



Coping with HIV-Aids



The Path of Life for Aboriginals living with
HIV/Aids

First Nations of Quebec and Labrador Health and Social Services Commission

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Produced by the First Nations of Quebec and Labrador
Health and Social Services Commission

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PREFACE

The First Nations of Quebec and Labrador Health and Social Services Commission (FNQLHSSC) is deeply concerned by anything that affects the members of First Nation communities in Quebec et Labrador. Support and assistance for persons living with HIV/Aids are an integral part of one the most important mandates that the FNQLHSSC has ever accepted. The HIV/Aids situation is all the more a cause of concern because the needs to be met are so great.

The life experiences of people living with HIV/Aids have already been dealt with in the two very interesting guides previously published. One of the guides was designed for the overall population in Canada and the second for specific Aboriginal populations in the Canadian West.

The first guide which was written by the **AIDS Committee of Toronto (ACT)** is called *Living with Dying - Dying at Home: an AIDS Care Team*. This guide focuses on how to accompany persons living with HIV/Aids who have chosen to finish their days at home. The guide contains several useful tools on how to set up an Aids care team.

The second guide, called *Nashine ginwenimazawin - Constant Care*, was prepared by **2-Spirited People of the First Nations**. The first guide is based primarily on the life experience of Aboriginal persons living with HIV/Aids from the Canadian West. A lot of attention is focused on the oral tradition and on the specific cultural experience of western Aboriginal Nations.

Both of these guides brought to light the necessity of creating a specific guide for Aboriginal persons living with HIV/Aids in Quebec and Labrador. The present guide was written specifically in response to the four primary dimensions of people living with HIV/Aids: the physical, the spiritual, the emotional and the mental. The guide is designed primarily for persons living with HIV/Aids as well as for those who are close friends, family or the caregivers who support them.

While making no pretence at representing the entire range of cultural concerns specific to the First Nations of Quebec and Labrador, we have nonetheless attempted to create a guide that is more closely adapted to local realities. As was mentioned by an Elder from one of the Western First Nations: (translation) "I can't speak for all traditional peoples, because there are many different nations as well as numerous and varying conceptions of the same thing."¹

¹ *Nashine ginwenimazawin – Constant Care* (1998), 2-Spirited People of the First Nations, Ontario: Toronto.



INTRODUCTION

1.1.Objectives of the Manual

The first objective of the manual is to inform and provide tools for people living with HIV/Aids, for those who are close to them and for caregivers. It aims at promoting a better understanding of the disease and of the physical, spiritual, emotional and mental issues that are associated with it, in order to create a propitious environment for Aboriginal persons living with HIV/Aids.

You will thus find in this manual information about:

- **Various life conditions of HIV/Aids;**
- **The rights of individuals living with HIV/Aids and the fight against discrimination;**
- **Treatments, including complementary and traditional Aboriginal therapies, that are available;**
- **Major resources available;**
- **Creation of a support team.**

1.2.Contents of Manual

This support manual has first and foremost been designed for Aboriginal persons who are living with HIV/Aids. It is also designed for those who are close to them and for the care team. Specific sections of the manual are of specific interest to close friends or family and the care team. Given the fact that non-Aboriginal caregivers are often required to accompany Aboriginal individuals living with HIV/Aids, specific cultural information has been included for them.

Specific cultural realities of the Aboriginal peoples of Quebec and Labrador are respectfully set out in this manual. The contents of the manual have been carefully adapted to the cultural realities of the Aboriginal peoples of Quebec and Labrador, and more specifically to their physical, spiritual and emotional health needs and values. The manual is divided into sections that correspond to the four main dimensions that make up the human being: the physical, spiritual, emotional and mental.

At the end of the manual specific fact sheets on HIV/Aids can be found. They have been written for easy and rapid consultation, as tools that can be handily accessed by anyone. Also



included at the end of the manual is a list of relevant resources for those who wish to obtain further support or information on the subject.

Throughout the manual, specific terms appear in *Italics*. In order to ensure the quick and effective understanding of such terms, they have been defined in a Lexicon that appears at the end of the manual.

1.3. HIV/Aids related data in Aboriginal environments



HIV/Aids has impacts on every community and social group at a global scale. It recognizes no borders, laws, or social classes. Canadians are no exception to this rule, and similarly Aboriginal populations have not been spared.

According to Health Canada (2003), although Aboriginals only constitute 2.8% of the entire Canadian population², they account for 5.5% of current cases of infection and 8.8% of all new infections in Canada in 1999. We therefore observe an over-representation of the Aboriginal population among individuals who have contracted HIV/Aids in Canada. The same observation appears to be true for reported Aids cases. In fact, in 1999, 10% of new reported Aids

cases, for which the ethnic origin was known, involved Aboriginals. During the first six months of the year 2002, it was reported that the proportion of reported Aids cases among Aboriginals had risen to 14.1%.

We also observed a substantial number of women who contracted HIV/Aids. As of June 30, 2002, 23.2% of all reported Aids cases among Aboriginals were women, whereas in the non-Aboriginal population, women accounted for only 8.2% of reported Aids cases. This over-representation of First Nations raises numerous questions.

² Percentage given in the 1996 Census



Why such a large disproportion?

Why is there such a large disproportion? It appears that people from Aboriginal communities have to cope with various personal and social issues that culminate in adaptive behaviours that place them particularly at risk of HIV/Aids infection (Barlow, 2003). It is highly likely that people who grew up with sexual abuse or violence experience intense interior suffering. If their suffering is not dealt with or treated, it may lead to negative behaviour adaptations, such as drug and alcohol addiction as well sexual and emotional dependencies. In some case it can even lead to compulsive and unhealthy sexual behaviours, to the recourse to violence, which behaviours in turn only perpetuate the vicious cycle of sexual abuse.

The past and present social and political contexts, in which Aboriginal communities are immersed, have engendered serious problems of loss of identity, cultural erosion, dispossession and loss of autonomy (Aboriginal Healing Foundation, 2002). The experience of such social difficulties at both the community and the individual levels is reflected in people facing an identity crisis related to their sexual, physical, psychological, cultural and spiritual suffering. Numerous caseworkers who are active in the Aboriginal communities have shown that the heritage of residential schools was devastating for the personal and community balance of both the survivors and their children. (Proceedings of the colloquium "Lumière sur l'héritage", 2003). One participant at this colloquium on the effects of such a heritage recounts his experience when he left the residential schools:

"I immediately went on non-stop consumption. I got married and had three children. I lost my son, which was maybe due to my consumption. Today I deplore the members of my community. Rumour runs rampant; there is so much rumour that you could destroy a person. Rumour is deadly."

It may therefore be inferred that HIV/Aids infection for some Aboriginals results from the development of negative adaptive behaviours, which are the results of suffering that has never properly healed.



Among Aboriginal individuals living with HIV/Aids, women and children are particularly vulnerable. Health Canada (2003) reported that in all paediatric centres across Canada, where women and children were screened for HIV/Aids between 1995 and 1997, 19% of all patients were of Aboriginal origin. Young Aboriginals are also disproportionately affected by HIV/Aids. It has been reported that 24.6% of all Aboriginal individuals who have been diagnosed with HIV/Aids are younger than 30, whereas there are only 16.5% from the same age group among the non - Aboriginal population.

There also appear to be differences based on the type of exposure to the virus among the Aboriginal and the non - Aboriginal populations. Health Canada again reported in 2003 that the majority of reported HIV/Aids cases in the Aboriginal population resulted mainly from the exchange of injection drug paraphernalia. Among Aboriginal individuals, the exchange of drug paraphernalia is also the cause of two-thirds of new infections. As of June 30 2002, 35.9% of reported AIDS cases among Aboriginals were due to sharing injection drug paraphernalia, whereas only 6.3% of non - Aboriginals were infected as the result of sharing drug equipment.

The second cause of exposure to HIV/Aids is the practice of

unprotected sexual recourse by either homosexuals or heterosexuals. A high rate of unprotected sexual relations has been reported in Aboriginal communities. This is also observed from the number of unwed mothers, which is again quite high in Aboriginal communities.

A word of caution however is necessary with regards to these three figures, because data gathered up to this point is characterized by certain significant gaps. Cultural differences, the size of the population, the data collection methods as well as incomplete or erroneous ethnic indicators will all have an impact on the data gathered (Barlow, 2003). We must also take into account the fact that there are numerous cases of HIV positive individuals who have not been diagnosed. We have though observed a distinct trend that may contribute to a better understanding of HIV/Aids related factors that impact on Aboriginal realities.

As was concluded by Health Canada (2003), the same information leads us to conclude that, despite incomplete data on the experience of Aboriginal peoples facing HIV/Aids, Aboriginals are infected earlier in life than non - Aboriginals, that the main mode of exposure to the virus is the sharing of intravenous drug paraphernalia and that the HIV/Aids epidemic in Aboriginal populations, as compared to non - Aboriginal population, does not



seem to be decreasing, despite the extensive efforts that have been invested in prevention in recent years.

1.4. The needs of Aboriginal persons living with HIV/Aids and the Medicine Wheel; the physical, spiritual, emotional and mental dimensions of health



Aboriginal peoples have a holistic vision of life and health. They do not reduce the person to his or her physical entity, but consider humans as an indivisible whole. The major dimensions of the human person are the physical, the spiritual, the emotional and the mental. These four dimensions are in constant interaction with each other and with the environment in which a person lives. Thus when dealing with health issues with a native person, it is normal to examine his or her spiritual or mental experience, rather than reducing the question to a mere matter of physical well-being.

It must also be remembered that the Aboriginal vision of health focuses

first and foremost on the question of balance and not on sickness itself. Western approaches to health are mainly concerned with sickness, their symptoms and their effects on the human body. The Aboriginal approach focuses much more on achieving the proper balance between the four dimensions of the human person and the environment..

The circle represents a type of predilection in this holistic vision of the human person and of life. Consequently, all the parts of the circle are inter-connected and influence each other for the establishment of balance. The relationship of each part towards the whole is central to the development of

Leslie Malloch (1989) offers a clear explanation of the holistic view of Aboriginals regarding health:

Good health is achieved through the proper balance between the physical, mental, emotional and spiritual elements of life. Each one of these elements contributes to the formation of a strong and healthy person. If any one of the elements is neglected, we lose our state of equilibrium and our health is affected in every domain. Disease prevention is part and partial of a traditional life style. We are healthy when we main a balanced relationship with nature and with the earth. Everything any one of us needs has been provided for us by our common mother, the earth: healthy food, clean water and air, cures, as well as the laws and the teachings which have shown us how to make wise use of such things. When we combine these gifts with a positive attitude and peaceful relationships with others and with the spiritual world, we acquire a state of good health.

intervention strategies aimed at restoring balance.

For instructional purposes, Aboriginals have portrayed their holistic vision of health as a medicine wheel. The wheel



displays the four dimensions of the human person and can be used for various purposes. As applied to the cycle of life, the medicine wheel allows us to shed light on the various stages of life that foster the development of the human person.



THE MEDICINE WHEEL APPLIED TO THE CYCLE OF LIFE



Quoted from the document *Guide à l'intention des professionnels de la santé travaillant chez les peuples autochtones - problèmes de santé touchant les peuples autochtones* (2001).



1.5. Testimony of an Aboriginal man living with HIV/Aids



Testimony of Harvey Michele

I now recognize that I received a gift from the Creator. It's now has been 10 years since I've been sero-positive. I lived negatively for the first 5 years. Since 5 years now, I'm living positively. Every day I'm balancing energies always dealing challenges and fears. Knowing myself, there's always a place to go. Always confronted with temptations, the fine balance between good and evil, my issues, limitations, commitments and expectations and finding life questions. Where am I in the cycle of life, HIV-Aids, my chronological age, the elder stage of self-actualisation and the famous after-life ?

Knowing myself, working on myself, keeps me living with HIV-Aids

The physical aspect is all an other shell. Yes, I have to deal with lipodystrophy, self-image and my hair and how I physically look like. Also, taking care of my organism. Taking vitamins, eating well nutritious, food and nourishment for mind, body and soul.

The spiritual aspect is covered: i.e. dealing with my Creator, taking time to thank him for another day, sharing the time I have on this world. Knowing when it's time to cross over I'll be content.

The mental aspects was a rocky road. Being told I had mental health issues. Seeing a train psychologist and psychiatrist. What a laugh. It's act in the head. I have genuine fears, It's all ended when I saw an elder, sharing with him, offering tobacco really changed my life.

The greatest impact HIV-Aids had on me was to deal with it.

In retrospect, It's not a mortal sin it was never a death sentence. Only to have the ones I have behind. They are ready. So am I.

The greatest milestone I've crossed is when I was ready to seek the appropriate resources. Since then I'm living positively.





Physical Dimension of HIV/Aids



Coping with HIV/Aids

Taking the time to understand the disease and its signs can help reduce the prejudices and fears that people can have about it. This section of the manual is for people living with HIV/AIDS, their entourage and health workers. Here we propose a range of physiological information which will ensure that you have a sound understanding of the physical changes that occur in persons living with HIV/AIDS.

The information supplied in this manual is not intended as medical advice. Any health decision should be discussed with the team of treating professionals before being applied.

Most of the information presented in this section of the manual are taken from the information packets for the person living with HIV/AIDS (Living with Dying - Dying at Home: an AIDS Care Team and *Nashine ginwenimazawin - Constant Care*) and the Internet site of the Canadian AIDS Information Treatment Network.

2.1 HIV and AIDS

What does HIV mean?

This acronym is used for the term Human Immunodeficiency Virus. HIV is a *virus* which attacks and gradually destroys the human *immune system*.

It renders the human body's defence system deficient.

What does AIDS mean?

This acronym is used to designate the **Acquired Immunodeficiency System**. A syndrome is a medical term used to designate a group of symptoms or diseases. Therefore, AIDS is a group of symptoms or diseases that attack the immune system. The term "acquired" refers to the fact that immune deficiency is neither innate nor hereditary. It occurs following the acquisition of an infection.

*Because many people do not develop diseases in a short period following the infection, we tend to believe that the virus can be found in the body without necessarily being active. Nonetheless, it has been shown in recent studies (CATIE, 2003) that **the virus is active at the time of infection**. If no disease appears at that point, it is because the immune system is still able to fight the virus.*

The diagnostic steps for HIV/AIDS

When a person is infected with HIV, a diagnosis can be made by a screening test (for more information, see the sidebar on the following page). Following this test, we do an initial diagnosis by a screening test, to see if the person has HIV.

When the person is infected by HIV, we say that he is seropositive. This first phase of infection is of variable length depending on the previous strength of the infected person's



immune system. However, at the beginning of the infection, the immune system, which guards the human body, is rendered fragile and starts to have difficulty defending itself against different infections.

The more the virus develops within the organism, the more the person will suffer from the different infections that his defence system is no longer able to fight off. Thereby, the person living with HIV will end up being defenceless against the most damaging diseases and will contract "opportunistic" infections. According to the Canadian Medical Association (1995), the appearance

of severe health problems can take from 10 to 14 years following the time of infection.

Some of these diseases and infections are recognized as being associated with a diagnosis of AIDS. AIDS is diagnosed when a person infected with HIV shows one or several of these opportunistic diseases associated with AIDS.

HIV/Aids Screening Test

The only way to screen for HIV/Aids is to provide a blood sample, that then undergoes a *serological test*. The screening test is performed by a physician. The test is available on demand and confidentiality is ensured. Some centres even provide anonymous testing. In order to find out the location of a screening centre near you, call the info hotline at 1-866-521-7432.

The main advantage of a screening test is to dispel any doubts about potential infection, prevent future infections and find out important information and adequate support, in the event that the results are positive.

