back and they eat there with us in a mass community, a big feast. It's called a death feast.

That's how we do ceremony with it. We pay respect. So, there's individual, family and community.

The people with AIDS that I've worked with, I've been with them when they're dying. I ask them, "Tell me when you're going and what you're seeing."

So, I know these stages. Then, you understand. That gives us an understanding of what to teach and what to share and where we're going. It's part of the belief.

- an Aboriginal Elder

I look at the whole body and see if there are a lot of systems that are not working. For example, maybe their kidneys or lungs or heart is failing. Sometimes you can tell if there is a decreased level of consciousness and a slowing of breathing. There might be a weaker pulse.

It depends on what they are dying from. If they are dying of PCP pneumonia, there will be increasing shortness of breath. If they are dying from some infection in the brain, it would be more decreased level of consciousness and loss of control over their bodies.

It was so gentle, that passing, just watching. It was almost as if the other side started to claim her and the prayer was answered, that she go in a nice, soft, easy way. It's extremely powerful because of recognizing that we are in that place of watching someone go to the Spirit World.

- an Aboriginal Elder

When people are very weak they have trouble clearing the secretions from their lungs and airways. That is very disturbing to a family member because it sounds like they are choking. Sometimes there are medications that can dry up the secretions. We don't know if that is distressing to the person because usually they are very sleepy when they are that weak.

The power of the spirit is very strong. I have been mistaken when I thought someone would die. The balance is very precarious for a lot of people with advanced AIDS because they are fighting multiple problems. It depends on their approach too.

Some people fight right up until the end and they want everything done right up until the end. Some young men would come into emergency and I would ask if they wanted to be admitted to an acute medical ward and if they had thought about palliative care. They would want everything done. We respected those wishes and that was important to those individuals. If someone was fighting like that, something could happen and their death would be very sudden. They might have a heart attack or become overwhelmed by their infections.

Someone else might be dying over a longer period of time. You can never predict what death will be like or when it will happen. I don't ever like to say that a person is going to die or set a

Nashine Ginwenimawazawin

time frame on it, because invariably they will hang on for a couple of weeks. Sometimes I can tell people that in my impression, a person is dying and it helps people prepare. The individual or their family may want to know. I try to talk in terms of months or weeks or days but always saying I could be wrong. I would never get more specific. It gives people a chance to arrange things but it doesn't set limits. We have all heard stories of people who are going to die soon but didn't.

- an Aboriginal support person

The body will be left behind. It is the thing that has come from the Creator and is returning to the Creator. Whatever help we do to help the person return in a good way, in a peaceful way. We're looking after the Earthly part of the person. That is the part that is actually here, being left in this plane.

To have the Spirit go, that's why so many traditions have their ceremonies and way of comforting that person, to help them go in a good way. To rejoin the Spirit World, it's now made easy. It's now facilitated because there's someone there who cares. If there's any way a peaceful environment can be created or whether there's a ritual which can be done; a harmonious environment not an anxiety ridden environment.

Nothing is carved in stone because there's so much we don't know about the next plane. There are many, many traditions and cultures that have found ways to smooth that passage and to honor the person in all their aspects. Of course there are many traditions that feel that even when the breath stops, the person isn't actually completely dead. With some traditions, you don't move the body for four hours. This allows all the energies there to settle into a certain pattern.

I think, myself, that is a very good thing, particularly if that is a person's or that tradition's belief, is to leave that person there. Unfortunately in some places and cases, they start immediately dealing with the body, moving it around and stuff like that.

- an Aboriginal Elder

The truth is, we're all going to die. It's just a question of when. In my own family it's something that's near, the question of dying and talking about it. I think everyone needs to feel comfortable. Unfortunately, western society doesn't do this. It comes as a big surprise or a big negativity.

In my traditions, my parents always prayed about having a happy death. They prayed about it. They were conscious of it. They didn't just leave it until the end to think about it.

Being comfortable about the idea of death should be for everybody. To be comfortable, to discuss it because it is there. That's why in the traditions where, even now, in Native communities I'm involved with, a funeral is a huge celebration of community. Most of the employers in the area where I live have come to realize that when a Native person tells you, "I have to go to a funeral," pretty much it's at least a day and a half that they're gone. There are the preliminary rituals that happens the night before the funeral, there's all the preparation for the feast.

That whole day is an expression of community. "We are here to support you." It's in that that the healing is already being taken care of, in that activity around it. And, everybody comes

Nashine Ginwenimawazawin

out, from the smallest one to the oldest one. There's so many aspects of how they deal with it, that it's so wonderful. It's just so wonderful.

On the West Coast, there are speakers, people who speak from the family. Then, there are people who will speak on behalf of the family. This is also their way of passing on the history of the family. That speaking could last for hours. So, everyone has an opportunity to contribute to it.

They have a table set up and everyone, whether it's a quarter or five dollars, the whole community's going to give something to help that family to pay for the expenses.

The last evening of the second day, they prepare games and play games with the spirit. They have an empty chair there and they do these songs and games. They say, "Go on your journey. These are the last games and songs that we're going to do with you. Everyone here will be okay. Don't come back, don't look back."

- an Aboriginal Elder

It's so joining, it's so supportive it makes it really community-based. It's quite different from the western thing where you just sort of run in and run out and that's the end.

- an Aboriginal Elder

The night before he died he was on a lot of life support and they had removed him from the life support. He was having problems breathing. He

was awake, he was conscious and he knew what was going on.

So, seeing him lie there and seeing him suffering the way he did was not good, it was not a nice thing to see. You could see him struggling on every breath to stay alive. At this point, he knew. He was still coherent and he understood what was happening.

It was hard to go up to somebody who was still alive, barely, and watch him fight to stay alive, and tell him, "It's okay. You can let go. It's alright."

It was hard to see him with his eyes open, he couldn't speak, but you knew what he was thinking.

You knew he was thinking, "I'm scared and I don't want to go."

You did your best to stay strong and talk to him. So, that was pretty hard. We stayed most of the night and they called us early in the morning, at eight o'clock and they said, "You better come now."

We got there and he was just looking around the room. He was breathing very hard. You could see that he really was frightened. No matter what how much you caressed him or touched him, there just wasn't anything you could really do to comfort him because he didn't want to go.

But then, all of a sudden, he just looked up at everybody and the breathing stopped. And he just looked up at everyone.

Nashine Ginwenimawazawin

Then, we basically all took our turns spending a little bit of time with him alone. The nurses and the doctors still had not come in yet to check on him. They knew that it had happened but no one came in to bother us. We each took our turn talking to him.

I've grown up with a brother who believed that people's spirits hover over their bodies for an hour after death. I'm not really sure if I believe that or not, but I go along with it.

So, when I was talking to him. I was talking to him like he was looking down at himself, knowing he was leaving. I would talk to him like he was still in the room.

Was it hard on me? I'd say, watching the disease progress to the point where it did, was probably harder than watching his death and seeing his death. In fact, when he died, I was released, just like he was.

It meant that the work that went into it, all that care we had to give to him, not once did we ever complain about doing it. It was never a chore, it was never a hassle to help him, ever.

- an Aboriginal person living with HIV/AIDS

He had only wanted to be laid out for one night. They actually had it for two because of the people were coming in from so far away.

They had taken the bed out of his room and put the coffin in his bedroom. They left everything there as it was. They put chairs in for people to sit in.

In my traditions, my parents always prayed about having a happy death. They didn't just leave it until the end to think about it.

- an Aboriginal Elder

His sisters, like they were doing all the food upstairs. They had the Medicine Man come. They had the drummers.

On the day of the funeral the church was almost full. Someone spoke in Ojibway and someone in English. Someone read a poem that he wrote.

Then, they went to the funeral home, took his body away because he had to be cremated. We went to the graveyard. They get someone special to make a cross for them, a white cross with their name on it. That's like the grave marker, until they get a headstone.

They had an honour drum that played up at the cemetery. They called for a ceremony in a month to bury his ashes. I turned around and there were blue irises growing behind me. I went and picked them and put them near him.

His foster mother had made a quilt with his photo, you know how they do that with laser? A small hanging quilt, and she had blue irises put in the bottom of it.

Everybody had to introduce themselves. They had a brief service, everybody had to tell how they had met him and how he had impacted their life. It was really quite nice because it brought all these people together, people that were outside of the caregivers circle.

- a support person

We use the coffins. It depends how traditional they were. There are ones that would be buried in a regular way, but they would take with them maybe their pipe, if they have one.

Nashine Ginwenimawazawin

Somebody would put sweetgrass in. Some of them would take their shell, which is our story of Creation. They would take that in their hand, tobacco in the other hand. That would be one way. Some make tobacco ties. We would talk to the spirit. Some, we sing the good-bye songs on the day you bury them.

On the last morning, there's no crying, because we talk to them about "looking back." When they look back, they must not see people crying. When you ask that spirit to look back one more time before they make that journey before they leave, everybody needs to not cry.

When we bury them, they always use tobacco at traditional funerals. At different places, there are different ways. Some amongst the Cree or the Sioux, that's different. Some use chokecherries or poplar trees, and there are certain things done with them.

Some places use the drum. My understanding is we talk about them going to the west when they die. There is a certain way that they face the west. We use the drum and certain songs are sung and the spirit is sent.

When you talk about traditional, it's such a varied way. Some beliefs are total and some are incorporated with Christian beliefs. They use the drum and sometimes use the pipe. Sometimes it's done at sunrise and other times it doesn't matter.

The body is usually washed by the family, friends, usually a female. Some would go in their traditional, ceremonial dress and moccasins so they can walk a long way in spirit.

- an Aboriginal Elder

GRIEF

Grief is an individual thing. How you feel and express your grief is going to be completely different than anybody else. It does not have to be a bad and depressing process. A lot of pain and sadness may be there, along with remembering and honoring the life of the person who has died. It can be a time when you support each other. Don't be afraid to ask others to support you.

Your feelings toward grief may range from a peaceful, spiritual understanding to feeling sadness and a great loss. You may want to do prayers for the spirits. Elders can play a major role in the healing process and expression of your grief.

Ceremony may occur one year after the death, four years after the death. This provides an on-going designation for everybody to be together and to remember what her life meant.

I don't care what colour his skin is or if he's straight or gay or has AIDS. He'll always be someone special to me and I'm thankful for all that he's taught me about life.

- a support worker

Some people struggle with grief and may be emotionally stunned by her death. Feelings of relief may occur because she is no longer experiencing pain. Some people will want to keep busy in order to cope with their feelings.

Nashine Ginwenimawazawin

You may be reaching personal conclusions and an understanding about her life and death. Some of the following stories talk about the honor of being on the care team.

In the Aboriginal community, many people have experienced deaths before. Multiple grief is the layering of loss upon loss. There are suggestions for coping with multiple grief that include counseling and asking for help. Some people cannot cope with the grief and avoid it by drinking or taking drugs. They could even become destructive to other people because they can't face their overwhelming emotions.

Practicing Aboriginal spirituality can provide a lot of comfort and understanding about your loss. Recognize the strength you have for accomplishing the care team work. Look through new eyes to recognize and appreciate the gifts you have in your life right now, including the memory of her life.

There are many reasons why we have so much grief in our community. To me, grief is sadness over a loss. I think a lot of two-spirited people have experienced a lot of losses. A lot of us have lost our cultural identity. Whether it's through the residential schools or through Children's AID Society. One way or another, some two-spirited people have been removed from their community. They've become disenfranchised and have totally lost contact with their people. So, you really don't fit in anywhere. You don't fit into the white community, you don't fit into the Native community. So, there's always that tension there.

I also think we've lost our right to express our sexuality in a safe environment. There is no homophobia out there and we face it every day. We're bombarded with it in the media and from our own families and communities. Even from within the gay community because people internalize that homophobia because that's all they've heard all their life is how bad gay people are.

I also think we've experienced grief because of the AIDS epidemic and so many of us have had multiple losses. Many of our friends have died. I've lost so many friends. Probably a hundred people. You end up shutting down. You face so much grief and so much pain that you find ways to numb yourself. You turn away from it because I don't think anybody can deal with that much pain without having some way to cope with being bombarded with it all the time.

Some people from my generation have lost very few people. When I sit down with them and I start to tell them how many people I've lost, they're flabbergasted. They say, "How do you cope with that?"

I say, "You just do."

I think it's just human nature to want to survive. As Aboriginal people, we've survived so much. I think it's an instinct for us to cope with it.

There's grief around loss of culture, especially language. So many of us don't speak our languages anymore. I went through a period where I almost lost my language. I've been working on regaining the fluency I had when I was a kid.

Nashine Ginwenimawazawin

You can look at it from many different angles. I say, as a people, there's a lot of pain. As a community, we have a lot of pain.

- an Aboriginal support person

I find it's interconnected with all the other people I've lost, my parents, my friends, grandparents, cousins, brothers and sisters.

The Christian tradition, it really didn't have a lot of meaning for me, as far as dealing saying good-bye to people. It's not that I don't respect the church or the people. I never really truly understood the spiritual side until I got involved in Aboriginal spirituality. To me, it has a lot more meaning to my identity. I connect with it a lot stronger as an Aboriginal person.

- an Aboriginal support person

My view on death is that it is a normal part of life. I have no fear of death, whatsoever.

At my Mom's funeral, as a matter of fact, I was the only one who didn't cry. No one could understand why I didn't cry. I didn't feel like I was obliged to these people to tell them why. I felt they were crying.....their tears were for the wrong reasons because they weren't there to take care of her when she needed it. When she needed them, they weren't there.

So, all these tears, as far as I'm concerned were false and I wasn't crying. I didn't feel bad because I knew that all this was happening and I knew that she was going to a better place than where she was for the past four years, sitting in that wheelchair, deteriorating and not being able to speak about it and all that.

So, as far as death goes for me, I just see death as a stepping stone to something better. When I see a lot of people out there suffering the way they were with AIDS and then they die, I kind of rejoice for them. They've actually been set free to go onto a much better place. So, I'm quite comfortable with death.

- an Aboriginal person living with HIV/AIDS

I have seen some things that are not explained properly. In certain traditions, you're not allowed to grieve past a certain point. The baggage they put on it is, if you grieve, you will hold the spirit back. That is actually a belief that came from Europe. It got intermingled with the traditions. Who is the judge of that? Me, on the earthly plane or the Creator?

There was a little girl who had been adopted out when she was a little baby. Later on, her mother died. The foster mother brought the little girl to the funeral. The little girl started to weep. She was not weeping for the other person. What I was hearing was the primal wound. The first "giving away." The first hurt, way on back.

Now, she was saying good-bye to her mother, again. This time, for real. Her mother was gone. She was just rocking. There was a certain ceremony around the gravesite. After a time, they tell you "That's it."

The little girl couldn't stop. They came and they were just like, "Stop it. Stop it."

Nashine Ginwenimawazawin

Where is the spiritual principle? This little girl, she has no adult skills. All she knows is what she is feeling. I could hear beneath the first layer of grief was the first going away from her mother. I just had to pray. They carted her off. I wonder how deep a wound that is now.

You have to look at it from a spiritual point of view. The expression of grief is a normal thing. Somehow, this whole power thing got in the way. It becomes cloaked in the veil. I can't get my head around that.

In Ireland, there was a belief that it had something to do with holding back the spirit. It wasn't explained properly. I think it's a much better explanation if one can show the griever that the person who has gone on, who loved you, would not want you to distress yourself past a certain place. To me, it's a much more positive way of looking at this.

What the other one says is, "The power is in our hands to hold back the spirit."

I find that personally distasteful. I find it much more healthy to say, "That other person would not want you to distress yourself more than is necessary."

In some traditions, they have their one-year ceremony and then they have their four-year ceremony. That is so beautiful because it takes care of the needed grieving at the one-year. Four years later they may have the big potlatch.

The person knows, "Okay, there'll be an expression again of the grieving. So they are willing to be with that and go with that."

Some of the traditions are so healthy but then there's all these other ones. So, you really have to look with wise eyes and see what the human element or spiritual teachings are behind something. What is it purported to do?

When I read about that Irish tradition, it sounded just like it was translated in this other one.

So, just look for the spiritual principle behind the teaching. See what it does, whether it supports a good way to be.

If it doesn't, well.... this thing about the funeral for a person who has committed suicide, to me, that's supporting the person and the family. That's good enough for me.

- an Aboriginal Elder

I think the people involved in palliative care are in a wonderful place to be. Personally, it's something that's been on my agenda for a long time. I pursue it because it's like, as I say, being present at a birth. In a way, it's the same thing as being present at the birthing of that person into the next plane.

It's a place of honor. It's a sacred place. It's sacred work to do, to be with dying people. For me, it's something I've been attracted to ever since I was a little person. It's almost as if I have been involved in it, somewhere. I believe it's probably one of my ancestors. They had special people designated to be with dying people. They had the care of dying people. They would have the carriage of supporting that person with ceremony and different practices. It is so present in my mind that I do believe that it is a very strong tradition in my background

Nashine Ginwenimawazawin

because it has never come as a strange or negative place to be at all. It comes as a really honorable, sacred place to be to help someone through to this place. It's like you're a spiritual mid-wife, helping a person through that place into the next realm. For me, I think it's a very strong calling. If they could keep focused on that, I think they would be much more effective as a group.

- an Aboriginal Elder

I had multiple grief issues. Around that time my brother passed away and a bunch of my friends died of AIDS. I think emotionally, I just shut down after awhile. I just wasn't reacting. I still think I'm working through a lot of my grief issues. The grief course I took was one place where I dealt with some of them. But still, it's a process.

I think in the Native community and the gay community death is so much a part of our lives. It's all around us. People are constantly dying. Tragedies are happening all the time. You learn to cope with it and it's ongoing.

This past year, I went into counseling to deal with some of my issues. I would say, get counseling and don't try to tough it out. Don't think that time will heal. Don't think you have to be strong because these are your emotions. Don't try to numb yourself or forget about it. You have to deal with these things because it has a big impact on your life. A lot of people spend so much time trying to avoid their emotions and trying to avoid their grief. It always ends up backfiring on them. It makes it worse.

Especially in the gay community, you see people numbing themselves with a lot of drinking, drugging and partying. In the Native communities, you see a lot of suicide and self-destructive behaviours. You have to deal with your grief constructively.

I think spirituality is very important, too. If we don't honor that part of who we are as a people, we're missing out on a part of our existence and our time in the physical world. Whether you do it privately or in a Sweatlodge or with other people, work on that, finding your spiritual path. It's a real source of strength for me.

It's not to say that I'm constantly smudging or praying. I live my life, day-to-day. Every day I pray. Every day I think about my life as a spiritual person. The longer I live, the more I realize my spiritual side is much larger and much more important than the physical part.

I think a lot of people are so focused on what they consider the real world that they ignore the spiritual one. These are my beliefs. I've grown to understand that. It's something that's taken me many years to figure out. Once I got to that point, it changed my outlook on life.

It also helps me deal with the issues around other people that have left this world and gone onto the spiritual world. It makes me understand that their path doesn't end at the graveyard or on a hospital bed. It's understanding that their spirit does go on.

- an Aboriginal support person

I'll never, ever forget. I'll never forget him and I'll never forget his exit. I'll never forget it. Every once in a while, I feel him, his presence. A lot of times he comes during the night and he wakes me and I can feel him hovering around me. He talks to me, I'm sure. Many times I've felt him talk to me.

Nashine Ginwenimawazawin

He was a practical joker. So, a lot of times, he will do something to me in my sleep and wake me up and I'll know he's there. He still comes around every once in a while. Not as much as before, but he's still there.

I'll always remember how brave he was first of all, to go through that. The planning he did. I'll always remember that. It's in my memory and it will always be there. Always.

- an Aboriginal person living with HIV/AIDS

You may have emotions that don't make a lot of sense to you. They may conflict with each other because they are coming from a variety of cultures and beliefs. You could switch from a happy emotion to overwhelming sadness in a flash. You could be driving and suddenly be overtaken by sadness. This is a time to be careful because accidents can happen when you are dealing with grief.

The mainstream has some weird ideas around grief. Television portrays guys standing around with a blank look on their faces while women cry uncontrollably. Everybody dresses up in black and walks around like zombies. It's not your funeral, you don't have to act like you're dead.

A friend of mine told me about the death of her aunt, who died in her late eighties. A bunch of family members drove up to her house and loaded their cars with her furniture, her clothes, her dishes. They even took her laundry that had been put in bags for charity. They went through everything. Is that a way to honour her and her memory? What a cold and bizarre way to look at things. Maybe greed and the obsession with material goods was an easier way for them. I have heard of this happening in Aboriginal country, too. That's so sad. It's such a non-personal way to look at the loss of a human being, someone the Creator sent here for a very valuable and special time.

Our traditions are great for providing guidance on grieving and feeling emotions and supporting each other. Some of us are just learning to do it again and others are teaching us. It's a good place to be.

- an Aboriginal support person

I guess the most profound thing is he allowed me the opportunity to be his friend, to be a caregiver, to be his student, to learn how to look after people dying of AIDS. He was the first to die in this community, on this island, of AIDS and he gave me the knowledge so that I can be better able, more prepared to look after those that follow.

This has given me the knowledge and experience to help other people that are dying. I'm not shy to say, "I'm honoured to be your friend and I love you."

I'm not shy to go beyond my professional status into the personal realm. I have become a family member since he died. He gave me the courage to go beyond that and not be afraid of the repercussions from other people.

- a support person

Nashine Ginwenimawazawin

I think the big lesson for me was in one way, I felt like it was an honour that I was there. I felt a lot of pride for being there for that person. I never thought I could do that sort of thing. I realized how strong I really am because I was put into a crisis situation. That gave me a lot of confidence in myself. It made me realize my own strength and resourcefulness.

I really learned the importance of spirituality. It gave me real insight into my life and the gifts that I've received, every day. I took them for granted, like my health, my friends, my family. We don't thank the Creator enough for those things, we just take them for granted. It gave me insight into what I have in my life, rather than complain about what I don't have. It made me more appreciative of the gifts that I receive every day.

- an Aboriginal support person

There is a lot of blaming. A lot of people are looking for someone to take the wrath for this disease, for AIDS and all their problems.

If a group of people stand and say, "Well, we want to do something." We don't get any recognition for the work that we're doing. All we get is criticism or told we're not doing enough. A lot of that goes on in our community. You'll find people attacking their own community members because they feel that we're not doing enough and they feel someone has to take the blame.

To me, that is the most bizarre behaviour. It's also one of the most painful. It's attacking the people who are trying to address it and make changes. It's like nothing is ever good enough.

- an Aboriginal support person

In an odd sense, I think the more you suffer, the more the good times are enjoyed. As a people, we relish the good times more than the average person does. I know when good things happen to me, I get real "over the moon" about it because it's something that is a gift from the Creator. I think it's a process of learning to appreciate the gifts that you do receive. Everything is temporary, everything is on loan to you.

We learn how to be more resourceful. It's bonded our community. In a crisis, people tend to come together. We're facing such a terrible crisis with AIDS, it's kind of the glue that binds the community together. I don't know if I would ever have met some people if 2-Spirited People (of the 1st Nations) hadn't come together. I think in many way it's brought me closer to my own community.

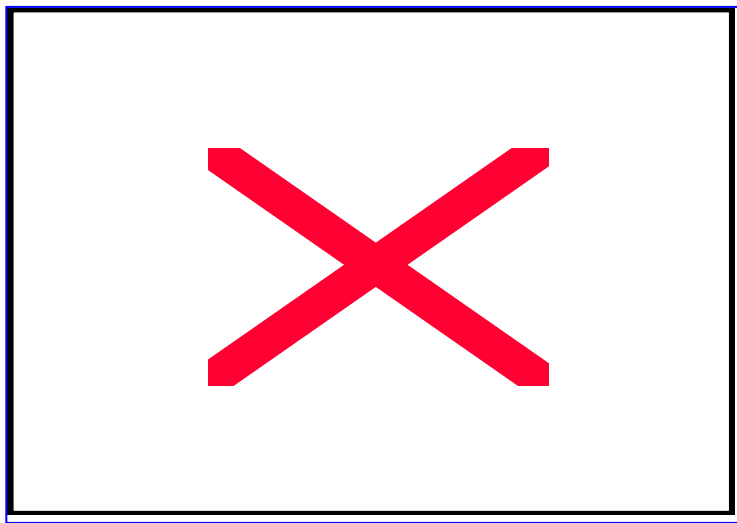
- an Aboriginal support person

CARE FOR THE CAREGIVER

SUPPORTING YOURSELF

Taking care of yourself while you are on a care team is different for every person. Take stock of what you are doing now to take care of yourself. Is your self-care plan enough? Can you handle this demanding work?

An Elder once told a group of counsellors that were being trained, “You can’t help someone past the point you’re at.” That basically means, if you’re a mess emotionally, how in the world do you expect to be able to support and care for someone else?



If you want to be able to provide constant care, you can’t do this without any emotional fuel. If you run out of fuel and you don’t take the time to energize yourself, you won’t have anything to give.

Some of the people in the following stories regret not having found outside help when they needed it. The cost of not getting support can be depression, frustration and anger.

Places you can go for help include: your care team meetings, Elders, counsellors, therapists, doctors, social workers, psychiatrists and psychologists. Involvement in spirituality can help, phoning some of the places listed in the resources section may be a great place to vent.

These are some ideas on how to care for yourself. Some may be new ideas you can use, others may not be for you. The powerful thing about taking steps to care for yourself is that you have options about where you want to seek support that is meaningful for you.

You have to take care of yourself. You aren’t going to be any use to anybody if you’re a basket-case and you’re trying to hold it all together. Don’t try to be superwoman!

- an Aboriginal support person

At the present time, I’m going for counselling and seeing my doctor on a regular basis. Since I can’t talk to my family about him, I felt I needed to talk to someone else. I’m also reading anything I can get my hands on about HIV/AIDS.

- a support person

Nashine Ginwenimawazawin

Well, I would like to say that if I had to do it all over again, I would be more aggressive. I would look after myself better. I think it's very important when you're involved in that kind of stressful situation, that you get help. It can be through Native means, going to see an Elder or somebody you trust, but don't go it alone. Get help.

Keep looking. If the first attempt doesn't work, don't say, "Oh well. The hell with that, they're no help." Somewhere out there, there is somebody out there who can help you.

If you feel more comfortable with the western perspective, seek counselling or go see a therapist, a social worker. Someone who has experience with grief and high-stress situations. Don't feel ashamed if you have to take tranquilizers or any kind of medication. They were put here on earth for a reason. They're medicines, too.

If you feel more comfortable smudging, do it. You don't have to suffer needlessly. You have to take care of yourself. You aren't going to be any use to anybody if you're a basket case and you're trying to hold it all together. Don't try to be superwoman!

- an Aboriginal support person

I think, just live your life. There's always struggles, there's always stuff to learn, there's always going to be hardship. As soon as things start going good, bam, something else comes along and knocks you down again. It's like the "Big Cheese" up there is giggling as He's watching you stagger around.

- an Aboriginal person living with HIV/AIDS

there's always going to be hardship. As soon as things start going good, bam, something else comes along and knocks you down again. It's like the "Big Cheese" up there is giggling as He's watching you stagger around.

Or She. I use the word "He" because that's how I was taught all the time. I don't know what this God or Creator concept is, it sounds very masculine. I think it's like two-spirited people, it doesn't matter. It's both but neither.

- an Aboriginal person living with HIV/AIDS

I suggested they should be meeting once a week because he was in such high need at the time. I also suggested there needs to be two or three full days where they aren't at the house. They're not going to visit, they're just away from that whole scene.

One of the relatives was there all the time. He quit his daytime activities. He was living there. I told him, "You need to go home. Go home, now."

The way it worked out was they did it in teams. There were three people on one team and three people on the other team. One would go all week and they would do intensive shifts, like three days in a row, all morning shifts. Then, they would be off the next week. They wouldn't go to the house at all, unless it was just to visit.

Nashine Ginwenimawazawin

You have that time off and it's just yours. You don't have to be there all the time.

- an Aboriginal support person

The people that were on it, they were very supportive of me. I don't think I could have gotten through it without their support. I felt very alone, afraid and kind of in a panic. They gave me some respite from the whole thing.

When I came to the decision that I was going to have to make some arrangements for him to go into a hospice or to a hospital, it was very difficult. They helped me make that decision. I talked it over with them. I don't know if I could have made the decision without their support because you go through all sorts of emotions.

Guilt is the main one. Grief. There is a lot of pain because you're realizing this person is dying. A lot of anger, as well. Anger at people, "Well, why aren't more people helping me out?"