The main disadvantage of a screening test is the intense psychological stress it entails as well as the anxiety over trying to hide the results from your entourage.

Test results are usually available in about 2 – 6 weeks after the sample. The sample is subjected to different steps in the testing in order to obtain the most precise results possible. Pre – and post – test counselling services are available in most screening centres or health centres.



2.1.1 Modes of transmission

One characteristic of a virus like HIV/AIDS is that it spreads by person-to-person transmission.

This virus can be transmitted by the blood, mother's milk and organic liquids such as sperm and pre-seminal fluid and vaginal fluid. To stay alive, this virus needs to be sheltered in a human body. It only lives a few seconds when exposed to open air.

Therefore, a person can be infected if his own body fluids come into contact with the body fluids of another infected person. We can identify five situations where the transmission of HIV is possible:

- An anal or vaginal sex act, either oral or without use of a condom (low risk, but likely if there is a sore);
- Sharing of syringes, hypodermic needles or any injection material (tourniquet, water, spoon, filter and even a straw);
- Transfusion of blood or blood products infected by HIV (since 1992, the risk of blood transfusion infected by HIV/AIDS has been practically eliminated with the establishment of new rules by Héma-Québec). Persons having received transfusions of blood or blood products before November 1986 should consider passing a screening test for HIV/AIDS;

➤ Pregnancy, childbirth or breast feeding when the mother is infected by HIV;

➤ Sharing of instruments for tattooing, piercing or ritual cutting infected by HIV.

HIV CANNOT be transmitted by other situations such as coughing or sneezing, the sharing of utensils, by food, a kiss, fondling or a blood donation.

2.1.2. The immune system

The immune system is responsible for protecting our body from different infections and diseases. For example, the immune system is called upon when we have the flu to expel it from our body. Without going into too much detail and complex scientific considerations, it is however important to address certain biological notions related to the immune system in order to understand HIV/AIDS.

The immune system is composed of two types of blood cells: red blood cells and white blood cells. The red blood cells transport nutritive substances and oxygen throughout the body, while the white blood cells stand guard. The latter are the ones that defend the body against intruders. Once inside the organism, these intruders are absorbed by a type of



white blood cells, which extracts *antigen* from them. Antigen is the mark of the virus or infection in question.

When antigens are identified, the immune system reacts according to the severity of the anticipated threat. At that time, different types of white blood cells can be called upon. *B lymphocytes* act in the event of danger to humoral immunity, whereas *T lymphocytes* act in the event of danger to cellular immunity. Each lymphocyte is specialized for a particular antigen. T lymphocytes destroy pathogenic elements that hide inside already-infected cells, such as cancerous tumour cells.

The HIV/AIDS virus is rather simply structured. Therefore, for reproduction it needs material from a host cell. The host cell used by HIV is the auxiliary T lymphocyte (also named cell CD4 for the name of the protein covering it). By using CD4 cells for reproduction, HIV prevents them from functioning normally and ends up destroying them. The virus kills millions of CD4 cells per day (CATIE, 2003) that the immune system does its best to replace by new CD4 cells. Nonetheless, the system ends up being no longer able to keep up and it wears out. This is when other viruses, bacteria or fungi can invade the body.

2.2 Opportunistic infections and diseases related to HIV/AIDS

By taking advantage of the reduced strength of the immune system busy fighting HIV, many other viruses, bacteria or fungi can enter and cause damage. This is what we call opportunistic infections and related diseases. Here we will give a summary presentation. Knowing which ones are the opportunistic infections and related diseases can help the person living with HIV/AIDS understand what is happening to him and live with the symptoms.

2.2.1 Opportunistic infections

The opportunistic infections presented here circulate currently in our environments. However, a healthy person will not develop these infections since his immune system is able to fight them. The immune system of the person living with HIV lacking the fighting forces will fall victim to viruses and bacteria present in the person's regular environment.



INFECTIONS	SYMPTOMS
<p><i>Candida albicans (thrush)</i> The thrush is the most common fungal infection among seropositive persons. This is a form of yeast that infects the mucus of the mouth, throat, vagina and anus. It can also affect the respiratory tracts and the lungs, the oesophagus, the gastro-intestinal tract and the skin. Eating sugar can worsen the infection.</p>	<ul style="list-style-type: none"> ➤ Inflamed sensitive areas ➤ Cutaneous eruptions (warm and moist areas) ➤ Throat irritation or cough ➤ Anal or vaginal discharge ➤ Difficulty swallowing and pain during deglutition ➤ Whitish spots that sometimes resemble cottage cheese
<p><i>Pneumocystis carinii pneumonia (PCP)</i> PCP is the most common disease among people infected with HIV/AIDS. This is a pneumonia caused by a parasite that mainly inhabits the lungs. Among certain people we can find the infection in the lymph nodes, bone marrow, the spleen and the liver.</p> <p>PCP reacts best to treatment, meaning that one can recover well enough from a first infection. However, among people living with HIV/AIDS, sometimes the infection reappears, leaving increasingly deteriorated tissues with each passage.</p>	<ul style="list-style-type: none"> ➤ Fever (often strong) and sweating ➤ Difficulty breathing, oppression ➤ Dry cough and absence of mucus ➤ Fatigue ➤ Nails and lips can become blue from lack of oxygen
<p><i>Toxoplasmosis</i> Toxoplasmosis infects humans through meat or eggs which are raw or not cooked enough, non-pasteurised milk or milk products, or cat excrements. The disease usually attacks the brain, but it can also affect the lungs, the eyes and the internal organs.</p> <p>One can avoid toxoplasmosis by ensuring that meat and eggs are well-cooked before consumption, by consuming pasteurised milk products and by wearing gloves to empty the cat litter box daily since the infectious agent is activated after 24 to 48 hours.</p>	<ul style="list-style-type: none"> ➤ Fever, discomfort, joint stiffness of neck ➤ Weak but constant headaches ➤ Sensory or personality changes <p>Less frequent symptoms</p> <ul style="list-style-type: none"> ➤ Trembling, paralysis and cerebral attacks ➤ Confusion, disorientation ➤ Coma
<p><i>Cytomegalovirus (CMV)</i> CMV is part of the herpes virus family. In industrialized countries, close to half the population is infected with it. The virus is easily transmitted by contact with mucus (saliva, vaginal fluid), blood or body fluids.</p>	<ul style="list-style-type: none"> ➤ Eyes: decrease in visual acuity, blurred vision, tunnel vision ➤ Ears: hearing loss, deterioration of hearing sensation ➤ Colon: abdominal pains, diarrhoea, weight loss ➤ Lungs: cough, difficulty breathing ➤ Oesophagus: burning sensation, pains, difficulty swallowing ➤ Nervous system : Changes in behaviour and personality



<p>Herpes viruses There are many types of herpes viruses. The three types most often associated with HIV/AIDS are type I herpes simplex (buccal), type II herpes simplex (genital and anal) and herpes zoster (smallpox virus).</p>	<ul style="list-style-type: none"> ➤ Buccal herpes: cold sores on lips or inside the mouth ➤ Genital and anal herpes: painful cutaneous lesions on infected areas ➤ Herpes zoster: eruption of painful vesicles near the spinal column, face or torso. Sometimes this can cause smallpox.
<p>Cryptosporidiosis This infection is transmitted to humans through contaminated water by infected animal excrements or even following contact with an infected animal.</p>	<ul style="list-style-type: none"> ➤ Serious diarrhoea ➤ Abdominal cramps, flatulence ➤ Discomfort ➤ Weight loss, anorexia, dehydration
<p>Cryptococcosis (cryptococcal meningitis) This infection is caused by a type of yeast present in bird droppings. It is transmitted to humans through the air they breathe. It mostly affects the lungs but can affect any organ.</p>	<ul style="list-style-type: none"> ➤ Fatigue ➤ Fever, discomfort, nausea ➤ Headaches ➤ Cerebral attacks
<p>Mycobacterium avium-intracellular complex (MAI) The MAI complex is an infection caused by two kinds of bacteria, one is present in bird droppings and the other is present in household dust, earth and water. These bacteria are natural contaminants of the environment. Among people in good health, the complex almost always attacks the lungs, but for a person infected with HIV/AIDS, the complex can attack the whole body.</p>	<ul style="list-style-type: none"> ➤ Fever, night sweating ➤ Weight loss, anorexia ➤ Fatigue, weakness ➤ Diarrhoea, abdominal pains
<p>Tuberculosis Tuberculosis is caused by a mycobacterium. Tuberculosis mainly affects the lungs but for people infected with HIV/AIDS, it can also attack the lymphatic and nervous systems. Certain types of tuberculosis are contagious and can be transmitted from one person to another in the air, without physical contact. Certain people can be carriers of tuberculosis without necessarily developing symptoms; nonetheless, this scenario is highly unlikely for a person with a weak immune system such as people living with HIV/AIDS.</p>	<ul style="list-style-type: none"> ➤ Cough, fevers, night sweats ➤ Weight loss, fatigue



2.2.2. Cancer

Close to 40% of people living with HIV/AIDS develop some form of *cancer*. A cancer is a disease produced by an irregular multiplication of cells, which thereby become unhealthy. Usually these unhealthy cells are destroyed by B and T lymphocytes. However, as we stated earlier, for people living with HIV/AIDS, these lymphocytes are considerably weakened and destroyed. Therefore, the cancer can take root and seriously compromise the functioning of the vital organs.

The most frequent types of cancer will be briefly presented in the following lines. However, other types of cancer can also occur. Among these, a major incidence of uterine cervix cancer has been noted for women living with HIV/AIDS.

Kaposi's sarcoma

This type of cancer appears in the form of skin sores. Men (either heterosexual or homosexual) seem more likely to develop Kaposi's sarcoma than women or children.

Usual symptoms

- The sores can appear all over the body, but especially on the face, neck, chest, back and the soles of the feet.
- Sores can be red, blue, purplish or darker than the surrounding skin.
- The sores are usually smooth, painless and itch-free.
- At the beginning, the sores can seem to be small clusters of flesh under the skin or bruises (contusions)
- Later, the sores can spread and connect between themselves.
- Several small sores can appear for a short period of time

Non-Hodgkin's lymphoma (NHL)

NHL is a type of cancer that affects the lymphatic system. It often starts with the forming of small tumours on the lymph nodes in the neck. Seeing as the lymphatic system runs through the whole body, it is not infrequent to find signs of cancer in the bone marrow, the internal organs, the gastro-intestinal tract or the *central nervous system*. When diagnosed rapidly, it can be treated rather effectively.

Usual symptoms

- Swelling of lymph nodes
- Weight loss
- Fever, night sweats



Primary lymphoma of the central nervous system

This cancer is found at an advanced stage of AIDS. It particularly affects the brain and is hard to treat.

Usual symptoms

- Headaches
- Confusion, lethargy, memory loss
- Paralysis
- Changes in personality and behaviour
- Cerebral attacks

2.2.3. Neurological complications

For a person living with HIV/AIDS, the central nervous system faces tough tests. Several neurological complications are foreseeable following the effects of opportunistic infections, cancer, symptoms related to AIDS itself or toxic elements of medication. We will present the most common ones in the following lines.

AIDS dementia complex

The AIDS dementia complex is the most frequent neurological complication for a person living with HIV-AIDS. One must be careful in the diagnosis to not mistake the side effects of medication or a depressive state for AIDS dementia complex. This diagnosis has important repercussions for the autonomy and dignity of the person because from that point on the person will be recognized as incapable of managing his own affairs.

Usual symptoms

- Decrease in concentration and slowing of physical activity
- Memory loss
- Slowing of motor skills

The person living with HIV-AIDS and displaying impatient, violent, malcontent, frightened, anxious or depressive behaviour by showing loss of control of his intellectual means.

Peripheral neuropathy

Characterized by a burning sensation and foot pain or by muscular deterioration, peripheral neuropathy is one of the most difficult medication-related complications to treat.

Usual symptoms

- Painful burning feeling or tingling in feet
- Hypersensitivity, shooting pains
- Dizziness, weakness
- Sensory deficiency



Progressive multifocal leukoencephalopathy (PML)

PML is caused by a virus for which 90% of adults have developed a natural immunity. However, for PML the virus is reactive and gradually destroys the protective envelopes of the nerve fibres and brings about sensory and motor troubles. The disease is often fatal since the known treatments are inefficient.

Usual symptoms

- Unsettled gait
- Loss of vision, double vision, headaches
- Memory loss and other intellectual troubles
- Weakness and lack of coordination in limbs
- Change in ability for self-expression
- Delirium
- Paralysis and coma in final stages of disease

Weight loss syndrome

One of the best-known signs of HIV-AIDS infection is involuntary weight loss. It can occur at any stage of the disease, but it is more prominent at the advanced stage. The malabsorption of the nutrients required feed the immune system is involved in chronic involuntary weight loss. The side effects of certain medication, diarrhoea, the lowering of dietary intake and the change in metabolism are other factors related to the syndrome.

Some people resort to vitamins or medication to increase the appetite. Surprisingly, some people have stopped losing weight and have even gained weight.

2.2.4. Women and HIV/AIDS

Although the AIDS epidemic has advanced among women, few research studies have looked into the lives of women living with HIV/AIDS. Therefore, most of what we know about AIDS-related diseases and possible treatments has been observed only with men. Nonetheless, we can note certain feminine symptoms related to HIV infection.

Opportunistic infections

Women living with HIV/AIDS run the risk of developing opportunistic infections just like men.

Nonetheless, certain infections tend to appear more frequently for a seropositive woman than for a seropositive man. This is the case for yeast infections (vaginal infections, candidiasis) which are widespread and difficult to treat. Pneumocystis carinii pneumonia and other types of bacterial pneumonia are not only more frequent among women, but sometimes



even more serious than for men. Also, herpes infections tend to be more virulent, more persistent and more resistant to medication.

Cancers

Kaposi's sarcoma is rarely seen among seropositive women. Nonetheless, it was observed³ that this form of cancer appeared four times more often among women whose spouse is bisexual than for women whose spouses are heterosexual. Although Kaposi's sarcoma is rarely seen among women, when it occurs it is more malignant than for the men.

Women living with HIV/AIDS are deeply affected by cancer and uterine cervix anomalies. The human papilloma virus (HPV) most frequently causes uterine cervix anomalies. It has been shown⁴ that seropositive women are more vulnerable to HPV infection and thus to uterine cervix anomalies. Certain studies also showed that seropositive women are five times more at risk to contract uterine cancer than seronegative women. In addition, the uterine cervix cancers that they present are more serious and are accompanied by a gloomier prognosis than for seronegative women.

³ For more information, consult the CATIE site:
http://www.catie.ca/f/org_services/communautes_specifiques.html#LesFemmes

⁴ *Ibid.*

Gynaecological diseases

We observe that the most widespread gynaecological diseases among women living with HIV/AIDS are salpingitis, uterine cervix anomalies and fungal vaginal infections. We also find inflammatory pelvic disease.

Salpingitis is an infection of the uterus, the fallopian tubes and the ovaries. This infection is caused by complications of sexually transmitted diseases (such as *chlamydia* and *gonorrhoea*) and also by the use of intrauterine contraceptives.

Cervical dysplasia is a disease which can be transformed into cancer if it is not properly treated. It occurs at the uterine cervix and is characterized by a growth or modification of the uterine cervix cells. It is caused by an HPV infection.

Inflammatory pelvic disease brings about the infection of female reproductive organs. It is characterized by the swelling and inflammation of the ovaries, the fallopian tubes, the uterine cervix and the uterus. This infection is caused by a sexually transmitted disease which was not treated or not treated properly. Inflammatory pelvic disease can be fatal.

HIV and the menstrual cycle

Many seropositive women notice major changes in their menstrual cycle



following HIV infection. Although research studies do not allow for the confirmation of a direct link between HIV and the menstrual cycle, we can name some frequent observations.

- More abundant and longer bleeding than usual;
- Bleeding or minor bleeding between menstrual periods;
- More frequent menstruations;
- Lighter menstruations with longer periods between menstruations;
- Irregular cycles;
- Complete absence of menstruations.

It also appears that seropositive women display stronger symptoms of *premenstrual syndrome* than seronegative women.

The effects observed on the menstrual cycle of a seropositive woman can be caused by many other factors besides HIV itself. Weight loss, metabolic changes, medication, changes in living tempo and diet are all probable causes of these effects on the menstrual cycle.

2.3 Treatments

Since HIV reproduces quickly, production errors occur. These errors constitute *mutations*. Certain mutations bring about weaker viruses. These do not survive for long. Nonetheless, sometimes certain

mutations bring about stronger viruses that are more resistant to medication. These improved versions of the virus are called *mutant*. These mutants multiply and replace the original version. These persistent and increasingly resistant mutations render inefficient the use of only one type of medication. This is why several types of medication are often combined to slow the reproduction of HIV.

In the present section, we will address the main medical treatments and their side effects. We will also present possible alternative therapies in addition to traditional Aboriginal medicine.

2.3.1. Categories of medicine

Several categories of medicine can be used in the treatment and relief of a person living with HIV/AIDS. These include prescribed drugs, over-the-counter-drugs, natural products or recreational drugs and alcohol.

Prescribed drugs

Prescribed drugs are those specifically prescribed by the physician of the treated person. They are accompanied by specific administration directions that have to be followed properly in order to optimize the benefits and reduce the appearance of certain *side effects*.



HIV is part of the retroviruses. Therefore, the drugs prescribed to counter them are called antiretrovirals. Other drugs, called protease inhibitors, can be matched with the antiretroviral agents to help reduce the *viral load*, meaning the quantity of virus in the blood.

The combining of antiretroviral agents and protease inhibitors offer various advantages. We note a longer rate of survival, a slowing of the virus's progress and a higher rate of CD4 cells in the blood than with just one type of medication. Nonetheless, to date, we do not know exactly which combination of drugs is most efficient, or when it is most appropriate to administer them. Nor do we know the long term effects of this type of medicated therapy.

Sometimes the medicated therapy does not work. This could be due to an HIV mutation which becomes resistant to the medication used, a *malabsorption* of the medication by the body or even a mutation of the virus caused by negligence in the prescription drug plan. One must not forget that the medication can end up being *toxic* and give rise to major side effects.

Over-the-counter-drugs

Over-the-counter-drugs are available at the pharmacy without prescription. They are used to treat various

ailments, such as headaches, colds or indigestion.

In the event that a person takes prescribed medication, he must receive complete information from the treating physician or pharmacist before taking over-the-counter-drugs. Sometimes, the mixing of different drugs can bring about serious consequences and side effects.

Natural products

Natural products are an alternative to consider for persons worried about the level of chemical substances contained in medication. Natural products are made from plant or root extracts. Many people have received interesting results with the use of natural products. Nonetheless, it is important to get information from a competent naturotherapist.

It seems that the most effective approach is the combined use of medication and natural products.

Recreational drugs and alcohol

Recreational drugs and alcohol are frequently used in society. If a person living with HIV/AIDS was using these products before the infection, it is highly likely that he will wish to continue using them. A frank discussion with the treating physician would be advised to avoid any



dangerous medicinal reactions between the prescribed drugs and the recreational drugs.

2.3.2. Side effects

Drugs can bring about different effects to both the emotional and physical states. Certain effects are desirable and others are harmful. The latter are called side effects. An exceedingly large dose of medication during a long period can have toxic effects.

The desired effect is the effect sought by the taking of the drug. For example, if someone has a headache, he takes an analgesic to relieve this pain. If the pain disappears, we attribute the relief to the drug's desired effect.

The side effects are other effects produced by the drugs. They are often numerous and sometimes unpredictable. Each person reacts differently to a given medication. Nausea, vomiting, diarrhea, dizziness, confusion, fatigue, fever and weight loss are often-observed examples of side effects. Certain side effects are more serious than others and can be stronger than the desired effect. For example, a person can take analgesics to relieve a headache and end up with dizziness or high blood pressure.

In certain extreme cases we have to abandon the taking of medication when the side effects seriously compromise the person's quality of life. To counter the side effects of the drugs, one can resort to other medication or alternative medicine.

The **toxic effects** of a type of medication appear after an extensive use of the drug in high doses. Normally, the liver and the kidneys eliminate the drugs present in the organism. When they do not function well or quickly enough, the drug's *toxins* accumulate in the organism and can poison or even kill the person. Particularly toxic drugs are those used in *chemotherapy* to fight cancer.

When a person has lost a lot of weight, he can normally eliminate a lower quantity of toxins. The doses must be adjusted in consequence to avoid more serious side effects or even a toxic effect that can poison him.

2.3.3. Alternative therapies

Alternative therapies are also called natural medicine, alternative medicine or, especially for HIV/AIDS, complementary therapies. These therapies are based on principles that distinguish them from the basic principles of traditional western medicine.



In the following grid, you will find a summary of the differences between these two types of medicine.

Alternative therapies are often called complementary therapies because their use is favoured as a complement to traditional western medicine. The combination of both kinds of medicine allows for the interaction of the four dimensions of the person living with HIV/AIDS.

This being said, different types of alternative therapies are available. It is important to receive complete information on the approach one wishes to take and on the professional one wants to consult. It is advisable to speak with a person living with HIV/AIDS who has already benefited from the therapy in question.

Here is an overview of different existing alternative therapies. The following information was directly taken from the Community AIDS Treatment Information Exchange (CATIE), presented in collaboration with [Asian Community AIDS Services \(ACAS\)](#).

Traditional western medicine	Alternative therapies
External factors are responsible for the disease	The balance of internal energies is involved in the disease
The purpose is the treatment of the physical disease	The purpose is to re-establish the balance of the individual's physical, mental, social and spiritual well-being
Drugs and other forms of treatment are subject to clinical tests before their use can be approved.	A large number of practices are not clinically assessed, but were learned through practical experience over the centuries



Acupuncture

Acupuncture includes the insertion of very thin needles into specific parts of the body to help stimulate and balance the flow of energy (called "Qi"). It is often used as a means to ease general pain and headaches, reduce neuropathy (burning sensations, tingling and pain in toes and fingers) and relieve other symptoms related to HIV along with side effects attributable to anti-HIV drugs.

Aromatherapy

Aromatherapy uses essential oils extracted from plants to treat the disease and improve the general feeling of well-being. In many cases, these oils are diluted in hot water and added to other oils for massages and lotions. People resort to aromatherapy to reduce stress, fatigue and the side effects of drugs.

Ayurveda

Originally from India, Ayurveda is one of the oldest known medical systems in the world. It seeks to heal diseases and attain sound health by re-establishing the harmonious balance between the mind, the body and the spirit. Treatments can include a combination of medicinal plants, dietary changes, purge therapies (using diets or medical products to eliminate "toxins" from the organism), yoga and prayer.

Homeopathy

Homeopathy is based on the principle of "fighting fire with fire" through substances that, in large doses, bring about the symptoms of certain diseases, but which can be used in small doses to treat the same symptoms. These remedies are natural substances diluted in extremely weak doses, which are used to treat a range of symptoms.

Chiropractic handling

Chiropractic handling seeks to treat diseases and relieve symptoms by handling the spinal column and muscles. In most cases, it is used for headaches, backaches, muscular pains, and also to reduce stress.

Massage

Massage is the handling of muscles and body tissue using a variety of techniques such as friction, percussion, kneading, applying pressure and brushing. It is a very efficient way to relieve stress, tension and muscular pains, and also stimulate circulation.

Traditional Chinese medicine (TCM)

Originally from China, TCM has been practiced for thousands of years. Popular belief says that good health comes from a state of harmony and balance between the mind, body and environment. It uses various methods, including acupuncture, medicinal herbs, healthy diet and exercise to adjust the flow of energies in an



individual's life in order to treat illness and promote health.

Meditation

Meditation involves deep-breathing methods and other techniques in order to help the individual concentrate his thought. It is often practiced in association with spiritual beliefs, and it is part of the numerous healing systems, including Ayurveda. This method is often used to reduce stress, anxiety and headaches.

Naturopathy

Naturopathy is based on the belief that the body has the natural capacity to heal itself. It uses various methods including plants, diet, homeopathic remedies, massage and hydrotherapy to stimulate the individual's self-healing faculty. People infected with HIV often use it as a means to stimulate the immune system's health.

Phytotherapy

Medicinal plant therapy is part of all medical systems, including Ayurveda and traditional Chinese medicine. It uses substances derived from different parts of plants as medicine to treat a series of diseases. The preparations obtained from the plants can be eaten, taken as herbal teas, smoked, inhaled or applied to the skin. These preparations can incorporate substances coming from one plant or a mixture of several herbs.

Reflexology

Reflexology is based on the principle that certain points on the hands and feet are linked to other parts of the body. Thus, by applying pressure to these points, one can help stimulate the healing of the corresponding body part.



2.3.4. Traditional Native Medicine

Traditional native medicine is not merely classified as an alternative therapy to Western medicine, since for most Aboriginal peoples it is their primary form of medicine.

Traditional native medicine focuses on the four main dimensions of the human person. Plant extracts and natural beverages are used to bring physical relief to the body. Rituals and ceremonies are organized to bring relief to the soul. Talking with a traditional healer or an Elder helps restore peace of mind and get emotions back on track.

Each Aboriginal Nation developed its own stream of traditional medicine over the centuries. Some nations use their own traditional medicines, such as sage, cedar and sweet grass, for healing purposes.

2.4. Nutrition

Food is a gift of the Earth which allows us Life. Nourishment is essential for the development of the body and to allow Life to grow within us. When sickness makes an appearance, it is a common custom to offer a drink or food to help a person regain his well-being and recovery. A

healthy diet is essential to the well-being of human beings.

For a person living with HIV/Aids, proper nourishment is an indispensable tool in the fight against infections and related opportunistic diseases. Nutrition therefore is a constantly recurring subject that which for any one who has to copes with HIV/Aids. For HIV positive Aboriginals, nutrition is more than just a mere ally in the fight against illness: it is the source of Life, a gift of the Earth.

2.4.1. Nutrition and Health

To be in good physical, mental, emotional, and spiritual health, human beings need to have balance in their lives. Good nutrition represents the balance that is contained in the essence of Nature. Some foods are an excellent source of energy, some are soothing and others fortify the body. Our ancestral experience has taught us to be wary of foods that weaken, excite or harm the body. The combination of certain foods provides a complete source of nourishment that meet the various needs of the body. Balanced and intelligent nourishment can be learned by observing Nature.

Nutrition also represents a state of balance between Nature and human beings. Even such a statement might appear to be old-fashioned in our modern world of instantaneous gratification, it is nonetheless true.



In this sense, nourishing oneself is akin to a spiritual ceremony, a replenishment that is possible because of the fruits of the Earth.

Physical, mental, emotional and spiritual health is therefore the result of the relationship of equilibrium that is produced between the human being and the Earth. One of the important elements in this equation is the way that a human being receives the gifts of the Terre. Thus the importance of nutrition and its role in sustaining the physical, mental, emotional and spiritual health for Aboriginal peoples must be taken into careful consideration. Some Native people add certain foods to their diet which might appear to non-Native health workers to be counter-indicated (such as fat or other foods lacking in nutritional value), but which actually represent foods that bring great emotional and spiritual relief.

2.4.2. Nutritional Needs

The nutritional needs of a person living with HIV/Aids are usually quite different from those of a person who is in good health. Some sources of nourishment are needed by the organism, while others should be banished. Both the quality and quantity of nutritional needs of such may be affected by the psychological state of the person, adverse reactions to medications, side, and physical

debilitation and by a whole other range of factors.

To be added or banished,,,?

The basic nutritional needs of a persons living with HIV/Aids are identical to the basic needs of a person in good health. However recent research⁵ has shown that some foods are particularly beneficial to persons living with HIV/Aids. Fibre rich foods are one example. The development of a range of related diseases and of side effects may be reduced by increased fibre intake. Fibre rich foods are whole grains, fruits and vegetables.

Some research has shown that there is additional benefit to eating adequate amounts of protein and calories. As is true for the general population, not smoking and regular exercise also appear to be beneficial for persons living with HIV/Aids. This presents the build of fats, which often occurs in smokers and people who get very little exercise to increase their resistance (weights are a very beneficial exercise in this case (CATIE, 2003)

As was mentioned in the Section dealing with HIV/Aids related or to other opportunistic infections, the immune system of persons living with HIV/Aids is weakened to the point

⁵ Hendricks, KM, Dong, KR, Tang, AM et al (2003). Quoted from the Canadian Aids Treatment Information Exchange (www.catie.ca)



where it can no longer effectively combat viruses, bacteria or other environmentally generated fungi. Thus raw vegetables which a person used to eat with impunity are to be banished. The same is true for milkshakes that contain raw eggs. Raw meat and eggs are to be especially avoided. The proper conservation and preparation of food, including thorough washing of both the food and the utensils used to prepare, are extremely important.

Psychological State and Side Effects

Learning that you have HIV/Aids is an extremely upsetting experience. Many people will go through hours, if not days and months of intense psychological and emotional distress. It is time of great soul searching. At such times, food appears to be of lesser importance. The person then begins to lack the energy even to think about preparing a proper meal. Some people might experience this reaction, because they are seeking to withdraw from the world to the point of refusing food. A person who experiences a depression to this degree needs to be treated, so that he can recover his taste for life and resume eating.

As HIV begins to wear down the immune system, even if the person does not experience depression, his appetite will likely diminish

considerably. As the body gets weaker, it requires less nourishment. Some medications can also generate side effects that modify the appetite. If a drug causes abundant nausea and vomiting, it is normal that the person will quickly lose any desire to eat. In such cases, there are other strategies that are available, such as alternative medicine. Special diets might also be prescribed in combination with a drug to prevent undesirable or harmful side effects. In any event, specific dietary issues or nutritional needs should be carefully discussed with the physician who is treating the side effects.

In order to prevent the decrease of appetite and to take into consideration, not only the physiological aspect of nourishment, but also the mental, emotional and spiritual aspects of food, the ambiance in which persons living with HIV/Aids consume their meals should be carefully examined. Food provides us with a link to Nature, but it can also provide us with a moment of comfort and pleasures that can be shared with others.

Various nutritional strategies can be considered. It might be a good idea to eat smaller snacks more frequently or to try different foods and seasonings. There are also food substitutes or medications that might be worth considering in extreme cases.



2.4.3. Alcohol and Caffeine

The effects of both alcohol and caffeine on the body and the spirit can be quite negative. Alcohol is a depressant, while caffeine is a stimulant. Some persons living with HIV/Aids enjoy consuming them and invoke the comfort that it gives them. Both alcohol and caffeine should be consumed in moderation. Careful attention must be paid to the quantities consumed otherwise they may cause harmful side effects. Drug interactions should also be carefully monitored.

2.4.4. Traditional Native Food

Traditional native food was developed from the sources that were available in the environment, as well as the dietary practices that grew out of traditional activities such as hunting, fishing and extended encampments in the forest. Such traditional diets no longer correspond to contemporary Aboriginal lifestyles. Traditional native food now competes with the processed foods we find in the grocery stores.