I was also angry at him because I felt that he was putting too much pressure on me. I was feeling really kind of trapped in the situation. It was like a vicious cycle. I was angry, then guilty, then angry, then guilty.

I was quite depressed during that time. Prior to that, in the previous two years, I had lost about five or six friends to the disease. The grand finality of it all was when he got sick. I was still dealing with unresolved grief from my friends who had died just recently. It was really an emotional upheaval.

The other people were really supportive and they realized what I was going through. In the same sense, they were going through the same thing I was because we were right in the midst of this horrible crisis.

- an Aboriginal support person

He was impatient. It was nothing really specific. I was used to it. He was always like that, anyway. I tried to shrug it off.

Now in retrospect, I think because I was under such enormous pressure, I should have sought out counselling. I should have been seeing a psychologist and been looking after myself at the same time.

It did eventually get to me, the strain. I think I could have coped with his illness better if I had been able to go see a therapist or a counsellor, so that I could vent. It was an extremely emotional time.

I think if you're prone to emotional strain and depression that you have to be very careful. Especially when you're in a situation like that because it could trigger a number of things. Feeling suicidal, feeling abusive towards the person you're looking after, all sorts of things if you're not in the right state of mind. So, you have to be careful.

Fortunately, none of those things happened to me. I was able to arrange quite quickly for him to be put in the hospital, when it got to be too much for me.

He had a couple of hospital stays during that period, where he got really sick. The doctors admitted him to hospital. That gave me a bit of respite.

- an Aboriginal support person

“I’M NOT DOING ENOUGH!”

There are times when you are caring for a person that is dying, and a very strong feeling of helplessness can come up. What can you do to care for yourself, during a time when you feel as though everything is out of control? Perhaps you want to be able to do a lot more, put in longer hours, cook all the meals, get everything done, because this person, who you love, is dying.

Anyone could feel this. A partner, a biological or chosen family member, a care team member or a health professional.

One Elder has some words about very active people who want to do everything, because their family member is dying. They can feel a very heavy weight because that person, who they care for so much, is dying. They want to do everything possible and feel enormous stress because they feel that not enough gets done.

Your care team is going to have to exert a lot of energy in order to make sure she is going to get the quality of care she needs. This is why it is so important for care team members to remember that they have their own life issues and not to put them on a backburner. It is also important for care team members to seek out help, so that they will be balanced and able to provide the strength for her during their care team shift.

It’s misguided concern. You see, part of the prevalent, Western thinking is, “If I care about you, I’m going to express that in worry.”

Obviously the saying is, “If you’re going to worry, worry good. Don’t worry bad.” If you care about someone and you’re sending them all these “worry” thoughts, vibrationally, that’s what they’re getting.

The whole family may be going around and around and around, “I’ve got to help them, I’ve got to help them, I’ve got to do this.” They’re pushing the pressure on him.

What if you just did a Circle with the other relatives and say, “Look, let’s calm down. Let’s pray about this.”

The person said, “I’m not religious.”

I said, “Okay, I’m not talking about religion, I’m talking about getting together and maybe asking God to bless your Circle, so you can support them.”

He said, “Well, I don’t believe in God.”

“Okay, do you believe in good?”

"Yeah."

"Okay, what if you asked the power of good to be with you and the other relatives? Then you can provide the environment for the relative that you care so much about. Can you see that your worry is pushing him, putting more pressure on him? Do you think that your worry is the extent of your concern? Allow the person to be free and supported by your love in a good way.

It's one of the hardest lessons. As a parent, I have a method of dealing with that. Once I start to think about my kids, and my thoughts start going in that direction, three words: don't go there.

Don't go there because that worry thought is the last energy that I want to send them. I want to send them a thought of ability. Capability. Okay-ness.

In truth, in spirit, they're okay. No matter what troubles they're going through, they're still going to go on their spirit path. Who knows what their spirit path is?

The thing is, people who are suffering a terminal illness, we don't know what their spirit path has decided for them to go. Even AIDS, that may be a path. Over and over again, you hear people who say, "This disease has been a gift. This disease has brought me a gift of awareness."

So therefore, their spirit path has found it necessary to give them that gift of imbalance and illness in order to be whole to themselves. So, we don't know what someone's spirit path is.

It's that ability to let them be. Do all you can to surround them with care and concern, yet to leave them be. Hold them able.

- an Aboriginal Elder

BURN-OUT

The emotions that may come up when you are caring for someone who is dying can be a lot to handle by yourself. It could be very obvious to you that you need some support. Often, however, burnout creeps up on you. You may not be aware of the effect the strong emotions and the long schedules are having on you. Before you know it, you're burned out.

Burnout can result in people quitting care teams. It can result in people hating the work they are doing, and this is always obvious to the one receiving the care.

Burnout is when the fuel or energy that you use to do your care team work runs out.

It's that ability to let them be. Do all you can to surround them with care and concern, yet to leave them be. Hold them able.

- an Aboriginal Elder

When your care team is small and there is so much work to do, it may be very hard to say "no" to taking that extra shift when there is no one else to take it. You may feel you have to take all those shifts to care for him, because there isn't anyone else who can.

Nashine Ginwenimawazawin

If this is contributing to your burnout, it isn't going to help him. If he is getting sicker, it is important that you be balanced for him. If you are exhausted, you may not be available emotionally for him, during the time when his needs are the highest.

You may have to ask other people for help. If the care team as a whole is becoming burned-out, you may have to ask health care professionals to increase their services. If you are working with volunteers from agencies or organizations, you may have to ask them to send in more volunteers for help. Approaching other places for volunteers may help for example, a respite organization may have programs where they can care for her while the care team can re-fuel itself.

One Elder speaks about a way of approaching your work, so that you can do it without becoming consumed by the emotions that come up. This approach can help you during your work and the Elder also suggests taking the time to build up your energy, so that you are able to do the work when necessary.

The best way to prevent burnout is to take care of yourself in a holistic manner. Think of the Medicine Wheel, and the four areas of your being. Are you looking after your physical, mental, emotional and spiritual needs? Are there support people to help you work through these things? When your care team is meeting, can the topic of burnout come up every now and then, to remind people that they have to take care of themselves?

Their heart's in the right place. They don't have the equipment, emotionally, to deal with all this stuff that comes up.

-an Aboriginal support person

When they come on to the care team, they need some workshops and they need some information. "These are the signs. You're not going to help you or anybody else if you get burned out. Here is what burnout is and here's what it looks like. Here's how you can tell that it's coming on from doing too much and too much stress. You need to work to set up a self-care plan in place for yourself when you're on a care team, so you can handle it. We're not magicians, we're not perfect, we're just human beings.

Something needs to be put in place when they come onto care teams, perhaps a requirement if possible. Every once in a while they have to be anyway.

-an Aboriginal Elder

I think that people need to have worked a little bit on their shit (emotional issues). At least have supports outside of the group, like, seeing a counsellor, seeing a therapist, group-work.

Even if you do caregiver support, you're entrenched in the group. You're right back at that place. You need outside stuff.

You need to have done your work. At least attempt to work on your own personal issues before you come in.

For a lot of people, stuff like this is a way to make themselves feel better about themselves. It's a self-esteem thing. Once they get there, they realize that they're totally overwhelmed and unprepared. Then, they quit.

- an Aboriginal support person

Signs of Burn-out:

- ◆ Constantly feeling tired. The more tired, the more burned-out you are.
- ◆ Working longer and longer shifts. This could progress to missing more and more shifts.
- ◆ Feeling useless, unless working on a shift.
- ◆ Feeling increasingly pressured by normal demands, family, friend, etc.
- ◆ Feeling angry or emotional about the person you are caring for and the care team.
- ◆ Feeling deadened or apathetic about the person you are caring for and the care team.
- ◆ Getting headaches and problems with sleep.

Burnout is when you have given all that you've got and just can't give anymore. I think at that point, what I did was ask other care team members to take over where I couldn't.

I had a feeling of helplessness, hopelessness and fatigue. Physical and mental fatigue. You know, you have to rest at some point.

I think that's where the other care team members or friends around me noticed a change in my abilities to cook or clean. This was because all my efforts were going towards changing the bed or reading a book to him. When I stopped taking care of myself and all my duties were on the other person, I think they could easily see that not only did I need help, but the person receiving care needs help as well.

- an Aboriginal person living with HIV/AIDS

There is a lot involved in taking care of someone who is dying, someone who is in a palliative situation. It's important to tell yourself that you can't handle it all because it's just impossible to handle it all. You have to rely on other people, whether it's nurses or someone to help you clean your house.

It's knowing your own boundaries. Talking about it and doing it are two different things. I would say 90% of the time people overstep their boundaries and end up with burnout or fatigue. They ended up needing care themselves because at some point it's going to take a toll on them physically and mentally. It might not happen right then and there. It might be hours after the death, days after the death or weeks after the death.

It's dealing with someone who is sick. Dying is a traumatic event. It changes anybody's perspective for the rest of their life.

Now, whether they can handle that or not, it's really up to them. It's not a moral judgement if someone can't handle it. Some people can't handle being around sick people because it

Nashine Ginwenimawazawin

brings up their own emotional issues. I think you sort of have to know yourself and just do what you can.

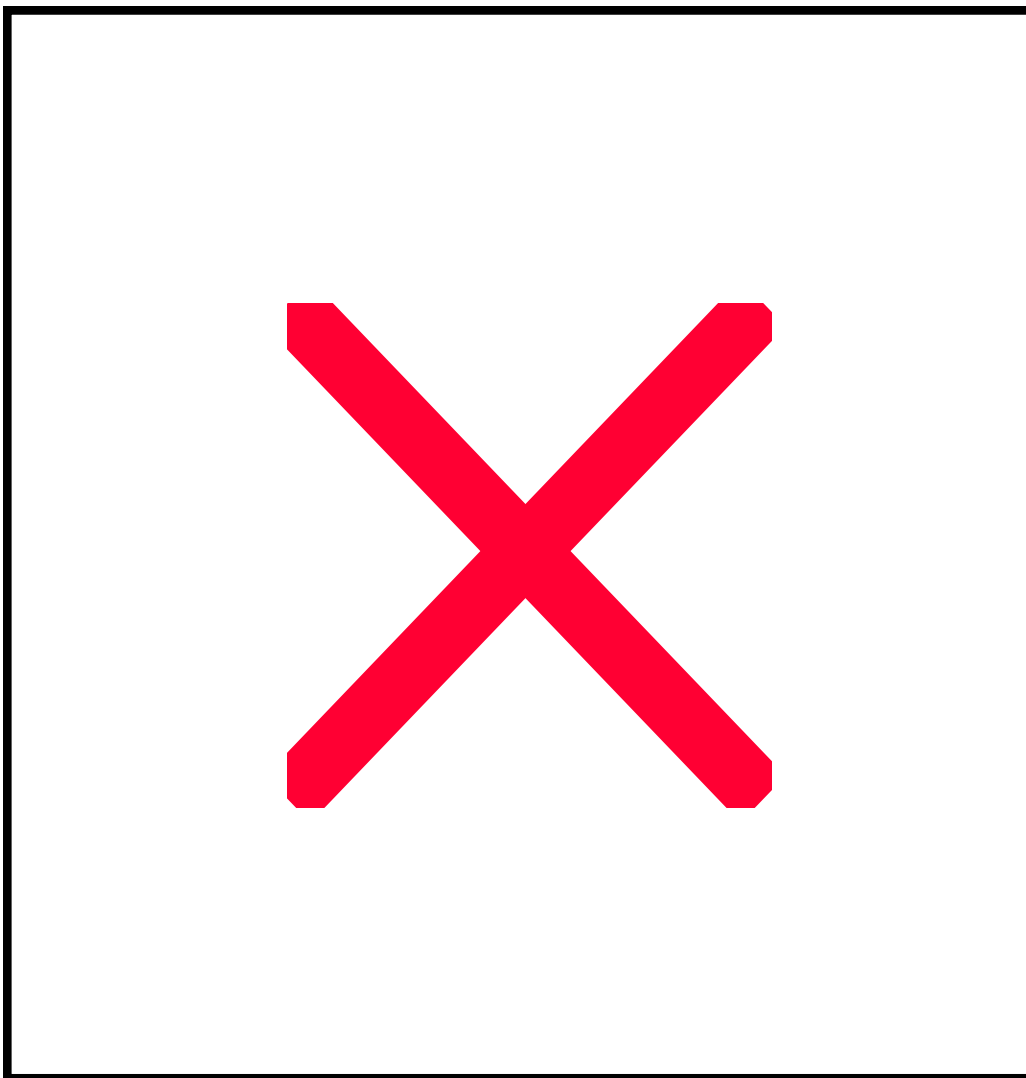
- an Aboriginal person living with HIV/AIDS

On reserves, I've noticed the patience level is really low. A lot of people are already sick with their own problems.

The person who is looking after the client can get pissed off. They need a break. Maybe they've been at it for three days. You have to space things out equally.

It's the whole deal of ownership and responsibility. Especially with family members on reserve, they feel they have to take it all on themselves.

- an Aboriginal support person



It was just like a blur. Things were happening so fast. I just coped the best I could. It was a tremendous strain on me.

Nashine Ginwenimawazawin

I was on U.I.C. during the summer. I wasn't working at the time he got really, really sick. Basically, my life was on hold when I was looking after him.

I couldn't see myself being his twenty-four hour attendant because my emotions were ready to snap at that point. I was in a relationship with somebody, then we broke up. That added to the whole thing. It threw gasoline on the fire.

If I had had fifteen people helping me I could have gone to work. I know for a lot of people who are caring for somebody who is chronically ill, going to work is a break for them. It's an island of normalcy in this chaotic life. When somebody is that sick, your life is turned upside-down. Everything is happening at the same time. There are all these different emotions.

- an Aboriginal support person

I visited him every day. I didn't care for him. It was an hour to get to the hospital. He wanted to go there because his doctor was there, she was his AIDS specialist. It also has the reputation of being the best hospital.

I just visited him. I would bring him magazines. I'd sit there and keep him company. Chit chat. Watch TV. Once in a while, we'd go to the lounge. He was restless and didn't want to stay in anyplace too long. I'd visit him for an hour and then I'd come home. When I got home, he'd phone me, so I was in constant contact with him.

I know for a lot of people who are caring for somebody who is chronically ill, going to work is a break for them. It's an island of normalcy in this chaotic life.

- an Aboriginal support person

He had a few other people visiting him as well. He had a friend that would go up there and bring him downtown a few times. Some of his other friends went to see him up there. But like I said, it was way up there. You know how gay people are, as far as going north of Bloor! It's like planning a trip to Europe.

For the other people on the care team, when we got him into the hospital it was a good break for them, too. They were burnt-out.

- an Aboriginal support person

Presumably there would be opportunities for the care team members to take a look at where they are. Opportunities for them to face that idea of burnout.

It's like any other health question. If you address it in an aware way, and you see the beginnings of a symptom coming up. You take the space, you take the chance to re-balance yourself. This is what good care is. It's the same thing in the mental or emotional area.

Detachment doesn't mean, "I don't care." Detachment means, "I care intensely. I care enough to have my full quota of energy available to help you."

- an Aboriginal Elder

People get burned out because there is some confusion around the roles of being detached and not caring. They're not the same thing. As a caregiver, when I do my own healing, I am more likely to be detached. This releases as much energy as possible for me to help you.

If I get totally sucked into your situation and worn out by the emotions around it, there's less

available for me to help you. So, as a caregiver, detachment is one of the values that should be really looked at.

Detachment doesn't mean, "I don't care." Detachment means, "I care intensely. I care enough to have my full quota of energy available to help you. But, if I spend that energy in emotionalism in the details of your case, it means to me that there is a place where I'm not healed."

Parts of western society say, "This is how I express my love." They get really emotional and then you're emotional.

That's not the way I see it, "When I can be as centered and grounded as I can when I am working with you, then I have more energy to help you. But, when I'm all spread out all over the place and in the throes of your story, I am taking away from the energy that is available to help you.

For a lot of people it's a tough one because emotions are gifts from the Creator. My view of that is that they are like little flags. They tell us when something needs healing.

As a caregiver, you find yourself really, heavily emotionally involved, you really should stop and see what the source of that is. It means that some place is not healed and it's taking away from your energy to help that person. Yet, your overall mandate is to help that person.

I'm not saying that it's not good for caregivers to heal themselves as they go along. I'm talking about going to such an excess that they become burned out.

If caregivers use that principle of, when they see the imbalance, to replenish themselves, there will not be the possibility of burnout there. They should constantly be replenishing and putting back something.

- an Aboriginal Elder

My life went back to normal. I had some space and time to deal with my issues. I could start looking for work and planning for my future. I think it allowed me to be more supportive of him because I was looking after myself.

Before he went into the hospice, I was neglecting myself and starting to fall apart. I wasn't as supportive as I can be because of the emotional state that I was in. It gave me time to take a breather. I went home for about a week, for Thanksgiving. I didn't see him for a while, so I was able to recharge my batteries.

- an Aboriginal support person

STAYING OBJECTIVE UNDER PRESSURE

There are people with strong personalities. They may not take the time to explain the "why" behind the message they are giving you but you feel attacked or under pressure from them.

This could be the person you are caring for. It could be other care team members or people in the health care field. Perhaps it is someone who isn't involved in the care team, but is involved in your personal life.

Regardless of who this person is, it would be helpful to have some ideas around how you can cope when someone is not being kind. Understanding people when they have extreme behaviour can be very useful to your own peace of mind. It is often not possible to change someone else, but it is possible to change how you react to what they are saying to you.

Part of self-care is being able to cope with the stresses that come up in your life. There are stresses that are related to the care team and stresses that come from your life outside the care team. If they aren't managed well, they can affect your life and the work you do on the care team.

If you happen to think that there's something in that criticism, you can use it as a building block for more wisdom, fine.

"Will I really need to tighten up my schedule. This person was angry because I am late, I'm very late. They're hurling those things at me. Yeah. I think it's sensible to say yes, that's the justice of it, I was late. I need to pull up my socks to make sure I don't do this."

Even if that person's response to it was hugely out of proportion. You know what it is? It usually relates back to an experience in their past where they felt less-than or oppressed in some way. Some little thing you did triggering the whole thing.

Hardly ever is it what happened here. It's the baggage that comes with it. So, learning to see what that is.

- an Aboriginal Elder

HELPING EACH OTHER

One of the hardest things to cope with is when you go to someone for help, make yourself vulnerable and share some of your struggles. Then, the unthinkable happens. You hear gossip about yourself. The people you have turned to for help judge you and attack you. Or, you are rejected or dismissed. Sometimes it is worse when it comes from your own community.

We would ideally be able to turn to our own community for support and help. Unfortunately, that sometimes turns out to be the worst possible thing. Our own community is sometimes in such a state that it isn't possible to turn to them.

I think it's all the stuff you hear day in and day out about who we are as human beings. It's dehumanizing and it's painful. That's why we try to numb ourselves. That's why for some people, it overwhelms them and they kill themselves one way or another.

- an Aboriginal support person

The following storyteller addresses some of the issues, especially how we internalize everything, and make it so hard to care and love for one another.

From there, the storyteller is able to talk about the many positive things that are helping us heal and moving us towards a place where we can trust one another when we are vulnerable.

Lastly, an Elder offers some suggestions of how you can use the power of your own mind to cope, when you are faced with someone who is questioning your feelings. They may even be attacking you. The words of this Elder offers some wonderful suggestions to understand and deal with such encounters, so that you can protect yourself emotionally.

It's internalizing public impression. It's the shame we grew up with all of our lives like our race, sexuality and sexual expressions. The type of home we come from, like the fact that a lot of us have come from poor families. A lot of us come from families where there was alcoholism. We're ashamed of that. We're ashamed that our parents were seen downtown, drunk.

Some of us are even ashamed of the colour of our skin. In the community I come from, a lot of people would say, "Oh, he's a black Indian," meaning he is a dark skin Indian. That was derogatory.

There are a whole bunch of shame tactics that go on in our communities that we internalize. I don't know how many times I heard one Indian describe another as, "He's just a dumb Indian" or "He's a typical drunk Indian."

It is typifying Indians as all the negative stereotypes and yet they themselves are Native. I think that's so ironic.

Even gay people in the gay community, "Oh, she's a big queen" or "She's a big slut." In the lesbian community, "She's a big, fat, diesel dyke."

It's always so negative, negative, negative all the time. Then, we're surprised why there is so much suicide, alcoholism and self-destructive behaviour. Well, no wonder. We can't even support ourselves, get our act together and start being proud of ourselves.

I think it's all the stuff you hear day in and day out about who we are as human beings. It's dehumanizing and painful. That's why we try to numb ourselves. That's why for some people, it overwhelms them and they kill themselves one way or another.

Overlying all that garbage is our beautiful culture and traditions. I think we, as Aboriginal people, have been able to preserve a lot of that. We're very lucky it's a part of our lives. A lot of us can still speak the language. There are a lot of people that are traditional dancers. There are a lot of people who follow the Aboriginal spirituality. Those are very powerful things. I don't think we should overlook that. Getting together and beading, it may seem innocuous but it's very beautiful. There's a lot of medicine in that. I think we have our medicines that will heal us.

It's all the brilliant people we have in our community. They are people who are willing to stand up and say, "Let's love each other. Let's enjoy life. Life is a banquet, so why are you starving? Go out there and enjoy it."

They are people who are willing to stand up and say, "Let's love each other. Let's enjoy life. Life is a banquet, so why are you starving? Go out there and enjoy it."

- an Aboriginal support person

The person that I'm thinking about is Tomson Highway. He's very adamant that people should go out there and grab life by the tail.

We have that legacy. People like Buffy Sainte-Marie. People who really inspire our people and are role models. I think we have a really good chance of turning it around. I've seen a big difference from when I was a kid in the sixties to the nineties. I know there's still a lot of bullshit that happens, but in the sixties, it was a third world. Worse than that, it was a nightmare. I think we're still waking up from it.

- an Aboriginal support person

It's a different thing to say, "I think this....." Quite often, people who use the word, "I think" and "I feel" interchangeably.

"Oh, my feeling is...." No. They're thinking that. That's a different thing when you say, "I'm feeling sad."

Particularly, when somebody does something and you say, "When you do that, I feel this." Don't let anybody dispute your feelings. If you are accurately reporting what you're feeling, no one in this world has the right to dispute it.

If someone says, "Oh, you can't feel that."

You look them in the eye and you say, "Don't tell me what I'm feeling. This is what I'm feeling and I'm giving you the opportunity to know that right here, right now."

All the crap that's gone into the mental level for Aboriginal people and others, all the crap that makes for the mental conditioning. It's one of the biggest jobs today, to look at mental conditioning and see where it's actually veiling us from our true spirit.

If someone does something, quite often it's not what the person does, it's what our mental conditioning tells us about that. If somebody came in here and said, "You're this or that." Unless you believe that in yourself, it couldn't hurt you.

If someone came in and said, "Oh, I like your red sweater."

You'd look down and say, "No, it's a turquoise sweater."

Right. But a lot of the times people address things to us and say, "You're stupid."

It's the conditioning from years ago, when someone told that little person that they were stupid, that comes up. It's not that they are now. That is not the truth.

So, we look in and the conditioning says, "Yeah, he's right. I am stupid."

That has nothing to do with it! It's being able to see that whatever is coming at you, when it's as obvious as colour, you can see that, right? So, you don't take it on. What if it just hits on what is already there? Being able to use clear thinking and recognize this. Recognize who you truly are.

All that old stuff that's in there, put it down to the baldest statement. Supposing someone was angry with you and heaped a whole bunch of abuse on you. It hit all that old stuff. If you

took it down to the baldest possible statement, you would say, "X was angry with me. Period." Then, you could just leave it there. That is actually the truth. That is fact. That is authentic.

But then all the stuff "X" was saying to you and it hits on all the things that are in there, it becomes a big hurt.

This is pragmatic thinking. This is power thinking. You know how to take situations and boil them down and just look at them. Also, don't forget the period.....close it off.

- an Aboriginal Elder

TALKING CIRCLES

It is important to stress the individuality of First Nations' ways. No two Talking Circles are the same. Different Nations hold them in different ways. Two Elders from the same Nation will hold their Talking Circles differently. Even a Talking Circle facilitated by the same person and with the same people will be different each time it is held.

The best way to understand a Talking Circle is to actually experience one. It is there that you will get the benefit of having a group of people listen to your sharing, your words, thoughts, emotions and beliefs. If you are grieving the loss of the person you love, or even before it happens.

Not everyone of Aboriginal ancestry has had the opportunity to go to a Talking Circle. Some people were raised with beliefs that discourage involvement in First Nations ways. This may be church beliefs or the shame that generations of residential schools have produced. Other people may have been in foster care or adopted.

While the care team may have meetings to discuss practical issues, such as who is going to do what shift, a Talking Circle is a way of being able to address issues that come up for the care giver, whether they are physical, emotional, mental or spiritual. When you are trying to understand the "why" behind your work on the care team and need a place where you can work out your issues, a Talking Circle for your care team is one of the places you can do this. Talking Circles are places where you can re-fuel, and reinforce that energy that you need to do your work. If you are able to work through your issues in a Talking Circle, then the weight of that load has the opportunity to lessen.

It's about you having a place where you can go and be brutally honest about what it feels like for you. If you're one of those people on the team, one of the helpers, you're going to be going through an incredible amount of emotional reactions to everything that is going on with the person who is sick.

- an Aboriginal support person

Circles give people the time and the space they need to be able to say whatever it is they want to. In groups where there is cross talk, I think what happens is we have to be very quick in terms of getting out what we're saying. Our train of thought can be lost and we can go off track when there's interaction between people.

Nashine Ginwenimawazawin

I think in this situation that's not so likely to happen because the person knows they can really take their time. If it takes them a while to get to what they really need to say or express the feeling, then that's good because they know they have that.

I use both kinds. Sometimes I will do it where we'll pass around something and people will have their time. Other times, I'll do it in a group format. It kind of depends on if there are some advantages to having the interaction amongst people, as well. I think both are good and I never use just one way.

Sometimes, even though I may have something planned for the night, if I sense I'm picking up something from the people, then I'll kind of throw it out the window. Those are the times when I'll do a Circle because my assumption is there's at least one person who's really afraid. I feel fear. Something's going on with at least one person, so in giving everybody an opportunity to speak, whoever it is and whatever it is, comes out.

- an Aboriginal support person

The care teams need a support group, where they can talk about these things. In the circles you use the medicines. Let them have a place to vent, where others understand. If you're part of that, you need to have some place to talk about it.

It's my son and his friend. I offered my help to talk to them. He say, "I need to talk to you, mom." I know he's struggling watching his friend die.

- an Aboriginal Elder

If you're not feeling anything, then you're denying it, you're suppressing it. You're doing something with it. I can't imagine that you wouldn't be feeling anything. That you can watch somebody die and not feel anything. It doesn't make sense.

Some of the things that need to be talked about are the physical deterioration that a person dying from AIDS goes through. I don't know how else to say it, except it's brutal. Particularly if it's somebody that you care about. To watch them change, literally, every day.

Are you allowed to talk about that? Can you talk about that with somebody, about how it affects you? Or, is the expectation that you're always going to talk about the person who is dying and what it's like for him or her? Is all the focus on them all the time? What about your own emotions?

The person who is dying is going to be going through a whole gamut of emotions. The people who are caring for that person are also going to be going through their own emotions. What does it feel like for them, watching this person die? What are their fears around it? What are they angry about? Is there a place where it's safe for you to let those things out?

I think a lot of it is frustration, too. Some of those frustrations are really around the practical things. How much work is there, in caring for somebody in this situation? What about when you get tired? What about when you feel, at times, like you don't want to do this anymore? Can you talk about those things or are you not allowed to? Are you supposed to be "nice" all the time about this? It's not nice. How can you have a place where you can dump that stuff out, get re-energized and carry on?

- an Aboriginal support person

What about your anger towards the person that's dying? Here's somebody who managed to contract a disease that people will say, "You could have prevented it. It's because of something you did, that you got this."

People still have some of that. But, we're not supposed to say that because it's not nice. What if there's a piece of you inside that still has that kind of attitude towards this person? You can't talk about it because it's not nice or we're not supposed to believe that or we're not supposed to judge this person. So, what happens when that person dies? Well, you've got all this guilt now, because you had this thought and, "Oh my God, maybe it made him die."

So, here you go. Now, your grieving process has yet another layer to it. Why is it a bad thing if a little piece of you is thinking and pissed off because you care about this person? If that is an honest thought, an honest feeling that you have, you ought to have a place where you can voice it. It's your true feelings.

What does it feel like for them, watching this person die? What are their fears around it? What are they angry about? Is there a place where it's safe for you to let those things out?
- an Aboriginal support person

It seems to me around this whole thing about AIDS is we're supposed to be politically correct, damn it. Politically correct is up here (points to the head). What's in here (the heart) may be very different.

It's trying to find that safe place where you can talk about those kinds of things and those kinds of feelings that we're sent a message that we're not supposed to say anything.

- an Aboriginal support person

Finding Good Facilitators

- ◆ Take the time to explain the different issues you may talk about. Can they handle those issues and emotions?
- ◆ Are there two or more facilitators? Do they debrief with each other after the Circle, in case anything triggered their own emotions or they want to review what happened?
- ◆ Is the facilitator able to be honest and say, "I don't know?"
- ◆ Can they let participants solve their own problems, or do they do it for them?
- ◆ Are they able to keep confidentiality?

Facilitators of Talking Circles

Talking circles are very intense. So many emotions may come up with so many issues. It would be careless to assume that every facilitator knows exactly what they're doing. If a Talking Circle isn't facilitated properly, it can end up doing more damage to the participants than good.

How do you find out if someone is skilled in facilitating Circles? It is not only about the amount and intensity of emotions that come up, it is also important that they get worked through in a skilled and safe way.

Nashine Ginwenimawazawin

Your care team may have to look around for someone who is skilled at facilitating and able to do the work that your care team needs.

When you are arranging for a Talking Circle, if there is an existing Circle, there is always the issue of confidentiality. Whether in small towns or big cities, gossip is always a concern.

You may be able to arrange for one or two facilitators to come and work with your care team only. You may be able to do this through an organization. If not, you may have to look within yourselves to make sure they are paid for their time and services.

A Talking Circle can be run by an Elder or a First Nations person in the helping and support field. When the work that your care team is doing is so vital, for the person that is dying, a Talking Circle can be the tool that keeps the care team on the right track.

Unfortunately, what I see happening sometimes is workers thrown into the job of running circles. They don't have the training and experience to do it. Regardless of what we want to call it, a Talking Circle or a Healing Circle, you still need to have a level of skill to be able to do that work.

If somebody's going to go into a Talking Circle, become educated about who is going to run that Talking Circle. What kind of a background do they have in doing the work? Can they handle the issues that are going to be brought up in the Circle?

Very often, a Talking Circle is a place where you can go and you can bring up anything. So, we could have a million and one different topics coming out of there. Is the facilitator of the Circle able to deal with all of those different things that could come up? Could they deal with somebody who may be suicidal? Can they deal with somebody who, for the very first time, discloses childhood sexual abuse?

These are the things that we invite people to talk about when we say, "You can talk about whatever you want." But that doesn't mean that any one person is skilled at dealing with those things that will come up.

Another thing I see a lot of is, it's one person facilitating the Circle. That isn't a good idea unless you've got lots of experience already at running the Circles. Very often, it's much more helpful to have two people in there. One person can't see everything. They can't pick up on each person. You have to be able to read everybody that's in the Circle. One person on their own, particularly if they don't have a lot of experience, it's going to be too overwhelming for them. They're not going to be able to read everything that's happening with the participants.

How many people do you let into the Circle on any given night? Sometimes there are these huge Circles with twenty-five people sitting in there. To me, I think that's really outrageous because again, how are you going to make sure that all of those people are okay? How are you going to make sure they're getting what they need out of the Circle? How do you respond to that many people?

Nashine Ginwenimawazawin

It's almost physically impossible. They need to have smaller numbers of people. It's like, how many people can the facilitators handle? That should be the answer to how many people you let in.

Circles with Elders and Traditional Teachers, again, we make this assumption that because someone is a Teacher or an Elder, they know everything about everything. We assume they are comfortable in listening to it and talking about it. We assume they have an incredible amount of knowledge on everything. That just isn't true.

I think sometimes we do a disservice to them because of that kind of assumption. We don't give them enough information about the people who will be in the Circle. We don't give them information about the kinds of things we're asking the Elder to do and the kind of topics that we're asking them to help us with.

When we take the time to sit down with an Elder and talk about the kinds of things that might be happening in the Talking Circle, you could find that they may not want to do it because they don't feel comfortable with the area.

When you don't tell them anything, you just throw them in there, the reality is sometimes they end up being messed up around it. They're human beings, too. We don't give them the information and we don't give them the choice. We just make assumptions about them and toss them in.

- an Aboriginal support person

As a facilitator, it's knowing what your limitations are. A lot of people who come into the Circle will believe that you have the answers to everything. I think what happens sometimes to facilitators is we think we're supposed to go, "Because I'm the facilitator, I'm supposed to have all the answers, so I better damn well come up with an answer."

Instead of being able to honestly say, "I don't know," we search for something. That's not helpful and I think that's where it can get harmful.

I think what happens sometimes to facilitators is we think we're supposed to go, "Because I'm a facilitator, I'm supposed to have all the answers, so I better damn-well come up with an answer."

Instead of being able to honestly say, "I don't know," we search for something. That's not helpful and I think that's where it can get harmful.

- an Aboriginal support person

about, we may give information that is hurtful instead of helpful. It's not that people do this on purpose. I think that there's just this incredible pressure about how you can't say, "I don't know" or "I don't know, but I'll find out for you."

For me, it's real simple. If you don't know what to say, say nothing. You can care for a person, you can listen and you can comfort them. You can do this without having to say anything or without having to think you have to solve a problem.

It's when we open our mouths and we don't know what the hell we're talking

- an Aboriginal support person

Nashine Ginwenimawazawin

I think that's really important is to co-facilitate with somebody who has experience. To assist in it but not take it all on by yourself right away. You prepare before the Circle, you do the Circle, you debrief after the Circle.

I think that's what I mean about "level of skill" for facilitators. It's like going through training. I don't know why people think this would be any different than doing any other kind of group. As though because we're Aboriginal people, we're supposed to be born knowing how to do this or something.

- an Aboriginal support person

What will happen when we bring people together, open them up and send them home without checking in with every single person? Checking in to make sure that they're actually okay to leave that Circle, to go out into the world and be alright?

It's really about safety. When you open people up and you shut them right down or you don't give them appropriate closure and assurance that they are safe, you don't know what's going to happen to them out there. A lot of bad things can happen if people's emotions are right out there on the surface, if they're hurting. If we send them out into the world and they're unprepared, then they're not safe. Any number of things could happen with them.

It's a matter of checking out with every person that's in the Circle. What are they feeling right now? What are they thinking about? It's coming right out and asking if you have a concern about somebody, "Are you okay to leave?" Ask those kinds of questions and don't be afraid to ask them directly because that's what you need to know.

Pay attention to those ones who may not have talked in the Circle, to make sure that you know what they're feeling, if they're okay.

If somebody isn't okay, then you need to do a little more work to make sure that they can leave. Find out what's going on with them. Maybe you find out someone has gotten really enraged about the topic or what somebody else said.

If someone's really, really angry, you have to think about, "Alright, this person's really angry. They're going out into the world. Well, the first person they see on the street may end up being the object of the anger. And then, here we go, we've got a person hurt out there. We've also got another Aboriginal person probably going to jail, thank you very much!

Even if they don't say so, it's being able to see, "I think that person's a little pissed."

To say, "To me, you seem like you're really mad. What is it that you're mad about?"

Let them talk to you about it and deal with their anger then. Make sure it's been lifted off and they're okay with it.

I do it in the Circle. I give a check-out with every single person to speak, individually in the Circle. If somebody is really angry, then I'll say, "Why don't you just stay after we close, and

we'll talk about it some more. We'll talk before we go."

Maybe they don't want to say it in front of everybody else.

- an Aboriginal support person

DEPRESSION

Depression may come up if you don't have the support you need to cope with what is happening to the person you are caring for. Many people in the world experience depression and often, people don't even know they are so close to depression.

When the up-and-down nature of life gets you down lower than usual and you can't get up again, that is depression. Depression can lower your energy, the way you function and your interest in things.

Feelings of sadness, guilt, helplessness, apathy, irritability, being overwhelmed and lacking in enjoyment are only some of the feelings that can come up in depression.

Depression affects the mind, with difficulty in concentrating and making decisions, criticizing and blaming yourself and focusing only on negative things.

I felt kind of weepy. I was feeling very hopeless. I guess at the time, whenever I had the chance, I would go out and drink to try to block things out. I used food to self-medicate myself. I was feeling very nervous at the time and fearful. I was having anxiety attacks all the time. It was all the usual signs of depression.

- an Aboriginal support person

Other changes in you may include, lower appetite, lower interest in sex and problems sleeping.

There are many different views of why people become depressed. Some say it is because there is an imbalance of chemicals in the brain. Others think it

is because of the way you were raised. Others suggest it is because of the lack of effective coping mechanisms, resulting in turning anger inward or seeing everything as negative. Elders speak about depression as a sign of the need for healing, on a spiritual level.

The good part is there is a lot you and your support system can do to help you with depression. If you aren't getting support when you are depressed, the people around you may make you feel bad for your low mood. No matter what, remember it isn't your fault you are depressed. Nobody enjoys feeling the emotions that go along with depression. It is not quite as easy to "snap out of it" and feel wonderful.

The support you are looking for can come in the form of kindness and understanding. The route you take to pull yourself out of depression will be unique to you. Many Elders and helping people are skilled in working with depression, through Talking Circles or one-to-one counselling. There are many people who have expertise in working with depression: therapists, counsellors, doctors, psychiatrists and psychologists. There are many books on depression and some organizations offer courses on how to cope with depression.

Methods for Coping with Depression

- ◆ Pray, attend ceremonies, ask sacred medicines for help.
- ◆ Accept support from others.
- ◆ Meditate.
- ◆ Set small, attainable tasks for yourself. Write them down, so that you have physical proof that your day is worth something.
- ◆ When you are thinking negatively, slow down your thoughts. Find a different way of looking at things. For example, “nothing matters because he is dying” can also be thought of, “I’m making a difference in his life, even during a point where he is dying. I am there for him and I am finding out ways to take care of myself in the process. This is an opportunity to celebrate his life, my life and our relationship.”
- ◆ If you have thoughts about harming yourself or feel you are in a severely deep depression, get help from someone you trust and who has a good understanding of how to work with depression.

I felt kind of weepy. I was feeling very hopeless. I guess at the time, whenever I had the chance, I would go out and drink to try to block things out. I used food to self-medicate myself. I was feeling very nervous at the time and fearful. I was having anxiety attacks all the time. It was all the usual signs of depression.

I would pray. Talk to friends. 2-Spirited People held a couple of Talking Circles. I felt very good, after that.

It’s a really big source of support for me because I felt, “These are my people.”

My friend had that personality, healing, supportive personality. She was a Traditional Mohawk woman. I also used my involvement with TPFN, in the social group.

Even though people were offering to help and my friend was turning them down, I felt supported by them, too. So, I was using the organization for that emotional aspect. Just the fact that it existed was a comfort to me.

- an Aboriginal support person

Certainly, depression is a huge issue in the Aboriginal community. There are a few stats out there that present depression as the number one thing. It’s something like four times greater than the general Canadian population. So obviously, there’s something going on there with Native people and being depressed.

It’s because we’ve lost our connection to the Spirit World, to the Creator, and all of those things that kept us healthy on a spiritual plane. We’ve lost those things. It’s like everything is out of whack because that’s gone, so depression is the effect of that.

- an Aboriginal support person

There are a number of reasons around depression. Sometimes, depression can be fixed by nutrition, diet. There’s a certain kind of salt that some people are missing in their system. There are those biological reasons for depression. Frankly, I don’t think chemical imbalances in the brain is what’s going on in the Aboriginal community.

Nashine Ginwenimawazawin

I think it has to do with all that other set of reasons. It comes from things like holding onto feelings, particularly anger. Being an oppressed population, powerlessness. Loss. We know how much loss there is for Aboriginal people and how we no longer know how to grieve these losses.

There are the emotional, psychological, underlying reasons for depression. Depressed people are holding on to something. They don't know how to get it out because they don't know what it is. It's like this big cloud that comes over us.

You can say, "Why do you think you're depressed?" They don't know. That's what depression is. You can't figure it out, you can't see what is so overwhelming.

In some of the talks that I've had with Elders; however, there's even another reason. The way they talk about it is, it's a spiritual illness. It's because we've lost our connection to the Spirit World, to the Creator, and all of those things that kept us healthy on a spiritual plane. We've lost those things. It's like everything is out of whack because that's gone, so depression is the effect of that.

I think what happens with us is that we'll start to feel something, but we don't have a voice and we don't have a place to go where we can deal with these kinds of things. For example, we feel powerless in this world. Of course we do. There's 'o way for us to voice that. What do we do about feeling powerless?

If we have a series of losses in our lives, it's like, "Well, get over it and move on." That's easier said than done, "Well, tell me how to get over it, then!" We don't do that.

It's just, "Okay, have your little mourning period, get back to work and do what you're supposed to do." It's not been dealt with inside. It's carrying all this stuff inside and having nowhere to go with it. There are so few avenues for people to deal with these kinds of things. So, we've got people walking around like this all the time.

In a situation where you're faced with somebody dying, well, watching somebody die is depressing if you're not able to talk about it. What it's like for you to watch somebody you care about die? If you have no place to go with that, that means you're holding onto it. You're just pushing it in and yeah, it's going to make you feel pretty depressed. Depression is that overwhelming feeling of not being able to do anything with those feelings or with your situation.

- an Aboriginal support person

We've seen so much horror in our lives, so much pain and suffering that it literally makes you physically and mentally ill. There are a lot of Aboriginal people who are suffering from depression, bi-polar depression or emotional trauma. It's from things like suicides, murders, sexual abuse, rape, car accidents, train accidents, fires, people drowning. The list goes on and on.

We've seen so much horror in our lives, so much pain and suffering that it literally makes you physically ill and mentally ill.
- an Aboriginal support person

Our mental health services are just only being developed. We really have to address the whole issue around mental health. Creating a mental health system where we can go and get appropriate counselling that's safe for us.

Nashine Ginwenimawazawin

We need something for two-spirited people, as well. A lot of what exists for Aboriginal people for mental health isn't safe for two-spirited people. We have to start looking at creating our own. We already are, at 2-Spirited People. The Aboriginal Healing and Wellness Program and the Grief Recovery training. We have to enhance those services. We're lucky to have the services provided by 2-Spirited People but that's only here in Toronto. Only a very small percentage of two-spirited people are able to readily access it.

- an Aboriginal support person

If we talk about it in terms of that spiritual illness, it's like a piece that we're missing. It's like not being a whole person. If you don't have a spiritual part of yourself, if you're not doing things to nurture it and take care of it. There's a part missing from us if we don't have that.

Deal with that, become involved in your own way of being able to nurture spirit. Understand what it means and what we do to take care of it. It opens up everything else. You're able to make better sense of things when you have that understanding of yourself.

There's a part to all this that is beyond everything we're going through. When you have that, things aren't so overwhelming. They just don't seem to be because you have this sense of something beyond everything that's here. It's making that kind of connection and doing these things that really help how we feel about ourselves.

The Elders I've made really good connections with are the ones who really believe in helping people release emotions, release feelings. Some of them will talk about how you just need to be out in the bush sometimes so that you can really scream your head off. If depression is holding onto those feelings, then we know what alleviates it, is to be able to get those things out.

I think when it comes to death, people go through depression because they don't know what happens after death. The afterlife or the Spirit World, they don't know about those kinds of things and they fear it because it's unknown. They may have adopted a whole lot of other belief systems that have nothing to do with us.

It's not knowing or not believing in something that's really hard for people. I find people who successfully move through a grief process believe in something after life. They are the ones who are able to get through it easier. I think that makes a big difference for the people who are left here.

- an Aboriginal support person

Crying

Many people think crying is something to be ashamed of. Others think it is a sign of weakness, that you aren't strong. Many people feel men should never do it and that women do it too much. With all these negative messages, it isn't a big surprise people are uncomfortable with crying, whether they are doing it

Crying is releasing, the gift of tears. Tears are a gift, to be able to cry, in sorrow and in joy. Tears release chemicals, that's something that science has already figured out. It's almost like there's a time to cry. To release the tears, whether you want to call it self-pity, well, go ahead and call it self-pity. It just helps to relieve the tension, the mind-set and the stress.

- an Aboriginal Elder

Nashine Ginwenimawazawin

themselves or watching someone else cry. The problem with stuffing down the feelings that want to come out through crying is that they just get suppressed. They don't go away.

Crying is a gift, it is prayer and it is cleansing. A lot of people approach crying as something that is healthy and necessary. Any emotion can be expressed through crying.

While you are taking care of yourself and you are doing work on a care team, you will need a place to be able to express yourself. Even if you have that place, you have to contribute, the healing doesn't just happen on its own.

Crying is only one of the expressions you can use to heal yourself.

There's three feelings in particular: fear, anger and sadness. What I like to do with people is let them tell me how they have been taught to deal with those feelings. What are the messages people got when they were growing up?

We've been bombarded, as children, about how you don't cry. "Big boys don't cry. If you cry, you're a sissy." Sometimes those statements have been made to us directly. Other times we have just picked it up.

If you're ever going to cry, the message is, "You do it all by yourself, alone, where nobody can see you and nobody can hear you, even if you let yourself do that." We learn. We just learn to push it in and push it in.

- an Aboriginal support person

I get people to tell me how they have learned to deal with their sadness. What do they do? Where did those messages come from? How did they learn that? Get them to go back to when they were a kid. What was it like for them to be shut down?

You get them to look at the natural way we were born to deal with these feelings. The Creator gave us gifts to be able to release our feelings in safe ways that keep us healthy. With sadness, it's the crying. The wailing is voice, too. That's why we have tears, or else we wouldn't have been born with our eyes to do this.

Get them to look at it from that perspective. When you were born, you were born perfect. You had everything that you needed, in terms of being able to do things in a natural way. What did you do when you were a baby or a little kid? It's like re-learning, very differently from what most of us learned when we were growing up.

Getting people to look at how they feel when they see somebody else cry. Most people are uncomfortable with it. How come? We are uncomfortable because we were taught not to do it: if we see somebody else doing it, there's something weird with them!

The media! The messages are everywhere in our world. We get them all the time. Our families, the media, everywhere we see this. It's getting them to look at it from a different kind of perspective.

You'll start to see people will go, "Oh, this makes sense." It will make people a little more comfortable with it.

Nashine Ginwenimawazawin

It is also tons and tons of permission about how this is a place where you can do that, and nobody is going to shut you down. Nobody is going to judge you. When people actually start doing a little bit, ask them, "What does it feel like?"

You actually have to practice it because people will still feel uncomfortable. As it happens a little bit more and a little bit more, they'll start to shift.

What does it feel like for you, after you cry? At first, you are going to feel shame, you're going to feel like you're a weak person. Those things too, will start to shift. People will see that when they can get some of that out. It's like this weight is taken off a little bit. Each time they do it, it's a little bit more.

There's also a lot of fear around, "If I start crying, I'll never stop." As though there's a bottomless pit. That never happens. In all the years I've been doing this, I've never seen it yet! There's always a stopping point! People have to go through it themselves to believe that. You cry, you always naturally come to a place where you're done, for now.

It's like you're storing it and storing it and storing it. If you're thirty years old, you've probably got thirty years in there. So, letting it out, bit by bit. It is like freeing up.

I talk a lot about how emotions affect us in those four aspects. It's all interconnected. If we're holding onto sadness, it's stored in certain parts of our body. There will be physical reactions.

With sadness, for example, it's a whole lot of heart and lung stuff. People with bronchitis, asthma, stuff like that. There's a really good chance that person is carrying around a lot of sadness that they're not able to release. I've actually worked with people who are on puffers for asthma. Over time, with being able to release the sadness more and more and more, they end up so they don't have to use the puffer. It's like, telling people stuff like that and getting them to start experiencing it for themselves.

- an Aboriginal support person

You have to tell them to talk about crying as a gift. Do you keep your mouth shut, too? That voice is a gift. Do you close your eyes? Your eyes are a gift, so your tears are a gift. How many fingers, how many hands have you got? Those are all gifts. Acknowledge them, use them.

We always have the opportunity to use them in a negative way. It's like a choice we have to make. If we choose or are programmed not to cry like men are, you have to work that through. Get somebody to help you to be able to cry. The crying is releasing, the crying is a gift, given to every person, equally. Cry, whatever you need to work through. Tell people, if they want to come in and cry, cry!

- an Aboriginal Elder

I think that in our efforts to make them feel better, what we're actually doing is trying to make ourselves feel better. We may be uncomfortable, for whatever reasons, with somebody expressing their sadness. That's where the, "Let's try and make this person feel better" comes from. It comes from us.

The whole idea, as far as I'm concerned, is if somebody starts to cry, let them cry. Try not to do something that's going to shut them down.

You have to tell them to talk about crying as a gift. Do you keep your mouth shut, too? That voice is a gift. Do you close your eyes?

- an Aboriginal Elder

Sometimes what we'll do is start asking questions or say, "There, there. It's okay, it's okay."

If you start asking somebody questions, then they have to answer you. If they have to talk, they're not going to be crying anymore. Again, that's another way of shutting the person down.

A lot of people have a hard time with silence. They will start talking. They'll say something to try and comfort the person or they'll ask the person a question because they're having a hard time with silence. It's like there always has to be talking going on.

There are a lot of different things that get cleaned out when somebody shows a lot of emotion, particularly crying. Again, I really think it does depend. Most of the time, this is one of those situations where you don't have to do anything. You just let the person be. Let them do as much of the work as they can do at that moment. It may just be a little bit and that's all they want to do. They may really be able to get in touch with that deep, deep sadness and wail some of that stuff out on their own, which is great.

- an Aboriginal support person

Your Voice

Crying is a gift and it brings awareness of the gift of your voice and the greater gift you have been given. Your voice is also something that can be a tool for healing. When you use your voice, it sends vibrations through your body. Talking, crying, shouting, laughing and singing are different ways you can use your voice.

Have you ever been in a car or your home, and sang along to a song at the top of your lungs? Doesn't it feel great? There are certain shouts that are used to close up ceremonies, which celebrate the use of the voice.

First Nations people have been silenced in many ways. Those losses have to be healed, and many people are already on this path. Find your voice and use it to celebrate yourself, the person you are caring for and your life.

They say singing brings you closer to that spiritual level. When you sing, you're moving more into the spirit part of you. Singing is also about voice. It is an expression and release of emotion. Anything where the voice is involved, and I think that's really important for us as Aboriginal people, it is so important because we've been silenced for centuries. That's where powerlessness comes into play.

- an Aboriginal support person

Humour is one of the greatest gifts Aboriginal people have. It developed from our Aboriginal languages. When you tell a story in Ojibway, Mohawk or Cree or any other language, it's ten times more hysterically funny than in English. You hear them in both Ojibway and English, about half-and-half. They usually get to the punchline and they'll say it in Ojibway.

Nashine Ginwenimawazawin

A lot of Aboriginal people are able to translate that humour into the English language. They're brilliantly witty, have a way of playing with words and a way with mimicking people. It's really a gift and they do it so off the cuff.

It has an enormous healing ability for our communities. If you go to a funeral or a memorial service at the band office or the reserve hall, the place is rocking with laughter. They'll be telling stories about the person.

I think laughter and tears are so close together. It's a release of that energy and it's very, very powerful. It can be infectious. The Zuni people, they have people called the Sacred Clowns and one of their roles is to go around, cracking people up. The thing is, they're sacred. Laughter is sacred.

A lot of times they're not jokes, they're stories about people. I remember one of my cousins, he's in his sixties, was telling me he went hunting with his uncle. He was a much older Indian man. They were guiding these American hunters. The hunters were spending a lot of money. They wanted a trophy to bring back to the States, so they could brag they shot a moose and brought back a big rack of antlers. On the last day of their hunting trip, still, they hadn't shot a moose. They were freaking out, so my cousin and his uncle said, "Okay, settle down. We'll go track a moose down for you and bring it back."

So, they went out and they shot that moose. All they wanted was the head, so they cut the head off. My cousin's uncle was a big, tall man, 6'4. He was really strong, he lifted up that moose head that was seventy pounds and was carrying it on his shoulders. It was dusk, in the fall. They were coming up the hill and the Americans saw them coming. All they saw was a moose head coming over the hill and they shot it in the head. My cousin's uncle flew on his back and they started yelling, "Don't shoot, don't shoot!" All the Americans saw was the head and they thought the moose was yelling, "Don't shoot, don't shoot!"

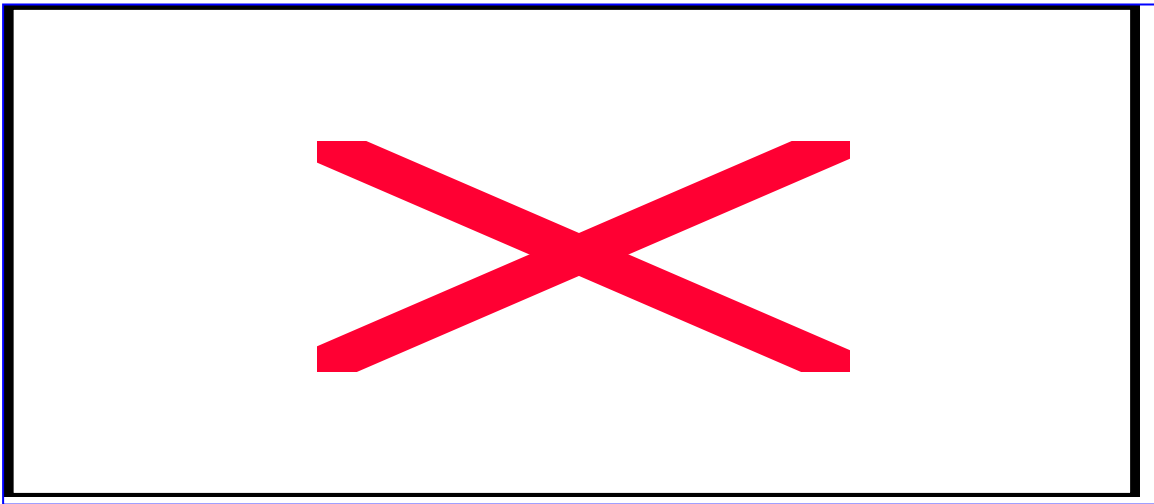
- an Aboriginal support person

COMMUNICATION

Communication is the way we pass information, such as feelings, thoughts, attitudes, ideas, and beliefs from one person to the next. Communication is a skill. It takes time to learn and energy to maintain those skills.

Everyone has the ability to communicate. The way in which people choose to communicate can open up the lines of communication or close them down. Do you want your communication to be positive, honest, and kind? When your communication is attacking, judging or accusing, it isn't going to contribute to constructive communication. Learning what skills open up communication lines are skills that are available to everyone. It takes time to learn, practice, and maintain communication skills.

Verbal communication is when you are speaking to someone. Non-verbal communication includes the physical appearance, posture, gestures, expressions, eye contact, touching and silence.



Verbal communication and non-verbal communication do not always tell the same story. Understanding this can help; when you want clearly to get your message across. It can also help with your listening skills. If the person you are caring for is giving conflicting messages, you may realize he is going through something that he is unable to talk about. For example, he may say, "I'm fine," yet, you notice his breathing is very shallow and he is holding his stomach.

With non-verbal communication, there may be someone on the care team who has an understanding of his non-verbal messages. Non-verbal communication can be very complex. If there isn't someone who immediately understands his non-verbal messages, trying to figure out what he is trying to say can only be guessed and assumed.

For example, if someone is being silent, it could mean a lot of different things:
They could be... ..

- ◆ taking their time to think about how they want to express something.
- ◆ angry, upset or offended.
- ◆ zoned out or tuned out.
- ◆ too tired to answer.
- ◆ feeling symptoms, such as fever or nausea.
- ◆ in pain
- ◆ forgetful about what the conversation is about, perhaps due to dementia or low concentration level.
- ◆ happy and want to savor the feeling.
- ◆ thinking you were going to say something more.
- ◆ frustrated that they keep getting cut off, before they finish speaking.
- ◆ no longer have an interest in the topic because the person they are speaking to is talking in machine-gun style: too fast with too much information.

You are not expected to know the thoughts of the person you are caring for, if he is not expressing it verbally. The above example shows many possibilities why someone could be silent. With that many possibilities, it becomes clear how there is a lot of room to misinterpret silence. If you are not clear on what he wants to communicate, ask him. Also, accept that he may not want to talk at the moment, which is fine.