Traditional native food generally consists of:

Meat caribou, moose,
duck, deer,

partridge, bear,
rabbit, fish...

Berries

Raspberry,
strawberry,
blueberry,
currants,
cranberry,
cloudberry...

Vegetables

corn, tomato,
potato, squash,
various tubers,
peas,
mushrooms...

Grains

Wild rice, nuts,
grains, bannock
(oats, barley),
corn...

Traditional native food has many nutritional advantages that are not found in pre-packaged store bought food. It is advisable to eat traditional native foods as often as possible and to only choose health pre-package food. Nutritionists recommend high fibre, vitamin and mineral intake and less fat, sugar and salt.

The foods that are richest in fibre are whole grain breads and cereals (wheat, linseed, oats, and barley). Leafy green, yellow or red vegetables are also rich in fibre (spinach, broccoli, celery, citrus fruits, pumpkin...). Leafy green, yellow or red



fruit and vegetables are usually a good source of vitamins and minerals. Minerals such as copper and zinc can also be found in fish and shellfish. It should also be remembered that fresher fruits and vegetables (or lightly steamed) have greater nutritional value as they maintain better vitamin and mineral content.

A balanced diet, based on the recommended food groups and frequent physical exercise are still the best ways to protect your physical health and to maintain good balance in life.





Spiritual Dimension



Coping with HIV/Aids

Spirituality defines everything relating to the human soul, the relationship we hold with our living environment and the creative force which lies within. It allows one to give meaning to his or her life experience or living environment. People who are faced with hardship often find great comfort in spirituality.

Each person holds his own conception of spirituality and is the sole person responsible for that spirituality. This is also true for people who learn they are HIV/AIDS infected. A person who practices his spirituality may develop a stronger sense of belief after finding out he is infected with HIV/AIDS. The opposite situation may also happen: a person living with the disease may turn away from spirituality. Respect is of utmost importance in this type of situation.

Spirituality reflects the different colours of a culture. In other words, a community may give a certain direction to its values, beliefs and rituals, but each and everyone is free to choose and to adapt his spiritual practices according to his own beliefs and values.

3.1 Native Spirituality

Spirituality is very important for Native people. Every Nation has developed its own spiritual ceremonies. None the less, some aspects are common to all Nations, as

for example, reference to the Creator of Life and the recurring theme of Nature and animals as benefactors.⁶

There are differences between all First Nation peoples. However, similarities can shed light on spirituality and make it easier to approach and understand.

Spiritual Values

The fundamental values which are at the heart of native spirituality are goodness, honesty, sharing, care, respect, wisdom and strength. Elders are important because they can pass on and reflect these values. That is why they can be very inspiring resource persons and can help others to practice their spirituality.

Religion

Catholic and Protestant religions are integral to the spiritual beliefs of many Aboriginals.

Although residential schools were a traumatizing experience for many people⁷ who then rejected religion, for others it is an important source of spiritual inspiration. Once again, it is

⁶ For those who aren't familiar with native culture and spirituality, some key elements are defined in the appendix to facilitate understanding and first time approach.

⁷ Residential schools were created in 1884 in order to prompt the cultural, social and religious assimilation of Canadian Natives. Several cases of ill-treatment, abuse and physical violence have been reported since the last residential schools were closed in 1990.



important to respect every person's beliefs.

3.2 Traditional Healers

Traditional healers are seen as wise people. They incarnate spiritual values and can be of precious help for people faced with hardship. In order to support a person, traditional healers use a holistic approach, reaching out to every dimension of a person's life.

The methods used by traditional healers include listening, observing, touching, sensation, reflection, speech, song, dance, tales, prayer and fasting. Sweat lodges⁸ are also part of some traditional healers' methods. However, not every First Nation community agrees on this method.

3.3 The Spiritual Dimension of Health

Ancestral traditional healers believed in three causes of disease: loss of one's spirit, an object entering the body or a bad spell thrown by a medicine man. To heal a person, spiritual techniques served mainly to restore balance, to extract the unwholesome object or to regain ones

spirit. To this day, our communities have a holistic conception of sickness and healing.

The spiritual dimension is one of the four fundamental dimensions of life and well-being. It cannot therefore be removed from the path chosen by a person living with HIV/AIDS. This dimension is also important for the physical, mental and emotional dimensions of life and can influence ones improvement, deterioration and health.

Loved and trusted family members and friends can help us establish a healthy relationship with spirituality. For example, a person can join a self-help group to discover spirituality with the support and friendship of others. Elders are often a good support to discuss spirituality and to find a balance between daily life and spirituality.

A healthy relationship with spirituality can help to restore inner peace with others and through the events disrupting daily life. This peace and balance can have a beneficial influence on the life of a person living with HIV/AIDS.

Spirituality is an important part of a person's health. Ancestral traditional healers believed in three causes of disease: loss of one's spirit, an object entering the body or a bad spell

⁸ It is a very warm tent in which a person goes to pray and meditate. The sweat evacuated during the ritual is in fact the harmful elements within.



thrown by a medicine man. To heal a person, spiritual techniques were therefore mainly used to find balance, to extract the unwholesome object or to regain one's spirit. To this day, our communities have a holistic conception of disease and healing.

The medicine wheel described in the introduction is an essential element to understand the spiritual concept that Aboriginals hold of health.



3.4 Native Prayer

The Amerindian Prayer

O Great Spirit, whose voice I hear in the wind, and whose breath strengthens the Universe, please listen to my prayer, for I am small and weak and I beseech your strength and wisdom. May I walk in your light and may I never forget the sight of red and crimson sunsets. May my hands respect all you have created and may my ears forever hear your voice. Give me your wisdom so that I may understand what you have taught my people. May I discover the lessons hidden in every leaf and under every stone. I wish to be stronger, not to be the best, but to fight my worst enemy: myself. May I always be prepared to walk towards you, with my hands unspoiled and my head up high, and at the twilight of my life, let my spirit meet you without shame.





Emotional Dimension



The emotional dimension of life is linked to the heart, feelings and emotions, which have an impact on a person's health, body and soul. The body and soul can also cause us to experience different emotions. People living with HIV/AIDS go through several emotions which can greatly affect their well-being.

Understanding the emotions which may arise and knowing that they may be normal and legitimate in destabilizing situations can prepare a person to cope with them and reduce their impact.

4.1 Pain

Pain is what a person feels when the body and soul indicate that something is wrong. It can be felt in the four dimensions of life: physical, spiritual, emotional and mental.

Every person has his own personal and unique way of experiencing pain. Everyone has a different threshold of tolerance when faced with pain. Although people who tolerate pain are often seen as strong and brave, it is important to remember that no one should have to uselessly endure pain. It is a signal of distress given by the body and soul. We must describe and discuss our pain with the people we trust.

Everybody conceives pain in his own personal way. Some people refuse to face pain because it means that death is close by. For others pain is precious because it is a sign of life. Others believe that they deserve to suffer because of the harm they've done or because they are HIV/AIDS infected. Although pain is physical, it gives rise to several emotions and difficult issues.

Different Types of Pain

There are different types of pain which have their own particular aspect. Knowing them can help us respond to them.

Acute pain is felt in a specific part of the body and can easily be identified. The pain is sharp, intense and short-lived. A person with acute pain can show facial contortion, cry, moan, sweat, be agitated, nervous or tense, avoid movement and protect the painful area.

Chronic pain is vague, diffuse and hard to support. It is linked to chronic illness. Its intensity can fluctuate or it can be constant. It considerably weakens the person. The body adapts itself to chronic pain and therefore few physical signs can be seen. On the other hand, the person's mood can be altered. Frustration, anxiety, irritability, loss of appetite, depression and suicidal tendencies can be observed.



Emotional pain comes from intense spiritual, psychological or emotional suffering. However, it can affect the body and give rise to physical symptoms. Even though it is hard to perceive by other people, emotional pain is just as real and difficult to cope with.

Pain Relief Techniques

There are several pain relief techniques. The use of medication is fairly widespread but there are alternative pain relief therapies.

Medication is sometimes the last resort when the pain can no longer be tolerated. It is usually effective and relieves the pain quickly. However, people don't always react the same way to a product. In some cases, the medication does not relieve the pain and some products can even lead to side effects which are also hard to tolerate. The choice of medication must be made wisely.

Alternative pain relief therapies include distraction, day-dreaming, massage, relaxation, therapeutic touch, skin stimulation and acupuncture. Here is a brief description of these therapies. Warm and respectful human contact is always comforting and soothing for people who suffer.

- **Distraction** is a way to take the person's mind off the pain, either by listening to music, taking up a hobby or just having a conversation with a loved one.
- **Day-dreaming** is a technique used to stimulate a person's imagination and to take a journey into a more pleasant world.
- **Massage** is used to bring soothing and comfort through muscle and skin manipulation.
- **Relaxation** can relieve tense muscles, fatigue and anxiety. It can also increase the efficiency of other pain relief techniques.
- **Therapeutic touch** is a technique through which hands are pressed on a person's body to release energy zones.
- **Skin stimulation** is similar to massage but it is a technique through which heat, ice or pressure is also applied on the body.
- **Acupuncture** is a technique through which needles or laser beams are applied to the body's important energy points. It is used to block out the pain.



4.2 Loss

People living with HIV/AIDS are often faced with loss. Not only do they have to live with the thought of dying, but they also have to deal with losing control over their body, physical capacities, self-image, work capacity, mental functions, social role, as well as family and friends. All of these types of loss are hard to cope with and give rise to a tremendous amount of grief for people living with HIV/AIDS.

HIV/AIDS infected people faced with loss don't always react the same way. Most common reactions include fear, anxiety, guilt, denial, anger and depression, all of which are completely normal in these circumstances.

4.3 Hope

People living with HIV/AIDS need to know they won't be abandoned, that they will always have someone to talk to and that there is always hope. This is what keeps us alive and helps us to keep on going, even in times of great loss and grief. Hope also helps people take care of themselves.

Throughout their journey, people living with HIV/AIDS can express

hope in many different ways. First of all, people hope that a cure will be found and that they will be spared by the perspective of death that comes with the diagnostic. Afterwards, when they realise that a cure won't be found in time, they often hope that a treatment will help them live as painlessly as possible and in the best intellectual conditions. When death is at close hand, they hope to live until Christmas or until a loved ones birthday. Finally, some wish for a peaceful death.

Not every person living with HIV/AIDS expresses hope in this order or in this way. However, it is important for everyone to keep on hoping.

4.4 Discrimination

Everyone who is physically or mentally different risks facing discrimination. Ignoring, making fun of, insulting, avoiding, pushing, denying a person his or her rights or excluding them from a community or group are all types of discrimination. People act this way through lack of understanding, fear or ignorance. Discrimination is sometimes hidden. For example, an employer may cite false reasons for firing an HIV-positive employee.

Discrimination can be very difficult for people infected by HIV/AIDS,



who need to feel supported by their community and loved ones. People faced with discrimination can feel rejected, angry, sad, disappointed, guilty, lost, helpless, lonely and terrified. Some people lose their self esteem and may even develop suicidal thoughts.

People living with HIV/AIDS who are drug addicts, sex-trade workers or bispiritual may face even greater discrimination. They may feel even more guilt and regret.

Being Native also has its share of prejudice and discrimination. Being Native and having the HIV/AIDS infection can be even harder when living in a community that is unaware of the facts or when social ties have been broken. Fear and misunderstanding can lead Band Councils to force HIV/AIDS infected person to leave the community. This type of rejection is dramatic given the native concept of community and solidarity. Discrimination and all the feelings that come with it make it even harder for HIV/AIDS infected people to fight for their life.

4.5 Experiencing Major Distress

Some living conditions lead to major distress. In the case of people living with HIV/AIDS, it makes it even harder for them to find a certain

balance in a situation that is already difficult and painful.

4.5.1. Prison

Living in prison is a difficult experience. Different living conditions, the restrictions on personal and intimate contacts, the resurgence of feelings of guilt, of rejection, misunderstanding and affective disassociation can greatly disturb many people. There is a high level of stress amongst people living in prison. In addition to the emotional dimensions of prison, there is a high risk of disease transmission.

The main purpose of prison is to place people who break the law in confinement. Confinement is imposed to protect society from criminal acts. However, the State is still obliged to respect every inmate's rights. Everyone is entitled to adequate health services and to a lawyer. On the other hand, people living in prison aren't protected from HIV and other diseases, like Hepatitis C.

As a matter of fact, numerous people seem to have contracted HIV/AIDS while they were in prison. About 1 out of 600 people in the Canadian population is infected with HIV/AIDS (not counting the people who are unaware they have contracted the disease). In Canadian prisons, 1 of every 100 people lives with



HIV/AIDS. Studies⁹ have shown that in some parts of prison, 1 out of 9 people is infected by HIV/AIDS. As we have already seen, the number of Native people as compared to the general population is even higher. The same situation seems to apply in prisons. Women are also highly at risk of being infected while in prison.

Inmates are offered very few means to protect themselves even though it is widely known that many engage in unsafe homosexual encounters or use injection drugs. By turning a blind eye to such situations, very little is done to help inmates protect themselves who consequently engage in even greater risks.

The Canadian correctional system is more and more open to visits from community members, healers or even elders. It makes the whole ordeal of living with the disease in prison a little more bearable.

4.5.2 Stress

Living with HIV/AIDS implies several changes and physical, psychological, spiritual, social, emotional and mental ordeals, all of which can be very stressful. One of the most difficult

challenges is the financial aspect of HIV/AIDS. Medication is expensive; people often have to stop working because of the symptoms and side effects, and therefore live in poor economic conditions. HIV/AIDS and poverty are both part of the same vicious circle.

Stress is a normal feeling whenever the body or mind perceives danger. However, intense and constant stress can be harmful. It can weaken the immune system of People living with HIV/Aids.

Several things can be done to reduce stress. Alternative and complementary therapies are interesting because of their relaxing aspect. Exercise, humour and hobbies can also reduce stress. Some people prefer to be directly confronted to stress to reduce its impact. Relieving stress can lead to the end of an oppressing relationship, a new job or moving from an uncomfortable apartment.

4.5.2 Substance Abuse

The use of narcotic substances such as drugs, alcohol, solvents or medication alters our physical, psychological, emotional and mental state. That is often why people use them. However, because drugs alter a person's state, the body and mind are also perturbed.

⁹ Canadian HIV/AIDS Legal Network (2002), *Action on HIV-Aids in Prisons Too little to late- A Report Card*.



An altered state of mind can expose people to dangerous situations. Because of substance abuse, some may engage in unsafe sexual encounters or share an injection needle. Furthermore, it can also lead people to forgetting their appointments or medication. Substance abuse is disruptive to all aspects of everyday life. These habits reduce the quality and life expectancy of people living with HIV/AIDS, especially when opportunistic infections appear.

Because of their substance abuse, people may not allow others to help them. They may have low self-esteem, very little group support or feel they don't deserve a better life, and therefore refuse to take care of themselves. Substance abuse or the struggle with quitting can lead to mood swings and uncomfortable side effects.

Even though complete withdrawal may seem like the best solution, in several cases it is impossible. When drugs are used to escape or to find comfort, the situation may not change after the diagnostic. However, some people manage to take control over their consumption.

The most important thing to do for people who abuse substances such as narcotics is to help them gain control

over their life and increase their self-esteem. This can be done by letting them make their own choices, telling them how to reduce the risks associated to their substance abuse and by bringing them moral support.

4.5.3 Alcoholism

Alcoholism is a major problem in some communities. Prolonged alcohol abuse is physically, mentally, emotionally and spiritually harmful for a person.