Communication can bring you closer to a place of understanding and relating to the person. If the body is going through many problems, the needs of the spirit, mind and emotions will often become more intense. Some of the stories in this section talk about how a person's world shrinks when they can't leave their bed. It becomes a very special time and a special environment; priorities of the person being cared for change constantly.

One of the cultural differences in communication is the time allowed for silence. Euro-western people may have conversations that go quickly. Interrupting someone before they are finished speaking happens a lot. Finishing somebody's sentence for them can also happen.

If you cut someone off before they finish speaking, it is a barrier to effective communication. It is natural for First Nations people to think about what we want to say, before answering. Silence is not an uncomfortable thing and we expect that our listener can wait respectfully until we can formulate our reply. You will probably be working with non-Native people on your care team. You will need creativity to keep the lines of communication open, especially if you are being cut off and not given a chance to speak.

It's hard because people don't want to talk about AIDS. It's like they try and avoid asking questions. If you're honest enough to tell them about it, they're like, "Oh." It seems like they don't know how to act.

- an Aboriginal person living with HIV/AIDS

The quick-changing and unpredictable nature of AIDS is sometimes described as a roller coaster or a yo-yo. This is when someone's health can go from good to bad, many times. There is no way of knowing what will happen next. He may prepare himself for death when he suddenly gets better. Living on such a roller coaster will cause many emotions to come up, such as anger, depression and sadness. The unpredictable nature of AIDS can be very hard on him and his caregivers, family, partner and friends. Honest and open communication is vital for these difficult times.

Communication is your opportunity in time. How often do you hear people saying, "I wish I had been able to tell him..." or "I made my peace with her..." Instead of living with regret or waiting until the last minute to tell someone that you love them, take the immediate moment. There may be a long history of pain however, you have control around how you want the conversation to go. Choose to make it a good one.

If you give him a chance to talk and share, it can help him cope with emotions such as anger, depression, fear and sadness. Letting him speak under comfortable conditions is a way of honoring him. It acknowledges he is valuable. It lets him know he is important and worth taking the time to speak with.

Trust often plays a part in good communication. For some people, it is necessary to have a trust foundation before they open up. A environment that nurtures comfort and trust will encourage honest communication. Trust has to be worked at on a regular basis.

If he doesn't choose you to confide in, don't be hurt by that. In caring for him, seeing that he has someone he can talk to contributes to his well being. Care enough that if he wants to share with someone else, it isn't a threat to you. Good communication doesn't always happen with someone who is very close. It is sometimes easier to communicate with a person who isn't right in the middle of everything.

I think a lot of people, they don't know what to say when someone is dying or they're really ill. It's like they're walking on eggshells.

- an Aboriginal support person

The care team is trying to provide the best possible care to the person who is dying. It makes sense that communication is open and without judgment. Good communication from all care team members will contribute to a comfortable environment for her.

Barriers to Good Communication

- ◆ Thinking about other things, zoning out.
- ◆ Reaching your own conclusions instead of hearing what they have to say.
- ◆ Thinking too much about what the other person is thinking about you.
- ◆ Feeling like you have to fix something when you are listening to anger, grief, sadness, etc.
- ◆ Suddenly changing the topic of conversation to an easier one.
- ◆ Focusing only on negative parts of the conversation.

It will take sensitivity on your part, to figure out the mood of her environment. Communication will help you determine what she needs at this particular time. Perhaps she is thinking about dying. If a care team member rushes in and cheerfully asks if she is ready to have a visitor, in that circumstance, a positive and upbeat mood would not be appropriate. You may realize she may not want a visitor. She may need you to just be there and listen to her and slow down a bit.

Communication can be different from day to day. One day, she may be feeling very energetic. She may be sitting up, chatting a lot and want some lunch. The next time, she may not want to do anything. Again, she doesn't need you to say or do anything, she may simply want your company.

Tips for Good Communication:

- ◆ We can think about faster than someone can talk. This is why it is so easy for your mind to wander. Focus on your speaker.
- ◆ Be prepared to listen. If you're tired or hungry, listening is hard.
- ◆ Make the time available for listening.
- ◆ Resist distractions (TV, thinking about what is happening at home).
- ◆ Observe your body language. Is it sending the same message about what you are saying?
- ◆ Observe your emotions. Are they positive, honest, and clear, or are there double messages that could be confusing and hurtful?
- ◆ Think of what the person is about to say as a mystery that only they can tell you about. If your mind is spending energy on jumping to conclusions or making assumptions, it will not be available for focusing on your speaker. If you listen attentively to everything your speaker is saying, you can avoid disrespectful communication, such as interrupting someone before they are finished speaking.
- ◆ Consider whether your communication is respectful. Does it show your listener that you honor them and care for their well being?

he ideal would be to create an environment that nurtures comfort and trust when he needs to communicate. Our Elders speak about treating all of Creation, everyone, and everything, with respect. Respect (or disrespect) becomes apparent in the way you communicate with someone. It is one of our most vital belief systems.

Remember to be patient with yourself. Don't expect yourself to be perfect. Learning communication takes time and practice. If you can stick closely to communicating with respect and kindness, the person you are caring for will be able to see this.

When you are communicating within the world of someone who is dying, you have a choice to speak in a good way, making the moment very meaningful. Some of the following words contain unique and valuable thoughts on communication.

Nashine Ginwenimawazawin

I think mainstream ideas around communication and the communication within the Aboriginal community are two different worlds. They're founded on different values, different ways of looking at things and different priorities. There is a gap in communication.

I think when Indian people are amongst themselves, we don't have to say as much to get a point across. We don't have to talk through an issue. A joke, something humorous will call someone on their behaviour. It gets awareness out and everyone knows. With Aboriginal people, it's understood. You don't have to go into this big, articulate spiel about it.

A Non-Native caregiver coming in, as good-hearted and well intentioned as the person may be, the truth is that sometimes they're going to end up doing things that are downright offensive.

The ideal would be to have people from everywhere feel comfortable with one another. A trust has to be there.

- an Aboriginal person living with HIV/AIDS

At that point, I don't want to worry about those little things because they're not important to me anymore. They wouldn't be a part of my life. I'd be at the final stages and I'm waiting for my body to be overtaken. Once it takes my last source of livelihood then my mental and spiritual side goes onto the universe. If that's all I have left, that's what I have to relate to other people with. If they could be considerate of that and realize what I need to be related to, it's so powerful at that point. It's so much more meaningful, what they say to me and how they treat me. The care team is the only thing surrounding my aura, my spiritual self. That is so important because I'm totally strapped to that bed.

- an Aboriginal person living with HIV/AIDS

Yeah, there's a loss for someone in the palliative situation. There's a great deal of loss. Mobility, being able to walk around and getting out. People's worlds shrink when they get sick. They get smaller and smaller until it gets to the point where they may be isolated in bed.

In my experience, some people don't want anybody around but just perhaps one, two or three people who will see you. For whatever reasons, whether you're just too sick and can't deal with people. Whether you don't want someone to see you, it's their decision and you have to respect it.

- an Aboriginal person living with HIV/AIDS

In a palliative situation, as I approach death, I don't want to see other people, especially children or close friends. I don't want them to remember me for what I looked like. I've heard people say, "Oh, I wish I never saw him because he changed so much. Now I'll always remember him as that sick person."

I felt my one big experience, my lover, it didn't matter to me what he looked like or what kind of illness he had or what needed to be done. His bed became the centre of the universe and everything has to go to him because, of course, he couldn't go elsewhere.

- an Aboriginal person living with HIV/AIDS

Nashine Ginwenimawazawin

Some people have been so close to the brink of death. All of a sudden, they're all better again. That's a whole different thing because you prepare yourself when you know that you're that sick. When that happens more than once, it can be like, "Enough already! Why can't I just die!"

It's so draining to be that sick and that tired all the time. You're praying for death because it's so hard just to live, day by day.

That's the other thing about care teams. You're on a care team for someone because they're sick and then they get better. So, then you all disband and you scatter across the country. That person gets sick again and a whole new set of people he doesn't know comes in.

Now, no one is there. The family has their own problems and he's just too demanding for them. Now, he's alone. He's still sick and he's still tired. Life is a great thing, but not when you're sick all the time. You're always tired and you can't even get out of bed.

He was on the edge. You could see death in this guy's face and he bounced back again. That's the thing with AIDS, you prepare yourself for one thing and you accept it. Then, when it doesn't happen, you can become a really angry person.

- an Aboriginal support person

My community and my family were there, supporting me. They know when I'm having a really rough time. They're there to tell me, "It's going to be okay" and that they love me. They tell me they want to help me deal with some of the things that I go through.

I think I'm really lucky for having that support. I know there's a lot of people out there that don't get the support they need.

- an Aboriginal person living with HIV/AIDS

Well, I've got a lot of people here and a lot of friends. When I'm struggling with something, I know that they're there. It's just talking with them and letting them know how I'm feeling and how I'm dealing with things. It's very helpful.

There's times where I'm not able to do that. I'm not able to share what I'm feeling, only because I don't want them to be upset or I don't want it to bother their life.

I feel that it's very important that I do take care of myself. When I am depressed or having a hard day, that there's always somebody there.

It took me a long time to realize that. The first couple of years was really tough. I wasn't able to talk about everything that I was feeling. The first couple of years that was the toughest out of the last few. I was meeting all my friends and noticing how much they don't have the support that they should be getting.

I think when Indian people are amongst themselves, we don't have to say as much to get the point across. We don't have to talk through an issue. A joke, something humorous will call someone on their behaviour. It gets awareness out and everyone knows. With Aboriginal people, it's understood. You don't have to go into this big, articulate spiel about it.

- an Aboriginal person living with HIV/AIDS

Nashine Ginwenimawazawin

I have so many people here that I felt like I was taking it for granted. I wasn't sharing enough. When I saw people that didn't have that support, it made me realize these people are here to help me. I should take that opportunity to get help when I need it.

- an Aboriginal person living with AIDS

I think it was their personalities. He felt comfortable around them. He grew to trust them. There were people with very caring personalities.

My reserve has been really good. Everybody treats me as I was before. It's just another disease that we have to deal with. It's very comforting to know that I don't have to struggle with a lot of different things; the ignorance.

All my other friends from the other communities all treat me the same. I've been pretty lucky, I think. I feel lucky because of that.

- an Aboriginal person living with HIV/AIDS

The other people that offered, he just didn't like their personalities. It may have been because of his past history with them in the bar scene. He just had that gay-man's attitude of judging people by their surface appearance or their gay-scene persona. That's what he gauged things by.

Those people that he let on his care team, he overcame that. He got to know them as real people, outside of the gay scene.

- an Aboriginal support person

Care team people need to have the ability to communicate, talk, or have non-verbal clues. I think that it's important that somebody who knows the person is present because there's always an understanding. When you know how someone behaves and thinks, it's easier to communicate than someone who is a stranger.

You don't know what might piss them off or make them happy. you don't know the indicators of being able to communicate, being able to express a point and being able to interpret the expression.

- an Aboriginal person living with HIV/AIDS

When people are very ill, I have noticed, some well-meaning people are at them all the time. "Why don't you try this, why don't you do this."

It's a tremendous amount of pressure on that person, who is experiencing this catastrophic illness. Even then, that team has to know how to provide autonomy in the middle of all this.

It wasn't so long ago someone was telling me about a person who is being seen by the family as dying. They were frantically trying to help him. They were putting so much pressure on him, he finally said to them, "Leave me alone. Let me die!"

So, what is he saying? If he could really articulate what he is saying, "Give me some space! Just surround me with your love and care. Let me be, in that space."

Quite often, my experience with people that are dying, is that they prefer to talk to someone outside the family because there's all the family dynamics. Where I've been involved with

Nashine Ginwenimawazawin

people who are in that place, because I'm a little outside of it, they can ask me anything or tell me some of their fears.

- an Aboriginal Elder

I found there are major differences between men and women that were taking care of the person. Women were more open to, "Do you need another pillow? Is your back sore? When was the last time you took a bath? Do you need your sheets changed? Would you like me to open up the window?"

The men in the group, I saw them going in, "Okay, okay, come one, we've got to do this right away."

The women, I really found had a lot more respect for the person. It was such extremes. I'm sure if you have somebody to show them the right way; they will go the right way.

They're there because they care for that person. If they didn't care for that person, there's no way they're going to be found. They'll be at the sugar camp. They'll be everywhere else than in that person's home. But, they care enough to be there and that means they care enough to learn things the right way.

- an Aboriginal support person

My own sister was in that position a little while ago. They were helping on the physical, mental, and emotional but nobody was looking after the spiritual. She's from a different tradition than me. One day I said to her, "Has anybody talked to your church?"

She said, "No."

I said, "Would you like me to?"

She said, "Yes."

So, I picked up the phone, called and someone came to see her. They spent a good half an hour with her, which was very good. Somehow nobody was looking for that.

At the same time, I don't think it's up to anybody on the care team to suggest anything, except to offer. Make it open, "How can I help you here? Is there someone you'd like to see?" In her case it turned out she did but she hadn't articulated it.

I was hoping she would bring out many things that were weighing on her. That was my intention, to make an environment where this could happen. It never did.

I did certain forms of healing work with her. There are ways to release emotional stuff or pain without actually going into it verbally. We did do work like that. Other stuff was weighing her down. So me, as a member of the family, was probably not the best person. That's why I got in the other party, to give her a chance if she wanted to talk to him.

- an Aboriginal Elder

People from remote communities have different non-verbal communication. The famous one is considering it impolite to stare people in the eyes.

Aboriginal people tend not to really elaborate or speak a lot in English. You ask them a question and they'll say, "Yes."

People may wonder why they are clamming up. They may not feel comfortable in the English language. A lot of people understand English perfectly, but if Ojibway or Cree is their first language, they may not answer as articulately as they want. They're very articulate in Ojibway or Cree but don't have the active English vocabulary. So, they give a very simple answer to a complex question.

I think a lot of people who go up there wonder, "What's going on? Why are they so quiet, am I offending them in some way?"

If you interrupt somebody or cut them off, they'll sit there and wait for you to finish. In English, it's very common for someone to start babbling away before you're finished. Basically, they'll wait for you to finish and they expect the same from you.

Some people will sit there and think for a while, before they respond. There's a silence there. Aboriginal people are quite comfortable sitting there, weighing their words and thinking about it. For others, it may seem like a long, dead silence. They may be wondering what's wrong and if they're catatonic. No they're just thinking! Some people just take longer to answer and they're not awkward around silence.

I think of the people back home, the older people and the people from the far north who are old-fashioned and traditional. They have a whole different way of communicating, different cadences, different rhythms.

- an Aboriginal support person

DOCTORS



ommunication with the doctor is something that needs to be considered.

Doctor's Checklist - Do They Do the Following?

- ◆ Take your phone calls?
- ◆ Visit you at home?
- ◆ Take the time to answer your questions?
- ◆ Explain things to you in a clear way?
- ◆ Have respect for the Aboriginal culture?
- ◆ Have respect for Aboriginal medicine, including the role of an Elder?
- ◆ Respect the choices of the patient and give them the power to make decisions?

A good line of communication with the doctor can benefit the care team. Some doctors have been very generous with support and sharing information with the person who is dying and the care team. They have supported the environment of the care team by explaining

complex health issues to the person who is dying and the care team. They can be a very important asset to everyone involved.

Doctors are human beings, as well. They can make mistakes, and occasionally they can make major mistakes. For example, a doctor in a remote area had a patient with thrush in his mouth. He prescribed medication and sent the man on his way. After trying to take this awful-tasting medication, he had a dose look at what it was. It turned out the doctor had given him vaginal inserts, to take orally!

Fortunately, his doctor admitted that this was not an appropriate prescription. He told his patient that he didn't know a lot about HIV and that he did want to learn more.

Not all doctors treat their patients in a respectful manner. It cannot be ignored that incidents of abuse can happen, including physical abuse and sexual abuse. A bad history with a doctor could cause her a great deal of anxiety.

Some doctors are intimidating and do not seem open to pass along information. If this is the case, **keep asking questions until you are satisfied**. They are being paid to help you. Doctors are not the only source of information. Explore the Resources chapter for other places you can obtain information.

The doctor you are working with may not have a lot of knowledge about HIV or palliative care. With the possibility that someone has moved home to die, if it is a very remote community, they may be the only doctor available. There are programs for doctors to overcome a lack of knowledge about HIV/AIDS. A

It depends on who the doctor is. Some doctors are really, really good and they'll fit the person in the next day. Some do home visits. Others are complete bastards. Their time is so precious that you have to call ahead and you have to book weeks in advance. A lot of them are really good. The ones that will come into the home are excellent. Usually, those are the specialists.

- an Aboriginal support person

A mentorship program pairs up a doctor who has limited knowledge with a doctor who has a lot of knowledge. Doctors can also work with AIDS service organizations to help get an understanding of HIV/AIDS.

In regards to palliative care, the doctor could work with the Community Care Access Centres and/or the Pain and Symptom Managers, palliative care nurses or any combination of these services.

In the interest of care of the person who is dying, hopefully the doctor would be able to utilize all of these services.

Aboriginal people have had very good and very bad relationships with doctors. The good stories offer hope that caring can come from all areas of the care team, including the doctor. With the stories that indicate there is a problem, some offer strategies for dealing with the situation. Others do not find solutions because the problem is so complex. They suggest more solutions have to be looked for and worked out.

Ideally, communication with the doctor could contribute to her environment in a positive way. It is likely she and the care team will be comforted if the doctor can take the time to

Nashine Ginwenimawazawin

visit and answer questions.

The biggest problem on reserve is the doctoring. They don't have a steady doctor. The damn doctors don't want to stay up there anyway. It's so hard to find somebody. All they do is go to emergency in the hospital.

If they're given anything, it's usually Tylenol, and told, "Go home." They belittle their pain. I don't know if it's because of a racism thing or they're too busy or they don't have the resources, but that's what I've seen.

With palliative care on the reserves, they don't have what we have here. It's obvious.

- an Aboriginal support person

Fortunately, my doctor's really good. He lets his patients decide and gives good information. My doctor has worked with Aboriginal Elders before and knows how the medicines work. He's totally supportive and even asked me to ask an Elder for advice. My Elder feels the same way, he thinks we need to work together with the doctor.

- an Aboriginal person living with HIV/AIDS

I think that's where I count myself lucky because I have a lot of information readily available. I can go to my doctor if I'm experiencing something and have a one-on-one discussion. That's great because I feel really good knowing that my doctor leaves the lines of communication open and we both know what we're talking about.

Sick people become pseudo-medical professionals. In fact, they can talk the lingo after a while because they've experienced it. They know the drug names, they know the treatments.

- an Aboriginal person living with HIV/AIDS

A friend of mine, he's bitter because he feels that a lot of the doctors didn't find the problems quickly enough. Which I believe, too.

There were a lot of things that the doctors should have looked for. There are basic things the doctor should have looked for, for people who are HIV positive, with their T-cell counts at certain points. For some reason, his doctors didn't check for these things. These are the things he had, they're supposed to be common things and they never checked for them, until six months later.

They found out, "Oh. You have a parasite."

Well, these are things you're supposed to check when their T-cell count is between a hundred and zero or something. Well, they didn't check for it. They check for it, like, two or three months later. So, that made us very angry and it also has left him a little bitter.

- an Aboriginal person living with HIV/AIDS

I have a doctor in Sudbury at the Haven Program and my doctor here. The doctor here, he's my family doctor. The one in Sudbury, he's the specialist. I go to Sudbury for my blood work.

Nashine Ginwenimawazawin

I talk to my family doctor about everyday things that go on. I was dealing with headaches. I get a lot of headaches.

He also just gives me the support that I need because he's close to me, here. I'm pretty much his first patient that he's seen through the whole process, from HIV to AIDS. He's had one patient that passed on now, but he didn't get to be with him through the whole process. So, it's an experience for both of us.

- an Aboriginal person living with HIV/AIDS

There's a nursing station that's about a ten-minute drive from me, that my doctor goes to once a week. I usually go see him there. If not, it's in town, which is about twenty minutes.

- an Aboriginal person living with HIV/AIDS

At first, when I went into the area, there was a bit of suspicion, like who is this person; she doesn't seem like a real Indian. So, people would check me out sometimes. I don't speak Cree or understand it, so people would see if I could understand Cree or Oji-Cree.

For me, it was important to understand that cultural difference so I would try and address it, maybe through humour. People in these communities wouldn't understand an urban Aboriginal person or where I am coming from, so there is a lot of testing. They are used to testing new physicians all the time. After a bit of testing or after I had been to a community a couple of times, it was quite positive.

Native or non-Native, I would have to be working in the same community for maybe two years before people would start to trust me.

When people are very ill, I have noticed, some well-meaning people are at them all the time, "Why don't you try this, why don't you do this?"

It's a tremendous pressure on that person, who is experiencing this catastrophic illness. Even then, that team has to know how to provide autonomy in the middle of all this.

- an Aboriginal Elder

The fact that I am coming and going in those communities, is regarded with distrust. They have seen so many people come and go. I have some awareness of that so I don't expect to be welcomed joyously.

I did feel pretty honoured by people confiding in me. Some people would assume because I am Native, that even if I might think a lot different than people in the community, there would at least be an assumption that I am not

going to be racist. It made it a lot easier for me in getting at what the problem was or getting a story from somebody. My cultural upbringing might be a lot different but I still do have some insight into what is happening in some of those communities, what the goals are and how I am going to be regarded. That helps, and overall it was quite positive.

- an Aboriginal support person

When I first had a doctor, I thought, "I am getting tired of a doctor who always likes to give me pills." I said, I want to meet a doctor I feel comfortable with. When I went to see him, I heard a lot of people say, "He is a good doctor, he knows how to deal with the illness, he'll help you out."

I went, "Fine, this is what I need, a doctor who knows about the illness."

Nashine Ginwenimawazawin

That's how he became my doctor. After a while, when I found what he was like, I was scared. I wanted to get rid of him.

He was alright as a doctor. But then he started putting pressure on me. I remember the first thing he said, and I never forgot, "If you want to be on family benefits, I have to have intercourse with you."

Or he gives me a hint, he wants me to go down on him, he wants me to play with him, or something. I was scared, I go, "No, thank you. I'm only your patient, not your sex toy."

He's like, "If you don't do this for me, you're not going on FBA, I'm going to force you to work."

And how can I work? I wasn't healthy at that time.

How he did it, I said, "What do I do? Sorry man, I'm telling you the truth, I have pimples."

He goes, "Okay, pull down your pants. Let me see. Okay. That's normal. He never touched me there, he touched me in the front and he says, "Oh, that looks okay."

I could tell he was playing with me and I was stunned. I didn't know what to say.

I said, "I'm not talking about that doctor, I am talking about my back."

"Oh." He's playing like he doesn't know anything.

He goes, "Okay. Turn over."

Then he puts his hand down, close, but more. I went, "Something is wrong. I feel this ugly thing inside me, like I felt when I was a kid and I was getting abused. Is this really happening?" I am watching him, and yeah, he is.

"Are you finished?"

"Yeah, you put your pants back up now."

After that, I went, I walked out. He said, "You make another appointment in two weeks."

I was afraid, because I didn't know who to talk to about it. It made me feel ugly inside. I go to what I had been through as a kid, I felt so ugly inside. It's like, "Why are these people doing this to me? Taking advantage of me like this? I am just trying to be a patient, trying to get help with my illness."

I felt so ugly inside, I didn't know who to talk to about it or anything, I kept it inside of myself.

- an Aboriginal person living with HIV/AIDS

Nashine Ginwenimawazawin

I know when I first made the decision I didn't want to be on any medication. The nurse at the Haven Program provided me with information. The doctor also talked to me about it. My doctor knew that was my choice. He never bothered me with it.

When I got to Sudbury, my other doctor would just let me know that they were available. He explained to me some of the things that have happened with some people that are taking it, you know, all the good things about it.

- an Aboriginal person living with HIV/AIDS

I know there was this one time, I had a cyst on my breast that I needed removed. I was laying in the room and I could hear the doctors and nurses out there. They were talking about, "This person has AIDS in there."

It really bothered me. All this stuff is confidential. They shouldn't be out there, talking about things like that.

When I told the doctor and the nurse that I was HIV and to be careful, right away the doctor was asking me, "Well, how did I get it?" Those things were none of his business.

The nurse was very nice. She said to me, "Well thank you for telling us."

It bothered me that this doctor would ask me questions that he didn't have any right to ask me. That's mainly the reason why I only go to see my family doctor or go to Sudbury.

- an Aboriginal person living with HIV/AIDS

The doctors that I've dealt with have been really good and really supportive. I just manage to find the right people to deal with.

- an Aboriginal person living with HIV/AIDS

A lot of people, our Native people, struggle with some of those things in town. I don't know if it's because we're Native or not.

There was one time, it wasn't just me, other people were going to the emergency and they had to wait hours before they were treated.

I actually know when my doctor's in the emergency. If I need anything I can go in because I know he's going to be there. He's really good. He's been my doctor since I've been diagnosed.

- an Aboriginal person living with HIV/AIDS

NURSES

Communication with the nurse is very important. Good communication with the nurse or nurses will make them a valuable part of your care team.

Most First Nations communities have a Community Health Nurse (CHN). The role of a CHN is determined by the needs of the community. Nurses can be excellent resources for helping the caregivers learn different skills.

As with doctors, the CHN may be the only one in the area. The CHN could already have his or her hands very full. The time that is required by a care team might not be available. What is the possibility of getting a palliative care nurse to come in and help? You may find a lot of people who tell you it is impossible and the person will have to be moved to a hospital. If he wants to stay at home, it may be a lot of work on your part to get in the resources that you need.

A Community Health Representative (CHR) has an important role in communities. They have been included in this section to acknowledge their vital role as health care providers.

Nurses are under a lot of stress. Often, they are overworked already. With downsizing, restructuring, and the closing of hospitals, there is less and less job security. In some remote communities, they do everything, yet because of the hierarchical health care system, they aren't recognized.

There is no excuse for unkind communication from people in the health field. Some understanding and acknowledgement towards the difficulties faced by nurses may open up communication lines with them. This will benefit the environment of the person you are caring for.

Some nurses can train people for specific skills, for example they can show you how to lift someone without hurting your back or how to feed someone. Do they have the time to explain a skill to you? Do they have the time to answer your questions?

A nurse is someone she has a relationship with. If it is a relaxed relationship, that nurse will be an important part of the team and contribute to her care.

We have a Community Health Representative (CHR) and a nurse. The nurse usually comes in once a week. I've known this nurse for awhile, she knows quite a bit about me. The CHR, she's very supportive too. The CHR works right here at the band office. The nurse comes in, I usually go in and talk to her, even if it's just to say, "Hello" and to let her know how I'm doing.

- an Aboriginal person living with HIV/AIDS

Usually the hospital staff or a nurse comes in and brings the equipment. It's up to the nurse to show you. Some organizations don't want anybody to touch the machine, but that doesn't always happen. Usually the nurse at the hospital would train the individual to operate the equipment and they could easily train or show the person what to do.

- an Aboriginal person living with HIV/AIDS

It takes me about an hour and a half to get to Sudbury. While I'm up there, seeing the doctor, it takes an hour to two hours, depending on how I'm feeling. I usually talk with the nurses.

- an Aboriginal person living with HIV/AIDS

I had to call in a palliative care nurse. He was not involved in the family problems or in the partner problems or in any of the crap that was happening between everybody else. He was concerned only with him, his health, and his dying. Everything else he totally ignored because

Nashine Ginwenimawazawin

it was irrelevant. It didn't deal with his patient, it dealt with the people around him. He brought an objective point of view and clarification to the situation.

- an Aboriginal person living with HIV/AIDS

A nurse would teach in the home what to do. I have been involved in teaching family members and friends how to do things. I would think the volunteers that are taking over would be able to teach as well.

There are certain techniques of protecting your back when you are lifting a person from a bed to a wheelchair and vice versa. Those lifting techniques are taught. It saves more back injuries.

I have taught safe bathing, mouth care, health care. One patient I had bed-bathing, skin care, treatment of pressure sores. Getting a patient up and swiveling him from the bed to the commode.

- a support person

If I get sick, I told my mom not to take me to town. I've had a few situations where I had to go to the hospital. I had blood all over me and it was my blood.

A lot of the nurses are very ignorant to me. It's from a lack of understanding. They're not educated enough to know that it's okay to come near me. It's hard to believe because they're nurses and doctors. They should know all these things.