As for any other substance abuse, it alters the person's state of consciousness. It often leads to fighting with their loved ones or the loss of trust in others. It can also lead to broken or damaged support networks. As they are faced with an involuntary and misunderstood solitude, alcoholics often tend to consume even more to forget the pain it causes.

The vicious circle of alcohol or substance abuse weakens a person's strength and will to fight against HIV/AIDS.

4.5.4 Emotional Dependency

Most people have to cope with some kind of emotional dependency. We are all more or less attached to our loved ones and to our spouse. However, some people express unhealthy



attachments. They are unable to make any decisions without the other person's consent; they abandon everything for the other and sacrifice themselves to fulfill the other person's needs.

Emotional dependence can lead to very difficult situations, especially because this type of person often ends up with a dominating spouse. Consequently, the dominating person imposes everything and the dependant one complies by fear of losing the other's affection.

Someone may accept to have unprotected sexual relations in order to please the other. When being subjected to another person's will, a person forgets her own feelings and opinions and loses all self-respect. Unfortunately the person is at risk of contracting a disease such as HIV/AIDS.

An emotionally dependent person living with HIV/AIDS may go through a difficult period. Not only is the person faced with the fear of losing the other's affection but must also cope with discrimination, guilt and reject. The resulting tension can lead to a point of no return and force the person to choose between herself and others.

Even though some cases have reported for men, it seems that

women are the ones most affected by emotional dependence. They are often unable to leave their husband even if they are victims of violence or abuse because they are incapable of existing outside the other. This reality can also be seen in native communities. In some cases, economic and social dependence are also part of the emotional dimension.

Helping a person to pick up the pieces, to discover her own tastes and to make her own choices can show the person that she can take charge of her life. A person can assume her own identity by regaining self-esteem and control over her life.

4.5.5 Violence

Violence can be verbal, physical, sexual and emotional and exists in every social and ethnic group, as well as in native communities. Every type of violence is harmful, both for the victim and the person perpetrating it.

A violent environment leads to higher insecurity, high levels of stress, constant mistrust, violent attitudes, prompt responses, which are usually inappropriate, fear, humiliation and so on. Violence harms not only the body but also the mind, the heart and the soul.



4.6 Death and Funerals

People living with HIV/Aids often die from diseases related to the virus. Although death is predictable, death does not follow any prescribed order or sequence.

However, certain signs can be seen in a person at the approach of death: loss of appetite, spasms through the whole body, difficult or intermittent breathing, tense muscles and different skin colour. These signs can wax and wane and aren't all present at the same time. Death comes when the person feels ready to die. The person might wait for the presence of a pet or loved one before leaving.

Dying people don't always seem to be aware of what is going on around them. Some are in a coma or semi-conscious state, while others sleep most of time and awaken every once and a while. It is often hard for them to recognize time and space and they don't always recognise the people at their side. However, it is important for them to experience peace, calm and affection so they can die as peacefully as possible. Some people believe that although someone is in a semi-coma, the person can feel and hear what is going on.

It is not easy to lose a loved one or someone we've taken care of. People take it differently and there is no

single best way to react. Witnessing someone's death can be experienced as an anticipation of what our own death will be like. It is important to respect our emotions and those of the others. Some people will want to touch the dying or dead person, while others can't even bear to look. Everyone should try to say goodbye in their own way. Death is also part of our life cycle.

4.7 Caring for the Caregiver

Caregivers are those who take care of others. Their responsibility implies giving a tremendous part themselves, love, respect, generosity, having an open mind, understanding, listening and having a warm heart. Taking care of others also brings a lot to the caregiver, such as feeling useful, earning recognition and self-esteem.

However, the caregiver must be able to take care of him or herself in order to be useful. There are several difficult challenges that come with taking care of others, especially for people living with HIV/AIDS. Although there has been medical progress and despite all the efforts invested by the caregiver, people living with HIV/Aids ultimately end up dying. Even though they know this, caregivers can exhaust themselves by trying to beat the odds.



4.7.1 Taking care of yourself

The caregiver's best tool is himself, as a human being with his strengths and weaknesses, courage and generosity. In this frame of mind, taking care of yourself means you can take care of others. It also implies that you have to take care of every dimension of your person, the same as you do when taking care of others.

There are several ways to take care of yourself. The caregiver has to take time for himself, to rest and to renew his energy. Such moments can be taken in the enjoyment of an activity or in spending time with close and loved ones. Humour and communication are important when taking care of yourself or of others. Relaxation, exercise, communication, self-expression through music, arts and crafts as well as hiking are good ways to take time out for yourself, to unwind and to evacuate whatever feelings you may feel as the result of attending at the bedside of a sick person.

Talking about your experience with the health care team, health professionals, family or volunteers can help to put things in perspective and to find group support. It is very important to find ways to take care of yourself so that you are able to take care of the patient.

4.7.2 Burn-out and Depression

Sometimes the caregiver can no longer take care of himself. In some cases, people choose to take care of others to amend for past mistakes. When taking care of a dying person, the suffering we put behind us may resurface. If the caregiver already feels like a failure, the patient's death can be seen as another personal failure. Exhausted caregivers often fall into two states, either burn-out or depression.

Burn-out

When the caregiver can no longer take care of himself, his strength weakens, which usually leads to exhaustion. He keeps on going because he considers that the other person is more important. Not only can this lead to physical exhaustion but also to emotion, mental and spiritual exhaustion. When this point is reached there is no longer any energy left, neither for the caregiver, nor for the patient. This is known as burn-out.

Here are some of the symptoms:

- Constant fatigue;
- Working more hours or being absent more often;



- Feeling useless except when working;
- Feeling unusually pressured when friends or family ask for a favour;
- Feeling emotional or angry towards the patient;
- Feeling depressed or indifferent towards the patient;
- Headaches or sleep disorders.

Depression

Depression sometimes appears when the caregiver takes whatever is happening to the patient personally. Highs and lows become harder to deal with. The person feels sad, guilty, useless, depressed, edgy, overwhelmed, and unable to be happy. The person may lose interest in his sexuality and may have sleep disorders.

Depression also has an impact on the person's mental dimension. It becomes harder to concentrate, make decisions, see the positive side of things, and easier to criticize and blame yourself for everything.

When the symptoms of depression and burn-out appear, the person is clearly unable to take care of others. It is therefore important to prevent these states by taking care of yourself for example, by taking part in a sharing circle.

4.7.3 Sharing Circles

A Sharing Circle is a group in which people can express their feelings, thoughts and emotions; it is also where people listen to others. Empathy, listening and respect and acceptance are at the heart of this experience. Unconditional acceptance and understanding are the Circle's great strength. It also allows people to regain the energy they have lost.

Each circle is unique because it takes shape from the people who are part of it and is therefore different from one nation to the next because each nation has its own concept of the Sharing Circle.





Mental Dimension



The mental dimension of life is what allows a person to communicate and put experiences, feelings and beliefs into words. We understand the world and reality with our mind. This dimension should not be neglected when living with HIV/AIDS.

5.1 Communication

Communication can be developed. Even though we learn to express our needs from early childhood on, some people communicate more easily than others. Some become great speakers while others who are shyer only express their emotions when faced with strong emotions.

Communication is at the heart of every relationship. Friendships are born when people talk to each other, understand what the other person is saying and feel they are listened to. On the other hand, sometimes relationships are ruined or contacts become more difficult because of communication.

Communication is either verbal or nonverbal. When words are exchanged, it is verbal. When body language is used, it is nonverbal communication. These movements show us how to understand words. For example, when a person says that everything is fine with hunched shoulders and a forced smile, you might feel that the person isn't that

fine. A lot of important information is expressed through nonverbal communication. Even silence is a type of communication.

Interpreting the message received is also part of communication. This message can be distorted by surrounding noise, a hearing problem or the inability to listen. Our mind quickly makes sense of all the words and movements it perceives within a given context. We give the interpretation a personal sense with our emotions, through our understanding of the person's experience and the history of our relationship. Our interpretation therefore isn't always right. This is why tension and conflicts sometimes appear between people.

Here are some obstacles that prevent good communication:

- Thinking about something else;
- Thinking about what the person thinks of us;
- Reaching our own conclusion rather than listening to what the person is really saying ;
- Trying to make up for the other person's sadness or anger;
- Diverting the conversation when the subject becomes too difficult;



- Seeing only the negative side of things.

Good communication takes practice and requires being aware of the other person's experience and of our own inner self. Paying attention and taking the time to listen without prejudice can make the difference between good and bad communication.

Here are a few tricks for good communication:

- Stay focused on the person;
- Being capable to listen (hunger and exhaustion can limit this capacity);
- Taking the time necessary;
- Avoid distractions (set aside your concerns and turn off the television);
- Pay attention to your body language (are you open and ready to listen?);
- Pay attention to your emotions (are you in a positive frame of mind, clear and honest or are you sending out a double message that could confuse or hurt the other?);
- Listen closely to the other's message. The person is the best one to know and express its reality;
- Respect others.

Avoid using negative communication, like promises, judgement, denial and testing. Paraphrasing, confirming, encouragement, recognition and acceptance are much more respectful and efficient.

Good communication skills can be acquired. They can really make a difference in difficult situations. People living with HIV/AIDS may be faced with conflict and new relationships will be created with external caseworkers. As with family and friends, good communications are essential, as they help to relieve suffering and avoid misunderstanding.

5.1.1 Communicating with the Medical Team

The medical team is often composed of people who are unknown to the person living with HIV/AIDS but in time they become familiar. These people will see a very private dimension of the patient so it is important to establish clear and honest communications. This helps people living with HIV/AIDS to set their limits and for others to respect them.

Health professionals are often seen as holding the key to every question. We are sometimes afraid to ask them questions or to explain the complicated words used by the medical team. However, people living



with HIV/AIDS must learn to understand disease and infections, to know their body and to be aware of the steps ahead in order to make the right choices. We should always remember that health professionals are there to help people and do the best they can for their patient's well-being. Don't be afraid to ask as many questions as you need to before making the right decision.

Like everyone else, these people are human beings. They are just as affected by courtesy and gratitude as they are by arrogance and mistrust. In every relationship, a good sense of humour is precious.

5.1.2 Communicating with People around us

We use the same communication skills with the people around us. The only difference is the context and the emotional dimension of the relationships we have with others around us. The people in close proximity to an HIV/AIDS patient are especially affected by the situation. Several strong emotions may come to surface during the whole process. Some may be linked to the past or to unresolved conflicts. In these cases communication may be more difficult. It may be wise to consult a professional who is skilled in helping relations, to start resolving


the conflict and to establish some kind of better communication.

5.1.3 Confidentiality

Confidentiality is important for people living with HIV/AIDS and their family environment. Because of the stigmatization and discrimination surrounding HIV/AIDS, it is important to keep the diagnostic and person's lifestyle confidential.

As a member of the support team, you are in close contact with the patient and are therefore aware of personal information. Unless the patient gives his consent, you must not reveal any information. It's a question of respect and dignity. The person's living environment and support team deserve the same respect.

5.2 Native Languages



Aboriginals in Quebec and Labrador are members of different Nations and therefore speak languages other than French and English. Many learned French or English (or both) but fluently speak their mother tongue. Everybody has the right to speak their own and language. It can be comforting, especially when the person is fragile.

Because other people take care of them, people living with HIV/AIDS need to express what they think



without being handicapped by language. When the medical team and interveners don't speak the person's native language, a translator should be hired. This person should be able to translate and explain all the medical terms in the person's language.

5.3 Legal Issues

Several legal issues must be considered after the patient's death. This can be a difficult situation especially when the person doesn't accept the diagnostic.

People living with HIV/AIDS will have to make several decisions concerning their health and finances before their death. They will have to designate a person to be responsible for their health and finances in the case they are no longer apt to do so themselves. They will also have to choose the person or persons to whom they wish to bequeath their personal belongings, in what circumstances they wish to die and how they want to be buried.

After the person's death, these decisions will have an impact on the persons who were close to the deceased. Conflicts can arise because some people were not included in the will. In order to avoid any family

drama, it is important to draw up a proper and legal will¹⁰.

5.4 Creating a Support Team

As you may have seen in this manual, people living with HIV/AIDS face many challenges. As the infection progresses and as the person weakens, several new difficulties come up. People often choose to spend their last days at home and need a support team to help them physically, spiritually, emotionally and mentally.

How to Create a Support Team

- 1- Clarify what the patient wants and needs
- 2- Determine what type of care is needed and who should be contacted
- 3- Find the volunteers and professionals who will be part of the team
- 4- Evaluate the financial resources and where the care will be given
- 5- Get whatever materiel is needed
- 6- Determine who will be responsible of the support team
- 7- Set a schedule and determine everyone's role
- 8- Organize a meeting to set everything in place

¹⁰ For more information, contact the Lands and Trust Services at the Department of Indian Affairs, www.ainc-inac.gc.ca



It is basically up to the patient to decide if he wants the help of a support team. However, some people have a hard time seeking help because they are afraid to lose their independence and privacy and fear what is ahead.

Before making such a decision, the person may speak to health professionals or to people with experience in home palliative care. Loved ones may also be asked to give their opinion.

When the medical team is created, it is important to remember that the person living with HIV/AIDS is the one making all the final decisions about the health services.

Communication is the team's best resource. Several measures will have to be taken to respect confidentiality and to make sure everyone's job is well done. The support team sometimes becomes a family member for the person and loved ones. The support team also needs the help of external resources.

5.4.1. Community Resources

Community support is very important for Natives. Solidarity is at the heart of the team's organization. Sometimes without even having to ask, some community members will

participate in the process, occasionally or regularly. Others may be afraid of the disease. Information and awareness are important to work together as a community.

The team can use several community resources for help. Every community has an organization that offers health care services as well as recreational and social activities. Friendship circles are also an interesting resource. Community kitchens, theatre troupes or youth centres can also be a resource for the support team working with patient.

Some communities also have organizations dedicated to HIV/AIDS and health in general, which can help to create the team. Several interveners have human and professional experience that can help the team and the patient.

5.4.2. Provincial Resources

The support team can also seek provincial resources. Native people can turn to the **First Nations of Quebec and Labrador Health and Social Services Commission (FNQLHSSC)** to find more information on health and social services.

The **Coalition des organismes communautaires québécois de lutte contre le sida (COCQ-sida)** can put



you in contact with national organizations and help you find the resources needed for the patient. Quebec's **Department of Health and Community Services (MSSS)** can also give you information on home care services and specific programs which you are eligible for.

5.4.3. National Resources

There are also national resources which can help you throughout the process with the patient. The **Canadian Aboriginal AIDS Network** is a national resource specialized in HIV/AIDS. It can give you information on health and legal issues.

The **Canadian AIDS Society** is also an important resource and can tell you where to find the best help. **Health Canada** can also give you information on specific programs.

5.4.4. Finding Information

As a member of the support team you may want to understand certain issues and what challenges lie ahead for you and the patient. Accompanying the person means that you have to understand what the person is or might be going through. Other community, provincial or national resources can help you find interesting information or can direct your own research. Here are the

libraries, bookstores and Internet sites where you can find information.

5.4.4.1. Libraries and Bookstores

Your local library probably has books on HIV/AIDS, death and home care. Some health organizations have their own library and information on the subject. You can also find brochures from the clergy or funeral home.

Most bookstores have information on HIV/AIDS. Some religious or homosexual libraries have more extensive information on death or HIV/AIDS. University bookstores have documents on the disease and palliative care but those are usually more expensive and technical.

5.4.4.2. Internet

Internet can be a good tool for information on HIV/AIDS, death, home care or any other topic concerning the patient and support team. Because there several sites available, you may want to visit Canadian or American sites that are more specific to our reality.