I had got cut and I went in. The ambulance had picked me up. When I got there, the nurse started yelling at the ambulance drivers about not wearing their goggles. To me, that really bothered me because they had protected themselves. I had told them. They put their gloves on and they were very careful. It bothered me because what do goggles have to do with anything?

She was very rude to me, I found. I had something covering my cut. When she came over, she just ripped it right off. She didn't give a shit about me and how I was feeling.

It hurt me. My way of showing it was I got angry. I started yelling at her and I was calling her names. I was swearing at her. It hurt me. Those things are probably expected for anybody who is HIV positive.

The next time I went in, she was in there again. I told my mom, "You keep her away from me."

There were things that I could have done, legally. I could have reported her for treating me that way. I didn't bother.

- an Aboriginal person living with HIV/AIDS

They treated me all right, I guess. They gave me everything I wanted. There was one nurse. She hated fags.

She was always coming in the room, "Get up, get up, I've got to change the sheets." She used to go off.

- an Aboriginal person living with HIV/AIDS

ADVOCACY

Most people are in the medical profession because they want to help people. With cutbacks, large work loads and hospital closures, the medical profession is now very stressful.

While there may be external reasons for stress, some health care workers have racist, AIDSphobic, homophobic or just plain miserable attitudes. Others may even be abusive. Whether they are doctors, CHN's, non-Native nurses, hospital staff, they are being paid to deliver services. It is not up to them to decide who will get service and who won't. It is also not acceptable for them to deliver services in a hostile way, whether it is obvious or subtle.

When the health care worker is someone you are forced to work with, it can cause a great deal of frustration and anger. You may find you will have to take an aggressive approach to get the services you need.

What channels of communication do you take when you are faced with extremely inappropriate behaviors from a health care worker? Advocacy is when you speak on the behalf of another person. The person you are caring for may not have the energy to do this themselves.

If you are not comfortable advocating, **there are agencies listed in the Resources section** who are skilled at advocating.

Some people have a strong belief in the Aboriginal value of non-interference. This goes against what advocacy sometimes has you do, which is call someone on their behavior. Advocacy sometimes involves calling a service provider on inappropriate behavior. To go to someone and outline the problem is not a part of some First Nations' value systems.

Go to the Patient Advocacy office. There's one in every hospital. Go complain, loudly.

There is a hospital that is supposed to be the most gay-positive ever. They're a bunch of racists, homophobic bastards. It's little comments from the orderlies and the nurses.

We had a client that was in there. He had some mental, cognitive problems, so he wasn't taking care of himself. His hair was all messy because he was out of it.

The one nurse, I actually heard her say, "Look at that dirty Indian."

I confronted her and said I heard it. She denied it, of course. Then, I looked at her nametag and got her name. I went directly to the doctor and said, "This is a problem."

He said, "There's nothing I can do."

So, I went to patient advocacy office and filed a complaint against her. I don't know if she got a slap on the wrist. Maybe they gave her a verbal warning, but she was still there.

- an Aboriginal support person

Respect is given to people to take responsibility for doing something unacceptable and deal with it. Telling people what to do intrudes on their ability to make decisions and learn. We do not have a need to try and influence someone else.

Nashine Ginwenimawazawin

Unfortunately, by leaving it up to someone else to realize they could have behaved in a kinder way, you will often be left waiting a very long time. Euro-western culture often tells people what to do, right from childhood. Silence is often interpreted as consent, meaning if you aren't complaining, then the inappropriate behavior can go on.

You may find yourself somewhere in between two value systems. It may make your role as an advocate difficult. If you leave a situation alone, the inappropriate behavior may continue. If you confront someone, you may feel you are not behaving within your own value system. There is the possibility you could contact an agency (listed in the resource section) to do the advocacy for him. On the other hand, you may be someone who has no problem aggressively demanding the services that he is supposed to get.

Ideally, the health care worker you are working with will have an open mind that will allow in new information, such as learning about First Nations culture. The following people talk about advocacy in different situations, such as demanding the services that the person being cared for was entitled to. Others talk about advocating in the face of racism, ignorance of culture, and physical and emotional **abuse**. One-person talks about the history First Nations people have had with institutions.

I called the coordinator of the service and said, 'Look, these guys are burnt out. They don't have a whole lot of people on their care team. I want to max out the hours. I know it's 60 hours a month.'

She said, "Well, we try and reserve those hours."

I said, "No. We need 60 hours a month."

They're paid to do that. It's funded all through the government. So, we maxed it; you have to demand things because they won't be given to you. You have to ask. They try to keep the hours as small as possible. If you can get by on three hours a week then that's all they can give you. They'll do an assessment and they'll say, "Oh, we can only give you three hours."

That's when you say, "Bullshit. I need more and I know I have 60 hours a month."

It's knowledge, knowing what they can and cannot do. She didn't have a choice because I knew what the deal was. I did my research I knew it was 60 hours a month.

I just said, "You're mandated to provide the service – DO IT!"

- an Aboriginal support person

I said, "Well, most of the time it's your own personal issue and you don't have that right, when you're being paid to deliver health services."

The person asked me, "Why?"

I said, 'You're being paid to advocate on behalf of the individual who is in need of services. So, whoever shows up on your doorstep for help, you must help them. You must be aware of

Nashine Ginwenimawazawin

your own issues and you must set them aside as a professional person. If you feel that those issues are impeding on your health care profession, then ask someone else to come in."

- an Aboriginal support person

I think there's a lack of knowledge with some mainstream organizations. This guy smudged daily. One lady kept saying, "I smell pot in this person's apartment."

I told her, "No, he's not smoking up. He's smudging."

She was still saying, "I think you should talk to him about his drug use."

I still told her, "He's smudging. I'll burn some Sweetgrass, you smell it. It's smudge."

Most people are willing to learn. They're really accommodating people. Most people who are in this field are in it because they want to be. The bad examples are very few and far between, but that's in the city. I don't know about outside the city.

- an Aboriginal support person

I've just prepared a nine-page document called Trans-phobia Curriculum that addresses the different levels of discrimination. One of the things I see in a health-care providing field is intentional discrimination, meaning that you intentionally discriminate against the individual and hide behind legalities.

For example, as a psychiatric nurse, I worked in a detox and saw that a lot. You have a transsexual who shows up for treatment. They're put on a male bedside because their male identity card says so. When I've argued with them, they say, "But legally, this person is a male."

I said, "Yeah, but you work in the field for ten, fifteen years. You know this person has shown up multiple times in the services. For you to do that, you're not creating a therapeutic environment. Your major role as a health care provider is to create a therapeutic environment for the individual. Not only are you impeding on that therapeutic environment, you're actually putting stress on the individual and setting up the individual to go back out using (drugs) or drinking or hurting themselves.

The bottom line is your role is to create a therapeutic environment. The client has a right to be involved in their decision and has a right to be respected as (such). Whether you're an IV drug user or a sex trade worker or a tranny (transsexual).

- an Aboriginal support worker

I had to go for a lot of blood work. There was this one lady in the lab, I'd know her for years, I grew up with her. She was taking my blood and she put the elastic around my arm. She said, "Make a fist. No, make a fist!"

She grabbed my hand and started squeezing it, "Make a fist, bend your arm, no, make it straight. No! No! No!" She just jerked my arm around like crazy. She was really rough with me.

Nashine Ginwenimawazawin

I told my friend and he told this doctor, who phoned the supervisor. She phoned me up and asked me who it was.

I said, "Will this get me in trouble?"

She said, "No, it won't. We need to know who this is."

I said, "Yeah, really. You guys work with the public. Ships are in and out of this town, loggers are in and out of this town. There are IV drug users, everything. We're not a big city but we have the things a big city has. This town is going to get a lot of people with HIV and a lot of them are going to want to commit suicide when they find out. If somebody is being treated that way in the hospital then it's going to encourage a person more to commit suicide."

She's like, "Yes, I know. Well, who is this lady?"

I really hated to give her name. I said her name.

She goes, "Do you want us to fire her?"

I said, "What? Holy shit, you want me to answer that?"

She said, "Yes."

I said, "No. I don't want her to lose her job over this. Just talk to her and tell her to be a lot nicer to people, especially people who have HIV."

She goes, "Thank you."

I felt really good because I could have said, "Yeah, fire her." I could have but I didn't. There are a lot (of) things I could have done but I didn't. I'm glad I didn't because it had a little part of my life and changed some things in my life.

- an Aboriginal person living with HIV/AIDS

His sister, I talked to her about it. I explained the situation and she spoke to him. Then, he agreed with her. He realized that I wasn't able to provide 24-hour care that he needed and I didn't have enough money.

I phoned the AIDS Committee of Toronto and I phoned his doctor about getting him into the hospital.

They said, "They won't admit him, as long as he's got a place to go."

So basically, you have to take him to the emergency and abandon him there. That was how we got him admitted into the hospital. We phoned the ambulance, it took him up to the emergency and he signed himself in.

They asked, "Do you have anybody to look after you? Do you have any relatives?"

He said, "No."

Nashine Ginwenimawazawin

They begrudgingly found him a bed. There were no beds available in any of the wards, so he was in the emergency for about two days. When he was in emergency, they treated him poorly. He was incontinent and they were giving him hell for that. They were yelling at him. I didn't actually witness this.

He was telling me, "They're not very nice to me in here."

They just kind of stuck him in this little, tiny room. There was nothing in there. He was there, by himself. It took them a long time to respond to him to get anything. They were still

harassing him, "Don't you have any family, friends?"

His sister came to see him and they found out that was his sister. They really wanted her to take him with her.

She said, "No, I can't take him, blah, blah, blah. I live out of province."

She had to lie so they would keep him there. She realized that he needed medical attention in a hospital. They really didn't want to have him there.

This is the case with anybody that wants to go into the

hospital if they're in the palliative stage. If it's not an emergency, they'll harass them. They don't want to take people that have full-blown AIDS into a hospital unless they can see the person is not going to recover. If they're coming in through the emergency, they don't like dealing with people having AIDS, I guess.

Once he was on a ward in the hospital, it was a lot better. He was treated a lot nicer and he was more comfortable. A couple of times he was able to come out.

They wanted him to wait at home until he could get into the hospice, Casey House. He told them he was on the waiting list but he was too sick to stay at home. They still didn't want him in. They're not always compassionate as you would see on ER. Doctor Welby and Conswello don't come around the corner with a bouquet of flowers saying, "Welcome to the hospital."

- an Aboriginal support person

TWO-SPIRITED PEOPLE

The person you are caring for may be two-spirited. She may have lived her life, faced with many incidents of homophobia. Homophobia can come in the form of silence, exclusion, discrimination, name-calling, and violence. If she has experienced a lot of this during her lifetime, she may not trust people easily.

She may also be very well adjusted to being a two-spirited person. In some areas, discrimination is lessening. Elders and traditional people and communities are beginning to work with two-spirited people. In the media, positive images of gay and lesbian material is in the media a lot more. Movies, TV, and magazines are increasingly featuring gay and lesbian characters and themes.

The following quotations talk about two-spirited people. They talk about experiences that two-spirited people have, living with HIV/AIDS. Some talk about dealing with homophobia. There are ideas about how a two-spirited person can be at peace with themselves, even in the face of homophobia.

There are some teachings about two-spirited people but there aren't very many Elders talking about those teachings. Some Elders say that there are no teachings. Other Elders say that there were specific teachings for anyone who is unique, including two-spirited people.

Because he is gay, I get a lot of comments like, "He deserves what he gets, if he had been straight, he wouldn't be in this mess."

I find I get defensive because people will sit around at work and make fun of gay people. I get quite upset and now I finally speak up and say, "Excuse me, but remember my friend is gay and he's a beautiful person. I would appreciate it if you didn't run down gay people."

- a support person

Two-spirited people are gifted. A description of the role of two-spirited people have is not possible because each individual is different. For example, some two-spirited people have a gift of mediating for people that are in conflict. This, however, is not something only two-spirited people can do and not every two-spirited person has that gift.

Some two-spirited people do not think they are valuable, because they are from a homophobic environment. This may prevent a two-spirited person from finding out what their gifts are and how to nurture them. There are few leaders, so it is hard for young two-spirited people to learn from role models that they can develop their gifts.

More and more two-spirited people are healing themselves.

There is no denying the devastating effect of AIDS within the two-spirited Aboriginal community, especially two-spirited men.

If your care team is caring for a two-spirited person, in order to communicate well, it would be helpful to know some of her issues, including: multiple grief, AIDSphobia, isolation, homophobia, racism, and sexism.

As two-spirited people, we've already dealt with our own issues around sexuality, identity, and homophobia. In that sense, we're able to talk openly and move beyond a lot of things that people who have less need for awareness or this false sense that we don't have a need to be aware. Denial. We're already working at a stage that's beyond that. People in the positions of influence are also perpetuating barriers, these phobias. Whether it's from a Catholic influence or residential schools, the point is, it exists. That type of denial essentially kills. If they can't accept and they can't look at the things honestly then they're obviously not going to do anything about it. That seems to be the mentality at some reserve levels.

- an Aboriginal person living with HIV/AIDS

I sometimes can't believe the hypocrisy of the so-called traditional people. One time, I had this traditional drummer tell me, "If you are two-spirited, you are abusing the gift of the Creator by not having kids." What a stupid crock of shit!

His brother has a real hang-up about him being gay but he only talks about it when he's drunk. Some people just don't take other people's feelings into consideration.

- a support person

people." They should be saying "Some of my relations."

I see these traditional people crawling out of a sweat, saying, "All my relations." The sweatlodge doesn't work like confession. You don't go in, purge yourself, make it all better, go out, and act like a jerk until the next time you go in. Yeah, their words are saying, "All my relations," but their behaviour is saying, "All my relations, except two-spirited

Elders are echoing the homophobia that was originally perpetuated by residential schools. They're saying two-spirited people don't exist because there aren't any teachings for them. There used to be teachings. We're all sent by the Creator with a specific purpose and this includes two-spirited people.

When you hear about the horrid sexual abuse that went on in residential schools, (that is now continuing within our communities), yeah, it's no wonder that Elders and their following generations have some pretty insecure ideas about sexuality. The people that ran those schools perpetuated hatred against two-spirited people. Combine the years of painful generational abuse with homophobic messages, and presto, you've got yet another reason for us to hate our own community members. The homophobia from residential schools and churches is now integrated into our own teachings.

This isn't to be mistaken for an attack on our teachings. They provide us with wonderful guidelines for living our lives in a caring way. This is about those people that abuse those teachings by saying one thing and then doing something else.

I see these traditional people crawling out of a sweat, saying, "All my relations." The sweatlodge doesn't work like a confession. You don't go in, purge yourself, make it all better, go out, and act like a jerk until the next time you go in. Yeah, their words are saying, "All my relations, except two-spirited people." They should be saying, "Some of my relations."

- an Aboriginal support person

We are all very obviously in pain. We all have our own horror stories about what we have lost, how we were abused and what we have to put up with now. Some people have found the strength to quit drinking and found the pride to find out what our traditions are. Take it a

Nashine Ginwenimawazawin

step further and stop hating the rest of the world. This wounded-healer shit has got to stop, if we ever expect to heal ourselves.

If a two-spirited person lived in a community where they were cared for in a non-judgemental way, why would they run away? If they were treated as one of the "all my relations," with respect and love, would they have a damaged self-esteem? True healing, instead of hypocritical healing has to start. Otherwise, we're just going to keep getting two-spirited people being forced to run away from their communities. Add a damaged self-esteem and that person isn't going to give a shit about themselves.

So, there's a lot resting on the shoulders of these traditional people and these Elders and leaders. A genuine healing process has to start in the two-spirited community as well. Our own people are clearly the best people for the healing process. The systems from other cultures obviously hasn't worked.

So, instead of reeking of homophobia, like fighting over HIV/AIDS dollars that are just going to dissolve into administration, actually do something to care for the people that are living with HIV/AIDS.

Going to all the sweats in the world isn't going to make the lives of two-spirited people better, especially the ones living with HIV/AIDS. The healing and spirituality has to be put into action to include everybody. It's going to start with your decision to heal your fears, value yourself for just existing and contributing in a genuine way to your community.

There are many places to start. If someone is on a care team, it is a wonderful opportunity to act in a healing way – with love, care, and non-judgement, whether they are two-spirited or not. Aboriginal communities, from reserves to cities to national leadership, have to care for two-spirited people. Homophobia in any form is just an insult to our own teachings.

- an Aboriginal support person

In my teachings, I have no teachings for them. I have an adopted mother, her people have teachings specifically for what you call two-spirited people

What we have is, anybody that is born different they used to be taken and taught they were special. There was an honoured position. They were taught right from birth and they knew. They were taught to be that kind of a person, the medicine person or the Elder or the Spiritual Helper to the people. They were taught from birth that they were special. It was anybody that was different. They had probably been dreamed about by some of the Elders.

Dreams were so much a part of our every day life. Now it's become something special. We have to get back in touch with it. It's our tradition.

They were special. It could have been anything. They were raised to have knowledge and help the people. It was the understanding they came specially for this reason. It was an honoured position. The opposites. Contrary.

- an Aboriginal Elder

Nashine Ginwenimawazawin

First of all, in the Aboriginal community, we're known as two-spirit, which includes gay, lesbian, bisexual and transgendered people. In my community, the only racism I've encountered were Christian-based influence. Religions are the ones that tend to discriminate and exclude, instead of being inclusive. Laws have been built on religious philosophies, they're very religiously influenced.

I do understand if I discriminate myself against people, then I'm no better.

One of the things I think is extremely important to realize is no matter who you are, you have key issues that will affect you that you're keen on. You want to take their cause up and help. Everyone wants to help someone that's poor, on the streets. That's in general. (I'm sure we'll find people that don't want to do that, and think the poor are poor and it's their fault). It's to realize that we all have issues that are keen to our heart, that we want to defend and take up and help. Then, there are issues that really make us cringe because they're personal and they affect us to the core of our belief.

To recognize that and to recognize that it is their issues, not my issue. Then, I'm comfortable with that because then I can work around the individual. I can say, "What is it you don't understand? Let me help you, if I can. I will pray for you."

- an Aboriginal support person

I know two-spirited people are gifted. Traditionally, we were the ones that could see Indian colours. We were visionaries, able to see the lights that come into ceremonies. Medicine people, healers, mediators. We were also like cupids. We could understand and see through the eyes of the male and the female. Not all two-spirits have that and it's not unique to two-spirited people.

I think two-spirited people start at a different point. If you look at our Elders, through all the years they get to a point where they come to terms with sexuality. They're not dealing with other issues. They can see things from the female's and male's perspective. They respect sexuality. That's how two-spirited people started their life. In a sense, we have a head start that way.

Not all two-spirited people are spiritually inclined or even have the motivation to develop their skills. There's no teachings and no talk about two-spirited stuff, so people can't even validate or recognize their own gifts.

One of the roles of two-spirited people was looking after the people that were dying. A lot of people couldn't deal with death or do that kind of work, but two-spirited people could.

I guess it's because we've had to deal with so much stuff, just by who we are and we've moved beyond that. We're able to put aside differences or sexualities, our convictions in order to benefit the whole.

When you talk about two-spirited people, it's hard not to generalize. I don't want to sound as though all two-spirited people are like this. I don't want to make it sound as though we're

better than anybody (else is). I also don't like the way that other people think two-spirited people are less than they are. It goes both ways.

- an Aboriginal person living with HIV/AIDS

Two-spirited people, through my observations, are respected. Whatever kind of forum it is. People stop and listen to us when we speak. People notice us when we come in. It's not because we're sashaying into the place, snapping our fingers and wiggling our snake hips. When a two-spirited person talks, everyone listens.

A lot of people, when they're gay, get ostracized or pushed away by the community. They know damn well the community's going to do it if they come out of the closet, so they leave anyway. That's why there are so many two-spirited people here in Toronto.

When they die, it's generally safer for them to stay in Toronto and then get shipped home after they have passed on. That's really unfortunate for the person and it's also unfortunate for the community. If anything, that is the shameful part of this whole process. It's not shame on the person who died, it's shame on the community.

- an Aboriginal person living with HIV/AIDS

Not to be bragging, but I really do believe the two-spirited people have a role. We are going to have that position of honour again. As more and more people come to realize that two-spiritedness isn't about sexuality. Why two-spirited people generally have sex with the same sex, I don't know what that's about. But, whatever it's about, two-spirited people are gifted, regardless of sexual aspect.

I know I'm gifted. We do have a lot to offer the community. We're not above the general community. I don't like this hierarchical system.

We are gifted and we have definite roles. It's not one role, we function in all components of community. The political realm, the warrior realm, the medicine realm, the artistic, the creative.

- an Aboriginal person living with HIV/AIDS

The behaviours associated with homophobia, it's a mentality. Everything that happens is connected with a core illusion of what masculinity is supposed to be about or what femininity is supposed to be about. That's how culture develops and behaviours and traditions carry on. It's by people. They think their behaviours are normal and healthy. That's why the bashing happens and the teasing.

That's also why the sexes are in conflict. Two-spirited people are coming back and filling the role of mediator, to bring back those sexes into reality. It's different than the superficial pretense of what they are supposed to be, according to someone else. It's going to take time.

- an Aboriginal person living with HIV/AIDS

I think the work with AIDS is most important. It is important that we all work on it and we all have an understanding and knowledge of it. I see it more predominant with two-spirited people, that this work is so special. That they were given the gifts and the entitlement to teach us about it and work with it. That's their work.

That's what I call the owl speaking. Their work is the owl speaking. What I mean by that is the owl talks, the owl speaks, and their work is with people that are dying. We always say that,

when we hear the owl crying, the screech owl, that means death is coming.

So, that takes a special kind of people to work with that death, to work with that space. There's so much involved in it, it's so heavy that only the two-spirited understand and know. They're the only ones I've seen taking it really that serious. The people that aren't two-spirited, they are working towards it.

They're just really sensitive people. Most sensitive. Their spirit is so big and so sensitive. They already know this. Their spirit is what we call, "The highest of spirit." They're already with the animals, working. I've seen a lot of white people like that, also. They're not afraid of it.

You can't be afraid of it because it's the inevitable for us. If we're all afraid, then we're all just going to keep running and not enjoying life. We can't live. I think what the owl teaches and speaks about and screeches about to us, is that responsibility. That's what I've seen with the two-spirited.

That's why I want to work with them. That's most important, the AIDS issues and how to die. A good, respectful, manageable dying, that we have in our culture.

- an Aboriginal Elder

FIRST NATIONS LANGUAGES

Some First Nation's people speak their own language and some don't. Some have understanding, but don't use their original language in everyday use. Loss of language is a painful part of many people's lives.

There are people who are committed to preserving First Nations languages. They are people who learn the language and use it. It is healing in and of itself, when you are able to converse in your language.

If he speaks his language, he may have understanding of both his original language and English or French (or both). If this is the case, you may not need a translator for the care team to communicate well with him. As a care team member, if you can arrange for someone who speaks his language to be there, it will be a great comfort and support to him.

Those missionaries, they used syllabics to translate the bible into Ojibway. Syllabics are used for Cree, Ojibway, Inuk, Dene. They call them syllabics because each symbol stands for a vowel or consonant. It stands for a cluster, usually a consonant, followed by a vowel.

You may have to find a translator for him. Translators are a vital link in being able to communicate. Not only do they have to have a complete understanding of medical terms, they have to be able to explain them into the first language. Their important role in being able

There's one that looks like an "L." Then, it's flipped upside down, then it's flipped another direction. It's quite logical because as the vowel changes, the syllable turns.

- an Aboriginal support person

to inform the First Nations patient as well as the medical staff is spoken about in some of the following quotations.

Nashine Ginwenimawazawin

In remote communities where the first language is still Ojibway or Cree or Inuk, if you're getting professional medical care or explaining complex issues, you need someone who is very knowledgeable about medical issues and terminology. They have to understand what they are in English and then translate them into the Aboriginal language.

Most of the communities are fly-in communities. The language is so strong because they're isolated, they hardly speak any English. Ojibway is the everyday language they use.

I think at some point they will have to translate things into Ojibway and Oji-Cree and syllabics. A lot of people use the syllabic alphabet.

No, that's one thing that I don't know how to do (speak my language). A lot of our people here aren't able to do that. I wish I knew how to. I find it very interesting when I see our Elders talking in our language.

- an Aboriginal person living with HIV/AIDS

A translator is going to have to be available. If you're about to fly up to Big Trout Lake you would need somebody to translate. Someone who really knows Ojibway well and English well.

English and Ojibway are so different. It is complicated to describe what the English term is. It takes a lot more words to describe the medical term in Ojibway or Oji-Cree. It's very important you get a speaker from the community because dialects vary from community to community. In most southern communities, English is the first language and most people are bilingual.

- an Aboriginal support person

I'm a big promoter of our languages and preserving them. I hope one day, our languages come back and we'll use them in our every day lives. Whether it's in Toronto or on reserves, it's important to promote them in any avenue that we can. Aboriginal languages have to be our languages of education and language of business. It's the most important issue today, above self-government, above economics. Language preservation is the most important issue

I speak my own language. I talk to some of my friends in the city. They're from Saskatchewan, but I understand them. My other friend, his accent is so different.

because if we lose our language, we will lose our culture. You can express a lot of our ideas in English or French. When our languages die out...

- an Aboriginal person living with HIV/AIDS

When someone from the Italian community forgets his language here in Canada, he can go to Italy and relearn it. If someone who is Chinese loses their language, they can go back to China and relearn it. But, if Haida dies out, where are you going to learn Haida? There isn't anywhere to go. This is where our languages are. We have to do something now.

- an Aboriginal support person

You could contact someone at the nursing station because there's usually Aboriginal people on staff. The CHR is usually bilingual. If they're not available, call the family and see if there is somebody there who can translate.

A friend of mine, his grandmother was in the hospital. She was getting a scope in her stomach. He translated into Cree what they were saying and what they were going to do. She was much

Nashine Ginwenimawazawin

more comfortable.

Same in Thunder Bay. There was an elderly woman in the hospital and she couldn't speak a word of English. They phoned my sister and asked if she could translate. They didn't even know who she was, if they had the right elderly lady. They had her on a stretcher and were wheeling her in for the operation. They were totally confused and nobody on staff was Native. Out of desperation, they phoned the university and were transferred to my sister.

My sister got there and spoke to the woman. She asked her, "Who are you? Where are you from? Are you here for an operation?"

She answered, "Yes."

They said, "Tell her we're going to give her a needle."

So, she knew what was going on, but I think she was very relieved. The nurses and doctors were very relieved, also.

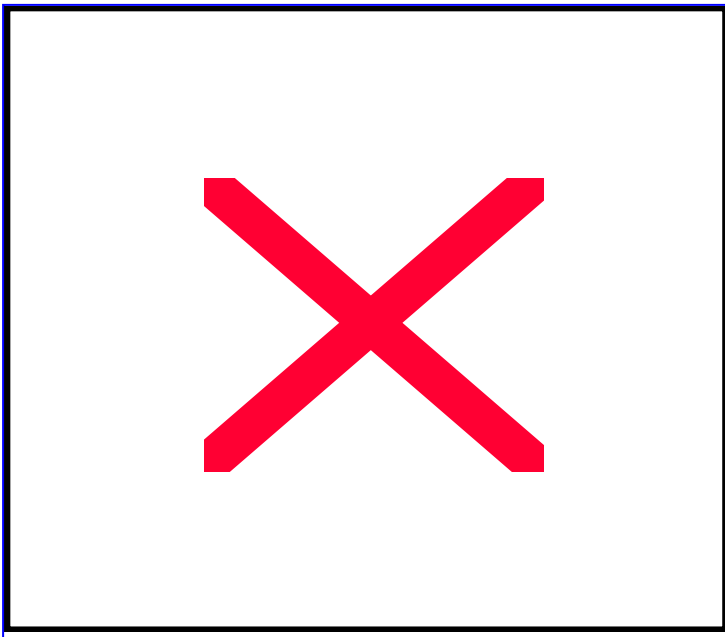
- an Aboriginal support person

LEGAL

There are legal decisions that are made when someone is dying. Legal decisions can be a challenging process for a person you are caring for.

He may have to think about whether he wants someone to take care of his health or his finances in the event that he becomes unable to make these decisions himself. He may have to decide where he wants his belongings to go when he dies and who is going to distribute these things. He may need to know that his funeral arrangements are going to be carried out exactly the way he wants.

He may need a lot of your support when he is making these decisions. It may not be easy



for him to think about dying and could be even harder for him to think about making decisions around his own death.

Legal documents can occasionally create conflict. For example, a partner could obtain a legal document excluding the family from any involvement in decision making. A family could also get that document and exclude the partner. It is important that he knows what legal decisions he is making, so that no one is going to be shut out of his life.

The following quotations include some legal issues that care teams caring for an Aboriginal person have experienced, and the person you are caring for may want to consider.

If the person has full-blown AIDS and is close to death, there would hopefully be somebody on the care team who walks the same path as them. They could look at the traditional wants and needs the person may have towards death.

Are there going to be ceremonies? Is moccasins or a ribbon shirt going to be done up? Who's going to do that? Who's going to be doing what? What will go with the person when they are buried? Are they going to be buried?

- an Aboriginal person living with HIV/AIDS

Nashine Ginwenimawazawin

There have been situations where same-sex partners have tried to get in and the family has excluded them. There is not really a lot you can do. That is why we should talk about a living will and the kinds of decisions you can make and directions you can give. A living will can prevent your partner from being excluded in decisions and situations where you want them to be there.

If you do not have any written instructions like that, the family can pretty well exclude you. In the absence of a legal document or a document expressing your wishes, the family is the one that a court or a doctor or anybody would look to. So, they could probably exclude the person.

- an Aboriginal support person

It is important to figure out before a person gets too sick whether or not the person would want to be resuscitated. There are important points for the person to talk about with their care team or their physician. "Running a code" in a hospital is a big intervention. It is one of the

If the person has full-blown AIDS and is close to death, there would hopefully be somebody on the care team who walks the same path as them. They could look at the traditional wants and needs the person may have towards death.

- an Aboriginal person living with HIV/AIDS

only things that we do in medicine without asking people. It is one of the most aggressive interventions and we should be asking people, more and sooner, whether they want this done.

If someone had a chronic or terminal or advanced illness, hopefully the physician would do that when they are admitted to

hospital. I would let them know that I ask everybody this question because it could be scary to the person. If a doctor says "If your heart stops beating....." and the person thinks, "Oh is my heart going to stop beating?" or "Do you want a breathing tube?"

I try to explain it in lay terms and I give choices. Some people would choose to have an effort at shocking the heart, to get it into a more regular rhythm but not to be intubated *a breathing tube) or not to be put on life support in the intensive care unit. I try to go through what the different interventions are.

The main aggressive things that we do are to try to shock the heart or put in a breathing tube or do CPR by pushing on the chest. Often people get broken ribs and things like that from CPR. I feel it is a cruel intervention if we don't know if the person really wants it.

Most of the time in hospital, a physician would be made aware of that wish for no interventions and they would write a "no code" order on the chart. So, I would write, "Do not resuscitate, no CPR, no intubation." Then they would put that chart in a different coloured binder so that hospital staff would know.

If I am on call at the hospital and I get a call to see the patient in the middle of the night, I would ask if the patient is a "full code" and that means they have asked for all of these interventions. The nurses are also aware of that.

- an Aboriginal support person

You should ideally have all of these things, a will, a living will, a power of attorney, and an executor. Part of the problem is that it is difficult for people to think about. With AIDS, we

Nashine Ginwenimawazawin

have to think about death. We have a lot of really young people who have hardly started to think about their life and what they want to do. They never think about their death. It can be really hard to get people thinking in these terms.

When you are talking about a living will, you are talking about a period of time when you will have lost control of your life and you are still alive but you can't do anything the way you used to. You can't make decisions, you can't take care of your health, your bills and pay your rent and stuff. You start talking about someone who is going to do those things for you and then you also have to start thinking about what is going to happen once you die.

It is very difficult for people to go there. What I always try and say to people is, go there when you are healthy and you are not worried about it. Try and do it now. It may mean that you have to revisit it more often as people in your life change. If you are lucky there won't be a lot of that. You will have the right people that you have picked to do things and you won't have to worry about it so much. It is really important. If you are going to do one, do them all at the same time while you are still able to do it.

- an Aboriginal support person

One of the things to think about and decide is whether or not to have a postmortem exam (autopsy). I would try to sort out those issues in advance because it is not very nice to have to ask the person in mourning, right at the time of death.

- an Aboriginal support person

If I am cremated, just to have my ashes spread either on the reserve, or somewhere related to nature. I would leave it up to my sister to just choose a quiet spot.

It doesn't really matter where I'm at, because the funeral service would be more for the individuals around me. It would be more for my friends to attend than for myself, basically.

- an Aboriginal person living with HIV/AIDS

I think I only had one experience where a Native guy was dying and that was my brother. His partner didn't believe in the Aboriginal practices. I don't think he respected the family's wants and needs on a spiritual level over how he was to be treated or cared for after death. That has caused a lot of hardship with my family and it's something I think we can never forgive him for. It shows a total disrespect for not only the Aboriginal belief but also for my brother as a two-spirited man.

There was no belief or respect for the practice of smudging or my brother's burial slippers. Where I'm from, if someone is dying, then a pair of slippers are made and given to them. They wear them for awhile to kind of embody the spirit within the slippers and they're buried with them. His partner didn't allow that to happen. It was never done and it caused a lot of anguish in the family.

When you are talking about a living will, you are talking about a period of time when you will have lost control of your life and you are still alive but you can't do anything the way you used to. You can't make decisions, you can't take care of your health, your bills and pay your rent and stuff. You start talking about someone who is going to do those things for you and then you also have to start thinking about what is going to happen once you die.

- an Aboriginal support person

Nashine Ginwenimawazawin

My brother was not able to communicate. His partner was the only one who legally had the power of attorney. The power of attorney was supposed to have been done with the family's consultation, but wasn't. A date was set for the legal matters to be prepared but his partner did everything beforehand without the family's consent or involvement. We didn't find out until afterwards. To contest it would have taken a lengthy process. It was an ugly scene.

Not too many people advance plan, especially for their death. I think advanced planning is good but letting people know what is to be done and not just letting one person know but a couple of people, whether it's family members or very close friends who will stick by you. I think it's very important that everybody knows the same information about what's to be done

about your pet or for the bank accounts or if you're to be cremated or not. That all has to be done in advance and told, so that there's no argument after.

- an Aboriginal person living with HIV/AIDS

I was afraid to deal with the will. I was so afraid I wouldn't go inside a funeral home.

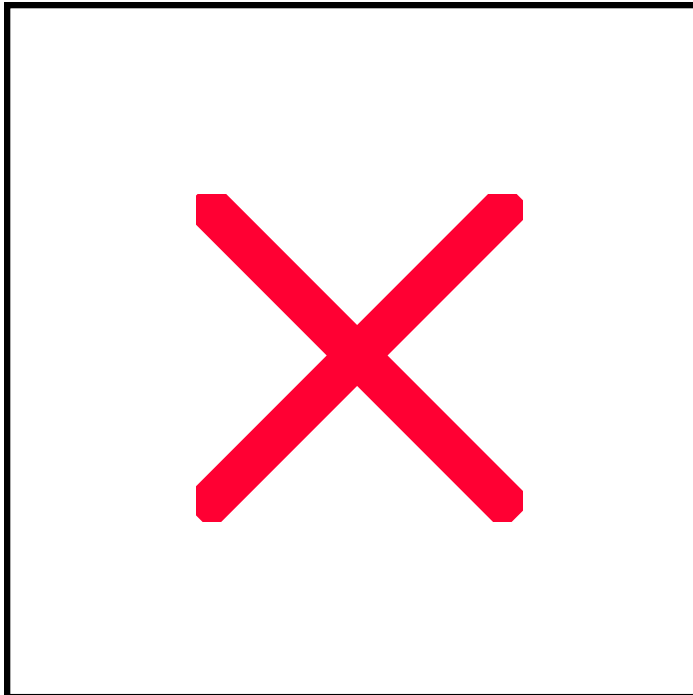
I met my friend at Positive Straight Men. We're still friends today. He calls me, to see how I'm doing. I call him and ask him how he is doing. He tells me how he's dealing with his, and I'm trying to encourage him, and tell him how I'm dealing with mine.

We come visit and be like normal friends and see how we're doing health-wise. Then after we know that we're doing all right, we stop talking about it. After, we just do normal things, "Do you want to watch a hockey game this winter?"

When I started to feel sick, my friends said, "You have to try it out."

I said, "Okay, I will think about it for a month or two."

I saw this phone line on a TV commercial about how to prepare for your death and all that. I called them up and I got the information. It talks about how to prepare yourself for when your own time comes, coffin, how you want to be buried, burnt, who you want the service to be done with.



Nashine Ginwenimawazawin

My friend said, "I will be with you if you want me to come." I went. Got it done. I only pay about thirty dollars a month, for my coffin and everything that has to be done.

If I never paid it off after two years, and something happens to me, I don't have to worry about paying it back, neither does my spouse, my wife. They say, "This company will pay the whole thing off."

I was looking at the ideas on how you want to do it. My friend, he wrote it all down because he knows I have a problem with reading. He looked up and said, "Do you want this, that, or this?" I tell him which one I wanted and he corrects it for me.

Then we went up to the funeral home. There's this guy that I have to talk to. I told him what I wanted. My friend said he would do the talking for me because he knows I have a hard time explaining how I really feel. Because of the virus, he might look at it the wrong way, when I'm trying to say it the right way.

The guy goes, "If you want to, I'll take you inside of the room, it's all coffins. Which one you want, bring the card in when you want it and we'll figure out how much it's going to cost you. He lets us go in there by ourselves.

I do want to get burned. I let him explain they give some kind of urn and you won't have to pay for it. If I want one of my own, like a gold urn, then I have to pay that out of my own money.

I want there to be a service before I go and I want to have my coffin open in case people want to see me for the last time. Everything what I told him I wanted done, he wrote it down. One part I have to do is write the will where I want all my belongings to go.

I did all that and he says, "This will be two thousand and something dollars for it. If you pay close to thirty-one dollars a month, after the two years, if something happens to you, this company will pay the whole thing. You won't have to worry about your wife, she won't be in debt.

My stomach was feeling sick, woozy. I'm like, "Whew, what am I doing?" I was feeling really like, awkward, like, "Oh, gross. Let's get out of here quick."

When I did get out of there, my stomach felt like I was going to vomit. I was that paranoid.

My friend goes, "Relax man, I'm with you. I felt the same way the first time I went in there. Don't worry about it. It's nothing to be afraid of. It's going to happen one of these days and you've got to face it."

But on my side, I'm saying, "It's not going to happen."

What I know I feel like I am getting close to death sometimes, I play the movie Beaches with Bette Midler. That song she sings, I never knew it was about someone who was dying, and I cried when I heard it. I started singing it, by myself, "I want to get this song to play, dedicated to me, if something happens." Two of them, Long Distance and Wind Beneath My Wings.

I get the movie, and boom, look what it is about. It's about Bette Midler, helping a friend of hers, he's dying of cancer. That was a shock when I seen that. I never even thought the movie was going to be about that.

That was the hardest thing I had to do. I was always afraid. I said "No, I don't want that, to look into that."

By the way, my friend told me, I have to face that one day. I know he understood. He is going through the same thing I am going through. I was like, "Okay."

I got a friend of mine, he is a pastor. He said he'll do the service for the family inside of a church. When that is over, they are going to play two special songs.

- an Aboriginal person living with HIV/AIDS

Once he got into Casey House, they arranged that. He did write a will. His sister had the power of attorney. I think Casey House spoke to his sister and she did that on her own. She arranged it through her lawyer.

- an Aboriginal support person

QUESTIONS AND ANSWERS

These are some very basic questions and answers to common questions about living wills, wills and the general state of the law. Everyone has different circumstances and the law may change. Please make certain that you go to an AIDS service organization, a legal clinic or get some legal advice to prepare you for some of the legal documents which you may need. The resources section has some useful contacts for these matters.

What is a Living Will?

A living will is what happens to you and the management of your health when you are still alive. It is written in the sense that at some point, you may fear that you will not be able to make decisions on your own because your mental health will have gone, you may have dementia, you may be confused or you may be so ill that you cannot express your wishes. A living will is that kind of document where you write out what you want done, who you want to speak on your behalf and make decisions for you when you are not able to do it.

- an Aboriginal support person

Why do I need a Living Will?

I think that one of the fears that everybody has is a loss of control or direction of your life. If you don't have something like a living will, what happens is that people who you may not want to make those decisions in your life, will be making them for you when you are not able to do so. So what a living will does is extends your own decision making authority beyond the time when you may not be able to express your wishes.

You want a living will, for example, if you have a disease like AIDS which can be quite debilitating. You have certain feelings about what you want to happen to you when you are very ill. Some people will want all sorts of interventions. They will want life support systems and will want to be fed through a tube in their noses.

Other people will not. So, what they will say is "When I am dying, I want to die with dignity and I don't want all of these machines plugged into me and all of these heroic measures (as they are called) taken to prolong my life. I don't want to be living in a world where I don't have any quality of life. What I am going to do is express my wishes in a document. I am going to say what I want done and what I don't want done."

You can be specific as you want, you can say, "No nose tube feeding, no life support or resuscitation and things like that. You can also say, "I want to be drugged into a painless state."

You can be as specific or as general as you want, for example, "No heroic measure if I am near death."

- an Aboriginal support person

It's up to the client if they want to be rescued or not if they're choking. If they don't care, they just want to die and are clear, "I do not want a 911 call. Just call my family and my doctor after I breathe my last breath."

- an Aboriginal support person

What is a Substitute Decision-Maker or Proxy?

Through your living will, you also tell people who you want to make those decisions for you and so that person is, in legal terms, your substitute decision maker or proxy.

What you are doing then is saying, "These are my wishes, these are my decisions which I am making while I am capable of making them. I'm mentally competent and I'm of legal age. I can make all of these decisions and these are the decisions I want carried out if I am not in a state to express them."

- an Aboriginal support person

Who should I make my Proxy?

What you have got to do is pick somebody as your proxy who will do what you want. What you have to do is sit down and take a really intense look at your life and the people around you. You have to have a lot of trust. Are they going to follow your wishes or not? It is a big decision you have to make.

- an Aboriginal support person

What things should I consider when I'm choosing my Proxy?

A living will and a proxy raises a lot of issues for two-spirited people. They may have been rejected by their family. They may be with a partner who the family doesn't like or they may not be "out" to their family or their community.

What they have to think about is, will the person they pick do what they want them to do? What kinds of trouble is that person going to have carrying out their wishes? Maybe the family doesn't like the person or they know the person doesn't like them.

If you think there is going to be a lot of stress around the person making the decisions, whether from the family or other persons that are going to be second guessing, then you should be very specific and you should pick a person who is really strong.

The way to guarantee that your partner will get to see you when you are sick and that your family won't try and get the doctor to take life-saving measures that you don't want, is to appoint your partner as proxy. But you have to really know your partner and that your partner will carry out your wishes.

When a lot of people are in a relationship, it is fine, you talk about these things. What happens when you are in a coma and you cannot express yourself or if you are in an advanced stage of dementia, it is easier when it is not happening now. You have to also trust that your partner is the kind of person that will not do what they feel but will do what you want.

- an Aboriginal support person

If a partner is racist and does not allow the family to do ceremonies, if there is nothing in writing then the family would be the one that a court, doctor or anybody in authority would look for as the best "substitute decision maker."

What the law generally recognizes is that the family is the one that has the closest connection. If there is nothing in writing, the family could just tell the partner to get lost and do what they needed to do.

If there is something in writing and say, the person was not traditional and they did not want ceremonies. Then they should write in their living will what they want done and what kinds of things they agree to.

Frankly, if the partner is racist and the person themselves is converted to another religion, then the family really could not do anything if it is in writing and is a legal document.

- an Aboriginal support person

It has to be someone who does what you want, not what they want. The more clear you are, in a living will or power of attorney, about what you want done and who you want to do it, the better it is. In a living will, you can pick two people. It is a good idea to have two because one of them may not be available or one may move away. You know Aboriginal people move around a lot. What if they are both there and they argue about whether or not this medical procedure should be done? Who has the authority? So you have to look at the strengths of

people, their willingness to take it on. Will they stand firm? Some people can be really miserable to each other because they are grieving, or afraid. There can be all sorts of nasty fights and you have to make sure that your proxy is going to do what you want and withstand a lot of criticism and pressure from family and friends. Is the person someone you can rely on in the long term? Hopefully it is not someone you met a week ago. It is someone who has proven to be trustworthy. It may not be some one you are very close to or anyone your friends like. It may just be someone who will do what you want done.

- an Aboriginal support person

What happens in case of Medical Emergencies?

When you are talking about palliative care, you are talking about a period of time when it is expected that someone won't get any better. So if you have a living will, a care team should become familiar with what the person's wishes are. That means for example, if someone is not eating, they are refusing liquids or food, they are not talking, they are sleeping all the time, you look at that. Those things are key. You don't force food on people. The question is what has the person said in their living will?

If something happens and the person stops breathing and they have a do not resuscitate order in their living will, you don't call an ambulance and you don't call a doctor. You let them go, because that is what the living will says. That is why you have to be very clear.

Now if a person is lying there and they are choking, you don't let them choke to death. You do what you can to clear the problem up and to ease that discomfort. It may be that you can't stop it and they die, but at least you make an intervention. You want to look at what the person wants, what instructions they have given and follow them. What they are often saying is, "If I am dying don't try and keep me alive."

There are certain humanitarian things that you do but if a person is at the palliative stage, you are not calling ambulances or doctors all the time. Certainly, some health professional is monitoring things and assisting the care team with how the person is doing. There has to be some contact with a health professional. Even in remote areas, it may be the Community Health Representative but in the palliative stage there is not a lot of medical intervention. Apart from the very basic needs the person has, to be relatively pain free and in comfort, you are not trying to do blood transfusions, you are not trying to make them eat or take medications. What you are doing is letting them go without artificially prolonging their lives.

There is a complete difference if you are talking about an episode where they have an opportunistic infection, for example PCP. You are not going to yank them off oxygen or throw away their pills, because they can recover from one of these episodes.

- an Aboriginal support person

What is an Enduring Power of Attorney?

There is another thing called an "enduring power of attorney." It is the same kind of thing as a living will, except that it doesn't talk about health, it talks about appointing a person who is going to pay your bills, take care of your bank account and stuff like that.

This is so things go smoothly if you cannot write cheques and go to the bank. That person can also be your partner, if you have the faith and trust in that person.

These kinds of legal documents that you need, they are not that complicated. If you are incapable of expressing your wishes about your health, you will probably be incapable of expressing your wishes about your money and who is going to pay your rent and your bills. Not everybody is in a position to go into a hospice and have people around them to deal with all of that stuff.

- an Aboriginal support person

Why do I need an Enduring Power of Attorney?

You may need someone to pay your bills. You may want these things done but if there is no one designated to do it, what would happen is if two doctors certified you as incapable of making these kinds of decisions, they might have someone appointed as "committee." It might be someone in the family or the Public Trustee. You may be okay with someone from the family but if the person designated by the Public Trustee is someone who has a lot of files and no personal interest in you, you will end up with strangers making decisions for you. So even if you don't have very much, it is important to express your wishes in a way that they can be carried out.

- an Aboriginal support person

Can I change my Living Will or Power of Attorney?

The thing with a living will and a power of attorney is that if you change your mind, you can change them any time as long as you are still mentally able to do that. You can change your proxy, your power of attorney.

A power of attorney for your financial and business stuff will end when you cancel it or on your death, so that person cannot carry on afterwards.

- an Aboriginal support person

What is a Will?

A will is something you write for what happens to you and your possessions after you die.

- an Aboriginal support person

What is an Executor?

When you die, it would be the executor of your will who will take over. They take all of your possessions and assets, then deal with them as you want in your will.

- an Aboriginal support person

Why do I need a Will?

There's always cases of who inherits what, after the person has died. This is really important for Aboriginal people, particularly status Indian people because if you die and you don't have a

Nashine Ginwenimawazawin

will, you die "intestate." This means that your property and anything you have, gets distributed to your family.

If you don't have any family it gets distributed to the government. The government will come in and deal with everything and take whatever proceeds there are. You will get the cheapest basic funeral and you won't have ceremonies. If you are a flash dresser you won't be dressed in your flash clothes.

- an Aboriginal support person

Sometimes there are tensions between family or friends. You may not have a lot of things but you may have some things which are important to you, that you want to give to certain people.

If you don't have a will, the first place it goes is to your family. If you are not close to your family or there has been some sort of split in your family because you are two-spirited or because you have HIV or AIDS that may not be where you want your things to go.

You may have pets that you want to make sure are taken care of. You may want them to go to your partner and your things to go to your partner.

- an Aboriginal support person

I have had experiences with horrible situations where people who died wanted their things to go to their partner. The family stepped in, removed the partner completely and the partner got nothing. That is a terrible thing and the law does not support the rights of same-sex partners. So, if you have a same-sex partner and you don't have a will, you might as well kiss your wishes good-bye.

It is really important that you think about, if you have things you want to go to certain people and whether you have stresses within your family. If you think they are going to come in and push your partner or friends aside, you should have a will. If it is done legally, with witnesses, the family would have a really hard time establishing that their wishes should go over yours.

- an Aboriginal support person

What decisions can I make in my Will?

- ◆ Who will get your property.
- ◆ Who will give out your property.
- ◆ Who will be a guardian to your children.
- ◆ How you want your funeral.

You can make decisions around funeral arrangements and things like that. If you are traditional and you want traditional ceremonies, you can provide for that in your will. If you don't want to be buried and want to be cremated, you can provide for that. Some people want to be dressed in their finest and some people don't. You can establish what you want.

Funerals are really for the people that remain behind. You may want people to have a great big party and celebrate your life. Whatever you want, unless you tell people what it is and put it in

some document, which has legal status, you are not going to get your wishes respected. That is the most important thing.

- an Aboriginal support person

During your funeral, if you want your body shown to the public, the body must be embalmed. Some funeral homes don't want to handle people with AIDS first of all, because they are ignorant and secondly, in the process of embalming, body fluids are drained and then embalming fluid is put in the body. Without appropriate precautions, there can be a danger of coming into contact with body fluids or there can be needle pricks. Some funeral homes have claimed that it is a health and safety issue for their employees, so they don't handle people who died of AIDS-related causes. It is difficult to address this kind of discrimination and it can be very stressful for a family or a partner when their loved one has just died. However, in Toronto there is a lot of experience with people who have AIDS and there are a number of funeral homes who can be relied on to act appropriately. Many people I know have been cremated, there is that choice.

- an Aboriginal support person

How do I make a Will?

Wills are very simple to do. There is a sample of what to consider in Managing your Health. (see Resources chapter) and some other documents put together by AIDS Service Organizations.

All you need to do is write up your wishes, sign it and have two witnesses to sign it. Have them sign it at the same time as you sign it so that they can see that you signed it and that nobody made you do it against your will.

- an Aboriginal support person

A holograph will is like a will, in that you write down what you want done with your things, yourself, etc. It has to be entirely in your own handwriting, it has to be signed and dated by you. There can be no typing or printing on it, it has to be entirely in your own handwriting. You also have to sign that it is your last will and testament and that there aren't any other ones or that it replaces any other ones. The great thing is that all you have to do is write your wishes down and date and sign it. It is the cheapest method.

- an Aboriginal support person

Who can help me with my Legal Papers?

It is really important that if you have something, if you own land or a house, that you get legal advice. You can get free legal advice from one of the legal clinics. There are some Aboriginal legal aid clinics, there is one in Thunder Bay and Aboriginal Legal Services here in Toronto. There are probably a few more around the province. You can get free advice on what to put in and what not to put in. They probably have samples for you. It is important to know what you are able to do and not able to do before you make a will.

- an Aboriginal support person

For someone in a remote area, it is really difficult. There is something called Dial-a-Law in Ontario which has a 1-800 number. You can get basic legal advice and referrals to lawyers.

Some lawyers will give advice for nothing, which is called doing "pro bono" work. Others will take legal aid certificates. Most people who don't have any money can obtain legal aid certificates for basic legal work such as wills. There are legal clinics in most areas of the province and legal aid plan offices as well. AIDS service organizations often have people who know how to write simple wills or can make referrals or who can assist you in drafting a living will. So that is where you should look.

- an Aboriginal support person

Can Wills become complex?

There are some complications because there are certain things you can't do. For example, you can't give somebody something you don't own. So if you are paying off a television, it doesn't really belong to you until the last payment is made. You can't give that away and you can't make arrangements for somebody else to take over the payments. That was your debt and once you die, it returns to the owner.

- an support person Aboriginal

There are some issues about wills that you should talk to someone with some legal expertise in this area. For example, if you are entitled to property on a reserve, you can't leave it to your partner if your partner is not a status Indian or if he/she is a same-sex partner. The law does not recognize these kinds of gifts and First Nations land is held quite differently than it is in the city or anywhere off reserve. There can be some very complicating legal issues for status Indians who have property on reserve.

With your personal possessions and anything you are entitled to give away it is much simpler. But if you have some kind of property like a pension plan, same-sex spouses are not entitled in the same way as heterosexual couples are. You should sit down and figure out what you've got and give a call to a legal aid clinic or an AIDS service organization and they will tell you what kinds of things you can write in your will.

- an Aboriginal support person

Where do I keep my Will?

The executor and your lawyer (if you have one) should have a copy of your will. You should make sure there is somewhere official where you keep the original. The executor can go and make sure that his/her copy of the will is a true copy.

- an Aboriginal support person

What should I consider when I am choosing my Executor?

The person has to be of legal age and of sound mind.

Often after someone dies, people might get upset because they didn't get what they thought they would. There might be some strife between the partner and family, so the executor must be someone strong and committed to doing what you want.

You can make your partner the executor and the executor can be a beneficiary of your estate.

Being executor is a lot of work and can be emotionally distressing to people. Make sure your wishes are very clear and the person you appoint knows what you want. For example if you want a traditional ceremony or you don't want one. If you want a dozen drag queens in front of your casket or whatever, this is where you put it.

- an Aboriginal support person

What do I do with my documents if I live on the Street?

Some people could go to an organization, such as Aboriginal Legal Services, and say, "If anything happens to me, this is what I want..." and have them write it down.

There is a Living Will Registry in Ontario and you could register your Living Will there. It doesn't mean it is any more legally enforceable but it is a place where people can check to see if you have a living will. They will send you a card for your wallet or whatever it is that you carry around, which says that you have one.

So, a street person could carry a card like that, saying they have a living will or a will and where it is. If something happens to you on the street, the authorities will search for identification. A legal clinic or an AIDS Service organization or an organization, which works with street people, could have the original in their file. So, even if you don't have possessions, you may want to express where you want to be buried or how you want to be dealt with after you die.

So, no matter where you are, if you have a piece of paper saying you have a living will or a will at say 2-Spirits (2-Spirited People of the 1st Nations, see Resources chapter), then anyone dealing with you will know where to find directions. Most AIDS service organizations and certainly 2-Spirits, will assist in finding family and resources to ensure that someone is cared for or assisted in their journey to the Spirit World. It is also possible to designate someone from an AIDS service organization to be the executor.

- an Aboriginal support person

What does the Executor of my Will do?

The executor carries out your wishes, that is the terms of your will, so far as he/she is able to. (For example, if there isn't enough money to carry out some of your wishes, they may not be able to follow through on all of your wishes).

They arrange the funeral, pay any outstanding bills. If you have a bank account, after you die the bank account is frozen. Even if your partner is a joint signatory to your bank account, he/she will not be able to access funds. That is why it is important that there be an executor and if you are able, make your partner the executor.

Every one of your possessions will go to your executor. It is almost like you leave everything to your executor, but your possessions do not really belong to the executor. They belong to the people you have given them to and the executor is like a trustee who holds everything for the beneficiaries (the people you want to give your possessions and property to).

The executor will make sure that the funeral is the way you want it. They also have to file your final income tax for that year. They will settle your debts and notify beneficiaries and distribute your assets to beneficiaries. They will also have the will "probated" (validated by the courts). If there are very few assets or if the will is very simple, the will may not have to be probated.

- an Aboriginal support person

What if the person I am caring for is not interested in any of this Planning?

If the person who is terminally ill is in denial, has been offered the information and they don't want to take it, I think there's a point where you have to honor that. They can't be hassled about it.

Just recently, I went to what's called a pre-arrangement session, where you learn all about what's available at the funeral home. You learn what the processes are and the current costs. You ask questions and you talk about it.

So, I was saying to my relative that perhaps it's something he'd like to know, but it was, "I don't want to hear about it."

"Okay. I'm going to mention it from time to time." I'm going to keep mentioning it. I know that he cares about his loved ones. If there's no preparation, they're the ones who are going to have difficulty.