It is important to make sure that the organization or person providing the information is recognised and that the information is updated. You will find a list of the most interesting sites up to date in the Appendix.





Appendix



Coping with HIV/Aids

The Main Elements of Native Spirituality



The Creator

The Creator is also known as the Supreme Being or the Great Spirit. He gives every human being the gift of spirit and is the Creator of the world as we know it. Because He gives every living thing life and spirit, we must give thanks to Him every time we take a plant, a fish or an animal. Our connection to Nature is sacred and privileged.

Nature and Animals

Our sacred connection to Nature gives meaning to our life and actions within the environment. Nature is the caregiver of all human beings.

Animals are at the heart of native spirituality. Storytellers often refer to them as the guides and protectors of our nations, which all have animal benefactors. Their qualities represent the ideals which the nation seeks to achieve, as represented by the totems (wooden sculptures with an animal head).

The Circle

The circle is the most important shape in native spirituality. Mother Earth is round, the sky's inhabitants are set in a circle and life is a round cycle. For Natives, the circle represents the integrity given to us by the Creator.

There are four colours in the circle, which correspond to the four peoples of the Earth: black, red, white and yellow. We are therefore all part of the same circle and are Brothers and Sisters. The circle also includes the four cardinal points and the four seasons of the year.

The circle is divided in four parts represents the four dimensions of human beings: physical, spiritual, emotional and mental. These four dimensions are all included in the same space and each one is just as important to find balance. If one of these dimensions is out of balance, the person becomes dysfunctional. That is why Natives always consider the four dimensions, especially during a healing process.



Rituals and Ceremonies

There are several rituals and ceremonies in native spirituality. Some are performed to celebrate an event and to give thanks, others to cast away evil spirits and misfortune.

Several objects are used in the ceremonies and rituals, like eagle feathers or tobacco smoke. Amulets are also important for some nations. Dancing and chanting are often part of the ceremonies and rituals.





Living with HIV/AIDS: Fact Sheets

Living with HIV/AIDS means that several important life changes will occur. This section was prepared to provide precise and immediate answers to questions frequently asked about HIV/AIDS.

The fact sheets can easily be used by anyone who wants to understand the issues dealt with. Those who wish to get further information should contact the help organisations listed at the end of the section.

Fact Sheets

1. Opportunistic Infections and HIV/AIDS Related Diseases
2. Medical Treatments
3. Preventing Infections
4. Food Groups
5. Sexuality
6. Pregnancy
7. Physical Activity
8. Taking Part in the Community
9. Rights
10. Mandatory Reporting of HIV/AIDS
11. Non Insured Health Benefits
12. National HIV/AIDS Mentoring Program for Nurses and Physicians
13. Resources



Opportunistic Infections and Diseases Related to HIV/AIDS

People living with HIV/AIDS have an immune system which is affected by the virus. Because it is weakened, it can't fight the infections and diseases as they occur. They are therefore prone to developing various infections and diseases.

<p>Opportunistic Infections</p> <p>Opportunistic infections are viruses, bacteria or fungi which appear because the immune system is weakened.</p> <p>Most frequent opportunistic infections <i>Candida albicans (oral candidiasis)</i> <i>Pneumocystis carinii pneumonia (PCP)</i></p> <p>Other opportunistic infections <i>Toxoplasmosis</i> <i>Herpes virus</i> <i>Cryptococcosis (cryptococcal meningitis)</i> <i>Cryptosporidiosis</i> <i>Tuberculosis</i> <i>Cytomegalovirus (CMV)</i> <i>Mycobacterium avium-intracellular complex (MAI)</i></p>	
<p style="text-align: center;">Cancer</p> <p>40% of people living with HIV/AIDS develop some kind of cancer.</p> <p>Most frequent types of cancer</p> <p><i>Kaposi sarcoma</i></p> <p><i>Non-Hodgkin lymphoma (NHL)</i></p> <p><i>Primary lymphoma of the central nervous system</i></p>	<p style="text-align: center;">Neurological complications</p> <p>Several complications can appear in the nervous system because of the medication or because of disease related to HIV/AIDS.</p> <p>Most frequent neurological complications</p> <p><i>HIV Dementia</i></p> <p><i>Peripheral neuropathy</i></p> <p><i>Progressive multifocal leukoencephalopathy</i></p> <p><i>Weight loss syndrome</i></p>
<p>Women and HIV/AIDS</p> <p>Women living with HIV/AIDS develop specific infections and disease. However, there is little research on their incidence and the reactions due to the medication.</p> <p>Women living with HIV/AIDS develop gynaecological infections, cancer and complications in their menstrual cycle.</p>	



Main Medical Treatments

Traditional western medicine has two types of prescription medication used to fight HIV/AIDS: antiretrovirals and protease inhibitors.

In most cases, the medical treatment combines several types of medication. Because HIV/AIDS can mutate, the medication has to be frequently changed in order to prevent the body from getting accustomed to the medication.

Main antiretrovirals

AZT (azidothymidine, zidovudine, *ZDV*, *Retrovir*)

ddl (didanosine, didésoxynosine, *Videx*)

ddC (didésoxycytidine, *HIVID*, *Zalcitabine*)

3TC (lamivudine, *Zerit*)

d4T (stavudine, *Epivir*)

Main protease inhibitors

Saquinavir (*Invirase*)

Indinavir (*Crixivan*)

Ritonavir (*Norvir*)

Nelfinavir (*Viracept*)

Side Effects

Side effects due to the medication include loss of appetite, body distortion and lipodystrophy, bone destruction, avascular necrosis, osteopenia and osteoporosis, cardiovascular problems, diarrhea, fatigue, gas and bloating, hair loss (alopecia), head aches, insuloresistance and diabetes, kidney stones, hepatic toxicity, muscle pain, nausea and vomiting, nightmares, anxiety and sleep disorders, pancreatitis, peripheral neuropathy, skin and sexual problems.



For further information on the treatments, medication and side effects, please contact the *Canadian AIDS Information Exchange* at www.catie.ca or 1-800-263-1638. For information on dangerous combinations between prescription drugs, over the counter medication and natural products, please consult the following web site: www.aidsmeds.com



Preventing Infections

Preventing infections means preventing ALL MICROBES and not just HIV. Certain widespread precautions are necessary to protect people living with HIV/AIDS from germs, viruses or fungi. With extra precaution, we can also protect the people in our living environment.

To protect the person living with HIV/AIDS

These precautions are simple but very helpful.

Wash your hands regularly

Washing your hands with soap and warm water is the easiest way to prevent infections. Hand lotion can also prevent blisters.

Wearing a mask if you have a virus

A cold is easily transmitted. Even though it is harmless for a normal person, it can be dangerous for a person with a weakened immune system

Throwing out the garbage properly

Use double bags when the garbage is moist. Empty the garbage often.

Preparing food properly

Avoid raw food, such as eggs and meat. Wash the dishes and utensils with soap and warm water.

Pets

People living with HIV/AIDS must have healthy pets. Litters and bird cages must be emptied and cleaned every day. Wash your hands after doing so.

To protect the people from his entourage

There are four ways HIV can be transmitted:

- Unprotected relations with an HIV-positive person;
- Sharing infected needles;
- From an infected pregnant woman to her child (giving birth, breast feeding...);
- Direct contact with infected blood.

It is important to remember the four ways the disease can be transmitted to protect the people from our living environment.

Surgical gloves can be worn when cleaning open wounds and cuts.

Sharp objects and needles should be handled with care.

Pregnant women are more vulnerable to infections caused by HIV/AIDS (cytomegalovirus, toxoplasmosis and herpes). They should avoid being in contact with anyone who has these diseases.



Food Groups

The food guide and products included in it provide a well balanced diet. Even if it was developed for North-Americans in general, it can be adapted to Native people.

Grain products 5 to 12 portions a day

Grain products are the most important group for our body.

Barley, wheat, corn, oat and rice are all easy to find in stores.

Grain products can be eaten in many different ways like bread, bannock, cereal, muffins, pasta, pancakes and many others.

Fruit and vegetables 5 to 10 portions a day

There is a wide range of fruit and vegetables. All you have to do is go ahead and discover them!

Berries, apples, oranges, pumpkin, squash, grapes, carrots, potatoes, turnips, onions and exotic fruit like kiwis, cantaloupe and papaya! So much to choose from!

Dairy products 2 to 4 portions a day

Dairy products are made from milk. You can find some made from cow milk but also from goat milk, which can be an interesting alternative.

Milk, cheese, yogurt and cream are good examples. The human body needs dairy products. However, be careful to choose low fat dairy products.

Meat and Protein alternatives 2 to 3 portions a day

Meat and protein alternatives are at the heart of traditional cooking. However, with a different lifestyle, they must be balanced.

Caribou, deer, hare, duck, pheasant, chicken, turkey, fish and sea food are good examples of meat. Alternatives include eggs, nuts, peanuts and legumes.



You can find healthy traditional natives menus on the First Nations of Quebec and Labrador Health and Social Services Commission web site: www.cssspnql.com (under the health- Canada Prenatal Nutrition Program section).

In 1992, the American Agriculture Department published a pyramidal food guide for North-Western native communities, based on the four usual food groups. It can be found on their web site: www.aaip.com/tradmed/tradmedfoodguide.html



Sexuality

Human sexuality implies different dimensions of our life. The body, spirit, heart and soul are all affected by it. Even if, for people living with HIV/AIDS, these four dimensions are wounded, they need to feel connected in a caring and sexual relation with someone else. Intimacy and communication are the heart of human sexuality.

A couple can have sexual relations even if one of the partners is HIV-positive. The person can still offer its love and affection. A sexual is possible with certain precautions.

Sexuality is a medium of life and not of death!

Communication and Affection

Abstinence is the best way to prevent contracting or transmitting HIV. However, because every human being has sexual needs, it is hard to imagine abstinence as a long term solution.

Sexuality can however be fulfilled without its genital dimension. It can be expressed through touching, kissing, intimate moments shared in bed and communication.

A profound intimate relation can be very fulfilling for people living with HIV/AIDS.

Safe Sex

Safe sex means having a sexual relation without taking any risks, without exchanging sperm, vaginal secretions and/or blood.

A condom must be used at the very beginning of the relation to contain the sperm and vaginal secretions. Masturbation and touching each others' genitals are safe sexual practices.

Several other practices can be explored when the person is comfortable with its partner and a little communication, respect and imagination.

For further information on sexuality and people living with HIV/AIDS, go to the following web sites:

www.survivreausida.net

www.multisexualités-et-sida.org



Pregnancy

The gift of life is beautiful. However, when an HIV-positive mother gives birth, it can turn into a gift of death. With the new treatment and preventive diagnostic, several children can be saved from the infection.

Transmitting the Virus during Pregnancy

HIV is transmitted by blood, body fluid (sperm and vaginal secretions) and mother's milk.

An HIV-positive mother can transmit the virus to her child because they share the same body.

The baby can be infected during pregnancy, when the labour starts, during labour or through breast feeding.

Encouraging Results

Recent studies have shown that the risk of transmitting HIV from mother to child can be reduced if she is quickly and well treated.

In Canada, the number of children exposed to HIV through their mother has risen in the last decade. However, since 1996, more babies were treated while in their mother's womb or after their birth. Since 1996, fewer children were infected even if they were exposed to the virus.

The Importance of a Diagnostic

Canadian epidemiology studies have shown that up to 15 000 people might be infected without even knowing!

If the disease is quickly diagnosed, the treatment can be given from early on. The virus doesn't progress as fast if the treatment is given early.

To prevent the spread of the virus, pregnant women must take an HIV test.

It is a question of respect for one and other!



Physical Activity

Physical activity is good for the body, mind and soul. It helps to find balance. Moving around outside, developing physical capacities and being involved in some kind of sport makes us feel good. For people living with HIV/AIDS, physical activity can help to fight the disease and stay healthy.

Physical Benefits

Sport gets the body going and strengthens its defence system. It helps to develop muscles, have a better cardio-vascular resistance and activates the organs. The whole body is called upon and gets moving.

The more we use our body, the more we are ready to react to different situations. It becomes like a boy scout: "always ready to go."

For people living with HIV/AIDS, it is important for the body to react against different situations (viruses, germs, bacteria...).

Psychological Benefits

As the saying goes, "A healthy mind in a healthy body". When a person practices a physical activity, the body is stimulated as well as its thoughts and emotions.

Who doesn't need to get moving to wind down after a hard day? Sport can help us to express ourselves. Our emotions are evacuated and lived out.

Furthermore, when the body is stimulated through physical activity, it secretes hormones that give us a feeling of well being and make us feel relaxed. Who can deny something that makes us feel better, helps us regain self-confidence and trust our body?

Social Benefits

Physical activity makes us get out of the house, meet other people and at least stay in contact with our environment. Social contact is important for people living with HIV/AIDS. They need to feel surrounded by the world they live in and take part in it. Physical activity can help them maintain this contact and socially gain self-confidence.



Some people living with HIV/AIDS fear sport because of the prejudice others have about transmission of the disease. Because the virus can't be transmitted through sweat and skin contact, any individual or group sport can be practiced. Some types of extreme sport, which can result in injuries, should be practiced with caution.



Community Involvement

Community involvement can have as many benefits as physical activity for people living with HIV/AIDS.

It is a type of exchange between the person and the community. Other than contributing in community development and enrichment, participating in the community gives the person social importance and helps to regain its capacities and self-confidence.

There are different ways to participate in the community. The person doesn't necessarily have to work in the field of HIV/AIDS. However, some people chose to share their experience by creating awareness in the community and amongst young people on the dangers related to HIV/AIDS.

Serving the Community

Discrimination comes from misunderstanding, lack of information and closed mindedness. To fight discrimination in the community, people must be well informed. We have to reach out to them.

People living with HIV/AIDS can participate in the community by being available for those who want to meet them, talk to them, get to know them and understand.

There are different ways to participate in the community, through conferences on HIV/AIDS, workshops on prevention in schools or taking part in existing organisations (meal on wheels...). The idea is to help the community and help ourselves.

A New Self

Participating in the community can be enriching for people living with HIV/AIDS.

They avoid living in isolation, get proactive, feel useful, develop new capacities, develop new important relationships, preserve or regain their self-esteem. Participating in the community helps to discover ourselves.

The person and community take advantage of every benefit.

You can also get involved in provincial and national organisations dedicated to creating awareness and defending the rights of people living with HIV/AIDS. To contact them, see the list of organisations in the appendix.



Rights

People living with HIV/AIDS have the same rights as those who don't have the virus. Native people living with disease also have the same rights, including the right to adequate health services. It seems that for Natives living with the virus, some elements prevent them from expressing their rights. The **Canadian HIV/AIDS Legal Network** and the **Canadian Native HIV/AIDS Legal Network** identified three elements: systematic and individual discrimination, government jurisdiction and financing as well as confidentiality. These elements have an impact on the spread of the epidemic in native communities and restrict the person's rights.

Discrimination

People living with HIV/AIDS are faced with different types of discrimination: institutional and cultural discrimination because they are Native and individual discrimination because they have HIV/AIDS.

Human rights are supposed to protect people from discrimination. However, few native people complain and when they do, some provisions of the Indian Act make it harder to have certain rights recognised.

Access to Health Services

Human rights are supposed to guarantee everyone with access to adequate health services.

However, because of some problems concerning native jurisdiction and access to adequate health services in the reserves or immediate surroundings, these rights aren't always respected. Native people don't always benefit from adequate health services even when they need them badly. Basic health services sometimes lack in financing and aren't always culturally adapted.