Here again, those communication skills, "I don't want to talk about it." It might be possible at that time to say, well, "What's the worse part of that for you?" They may be looking for a way to express that feeling.

They could still say, "I don't want to talk about it."

So, we always have to look at that and say, 'Okay, if they are in serious denial and the time is getting close, we can bring it up every now and then. If they're really, really strong on that position, we have to respect that more than the provision of the relations.'

There's a certain position I wouldn't go past, to hassle a dying person, You've got to get your power of attorney, you have to get your will!" It's not respectful.

- an Aboriginal Elder

What if I am a Caregiver and I believe that the person I am caring for is no longer capable of making competent decisions about their health, personal safety, or finances?

This is a situation where the care team has to have a relationship with the doctor(s). Two doctors can certify that you are no longer capable of managing your finances or your personal affairs. It could go to a court and the court will appoint a committee or substitute decision-maker. It could be family members or the partner or the Public Trustee. A Public Trustee is a situation you hate to see happen because it might be someone who is not personally involved with you at all. You may be one of a hundred people that the person is already acting for.

- an Aboriginal support person

Is there anything I can do if the Band has passed a Band Council Resolution to kick me off the Reserve?

Yes there is. I would find a lawyer fast. (See Resources section). However, if you don't have money it is another issue. I would find it unbelievable, although we have heard stories about it, that someone would be kicked off the reserve because they had HIV or AIDS. It would offend human rights legislation and the federal Canadian Human Rights Act would apply. The question would be whether the Canadian Human Rights Commission could act effectively to do anything about it. But that is where I would go next.

The person should get a copy of the Band Council Resolution (BCR). There are a lot of people out there who would support any action taken to support the person who had been BCR'd off the reserve.

I think this would be a real sign of the fear and panic that is so unreasonable and stupid which happens in First Nations communities when you are dealing with HIV and AIDS. It would be something, which would need to be publicized and fought immediately.

- an Aboriginal support person

Where do I turn if I have been Discriminated against?

There are some differences between us. When we are talking about human rights and you are talking about discrimination against someone who has HIV or AIDS, if you live in Toronto, it is more than likely that it would be the Ontario Human Rights Commission (see Resources Chapter) which would handle the complaint. In Toronto, there is also the HIV/AIDS Legal Clinic of Ontario (HALCO) (see Resources Chapter).

If your employer was a federal entity and there was discrimination, then it would be the Canadian Human Rights Commission. (see Resources Chapter).

There are jurisdictional issues around human rights. If you are a First Nations person, you live on a reserve, you are a status Indian and you are discriminated against by the Band Council, that is a federal matter. Indian reserve lands come under federal jurisdiction and then you would go to the Canadian Human Rights Commission.

- an Aboriginal support person

EUTHANASIA AND ASSISTED SUICIDE

What are the laws on Assisted Suicide and Euthanasia?

Euthanasia is when a person takes an action that ends the life of another person who is suffering from a terminal illness. This may happen by lethal injection or stopping medical treatment that would prolong life, such as IV feeding and respirators.

Suicide is intentionally taking your own life; assisted suicide is when someone helps another person to take their own life.

There are many opinions and arguments about euthanasia and assisted suicide. The following points are only a few of the arguments for and against euthanasia and assisted suicide.

What is the Law on Euthanasia?

Euthanasia is essentially killing someone because they have a horrible disease and the quality of their life is very poor and you are assisting that person to die. It is against the law and doctors and nurses are not allowed to do it. It is a criminal offence and people have to be very careful about things like this. There is no foolproof way of establishing that you are acting in that person's wishes.

- an Aboriginal support person

Why is Euthanasia so complex?

Euthanasia and suicide are two areas that cause some people in our communities some trouble. Hopefully what you are doing is carrying out their wishes, and that is why euthanasia is such a difficult issue for people.

The trouble I have in this question is that there is a moral and ethical debate about this stuff. Assisted suicide and euthanasia can be the same thing. You are in the hospital or at home and you need to be on life support so that you can carry on living. You decide that you don't want to be on life support and you make it clear. The doctors and nurses are following your living will and you say you don't want any life support. Your family and partner and friends are all hearing this. You are dying and everybody is helping you die by not doing what may be medically necessary. It is not black and white, it is in the area of the greys. You are essentially killing someone by not intervening. That is why someone makes a living will because they

don't want to be on life support for a couple of miserable weeks. They would rather die peacefully and go quickly. But it is still euthanasia, if you look at the definition of it.

- an Aboriginal support person

What are the laws on Suicide and Assisted Suicide?

Committing suicide is not a criminal offence. Assisting someone by aiding, abetting or counselling someone is an offence.

- an Aboriginal support person

Why is Assisted Suicide complex?

People can print pamphlets on how to commit suicide and the best ways of doing it. But the person has to go and get the pamphlet and follow it. So that is not seen as counselling, aiding or abetting someone. Where does the grey stop and become black or white? You say "I'm going to help you save your pills and I am going to watch you take them. I am not going to stop you and I am going to sit here and be with you. I am going to ensure that there is a doctor nearby to come in and pronounce you dead." Is that aiding and abetting suicide or is it allowing you to do what you want?

- an Aboriginal support person

Why are there laws for Euthanasia and Assisted Suicide?

Apparently, the law is there to capture the person who is going to go around killing people when they are not ready to die. The law wants to prevent people from killing other people because they want their estate or their money or just to be rid of people who are sick. The law of course, deals in black and white. Euthanasia and assisted suicide is not about black and white situations.

- an Aboriginal support person

ABORIGINAL VOICES SPEAKING ABOUT EUTHANASIA AND ASSISTED SUICIDE

Euthanasia and assisted suicide often provoke heated arguments because they are not only legal topics, they are also many moral and ethical points of view on whether or not they are acceptable.

Within the Aboriginal community, there have been many, many suicides of children, youth and adults. Some communities are in a constant state of shock and grief, due to suicide. With this painful reality, talk about suicide is likely to be very emotional.

The following stories contain beliefs around euthanasia and assisted suicide. Elders talk about what happens to your spirit when you take your own life. Some Elders have been known to state that they will not do certain ceremonies if someone has taken their own life.

Nashine Ginwenimawazawin

Others will do ceremonies that will honor the person. Still others will do a particular ceremony for someone who has taken their life that is different from a ceremony that would be done for someone who didn't take their own life.

If you are thinking about suicide or talking about it, there are Traditional people who tell us that suicide is really a horrible thing. I don't know how much of that is traditional or how much of it is because so many Elders have been Christianized. There are stories of old people who felt they could no longer contribute and because of times when there was a lot of hunger and game was scarce, the old person would go off in the bush and die because it was their time or they didn't want to be a burden. Now was that committing suicide? If that was committing suicide then how come the community accepted it as a norm? We have heard these stories from all sorts of nations that this was accepted as something that was done in communities. So, if the Elders are telling us that it offends some kind of natural law then I don't know what to think about that.

- an Aboriginal support person

There have been teachings, the teaching of the fire. Putting something out of its misery has been...there were ceremonies around that, with wounded animals that people have come across when they were trapping. I believe there were actually ceremonies to put that animal out of its misery. I'm sure those happened with people as well, especially when there were times of war and someone was wounded and couldn't be healed. But, maybe not.

Euthanasia and assisted suicide, whether or not I'm for it? When it comes to "pulling the plug", for lack of a better term, if somebody is technically dead, don't resuscitate them. If they're brain-dead and obviously not going to get any better, pull that plug, by all means. If it happened to me, I'd want you to.

Some people, when they're diagnosed HIV positive, they become suicidal. Other people go on and go through the whole cycle. Unfortunately, they may go through a lot of pain, or their faces and eyes may cave in. They may be getting sores. Yet they just keep holding on and holding on. I wouldn't want to suffer like that. When I look at my life, I've done enough suffering already!!! I get the point!!! Thank you!!!

I think it's up to the individual and it's up to the community. It's up to the people involved, the Medicine People involved. It's not solely up to the Medicine People. It's got to be done in a consensual way, where it's a decision that everyone can abide by and live with. That's the best way to approach it. You can take one position which may be fine with some people but will offend others.

- an Aboriginal person living with HIV./AIDS

I wouldn't do it myself. But, I would not stand in the way of someone who wanted to do it. Again, it's respect and non-interference. That is their opinion of where they want to go.

My belief for myself is that my spirit has given me a path to walk through and I trust my spirit and I trust the Creator is going to take me through that path. Therefore, I need resources and I need help to go through that. I don't want to get in the way of the Creator. Personally, what I would hope, that I would have the strength to do that, myself. If someone else decided that they wanted to go through with euthanasia, then I have no business interfering. It's not

Nashine Ginwenimawazawin

my business. It's that spirit's choice and that spirit's path. I'm not suggesting anybody else do it. For me, I would not interfere with somebody who wanted to do it.

- an Aboriginal Elder

A couple of years before, we had discussed suicide and I had told him what he needed to say if he was ready to take it, if he decided he couldn't carry on. Without going out of his way, he had access to a medication that would have ended his life. He chose not to, but at least he had the option.

I think with AIDS, the way it is, it should be discussed with them sometime when they are healthy, or at least reasonably healthy. I appreciate that not everybody is going to agree with me, but I think they at least deserve to be able to think about the option. The actual last few weeks of their lives are not worth a crock of shit, from my point of view. I would certainly appreciate giving me that information. I know that's not for everybody.

- a support person

There are really strong value systems against suicide. You do not have the right to take that life given to us by the Creator. We do not have the right to take it. It's perceived as the "God" part of you. When it's time to go and whatever happens, happens. Nothing I have ever heard says it's okay. It's just a no-no. When you talk about assisted suicide, again it's not in our ways.

It's like in the prison, when some of those prepare to die, they "go to the wall." They don't eat or drink for however long, they're prepared to die and that's their choice. They're not supposed to do that and you're not supposed to assist them. You don't try to force them either. It's their choice and their decision, but nobody else has the right to do it.

I have walked 25, 32 days with one guy in the prison. I walked with him and had given up trying to talk him out of it. I just walked with him. At the end, he did eat. But it's like that, I would walk with them to the wall, to death. But I wouldn't help him.

- an Aboriginal Elder

That's why a lot of old people would refuse drugs or say "don't put me on any machines, just let me go. Don't keep me here either, past the time that I should go. Keep me as comfortable as you can, and then just let me go."

- an Aboriginal Elder

I would have to talk to the spirit about going on. I would alert some of those spirits I know and have seen work with those suicides. The spirit stays wandering. There are people over in the spirit world that work with them. They help those lost souls so that they can go across afterwards.

We limit God and we have no business limiting God, to say "this is the way it is." It's cause and effect: you do this and this happens. If you take your life, there are things over there. It's common sense.

When I've gone fasting, they've showed me, I haven't just asked my Elders. Creator gave me a mind, Creator gave everyone a mind. He didn't give my mind to you, he didn't give it to my daughter or my mother. He gave my mind to me, so I have a responsibility to use it. When I went searching, they showed me. I incorporate it.

- an Aboriginal Elder

Nashine Ginwenimawazawin

To say that I would not do a ceremony if someone committed suicide? Well, for me, that's setting myself up in a certain place that I wouldn't want to set myself up.

I would boil it down to the lowest common denominator. Here is a person who has chosen to do this. I'm not going to honor their earthly remains? I'm not going to honor them with ceremony? When I boil it down to the lowest common denominator, if there is any way a ceremony would help the person who has gone on, plus the people who are left behind, then I would do it.

I'm not rigid in that way. I don't say, "This is the only way." I'm not very good at that. It's always the immediacy of the moment and what's happening there, too.

That smacks in the way of certain church groups who say they don't allow people who commit suicide to be buried in their cemetery. I have always had a problem with that. If you boil it down to bare essentials, here is a person, here is the burial. To me, it's a person-made rule. I don't think it's a Creator-made rule.

Therefore, someone who belonged to that tradition strongly enough and said they couldn't do it, so be it. I would suggest to the family, "Get someone else who will do a ceremony to honor this person."

There are many things like that, which is why you need clear thinking. You have to see where these things came from. When they're person-made rules, what is the spiritual principle? Always, my guiding question is "What is the spiritual principle here?"

The spiritual principle in many traditions in many cultures is to honor the dead. You can see it in ceremonies all over the world. Honor the dead. That is the basic thing. If I'm going to snub this person at that time and the family at that time, that is not honoring the dead.

There are many person-made rules that have crept into the traditions. One needs to be wise, to look for the spiritual principle. Some of those rules are made, not to promote a spiritual thing but to promote power.

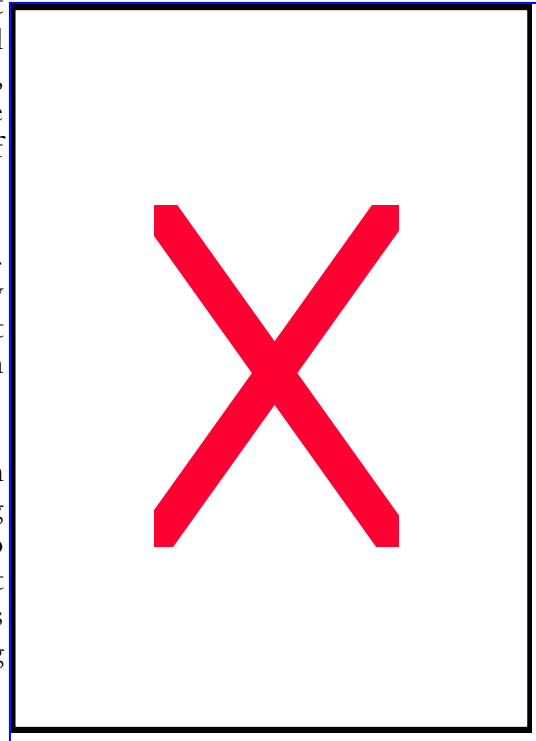
- an Aboriginal Elder

RESOURCES

Resources are people or places that can help you and your care team. Your family, friends, and community are resources. This chapter is about the assistance or resources you will find within different organizations. Resources can provide a great deal of assistance, including information, support, services or supplies. You may find that the people providing services will become valuable partners of the care team.

Each area of the province has different resources. Resources on a reserve are going to be very different than those in a city. The resources that one reserve uses will probably be different than another reserve.

Resources change. Some of the information on this list may be out of date or on its way to being out of date. Some services may disappear due to funding cuts. There may be new resources that have come into existence after this document was printed. Other resources and programs are being taken over by First Nation's communities.



Tips for Phoning Resources:

- ◆ Have a list of questions before you call. As your questions are answered, it may be helpful to jot down notes.
- ◆ Write down the name of the person you spoke to. This will be beneficial if you expect to continue working with them and will help avoid confusion when you have to phone again.
- ◆ Don't hesitate to ask questions if you are confused about something. There are so many details to remember when you are a care team member that some confusion is bound to happen. If you are faced with a great deal of information, it may take you a bit of time to formulate a specific question. Give yourself the time to think it through, then simply phone the organization again.
- ◆ It may take a few phone calls to get what you need. If the resource you are phoning is not able to help you, they may know who can.
- ◆ Most people are in the helping field because they like others and want to help.

Unfortunately, there are some people who don't care. There are also over-worked helpers who are expected to do everything. Many people in the helping field are dealing with the

Nashine Ginwenimawazawin

erosion of their job stability. Racism, internalized racism, homophobia and AIDSphobia exist in places that are supposed to be helping you. If the person you are phoning is not cooperative, you may need to contact somebody from another organization to advocate for you. An advocate will work on your behalf, so that the person you are caring for will not be denied services that are his or her right.

The following are experiences people have had with different resources. Some people using resources have found that the organizations have been very constructive, helpful and supportive. Others have experienced negative and destructive behaviours from people within resource organizations. As with everything, there are the mixed experiences where both negative and positive situations occurred.

Within the following stories are details of what services are offered by different resources. You may not know that a particular resource exists in your area. Perhaps there is a service that the person you are caring for is entitled to and no one told you about it. An advocate worker may inform you about it and help you access that service. Also within these stories, you may find solutions to help you resolve problems you are having with a particular service provider.

At the end of this section, there is a list of resources found throughout Ontario. The resource list has contact information, phone and fax numbers, addresses, etc. In addition, there are brief descriptions of the services provided. Again, remember that the services offered may change.

The **highlighted** word refer to the resource that the storyteller accessed. This is to give you an idea of different resources that may be available to you. If you are in a remote area, you may recognize that work has to be done to create resources in your community. While you are putting energy into the care team, you may not have the time to do this yourself, but you could bring it to the attention of someone who can.

You might want to contact the band or the nurse in charge of the nursing station. I would see the nursing station as a positive thing, in terms of wanted to work together with somebody who was going to do that. It depends on the band.

Unless AIDSphobia or homophobia was getting in the way at a band level that would hopefully be seen as a positive thing. What they try to do here is have one physician who works with the community most of the time. We give in-services at the nursing station. We do weekly rounds with all the nurses calling in. You could try to get the support of some of those people.

There are some physicians who have worked for seven to ten years, so those are the people who are more trusted. They have been there longer. If the community physician is well respected, the community will support that program.

It would also be important to get the support of the band. The communities are usually quite small, so you try and identify the community leaders, in terms of health and get them on your

Nashine Ginwenimawazawin

side. It would depend on the individual but you would hope that there would be enthusiasm for that kind of project.

- an Aboriginal support person

Most Reserves, at least in Ontario have the CHR (Community Health Representative) program. They have the Family Support Workers, at least up in my area. The Nechi Institute does a lot of work with the Family Support Workers. Nechi is the actual trainer of the Family Support Workers, at least in my tribal area.

The role of the Family Support Worker is kind of like crisis intervention, prevention, something similar to a counsellor or a social worker. They educate and provide workshops to the community.

- an Aboriginal person living with HIV/AIDS

Most Reserves have their own Home Care set up. It depends on the reserve. I know they're not all the same but most have Community Health Representatives. They can either go into the house themselves or they have paid homemakers to go in there.

From what I heard, there aren't enough hours. It just ends up being one person doing all the hours. Then, there are big gaps where the person is just left and the family fills in as much as they can.

- an Aboriginal support person

Casey House does really good training. 2-Spirited People of the 1st Nations can do it. Any place with cancer or terminal illness usually has that kind of training, if the AIDS Service Organizations aren't around.

- an Aboriginal support person

Sometimes it's the VON (Victorian Order of Nurses) that comes in. We work quite a bit with Casey House Home Hospice. They provide volunteers. They have access to massage that will come into the home once a week. There are Social Workers through different agencies. They go talk to the people about how they're feeling and providing support. That's very individual, it's like counseling.

The massage and therapeutic touch is usually through Casey House, but some other places have it, too. Sometimes, it's free. Usually, you have to pay for it, if it's outside of Casey House. Sometimes your doctor can arrange for it to happen free if it's part of treating your peripheral neuropathy.

We work with the Metropolitan Community Church of Toronto. They have a group of volunteers, too. A lot of the churches do volunteer programs.

Sometimes an occupational therapist will come in. That's mostly for people who have cognitive problems. Like if they had brain surgery and some of the cognitive stuff isn't there. They'll teach them different ways to overcome that, memory tricks. They also do a little bit of counseling, too.

- an Aboriginal support person

Nashine Ginwenimawazawin

They treated him really well at Casey House. It was mostly gay people working there, the staff, the nurses, the doctors. He felt very comfortable. It was downtown, near the Village. It was more accessible for people to visit him, so he was getting more visitors. They had a taxi chit program, so he could take taxis home to the apartment.

Friends were able to take him out to the bar or take him to church. He was a member of the Metropolitan Community Church of Toronto. He used to go to church on Sundays.

He had a life at Casey House. Up in the hospital, he was so isolated and far away from everybody. It was a hassle.

He felt comfortable in there. He had a private room because he was so restless. He was disturbing to other person so they put him into a private room.

He liked the food. He had a TV and a phone right beside him. It was all the things that he needed. He felt comfortable there. He got to know all the nurses and the doctor on a first name basis.

Most every day he went out or he'd wander around the building. They found him in the basement, one time. He was snooping around. He was into everything, just like a little kid.

- an Aboriginal support person

Usually, you can call AIDS Service Organizations or the band office. It depends because some places are only mandated for a certain area. It never hurts to ask. Maybe they could give on-reserve people training. It's being creative with your options.

The other thing is talking about people restructuring what their roles are. Some people might be in the community as homemakers, but maybe they could be taught to give needles or to do lifts and transfers. Give them extra training and boost their dollars a bit.

When you're looking for volunteers, not just looking within the AIDS service area. There are other terminal illness places, like cancer organizations that might have volunteers available. Churches, community groups. If there's a church on the reserve, and there usually is, use that as a way to mobilize people.

I'd say the first thing would have to be education. HIV/AIDS 101. Bring in people that are knowledgeable about it in to do community workshops. Find the people in the community that aren't messed up and that people look up to. Try to connect and organize with them.

- an Aboriginal support person

We have medical trips here at the reserve. They pay for it, for someone to take me in. When I go to Sudbury, the band was paying for and I was approved. The government pays for my travel to go to Sudbury. It's not a whole lot of money but it's something to pay the driver.

- an Aboriginal person living with HIV/AIDS

We discuss it with the patient. Quite often if their wish is to stay at home, I can go by that request. To get them stabilized, or if they are not coping well, or they don't have the support at home from family members or friends, I suggest they go in to Casey House for two-week respite.

Nashine Ginwenimawazawin

They don't have to worry about the drugs. They don't have to worry about what food they are going to be having for supper or breakfast or otherwise. They can go in there and get their stress released. In there, they have no worries at all to think about it. Maintaining their own health, it's taken care of and they seem to do an awful lot better.

I think death is probably enhanced by stress issues. The one I sent to Casey House didn't have family members who would look after him at home because they were out of town. He had some very good friends, but you know, the friends were still working. They couldn't be there all the time with him.

We had homemaking in there to prepare meals and stuff. But the amount of homemaking from Homecare is really pittance unless you are on death's door. I mean, they may get two hours a day which they could do some laundry for them or personal care or a little bit of cooking, shopping, that kind of thing. Two hours is not long to do anything, for a patient depending on you getting food in the house and preparing something.

By the time a patient has got up, got stuff out of the fridge, prepared it all to cook and to eat, he was too damn tired to eat. You're lucky if he gets it prepared. So, I think it's important they do have supports in the home as much as we can give them. Getting Casey House home hospice involved along with Homecare is great, along with Trinity Hospice, they put additional hours on to care for the patient at home. It works very effectively because you have a team leader. They organize all these different people going in and volunteering to go in. Even to the point of twenty-four hour coverage, at the end when they really need it.

- a support person

Medical Services put out a directive that all medication for HIV and AIDS clients be covered. That was fine, but he was non-status. I talked to the Sudbury Access Group about getting onto the federal disability pension. One of the chaps over there said, "I'll send you the forms. In the mean time, send him to the general welfare office, they'll issue him a temporary Ontario Drug Benefits card so that he can get all of his medication.

- a support person

Well, right now, we have a Healing Centre going up. There will be a doctor that's going to be coming on to our reserve to work with our people. I know that's another person that I can turn to.

- an Aboriginal person living with HIV/AIDS

I think it would really depend on reserve politics. Your family and how they are with the people in control of the reserve. If they don't like your family, they're going to give you the minimum possible effort they can. If they know and like your family, they'll do triple back-saults for you. That's what I see. Some politics are ingrained so bad.

If the community calls resources in and says, "Look, I need some extra help. I heard of you guys before. I was wondering if I could talk to you about palliative care?"

Nashine Ginwenimawazawin

As long as they know that you're out there and they know that it is available. It will be training the people to help the people. Then, it won't be, "Oh, let me see if Chief So-and-so will let them come in."

- an Aboriginal support person

It isn't like a shut door for anybody if the band office doesn't help. It would be a major bonus if the band office would help, but it's not just band offices that are on reserves. There are cultural centres, health centres, there are centres for seniors.

People think there's just one address to talk to a reserve. Well, there's not. There's a lot of different buildings you can go to.

I would say, if anything, try the medical centres first, to do the training. If somebody's sick, they're going to the medical centre, they're not going to go to the band office.

- an Aboriginal support person

With Elders, if they're a traditional person, then they usually have their own people that they talk to. If not, I would probably ask one of the staff members who would be an appropriate person. Yeah, there's a lot of people out there who have a really good reputation but that means nothing to me. They could totally snow me and I wouldn't know the difference.

- an Aboriginal support person

We knew someone who could do all of the MSB (Medical Services Branch) stuff. We called her and she got a lot of the stuff covered. Like, even the delivery charge. Some of his medications weren't paid for so she got that covered.

It was getting in contact with someone who knows their stuff. It's hard to know your stuff because there is this big, thick booklet of all these things that MSB covers.

He was status, so he got all this stuff covered through his status card. Some reserves will pay if you have to go to appointments out of town or off reserve.

I just depends on how well your band council is updated on all that stuff and how much they're willing to work for it. The money is there. It's just accessing it.

- an Aboriginal support person

There was an AIDS Committee, they had a fund for people living with HIV/AIDS. They were accessing that. It's calling and asking. What we would do is give them the name of the AIDS Committee and the care team would do the groundwork.

- an Aboriginal support person

We have a booklet on what is covered. It's then calling and demanding that it be covered. It's calling MSB.

It's like if you're buying supplements, like Ensure, if you keep receipts and bill it back to MSB, they'll reimburse you.

- an Aboriginal support person

Nashine Ginwenimawazawin

Right now, I'm receiving Family Benefits and I have a Drug Benefit card from the government. So, the government is paying for my drugs at this time.

When I'm first going onto a new drug I basically get the prescription from my doctor. Since most of these drugs are not available in your corner drug store, most of them you have to get filled in the hospital drug store. All these drugs are released by Sunnybrook Hospital, to different hospitals. So, you're not going to get them at the drug store.

There's usually a procedure of up to a month to get permission from the government to allow you to use these drugs. You're a number and the government decides whether or not you are ill to a point where you need these drugs. So, usually it takes a month before you get your first dose or your first batch or prescriptions.

I'm talking AZT and ZTC and Saquinavir, these types of drugs. It usually takes a month before you get your first prescription filled. After that, it's basically you're on the computer at the hospital and when you need to refill them, you call your doctor or your nurses' station at the Immunodeficiency Clinic.

- an Aboriginal person living with HIV/AIDS

The protease inhibitors are expensive and again, for someone who is living below the poverty line, how are they supposed to afford the food? You need to be eating really nutritious food to be able to take that or it's hell on your stomach. I have a client who can't take them because he doesn't have the money to buy food and eat properly. Food bank stuff doesn't always have an adequate quality.

- an Aboriginal support person

You can get a lot of stuff through Home Care. You have to ask for them. Like, the bars in the showers and the one by the toilet, too. They can give bed pads. Bed stuff, you know that pulley-thing.

They have something that clips onto the edge of the tub. It's completely detachable, so you don't have to rip a hole in your shower wall. It just clamps onto the side and then the person can either get out by themselves or it's a little bit easier when someone's helping them out. They can support themselves a bit.

- an Aboriginal support person

We had Home Care, a homemaker. It was very sporadic because he harassed them. So, they were always changing because nobody wanted to come and see him. He was so miserable. He yelled at them and insulted them. He was really, really difficult.

There was a nurse who would come in and change his IV and just check him out. Then, there was a homemaker who would do laundry and tidying up. They were changing quite frequently because he was really hard on them. He was very, very finicky about how housework should be done. Cleaning the bathroom, doing dishes, vacuuming, dusting and laundry. He would be there on their case, watching how they were doing things. He was really vicious towards them.

Well, they couldn't handle it. They don't expect that. A lot of them just said, "Well, I'm not going back there." So, somebody else would show up.

Nashine Ginwenimawazawin

They would come in a couple times a week. This only lasted like a month or two because he went to the hospital not too long after all these services started to kick in.

It was chaotic, the whole time. From day to day, I didn't know what was going on. He was a chaotic person. That was his nature, so we just went by the seat of our pants. We winged it a lot of times. A lot of times there were big gaps because of his personality. It ended up just being us looking after him.

After, Home Care wouldn't show up because I guess they were having a hard time getting the Homemakers to come into the apartment. He had a reputation of being nasty.

At that point, he had already been assessed by a person from Casey House. He was on a waiting list. While he was in the hospital a bed became open and he moved to Casey House.

Once he was in Casey House, then it was a lot easier. Casey House is just around the corner from my place. He was able to take a taxi over, spend a couple of hours, and then go back. I was able to visit him every day. It was just a short walk there.

Once he was in there, he was a lot more comfortable. His appetite improved. His nutrition was better. They had a really good cook there. He seemed to rally and get better for a while.

- an Aboriginal support person

There's a bit of a divide right now because Medical Services is supposed to be only providing acute care. Funding for palliative care is supposed to be going directly to some of the Bands but I don't see the palliative care programs coming yet. When I inquired, I was told by Medical Services staff that the dollars are going directly to the band, it's the Band's responsibility. It's kind of like passing the hot potato.

- an Aboriginal support person

Most northern communities have a nursing station. The bigger communities have a nursing station with several nurses who are there twenty-four hours a day. It's very rare that a nurse would be from the community. The smaller communities might still have a nurse's station or a health centre but it might not be staffed by a nurse, it might be staffed by a Community Health Representative.

With some of the closer ones, the doctor might come once a week for a couple days a week. There are some that the doctor might go more often. The Northern fly-in communities it's once a month. I think some get more than one doctor. Some larger communities, I think get two doctor visits a month, so they would have a doctor there half the time.

You have some Community Health Representatives who have health training, who do some of the community outreach and help arrange day to day scheduling and help with translation. Then, there's twenty-four hour contact with the Base hospital.

Usually, physicians come visit one week a month to the community and that's kind of the basic situation. Some of the communities have a public health nurse. I didn't know of anyone in any community that was a palliative care worker or who had special training.

Nashine Ginwenimawazawin

I think what happens is, instead of it being palliative care, the mind set is usually acute care. We have to find out how ill a person is and then make a decision about where they can be appropriately treated, like, in the community, the nurse's station, or do they need to come to the hospital.

I think those decisions are totally different once you start getting into palliative care. You're no longer dealing with something that you think you can cure, so you're dealing with quality of life. For instance, if you have a fifteen-year-old with pneumonia who was quite sick you would want to treat them in hospital or at the nurse's station. You'd just want to cure the pneumonia.

If you have somebody with advanced AIDS who has like a bad Pneumocystis pneumonia then the decision changes. It depends on what their quality of life is. A lot of times you would choose to treat that because we have some treatments that can work quite well. It would depend on so many things. Do they want to leave the community to get treated for that? If they had some advanced neurological illness as well that was irreversible and their quality of life was quite low, the person may decide they don't want to fight this anymore.

- an Aboriginal support person

When I was there, the Mentor Program for physicians was limited, but it was very good. I found the support in Toronto excellent. If you had a question the physician would call you. I had excellent support from a doctor. There was some exposure to HIV during pregnancy and the support from the hospital was great. When I was a resident I worked with a primary care physician who told me about the program.

- an Aboriginal support person

Things are in transition now. I think the responsibilities are changing. For different communities, it might either be the band's responsibility or Medical Services. Because of transfer, some communities are responsible for their own transportation. I'd have to contact someone in the community. Some communities are still under Medical Services.

For instance when I had a patient dying in the hospital and I wanted to see if I could get his wife to come. I'd call various Medical Services personnel and I'd say, "Can you authorize this?"

If it is a special thing and I have somebody in the hospital and they want a relative to come, usually there are rules. Medical Services sometimes bends the rules for humanitarian reasons. That is where I would step in and maybe try and advocate for the patient with Medical Services. I would write a letter or something like that.

- an Aboriginal support person

Smaller communities need to look at their palliative care program. Some people are aware of what the issues are. Right now in the communities overall, there are not the trained personnel or the equipment available for people who are at an advanced stage of illness.

I think in each community it might vary. I was told that there aren't any extra nursing people on. I could clearly see that the nurses wouldn't want to try and support the person because they were already overworked.

Nashine Ginwenimawazawin

I was told that the band should be getting the funding for palliative care. I think that might be happening now. The monies might be just starting to flow. Like what's happening with the Life Long Care Program in urban communities, the money is starting to go directly to the bands. I'm not sure which bands have got the money and which ones haven't. I'm not sure whose responsibility it is now, but right now I'm not aware that Medical Services is providing that service or that they are mandated to provide it.

- an Aboriginal support person

It's hard to say why there is a high turnover up north. I think that the work is stressful. I think that it is difficult with this fly-in system. We are still not getting a lot of people from the communities that are getting medical training and going home. So, most of the time it is somebody not from the community.

Most people trained as doctors have lived in an urban centre for some period of time. Whether they are Aboriginal or not, or even from those communities, the rural communities might be seen as having not as much to offer from an urban viewpoint. Most of the doctors are non-Native, so there are issues about not feeling part of the community and there are chronic cross-cultural issues.

- an Aboriginal support person

In terms of the mandate, this is probably written down somewhere and it may vary from community to community. The Community Health Representative (CHR) is the person who is from the community and who does not have the same formal medical training as a nurse or a doctor. They have gone to a course several months to a year in length.

Their role basically is to work with the rest of the health care team to provide health care in the community. I have seen them do almost everything. They might drive the ambulance.

Other health care professionals are not from the community, so since they are from the community they have a lifetime of knowledge of the people in the community. When I am at the nursing station, it would be the CHR, along with the nurse who would decide who I am going to see. When I do home visits, the CHR takes me into the homes of people. They might identify people in the community at risk who the nurses didn't know about. They also would help me with translation and a lot of issues like if someone isn't taking their medication.

They provide tons of information to me about people in the community, like what their particular social circumstances might be or how they got to be at risk. Usually they are very dedicated, overworked and unrecognized. They might have the most insight into what is happening in the community but the way the nursing station is set up, it is really quite hierarchical. There would be a nurse who would be their boss.

It is a very difficult job. In communities where there is no nurse then they are it. In terms of providing medical care, they would call me if they thought there was a problem. So, in communities where you are the only person, that job is twenty-four hours a day, seven days a week.

- an Aboriginal support person

Medical Services has nurses in the nursing station and they are not community health nurses per se. They are nurse practitioners or clinical nurses and they would have a wide variety of backgrounds. They would all have nursing training and some of them would have more training than a university degree. There are different programs available over the years to help them develop more clinical skills. Nurses' training doesn't involve training in terms of treatment and diagnosis.

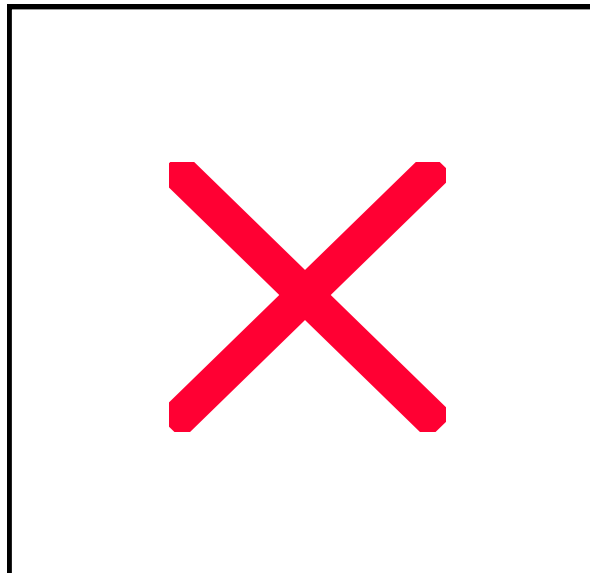
A lot of nurses in nursing stations are doing treatment and diagnosis, so they have more training in that area. There are certain antibiotics in medicine, for example, if someone comes into the nursing station with a sore ear, the nurse could identify it and treat it with medication whereas in the city a nurse wouldn't be allowed to do that. A Community Health Nurse has more focus on public health.

I noticed in one place, a Community Health Nurse came to the community, so her mandate was a bit different than the nurses who are involved in active day to day treatment of the people in the community for acute medical problems, or chronic medical problems. Her mandate was more to identify public health concerns like dental issues or promote breast feeding in the community, check on immunization in the community. A more preventative public health mandate. It could be in her mandate to look at what palliative care services are available in the community. So it would be Medical Services and hopefully the community who identified what public health issues they wanted addressed.

- an Aboriginal support person

PLACES YOU MAY GET INFORMATION, SUPPORT AND SERVICES:

- ◆ Group meetings, counseling, people living with HIV/AIDS phone lines, TV, newspapers, magazines, books, newsletters
- ◆ Elders and Medicine people
- ◆ Community Health Nurses and Community Health Representatives
- ◆ Healing Lodges, Healing Centres
- ◆ Independent First Nations organizations
- ◆ Provincial/Territorial organizations
- ◆ Local AIDS service organizations
- ◆ Doctors, nurses, HIV specialists
- ◆ Partners, family and friends
- ◆ Email and websites – an increasing number of Aboriginal organizations are listed on these. You can also access information on palliative care and HIV/AIDS.
- ◆ First Nations Tribal Directory, Ontario Aboriginal Directory provide listings of hundreds of resources



RESOURCE LIST

The following resource list is very long, as it covers the entire province of Ontario. Your care team will only use resources that are available and specific to your needs. You won't be using them all. You may want to circle or highlight the resources that you use. You could also create your own list of resources on a separate sheet of paper.

AIDS SERVICE ORGANIZATIONS AND PROGRAMS: ABORIGINAL

Provincial & Territorial Organization HIV/AIDS Coordinators

ASSOCIATION OF IROQUOIS
AND ALLIED INDIANS
(519) 434-2761
(519) 679-1653 (fax)
e-mail: dstonefish@aiai.on.ca

UNION OF ONTARIO INDIANS
(705) 497-9127
(705) 497-9135 (fax)

NISHNAWBE-ASKI NATION

(807) 623-8228 OR 1-800-465-9952
(807) 623-7730 (fax)

- Services are mainly provided on-reserve. Direct education (workshops, information sessions) and indirect education (health fairs, pamphlets) resource development based on community needs, such as videos, written material, child and youth specific material, educational items (key chains, condom wallets, etc.). Annual HIV/AIDS Conference.

ONTARIO ABORIGINAL HIV/AIDS STRATEGY

(416) 944-9481 OR 1-800743-8851
(416) 944-0541 (fax)

- HIV/AIDS workers deliver HIV/AIDS awareness, promotion and prevention programs, school programs and increase awareness and access to traditional teachings, medicines and traditional healers. They also advocate for and provide counselling services to Aboriginal people living with and affected by HIV and AIDS and promote respect for their rights, freedoms, autonomy and dignity.

ONTARIO ABORIGINAL HIV/AIDS STRATEGY WORKERS THROUGHOUT ONTARIO:

Ontario Metis and Aboriginal Association

Virginia Forsythe, HIV/AIDS Worker
P.O. Box 1795
Cochrane, POL 1C0
(705) 272-2562
(705) 272-3645 (fax)
e-mail: vkf249@hotmail.com

2-Spirited People of the 1st Nations

Terrence Sands, Advocate/Counsellor
Doe O'Brien, Assistant Counsellor
43 Elm Street, 2nd Floor
Toronto, M5G 1H1
(416) 944-9300
(416) 944-8381 (fax)
e-mail:
terry@2spirits.com
doe@2spirits.com

Ontario Native Women's Association

Tony Nobis, HIV/AIDS Worker
212 Miles Street East
Thunder Bay, P7C 1J6
(807) 623-3442
(807) 623-1104 (fax)
e-mail: tnobis@tbaytel.net

Ontario Aboriginal HIV/AIDS Strategy

LaVerne Monette, Provincial Coordinator
43 Elm Street, 2nd Floor
Toronto, M5G 1H1
(416) 944-9481 OR 1-800-743-8851
(416) 944-0541 (fax)
e-mail: strategy@2spirits.com

HIV/AIDS Regional Services (HARS)

Ken Morton, HIV/AIDS Worker
844A Princess Street
Kingston, K7L 4V6
(613) 549-7540
(613) 561-4110 (fax)
e-mail: kingstonstrategy@bellnet.ca

AIDS Committee of London

Lyndon George, HIV/AIDS Worker
Unit 120, 388 Dundas Street
London, N6B 1V7
(519) 434-1601
(519) 871-5242 (fax)
e-mail: leg_jam@hotmail.com

AIDS Committee of Sudbury

Lorie Pelletier, HIV/AIDS Worker
111 Elm Street, Unit 203
Sudbury, P3C 1T3
(705) 688-0500
(705) 688-0423 (fax)
e-mail: nishkwe@cyberbeach.net

2-SPIRITED PEOPLE OF THE 1ST NATIONS

43 Elm Street, 2nd Floor
Toronto, M5G 1H1
(416) 944-9300
(416) 944-8381 (fax)
e-mail: info@2spirits.com

- Services for Aboriginal persons living with HIV/AIDS including pre and post HIV test counselling, information and referral, advocacy and emergency fund for monthly personal expenses (PHA Fund). Provide help arranging benefits and housing, volunteer care teams and caregiver training, grief and bereavement,

Nashine Ginwenimawazawin

healing and wellness, talking circles, traditional teachings and social events (beading, carving and quilting classes).

ANISHNAWBE HEALTH TORONTO

(416) 360-0486

- HIV/AIDS counselling, Ojibwa, Cree, Oji-Cree, Iroquois, Inuktitut translation, special meals, doctors, nurses, prescriptions, traditional healers and transportation.

Legal Services: Aboriginal

ABORIGINAL LEGAL SERVICES OF TORONTO

(416) 408-3967

(416) 408-4268 (fax)

- Legal clinic for metro Toronto, will give offer summary advice to others in the province. Wills, Power of Attorney, Human Rights issues, referrals to specialist for wills (land on reserve), Criminal Injuries Compensation, Landlord and Tenant, Social Assistance, Canada Pension Plan (Disability Applications), Employment Insurance Representation and appeals for denials of non-Insured Health Benefits coverage.

NISHNAWBE-ASKI LEGAL SERVICES CORPORATION

(807) 622-1413

(807) 622-3024 (fax)

KINNA-AWEYA LEGAL CLINICS

Thunder Bay:

(807) 344-2478

Armstrong:

(807) 583-2631

Geraldton:

(807) 854-1278

Marathon:

(807) 229-2290

MANATOULIN LEGAL CLINIC

(705) 368-3333 OR 1-800-465-4882

(705) 368-3712 (fax)

Legal Services: HIV/AIDS

HIV/AIDS LEGAL CLINIC ONTARIO (HALCO)

(416) 340-7790

1-888-705-8889

(416) 340-7248 (fax)

e-mail: talklaw@halco.org

website: www.halco.org

- Free legal advice for people or organizations are affected by HIV/AIDS. Referrals if they are unable to represent. Topics include: social assistance, human rights, powers of attorney, Health Care Consent Act and Charter of Rights and Freedoms.

Written Resources, Clearinghouses and Hotlines

NATIONAL AIDS CLEARINGHOUSE

(613) 725-3434

(613) 725-1205 (fax)

e-mail: aids/sida@cpha.ca

- The Clearinghouse has copies of most AIDS-related documents, brochures, posters, pamphlets and other written materials on anything to do with HIV and AIDS. One copy can be received free of charge and multiple copies have a service charge. There are also videos for a reasonable rental fee.

ZA-GEH-DO-WIN INFORMATION CLEARINGHOUSE

(705) 692-0420 OR 1-800-669-2538

(705) 692-9039 (fax)

e-mail: manotnan@cyberbeach.net

website: www.anishnabek.ca/zagehdowin

- A library of information about Aboriginal initiatives in health, healing and family violence. Resources include books, audio and videotapes, articles, reports and documents. Most of the resources are free of charge.

MINISTRY OF HEALTH AIDS HOTLINE

TOLL-FREE in Ontario 1-800-668-2437

- Provides information and counselling on HIV/AIDS and information on services (including your local AIDS Committee) in your area.

HEALTH PROGRAMS SUPPORT DIVISION

Medical Services Branch

20th Floor, Jeanne Mance Building

Postal Locator 1920A, Tunney's Pasture

Ottawa, K1A 0L3

(613) 954-8107 (fax)

- A national clearinghouse for free Aboriginal-specific material. Videos and printed material: addictions, family violence, sexual abuse, nutrition, solvent abuse, suicide, child/sexual abuse, diabetes, HIV/AIDS and mental health

**HIV HEALTHLINE FOR PREGNANT
MOTHERS**

1-800-246-5840

- Free, confidential counselling about the risk of HIV infection and HIV treatment during pregnancy. Part of the Hospital for Sick Children's Mother Risk Program.

**THE ONTARIO AIDS NETWORK – PHA
NEWS**

(416) 364-4555

(416) 364-1250 (fax)

- A twice monthly newsletter that provides updates and information for and by people living with HIV/AIDS.

AIDS SERVICES ORGANIZATIONS AND TREATMENT INFORMATION

AIDS Service Organizations: Non-Aboriginal

There are a number of multi-service AIDS Service Organizations throughout Ontario who may not provide specialized services to Aboriginal people but who may be very helpful to you when you have questions as to what services and resources are available especially when there is no Aboriginal AIDS Service program locally. Some of these specialized and we have provided a description and full address. For general organizations, we are providing the name, phone numbers, fax and e-mail addresses where available.

AIDS Committee of **Cambridge/Kitchener/Waterloo and Area**
director@acckwa.com

(519) 570-3687
(519) 570-4034 (fax)

AIDS Committee of **Durham Region**
peter_r@auracom.com

(905) 576-1445
(905) 576-4610 (fax)

AIDS Committee of **Guelph & Wellington County**
acgwc@aids.guelph.org

(519) 763-2255
(519) 763-8125 (fax)

AIDS Committee of **London**
aidslondon@wwdc.com

(519) 434-1601
(519) 434-1843 (fax)

AIDS Committee of **North Bay and area**
acnba@efni.com

(705) 497-3560
(705) 497-7850 (fax)

AIDS Committee of **Ottawa**
aco@netrover.com

(613) 238-5014
(613) 238-3425 (fax)

AIDS Action Committee of **Perth County**
aap@cyg.net

(519) 272-2437
(519) 272-0816 (fax)

Nashine Ginwenimawazawin

AIDS Committee of Simcoe County acsc@bconnex.net	(705) 722-6778 (705) 722-6560 (fax)
AIDS Committee of Sudbury (ACCESS) access@cyberbeach.net	(705) 688-0500 (705) 688-0423 (fax)
AIDS Committee of Thunder Bay actb@tbaytel.net	(807) 345-1516 (807) 345-2505 (fax)
AIDS Committee of Toronto - Deaf AIDS Outreach Project - TTY croy@actoronto.org	(416) 340-8484 (416) 340-2437 (416) 340-8122 (416) 340-8224 (fax)
AIDS Committee of Windsor admin@aidswindsor.com	1-800-265-4858 (519) 973-0222 (519) 973-7389 (fax)
AIDS Niagara aidсниag@vaccine.com	(905) 984-8684 (905) 988-1921 (fax)
Algoma AIDS Network aan-ssm@soonet.ca	(705) 256-2437 (705) 256-1182 (fax)
Hamilton AIDS Network	(905) 528-0854 1-800-563-6919 (905) 528-6311 (fax)
Huron County HIV/AIDS Network sbechtel@odyssey.on.ca	(519) 482-1141 (519) 482-1191 (fax)
HIV/AIDS Regional Services (HARS) (Kingston) hars@kingston.net	(613) 545-3698 1-800-565-2209 (613) 545-9809 (fax)
Ontario AIDS Network	(416) 364-4555
Peel HIV/AIDS Network bprimeau@phan.ca	(905) 896-8700 (905) 896-9980 (fax)
Peterborough AIDS Resource Network pam@kawartha.com	(705) 749-9110 1-800-361-2895 (705) 749-6310 (fax)
AIDS Support Committee of Sarnia Lambton Inc. aidscomm@xcelco.on.ca	(519) 383-7704 (519) 383-8299 (fax)

AIDS Committee of Timmins & District
937893@ican.net

(705) 268-8345

**COMMUNITY AIDS TREATMENT
INFORMATION EXCHANGE (CATIE)**

(416) 203-7122
1-800-263-1638
(416) 203-8284 (fax)
e-mail: info@catie.ca
website: www.catie.ca

- They provide information for people living with HIV/AIDS and their caregivers. They have updated information on new treatments. Calls are confidential. It is accessible in French and English. The language used is to explain things to people in a way that is easy to understand. The information ranges from basic to complex. The emphasis is to allow the service user to make their own decision based on the information provided. Information includes; drugs, medical treatments and complimentary therapies. Information on AIDS services, clinical trials. Resource library, on-line computer database, newsletter, fact sheets and peer treatment information.

**TORONTO PROSTITUTE'S COMMUNITY
SERVICE PROJECT**

(416) 964-0150
(416) 964-9653 (fax)
e-mail: maggies@ica.net

**THE DAVID KELLEY HIV/AIDS
COMMUNITY COUNSELLING PROGRAM**

(416) 595-0307
(416) 595-0242 (fax)
e-mail: dkp@ssatoronto.com

**PRISONERS HIV/AIDS SUPPORT ACTION
NETWORK**

(416) 920-9567
(416) 920-4314
e-mail: pasan@interlog.com

- Education and prevention work with prisoners throughout southern Ontario, supportive counselling in person or by telephone. Help accessing community supports, advocacy for prisoners living with HIV/AIDS, they accept collect phone calls from prisoners in Canada.

TERESA GROUP

(416) 596-7703
(416) 596-7910 (fax)
e-mail: theteresagroup@on.aibn.com

- For children living with HIV/AIDS and their families. Transportation, child-care and assistance in the home. Health Fund: nutrition, vitamins, baby formula and clothing. Counselling, support groups, resources, legal advice. Peer support.

Nashine Ginwenimawazawin

**TORONTO PEOPLE WITH AIDS
FOUNDATION**

(416) 506-1400

(416) 506-1404 (fax)

e-mail: ledmiston@pwatoronto.org

- Counselling, drop-in, advocacy, financial assistance, food bank, resources, speakers and volunteers program are all available.

VOICES OF POSITIVE WOMEN

(416) 324-8703

(416) 324-9701 (fax)

e-mail: vopw@idirect.com

- For women living with HIV/AIDS in Ontario; support, counselling, advocacy, newsletter, food, speakers and volunteers.

PALLIATIVE CARE INFORMATION

Palliative Care Information Centre for the general public, family and friends. Calls, faxes, visits, education, linkages with the community and service organizations. Metro Toronto.

SUNNYBROOK HEALTH SCIENCE CENTRE

2075 Bayview Avenue L102 – B & C

Toronto, M4N 3M5

(416) 480-6100 ext. 3427 OR

(416) 480-4844

(416) 480-5210 (fax)

- Fact sheets (e.g. transportation organizations, palliative care associations and chronic care hospitals or nursing homes).

Pain and Symptom Managers: First Nations

Pain and symptom managers work with First Nation's representatives, spiritual advisors, HIV/AIDS specialists, doctors, nurses, social workers and pharmacies to provide palliative care.

Right now, the staff are directly employed; however, this is changing to a 'brokering' system. Brokering means different organizations bid for the opportunity to provide services. The Community Care Access Centres will broker or contract services.

Most reserves have their own homemaking workers but are not designated palliative care workers. The Pain and Symptom Managers Team looks at providing education, support and information exchanging with the resources that are in the community. They will do phone or e-mail consultations. If a health care worker has an issue with palliative care, for example, if a nurse has a question about nutrition and wants information, they can call the team.

Anyone can contact them, an individual, a nurse, the band or the doctor. A lot of communities are working towards their own nurses doing the care. A case manager from Community Care Access Centres will go in and they figure out what they think is needed within the home or community setting.

COMMUNITY CARE ACCESS CENTRES provide services almost everywhere except the most remote areas. The person would have to be moved to a hospital or a community that is closer.

Nashine Ginwenimawazawin

- ◆ Homemaking, nursing, dietitian, pastoral care programs, social workers, hospice volunteer visiting programs.

[FIRST NATIONS PALLIATIVE CARE EDUCATION PROGRAM](#) provides education and sensitization for health care workers that are working in First Nations' communities.

[THE INTERDISCIPLINARY EDUCATION PROGRAM](#) provides palliative care training for health care workers, including First Nations homemaking programs.

[THE PALLIATIVE CARE EDUCATION FOR FAMILY PHYSICIAN](#) provides palliative care training for doctors.

HOUSING, HOME CARE AND PALLIATIVE CARE

127 ISABELLA NON-PROFIT RESIDENCE

e-mail: 127isabella@sympatico.ca

(416) 928-9458
(fax) (416) 928-3126

BRUCE HOUSE

e-mail: brucehouse@on.aibn.com

(613) 729-0911
(fax) (613) 729-0959

BARRETT HOUSE

(416) 864-1627

BRANT COUNTY HOME CARE PROGRAM

(519) 759-7752

CASEY HOUSE HOSPICE

e-mail: drandall-wood@caseyhouse.on.ca

(416) 962-7600
(fax) (416) 962-5147

COMMUNITY HOSPICE ASSOCIATION OF ONTARIO

(416) 510-3880

FIFE HOUSE FOUNDATION

e-mail: rtucker@fifehouse.org

(416) 963-8218

JOHN GORDON HOME (London)

e-mail: johngordon@wwdc.com

(519) 433-3951
(fax) (519) 433-1314

TRINITY HOSPICE

(416) 364-1666

LIFE LONG CARE AND HOME CARE PROGRAMS

ONTARIO FEDERATION OF INDIAN FRIENDSHIP CENTRES

290 Shuter Street, Toronto, M5A 1W7

(416) 956-7575

(416) 356-7577 (fax)

Life Long Care Program

- ◆ For seniors, disabled or chronically ill. Service providers are Community Health Nurses, Nurses, Community Support Workers, Services provided by each Friendship Centre is different, in order to meet the needs of the community. Some services include in-home support: homemaking, transportation, meals on wheels, shopping, minor repairs to the home, food bank, friendly visits and volunteers. It is run through Friendship Centres. Palliative care training. Service is provided to anyone, regardless of status. To reach them, contact the Friendship Centre and ask for the Life Long Care Worker.

COMMUNITY CARE ACCESS CENTRE (CCAC)

(416) 229-2929

(Formerly the Home Care Program of Toronto)

Home care and placement coordination, provides access to health and support services and home and in the community. In-home services, supplies and equipment are to be provided by non-profit and commercial agencies.

By phoning the CCAC in your local area, you can access long-term care services, information and referrals. Staff is able to do a needs assessment in the home and help work out a plan. Referrals to long-term care facilities.

- ◆ Services provided include; visiting nurses, physiotherapy, occupational therapy, speech therapy, social work, nutrition counselling, homemaking, personal support, adult day programs. Referrals to: Meals on Wheels, Friendly Visiting, Security Check and Transportation.

More information:

Central Region Office, Long-Term Care Division,
Ministry of Health, 2161 Yonge Street, 2nd Floor, Toronto, M4S 3A6
(416) 327-8952

COMCARE

Have thirty offices throughout Ontario. Visiting nurses go on the streets to work with people. They work with Aboriginal agencies. Services are obtained through Home Care, doctors referrals, phone calls, insurance, etc.

- ◆ Services offered: nursing, occupational therapy, speech, rehabilitation, physiotherapy, training on symptom management, how to set up a home to make it comfortable, positioning someone comfortably. Training around catheters, pain pumps.

Advocacy around pain management – new products, patches, some people don't know about them.

MEDICAL SERVICES BRANCH, HEALTH CANADA

For information on benefits: Contact your local Medical Services Branch office or your First Nation.

Non-Insured Health Benefits - Medical Services Branch, Health Canada

Benefits can be received by people that are registered Indians. Covers drugs, medical supplies and equipment, dental and vision care.

The government is changing these programs. For example, if a prescription is available in a cheap, generic form, this is the only one that will be covered. The list that has the drugs that are available is also changing, with some drug coverage being removed.

Medical Services Branch is transferring the administration of some medical services to the Community Health Services. Control is being transferred to local and regional services. Some of the areas being transferred are medical transportation, podiatry (foot care), chiropractor and physiotherapy. Contact your First Nation for more information.

Non-Insured Health Benefits

(Indian status card) covers drugs, mental health, medical supplies and equipment. Someone with a status card can get Non-Insured Health Benefits (NIHB), regardless of location or income.

Transfer of medical services is still in transition. It may be confusing. The difficulties in the short term will be which service will be covered by which source.

THE LAST WORD.....

Have you ever seen the Wizard of Oz? There's no place like home! Actually, I'm the baby. It's like, I'm flying around, all by myself. I have eleven brothers at home. I don't care if they're not going to accept me because I'm under my mother's wing. They can hate me, as long as when she comes in, I can say, "Hi, mom!" I want to be normal, I guess.

- an Aboriginal person living with HIV/AIDS