Screening Test and Confidentiality

Few native people take a screening test because they fear that confidentiality won't be respected. Several native people living with the virus found out late and started taking medication when the virus had already considerably damaged the body. Some may have kept high-risk behaviours and may have infected other people. In that sense, protecting the person's rights prevents further infections.

It isn't easy to protect a person's confidentiality in place where everyone knows each other but it is absolutely necessary to protect the person's rights.

For more information on the rights of people living with HIV/AIDS, consult the Canadian HIV/AIDS Legal Network web site: www.aidslaw.ca



HIV/AIDS Mandatory Reporting

Reporting is mandatory for certain infections and diseases in order to help provincial governments to protect the general public health. It is **mandatory to report** HIV/AIDS. This only concerns physicians and medical laboratory directors. When a case of HIV/AIDS is detected, they must advise Quebec Public Health. This type of reporting concerns the number of cases but not the person's identity.

When a Case of HIV is detected

When an HIV test comes out positive, the physician or health professional who requested the test must report it, by telephone, to the Quebec Public Health Laboratory.

If the infected person received or gave some blood, blood products, tissues or an organ, the physician must write a notice to declare it, within 48 hours, directly to the public health of his region.

As of April 18th 2002, every screening test must be reported, whether it is a new case or a confirmed diagnostic.

The information is collected for epidemiological purposes and to survey the state of health of Quebec residents.

When AIDS is diagnosed

If the physician diagnoses a disease related to AIDS, he must fill out an SP-100 form.

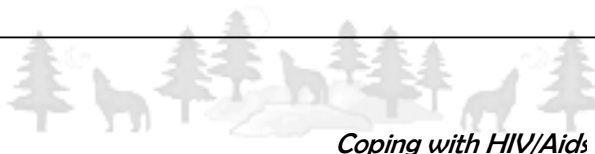
The physician must send the properly filled form to the Quebec HIV/AIDS Surveillance Program of the Direction générale de la santé publique du Ministère de la Santé et des Services Sociaux.

If the infected person received or gave some blood, blood products, tissues or an organ, the physician must write a notice to declare it, within 48 hours, directly to the public health of his region.

This mandatory reporting was established to protect public health. The data collected is non identifiable, in other words the person's identity is not given. Thus, the right to privacy and personal confidential information are protected.

Mandatory reporting is not managed this way by every province. That is why it is difficult to gather the surveillance information on the state of the population's health in different provinces.

For further information, contact the Direction générale de la santé publique du Ministère du Québec.



Non Insured Health Benefits (NIHB)

The non insured health benefits plan is designed for all members of the First Nations, Inuit and Innu. This program provides people with required health products and benefits. The medication taken against HIV/AIDS is covered by the program which is free for the First Nations, Inuit and Innu.

The program is managed by the First Nations and Inuit Health Branch (FNIHB) of Health Canada. The program was created under the 1979 Health Act to guarantee access to health services for members of the First Nations and Inuits who do not have access to provincial or private health insurance.

Most of the medication given to people living with HIV/AIDS is on the list of medication covered by the Non Insured Health Benefits program. The list is updated regularly due to medical breakthroughs.

However, some medication is not on the list or is subject to certain restrictions and thus harder to have access to. In special circumstances, it is possible to have the medication approved. In order to do so, the person must get a written authorization from the First Nations and Inuit Health Branch.

To get a copy of the list, please contact the FNIHB:

<http://www.hc-sc.gc.ca/dgspni/ssna/index.htm>

For further information

**NIHB Regional Office
Quebec Region**
1-877-483-1575 or
1-514-283-1575

**Canadian Aboriginal AIDS
Network**
1-888-285-2226 or
1-613-567-1817

Canadian Treatment Action Council (CTAC)

1-416-410-6538
ctac@ctac.ca



National HIV/AIDS Mentoring Program for Nurses and Physicians

HIV/AIDS and other related diseases require specific treatments and the medical staff must be trained accordingly. That is why the Centre québécois de coordination sur le sida (CQCS) and the Ordre des infirmiers et infirmiers du Québec (OIIQ) created a mentoring program for nurses and physicians in 1999.

The program's strength lies in the teaming of a new health professional with a more experienced professional to the further the training and knowledge of new professionals with respect to the treatments available for people living with HIV/AIDS.

The mentors are chosen according to specific criteria.

The professionals must be recognised for their experience and expertise in the field and in the clinical aftercare of people living with HIV/AIDS.

As mentors, these people are available to answer questions and if necessary, to refer the person to other specialized resources in the region.

The following services are offered through the program:

- Consultation services from a mentor to a new recruit;
- Field work placement in clinics, hospital research, teaching and care units, CLSCs, community organisations and in multidisciplinary teams;
- Continuing professional education: seminars, in-service workshops, conferences;
- Regular access to specialized documents on HIV/AIDS and medical breakthroughs .

This program has several positive benefits. It facilitates the access to information, gives better access to specialized resources for health professionals and prevents clinical isolation.



Resources

People living with HIV/AIDS have access to several resources. The objectives of community and government resources include overcoming isolation and prejudice, informing people, protecting patients' rights and providing them with real support. Here are a few useful resources that you can always use.

Aboriginal Resources

First Nation of Quebec and Labrador Health and Social Services Commission (FNQLHSSC)

To find information about the health of the First Nations of Quebec and Labrador, including a file on AIDS.

418-842-1540

www.cssspnql.com

Canadian Aboriginal Aids Network (CAAN)

Aboriginal regrouping for sensitizing, information and defence of the rights as regards HIV-AIDS

1-888-285-2226

www.caan.ca

Provincial Resources

Coalition des organismes communautaires québécois de lutte contre le sida (COCQ-sida)

Regrouping of Provincial organizations

www.cocqsida.com

Comité des personnes atteintes du VIH du Québec (CPAVIH)

Defence of the rights

1-800-927-2844

www.cpavih.qc.ca

Ministère de santé et des services sociaux du gouvernement du Québec (MSSS)

Information, policies and statistics

1-800-707-3380

www.msss.gouv.qc.ca

National Resources

Canadian AIDS Society

Regrouping of Canadian organizations

Québec : 1-866-521-7432

Labrador : 1-800-563-1575

www.cdnaids.ca

Canadian AIDS Treatment Information Exchange

Complete information on the life with the HIV and the treatments

1-800-263-1368

www.catie.ca

Canadian HIV/AIDS Legal Network

Defence of the rights and legislative information

1-514-397-6828

www.aidslaw.ca

Health Canada – government

Information, policies and statistics

Au Québec : 1-514-283-2306

www.hc-sc.gc.ca



List of aboriginal HIV-AIDS resources in Canada

2-SPIRITED PEOPLE OF THE FIRST NATIONS

14, College street, 4th floor

Toronto (Ontario) M5G 1K2

Tel : (416) 944-9300

Fax : (416) 944-8381

Email : spirit2@aracnet.net

- information, pre and post test counselling, training of support team, sharing circle, traditional lesson.

CANADIAN ABORIGINAL AIDS NETWORK

251 Bank Street, Suite 602

Ottawa (Ontario) K2P 1X3

Tel : 1-888-285-2226 ou (613) 567-1817

Fax: (613) 567-4652

Email : caan@storm.ca

- Aboriginal group for awareness, information and defence of rights regarding HIV-AIDS

FIRST NATION OF QUEBEC AND LABRADOR HEALTH AND SOCIAL SERVICES COMMISSION (F.N.Q.L.H.S.S.C.)

250, Place Chef Michel Laveau

Wendake (Québec), G0A 4V0

Tel : (418) 842-1540

Fax: (418) 842-7045

Email : reception@cssspnql.com

- To find information about the health of the First Nations of Quebec and Labrador, including a file on AIDS.



**THE NATIONAL INDIAN & INUIT COMMUNITY HEALTH REPRESENTATIVES
ORGANIZATION (NIICHRO)**

C.P. 1019

Kahnawake (Québec) J0L 1B0

Tel : (450) 632-0892

Internet : www.niichro.com

- Prevention and promotion of Community health
-

ONTARIO ABORIGINAL HIV/AIDS STRATEGY

14 College street, 4th floor

Toronto (Ontario) M5G 1K2

Tel : (416) 944-9481 ou 1-800-743-8851

Fax : (416) 944-0541

Email : spirit2@aracnet.net

- Prevention and promotion program on traditional medicine and health
-

ABORIGINAL LEGAL SERVICES OF TORONTO

197 Spadina avenue, suite 600

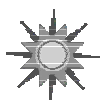
Toronto (Ontario) M5T 2C8

Tel: (416) 408-3967

Fax : (416) 408-4268

- legal opinion, will, human, rights, access to assistance programs
-





List of Community organizations HIV-AIDS in Québec

A.C.C.M.

Mr Ken Monteith
 (Aids Community Care Montréal)
 2075, rue Plessis
 Montréal (Québec) H2L 2Y4
 Tel: (514) 527-0928
 Fax: (514) 527-0701

Email : info@accmontreal.org

- Accompaniment - Support - Reference - Animal Therapy – Day centre – Bilingual Services

ACTION SÉRO-ZÉRO

Mr Robert Rousseau
 2075, rue Plessis
 Montréal (Québec) H2L 2Y4 C.P. 246, Succ. "C"
 Tel: (514) 521-7778
 Fax: (514) 521-7665

Email : direction@sero-zero.qc.ca

- Primary and secondary prevention - Education - Intervention near the target groups

CENTRE OF RESOURCES, INTERVENTIONS AND SERVICES IN SEXUAL HEALTH C.R.I.S.S.

Mrs Marie Anesie Harerimana
 5410, 2^e Avenue
 Montréal (Québec) H1Y 2Y3
 Tel: (514) 855-8991
 Fax: (514) 855-8994

Email : criss@bellnet.ca

- Services AIDS women - Services STI women - Prevention

CACTUS

Mrs Marianne Tonnelier
 1626, rue St-Hubert
 Montréal (Québec) H2L 3Z3
 Tel: (514) 847-0067
 Fax: (514) 847-0728

Email : cactusm@videotron.ca

- Prevention – Needle Exchange



THE CENTRE FOR AIDS SERVICES OF MONTREAL (WOMEN)

Mrs Daniella R. Boulay
 1750, rue St-André , 3^e étage
 Montréal (Québec) H2L 3T8
 Tel: (514) 495-0990
 Fax: (514) 495-8087

Email : casm@netrover.net

- Education - Prevention – Women Projects

CENTRE DES SERVICES SIDA SECOURS DU QUÉBEC

Mrs Hélène Légaré
 3702, rue Ste-Famille
 Montréal (Québec) H2X 2L4
 Tel: (514) 842-4439
 Fax : (514) 842-2284

Email : sidasecours@hotmail.com

- Lodgings

COALITION SIDA DES SOURDS DU QUÉBEC

Mr Michel Turgeon
 2075, rue Plessis
 Montréal (Québec) H2L 2Y4
 Tel: 1-800-855-0511 ask for the following
 number: (514) 521-1780
 Fax: (514) 521-1137

Email : cssq@qc.aira.com

- Information – Support during anonymous testing - Support Group -
 Psychosocial services - Prevention and education

GEIPSI

Mr Yvon Couillard
 (Groupe d'entraide à l'intention des personnes séropositives et itinérantes)
 1223, rue Ontario Est
 Montréal (Québec) H2L 1R5
 Tel: (514) 523-0979
 Fax: (514) 523-3075

Email : info@geipsi.ca

- Support for the itinerant people living with HIV-AIDS and drug addicts



HÉBERGEMENT DE L'ENVOL

Mr Bernard Gendron
 6984, rue Fabre
 Montréal (Québec) H2E 2B2
 Tel: (514) 374-1614
 Fax: (514) 593-9227

Email : hebergementlenvol@hotmail.com

- Collective hearth for people living with HIV-AIDS in loss of autonomy
-

LES ENFANTS DE BÉTHANIE

Mr René Légaré
 8454, rue St-Denis
 Montréal (Québec) H2P 2G8
 Tel: (514) 384-8070 / 384-8160
 Fax: (514) 384-3092

Email : ledb@videotron.ca

- Baby-sitting - Transport and accompaniment - Support for the family - parental Resource
-

MAISON AMARYLLIS

Mrs Hélène Légaré
 1462, rue Panet
 Montréal (Québec) H2L 2Z3
 Tel: (514) 526-3635
 Fax: (514) 521-9209

- Lodgings for people living with HIV-AIDS, homeless people and poly drug-users
-

MAISON D'HÉRELLE

Mrs Michèle Blanchard
 3738, rue St-Hubert
 Montréal (Québec) H2L 4A2
 Tel: (514) 844-4874
 Fax: (514) 842-2991

Email : herelle@videotron.ca

- Rooms, means and long term for people living with HIV-AIDS and in loss advanced of autonomy - Transition and respite
-



MAISON DEHON

Mr Claude Bédard
 2830 A., Boul. Gouin Est
 Montréal (Québec) H2B 1Y7
 Tel: (514) 384-0450 / (514) 388-5750
 Fax: (514) 388-8290

Email : jcbedard@scjcanada.org

- Lodgings for people living with HIV-AIDS in loss of autonomy
-

MAISON DU PARC

Mrs Marielle Delaney
 1287, rue Rachel Est
 Montréal (Québec) H2J 2J9
 Tel: (514) 523-6467
 Fax: (514) 523-6800

Email : maisonduparc@qc.aira.com

- Rooms for people living with HIV-AIDS and in loss of autonomy
-

MAISON PLEIN COEUR

Mr Louis-Marie Gagnon
 1611, rue Dorion
 Montréal (Québec) H2K 4A5
 Tel: (514) 597-0554
 Fax: (514) 597-2788

Email : mplcoeur@ca.inter.net

- Services – Daycare Centre - Maintenance in residence - Massotherapy - spiritual Accompaniment - collective Kitchen - Lodging
-

CANADIAN HIV/AIDS LEGAL NETWORK

Mr Ralph Jürgens
 1417, rue St-Pierre , #408
 Montréal (Québec) H2Y 2M4
 Tel: (514) 397-6828
 Fax: (514) 397-8570

Email : info@aidslaw.ca

- Defence of the rights - Search for legal, humane and policy order regarding HIV-AIDS - legal Assistance for people living with HIV-AIDS.
-



CANADIAN HEMOPHILIA SOCIETY (QUÉBEC)

Mrs Aline Ostrowski
 625, rue Président-Kennedy - Suite 1203
 Montréal (Québec) H3A 1K2
 Tel: (514) 848-0666
 Fax: (514) 848-9661

Email : info@schq.org

- Defence of the rights - Support and mutual aid for haemophiliacs, transfused and their families - Information

SPECTRE DE RUE

Mr Gilles Beauregard
 (Service de prévention, d'écoute communautaire et de travail de rue éducationnel)
 1347, Ontario est
 Montréal (Québec) H2L 1R8
 Tel: (514) 528-1700
 Fax: (514) 528-1532

Email : spectrederue@videotron.ca

- Support and prevention - Sensitizing and education

STELLA

Mrs Michèle Burque
 2065, rue Parthenais, suite 404
 Montréal (Québec) H2K 3T1
 Tel: (514) 285-8889
 Fax: (514) 285-2465

Email : stellapp@videotron.ca

- Support and prevention - Sensitizing and education

ACTIONS SIDA CÔTE-NORD

Mrs Caroline Thériault
 700, Boul. Laure, # 235
 Sept-Îles (Québec) G4R 1Y1
 Tel: (418) 962-6211
 Fax: (418) 962-6401

Email : actionssida@bbsi.net

- Education - Prevention - Support - Help for people living with HIV-AIDS and their close relations



B.L.I.T.S.

M. André Beaudry
 (Bureau local d'intervention traitant du sida)
 59, rue Monfette - Local 116
 Victoriaville (Québec) G6P 1J8
 Tel: (819) 758-2662
 Fax: (819) 758-8270
[Email : blits@cdcbf@gc.ca](mailto:blits@cdcbf@gc.ca)
 ➤ Prevention - Support - Intervention

B.R.A.S. - OUTAOUAIS

Mr Alain Godmaire
 (Bureau régional d'action sida)
 109, rue Wright
 Gatineau (Québec) J8X 2G7
 Tel: (819) 776-2727
 Fax: (819) 776-2001
[Email : b.r.a.s@videotron.ca](mailto:b.r.a.s@videotron.ca)
 ➤ Prevention - Support – Intervention - Lodging

ÉMISS-ÈRE

Mr Sylvain Gauthier
 462, Boul. Ste-Foy
 Longueuil (Québec) J4J 1Y2
 Tel: (450) 651-9229
 Toll free: 1-888-CAP-SIDA
 Fax: (450) 651-3420
[Email : info@emiss-ere.ca](mailto:info@emiss-ere.ca)
 ➤ Support - Prevention

CENTRE DES R.O.S.É.S.

Mr Samir Baccouche
 (Centre de ressources œuvrant au soutien
 et à l'écoute des gens qui vivent avec le sida)
 380, rue Richard, suite 220
 Rouyn-Noranda (Québec) J9X 4L3
 Tel: (819) 764-9111
 Fax: (819) 762-8403
[Email : centre-r.o.s.e.s@cablevision.qc.ca](mailto:centre-r.o.s.e.s@cablevision.qc.ca)
 ➤ Reception - Support and listening for people living with the HIV-AIDS and
 their entourage



CENTRE SIDA AMITIÉ

Mrs Josée Talbot
 527, rue St-Georges
 St-Jérôme (Québec) J7Z 5B6
 Tel: (450) 431-7432
 Fax: (450) 431-6536

Email : csa1@gc.aira.com

- Support - Education - Prevention - Info-Sida Line

MAISON SAINTE FAMILLE

Mrs Chantal Bisailon
 132, rue Jean
 Lachenaie (Québec) J6W 1B8
 Tel: (450) 961-4447
 Fax: (450) 961-4270

- Lodging - Relation of assistance - spiritual Accompaniment - Financial assistance - Support for the maintenance in residence - Search for resources

I.R.I.S. - ESTRIE

Mrs Susan Garand
 (Intervention régionale et information sida)
 505, rue Wellington Sud
 Sherbrooke (Québec) J1H 5E2
 Tel: (819) 823-6704
 Fax: (819) 823-5537

Email : iris.estrie@videotron.ca

- Prevention - Support - Intervention - Break-down service drugs – Daycare centre - Lodging

M.A.I.N.S. - BAS ST-LAURENT

Mrs Marielle Fortin
 (Mouvement d'aide et d'information sida du Bas St.-Laurent)
 C.P. 254
 Rimouski (Québec) G5L 7C1
 Tel: (418) 722-7432
 Fax: (418) 722-7847

Email : mainsbsl@hotmail.com

- Intervention - Education - Prevention - Support



MAISON RE-NÉ

Mrs Christiane Blais
 2800, Boul. Des Forges
 Trois-Rivières (Québec) G8Z 1V2
 Tel: (819) 379-2495
 Fax: (819) 379-9195
 ➤ Lodging for people living with HIV-AIDS

M.I.E.L.S. - QUÉBEC

Mr Mario Fréchette
 (Mouvement d'information et d'entraide dans la lutte contre le sida à Québec)
 281, chemin Ste-Foy
 Québec (Québec) G1R 1T5
 Tel: (418) 649-1720
 Ligne Info-Sida: (418) 649-0788 (in french)
 Fax: (418) 649-1256
 Email : miels@miels.org
 ➤ Prevention - Support - Intervention

M.I.E.N.S.

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 Chicoutimi (Québec) G7H 5E1
 Tel: (418) 693-8983
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 ➤ Prevention - Support - Intervention

R.P.V.V.I.H.

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 Tel: (418) 529-1942
 Fax: (418) 529-5470
 Email : rpvvih@rpvvih.qc.ca
 ➤ Defence of the rights for people living with HIV-AIDS - Information - Support
 between pars - Prevention - References



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- Prevention - Support - Intervention
-

SIDA-VIE LAVAL

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Fax: (450) 669-3421
[Email : sidavie@lavalnet.qc.ca](mailto:sidavie@lavalnet.qc.ca)

- Education - Prevention - Accompaniment – Support and listening – voluntary service
-

S.I.P.E. - LANAUDIÈRE

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Fax: (450) 752-4224
[Email : sipe@sympatico.ca](mailto:sipe@sympatico.ca)
















- Information - Prevention - Sensitizing - Accompaniment
-





Links to HIV/AIDS Treatment Web Sites



This list is drawn from Internet site of the Canadian AIDS Treatment Information Exchange (CATIE)

About Herbs, Botanicals, and other Products	http://www.mskcc.org/aboutherbs
AIDS Committee of Toronto [ACT]	 http://www.actoronto.org
AIDS Community Research Initiative of America (ACRIA)	http://www.criany.org/acria.html
AIDS Education Global Information System (AEGIS)	http://www.aegis.org/
AIDS Mailing List (AEGIS news service)	http://ww2.aegis.org/todaysnews/list.asp
AIDS Map	http://www.aidsmap.com
AIDS Vancouver	 http://www.aidsvancouver.org/
AIDSinfo	http://www.aidsinfo.nih.gov/
AIDSmeds.com	www.aidsmeds.com
Alliance for South Asian AIDS Prevention (ASAP)	 http://www.asaap.ca
Alternative Medicine Homepage	http://www.pitt.edu/~cbw/altm.html
AmFAR Treatment Directory	http://www.amfar.org/cgi-bin/iowa/index.html
Asian Community AIDS Services	 http://www.acas.org/
Association of Nutrition Services Agencies (ANSA)	http://www.aidsnutrition.org/
BC Centre for Excellence in HIV/AIDS	 http://cfeweb.hivnet.ubc.ca
BC PWA	 http://www.bcpwa.org/
BETA (Bulletin of Experimental Treatments for AIDS) Online	http://www.sfaf.org/beta/
Body, The	http://www.thebody.com/cgi-bin/body.cgi
Canadian Aboriginal AIDS Network	 http://www.caan.ca/
Canadian AIDS Society	 http://www.cdnaids.ca/
Canadian Association of Nurses in AIDS Care (CANAC)	 http://canac.org/english/WELCOME.htm
Canadian HIV Trials Network (CTN)	 http://www.hivnet.ubc.ca/ctn.html
Canadian HIV/AIDS Information Centre	 http://www.clearinghouse.cpha.ca/
Canadian HIV/AIDS Legal Network	 http://www.aidslaw.ca
Canadian Medical Association Online	 http://www.cma.ca/
Canadian Treatment Action Council (CTAC)	 http://www.ctac.ca/
CAPS - The Center for AIDS Prevention Studies	http://www.epibiostat.ucsf.edu/capsweb/
CDC National Prevention Information Network	http://www.cdcnpin.org/
Clinique Médicale l'Actuel	 http://cliniquelactuel.com/



Community-Linked Evaluation AIDS Resource (CLEAR) Unit	 http://www.fhs.mcmaster.ca/slr/clear/
Conference on Retroviruses and Opportunistic Infections	http://www.retroconference.org
Division of HIV/AIDS Epidemiology and Surveillance	 http://www.hc-sc.gc.ca/pphb-dgsp/hast-vsmt/index.html
FIAR : The Foundation for Integrative AIDS Research	http://www.aidsinfonyc.org/fiar/
Gay Men's Health Crisis	http://www.gmhc.org/
Health Canada	 http://www.hc-sc.gc.ca/english/
Health Care Information Resources: AIDS Links	 http://www-hsl.mcmaster.ca/tomflem/top.html
HeteroChat	http://www.Heterochat.org
HIV and Hepatitis.com	http://www.hivandhepatitis.com
HIV Community-Based Research Network	 http://www.hiv-cbr.net/index.php?newlang=english
HIV Insite	http://hivinsite.ucsf.edu/
HIV Medication Guide	 http://www.hivmedicationguide.com
HIV Positive	http://www.hivpositive.com/
HIV/AIDS Links from Concordia University	 http://juno.concordia.ca/collections/subpages/hiv2.html
Interagency Coalition on AIDS and Development (ICAD)	 http://www.icad-cisd.com/
International Association of Physicians in AIDS Care	http://www.iapac.org/
JAMA & Archives Journal Collections	http://pubs.ama-assn.org/cgi/collection/hiv_aids
Johns Hopkins AIDS Service Website	http://www.hopkins-aids.edu/
Live Positive	 http://www.livepositive.ca
Marty Howard's HIV/AIDS HomePage	http://www.marty-howard.com/
Medibolics	http://www.medibolics.com/
MEDLINE	http://www.ncbi.nlm.nih.gov/PubMed/
Medscape	http://www.medscape.com/
MedWeb	http://www.medweb.emory.edu/MedWeb/
National AIDS Treatment Advocacy Project (NATAP)	http://www.natap.org
National Institute of Allergy and Infectious Diseases (NIAID)	http://www.niaid.nih.gov/
New Mexico AIDS InfoNET	http://www.aidsinfonet.org/
Office of Natural Health Products (ONHP)	 http://www.hc-sc.gc.ca/hpb/onhp/welcome_e.html
Ontario AIDS Network	 http://www.ontarioaidsnetwork.on.ca/



Ontario HIV Treatment Network	 http://www.ohtn.on.ca/
Pacific AIDS Network	 http://www.pan.ca/
PARC Library	 http://www.aidsvancouver.org/services/library/
Pauktuutit Inuit Women's Association	 http://www.pauktuutit.on.ca/
PHA Discussion Group	 http://www.ontarioaidsnetwork.on.ca/
Physicians' Research Network	http://www.prn.org
Project Inform	http://www.projectinform.org/
Protease Inhibitor Treatment List	http://www.pozlink.com/
PWA Ring	http://www.geocities.com/WestHollywood/3390/PLWAHP.htm
Red-Road, The	 http://www.red-road.org/
Sensible Guide to using Complementary Therapies for HIV, The	 http://www3.sympatico.ca/devan.nambiar
Southern Alberta Clinic (SAC)	 http://www.crha-health.ab.ca/clin/sac/sac.htm
Test Positive Aware Network (TPAN)	http://www.tpan.com/
Toronto Hospital Immunodeficiency Clinic	 http://www.tthivclinic.com/
Toronto People With AIDS Foundation	 http://www.pwatoronto.org
US Pharmacist	http://www.uspharmacist.com
Vancouver Native Health Society	 http://www.vnhs.net/
Voices of Positive Women	 http://www.vopw.org
WAVE: Women and AIDS Virtual Education	 http://www.pwn-wave.ca/
Wes and Tom's site	http://www.westom.com/coolsite/aidsindx.htm
Yoga for HIV/AIDS	http://www.yogagroup



Glossary

Definitions found in the Petit Larousse 2004 Dictionary

Infectious agent:	Anything that acts or operates to produce an infection.
Analgesic:	Describes any drug, substance or product that reduces the sensation of pain.
Antibody:	Substance (immunoglobulin protein) that is synthesized by the cells of the immune system and that is able to attach itself specifically to an antigen.
Antigen:	Any chemical substance that is isolated or borne by a cell, a micro-organism, which, once introduced in the body, can cause a specific reaction of the immune system that aims to destroy it or neutralize it.
Bacteria:	Micro-organism the cell of which does not have a nucleus; can be found in all areas and comes under various forms.
Blood cell:	Name sometimes given to certain cells in the body. – <i>White blood cell</i> : leukocyte. – <i>Red blood cell</i> : erythrocyte.
Cancer:	An abnormal growth of cells which may invade and destroy nearby tissues and organs or spread to other parts of the body.
Central nervous system:	Portion of the nervous system which includes the encephalon (brain) and the spinal cord.
Chemotherapy:	Treatment by chemical substances, used in particular for cancers.
Chlamydia:	Type of bacteria responsible for common contagious infections which affect men (such as certain sexually transmitted infections).
Copper contraceptive:	Plastic or copper contraceptive device, placed in the uterine cavity.
Diagnostic:	Identification of a disease through symptoms.
Droppings:	Excreta of certain animals, particularly of birds



Fungal infection:	Infection caused by the penetration of fungi into the body.
Fungus:	Certain fungi are formed by a single cell (yeast). Most of them have many cells which are assembled in threadlike networks, the mycelium. There are also many fungi which have reduced or microscopic mycelium, including superior fungi, such as the penicilliums, and the group of fungi known as the <i>inferior fungi</i> , including mould and many plant parasites (mildew, rust, and blackleg), animal and human parasites (mycosis).
Gastrointestinal tract:	Group of fibres or organs which are continuous and form the functional unit of the stomach and the intestines
Gonorrhoea:	Sexually transmitted disease due to gonococcus, leading to the inflammation of certain regions of the urogenital system (urethra, prostate and bladder with men; bladder and cervix of uterus with women).
Host cell:	Cell acting as the recipient in the transfer of genetic information.
Immune system:	Group of cells, of tissues and organs (white blood cells, lymphoid system, etc.) which ensure the body's defence against outside agents.
Infection:	Penetration and development in a living organism of micro-organisms which can create lesions by multiplying, and eventually by releasing toxins or by propagating themselves through blood streams.
Lymphatic system:	Group of lymph glands and of vessels which contain the lymph, involved in the tissue drainage and in the immunity.
Lymphocyte:	White blood cells that mature and reside in the lymphoid organs and are responsible for the acquired immune response.
Malabsorption:	Defective absorption of fluids or of any other nutritive substances.
Mutant:	An animal or a plant life which has new characteristics compared to all its ascendants.
Mutation:	Sudden origination, in all or a certain portion of cells of a living organism, a change in the structure of certain genes, transmitted to the oncoming generations if the gametes are affected.



Mycobacterium:	Type of bacteria such as the tuberculosis (Koch's bacillus) or leprosy (Hansen's bacillus) agent.
Nervous system:	Group of organs and of structures composed of nervous tissues, ensuring the sensitive and sensory reception, motor command, organ and body function coordination, and psychic life.
Parasite:	Living organisms may or may not be microscopic, which can penetrate the organism or live on its surface.
Premenstrual syndrome:	Highly noticeable physical and affective tension which occurs before menstruations.
Prognosis:	Predication of the evolution of a disease, particularly how dangerous it might be.
Retrovirus:	ARN virus which family includes namely HIV, which causes AIDS.
Serological study; see Serodiagnosis:	Diagnosis of infectious diseases based on search for the specific antibody of an infectious agent in the serum.
Subcutaneous:	Relative to the hypoderm, to the tissue beneath the skin.
Syndrome:	Group of de signs, symptoms, and problems in which the causes are unknown or multiple.
Symptom:	Subjective problem perceived by someone (pain, for example), that reveals a disease.
System:	Group of organs or of tissues of the same nature designed for analogous functions.
Toxin:	Waste of the organism the effect of which is pathogenic when accumulated; poison.
Toxic:	Harmful substance for living organisms.
Tumour:	Abnormal, non inflammatory, proliferation of grouped or disseminated cells, more or less undifferentiated and autonomous. – <i>Malignant tumour</i> : cancer.



- Virus :** Very small infectious agent, which possesses a single type of nucleic acid, ADN or ARN, and which can only reproduce itself as a parasite of a cell.
- Viral load:** Quantity of virus present in the blood.
- Yeast:** Asexually reproduced unicellular fungus.



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