

**ONTARIO FIRST NATIONS HIV/AIDS
EDUCATION CIRCLE
“Coming Home”**

**HIV/AIDS Reference Manual:
A Guide for First Nation Service
Providers**



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Health Canada, First Nations Inuit Health Branch.**

Disclaimer

Through the production of this manual, the Ontario First Nations HIV/AIDS Education Circle strives to improve HIV/AIDS related services provided to First Nations people. However, all information contained herein is Ontario specific, and is meant as supportive information only. The manual is not meant to be a comprehensive care guide for people living with HIV/AIDS, nor a substitute for medical care and attention.

Dedicated to Gabe Kakeway.

**A Husband, a Father, a Friend and an Educator,
who taught us that the best way to create change was to create a Circle.
He had a vision – to bring our skills, knowledge, beliefs and spirit into one
Circle, so we can be the change that we strive for in our communities.**

**For this we are most grateful.
Chi Miigwech**

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Ontario First Nations HIV/AIDS Education Circle

Funded by Health Canada, First Nations and Inuit Health Branch, the Ontario First Nations HIV/AIDS Education Circle (hereafter referred to as the Circle) is comprised of ten members; a representative from each First Nation Provincial Territorial Organization, people living with HIV/AIDS, an Elder and a Youth.

The Circle Members are:

Elly Antone, Association of Iroquois and Allied Indians
Jody Cotter, Union of Ontario Indians
Gwen Medicine, Nishnawbe Aski Nation
Ida Copenace, Kenora Health Access Centre
Lyndia Jones, Independent First Nations
Doris Peltier, Canadian Aboriginal AIDS Network
Christina Ashawasgai
Rene Boucher, First Nations Person Living with HIV/AIDS
Trevor Stratton, Canadian Aboriginal AIDS Network
Youth and Elder Representative (invited)

The goal of the Circle is to support each other on collaborative efforts designed to enhance the level of HIV/AIDS awareness, prevention and education among First Nation communities. The strength of the Circle is grounded in its diverse levels of skills and knowledge, and its guiding principles that direct and support the Circle in its efforts to address the diverse needs of Ontario's First Nation communities.

Vision and Guiding Principles

The Ontario First Nations HIV/AIDS Education Circle envisions a future whereby our Nation communities, families and individuals are free from the negative effects of HIV/AIDS.

The guiding principles are:

Both First Nation healing traditions and modern technologies contribute to the concepts and practices of holistic health. First Nations consider the holistic perspective does not only include the well being of the individual but also the social, emotional, physical and mental well being of the entire community.

Self-determination is fundamental, thus First Nations people must be involved in all aspects of health care delivery, including research, planning and development, implementation and evaluation. Commitment is required for full involvement of First Nations peoples at all levels in decision making.

It is the right of First Nations peoples to choose to be different and to choose different models of health care. First Nations as First Nations are not a cultural or homogenous group. Similarly, diverse geography, history, access, and a range of issues also influence their health needs. Health programs must be tailored to meet the needs of each community as identified by that community.

The social, economic and environmental contexts in which First Nations peoples live have significant impact on their health issues. Many First Nation communities in Ontario experience higher levels of poverty and unemployment, lower education status, inadequate or unaffordable housing, food insecurity and loss of identity and culture. These and other factors negatively impact the health of First Nations peoples. Improvement in these areas will contribute to significant gains in First Nation health status.

Health services must be provided in a culturally secure environment and manner. A Health/Provincial hospital policies and practices need to accommodate legitimate cultural rights, views and values and expectations of First Nations peoples.

A coordinated and collaborative intersect oral approach is required. Service delivery needs to be coordinated within the health care systems, such as between primary and secondary services.

Improved, guaranteed funding and willingness and commitment are central to all health plans for First Nations peoples. Access to all health services must be based on need, and an equitable allocation of resources based on need is required to enable equality of health outcomes.

Background

In May 2008, the Circle conducted an environmental scan of the HIV/AIDS programs and services being provided to the First Nation communities across Ontario. Among the various findings, the report noted that First Nation service providers were not knowledgeable on which frontline service provider was responsible for servicing the specific needs of their community members living with HIV/AIDS. They were also uncertain about their specific role in service provision. Lack of awareness on service provider roles and responsibilities increases the possibility that the needs of First Nation people living with HIV/AIDS, and their family and caregivers, may go unmet. Furthermore, the report identified that frontline workers also require training in the areas of testing and counseling.

These findings have directed the Circle to commission the development of this manual and improve accessibility and quality of services and programs, such as testing and counseling, needed by First Nation people living with HIV/AIDS.

Purpose

The HIV/AIDS Reference Manual (hereinafter referred to as the Manual) is a learning and resource tool for First Nation service providers. Regardless of the field of service (ie. Health, education, social, etc.), each service provider has a role in addressing the holistic needs of First Nation members living with HIV and/or AIDS.

The information contained in the manual is Ontario specific, and is not intended to provide comprehensive health or medical information. If you require medical information, please consult a regulated health care professional.

Preface

According to the Public Health Agency of Canada (PHAC), Aboriginal people are overrepresented in the HIV epidemic in Canada.¹ Between 1979 and December 31, 2008, there have been 21,300 AIDS cases reported to the Centre for Communicable Diseases and Infection Control (CCDIC), of which 16,824 (79%) included information on ethnicity. Of these 16,824 cases, 690 were reported to be Aboriginal peoples (4.1%). Yet, according to Census Canada (2006), Aboriginal people only make up 3.8% of the population.

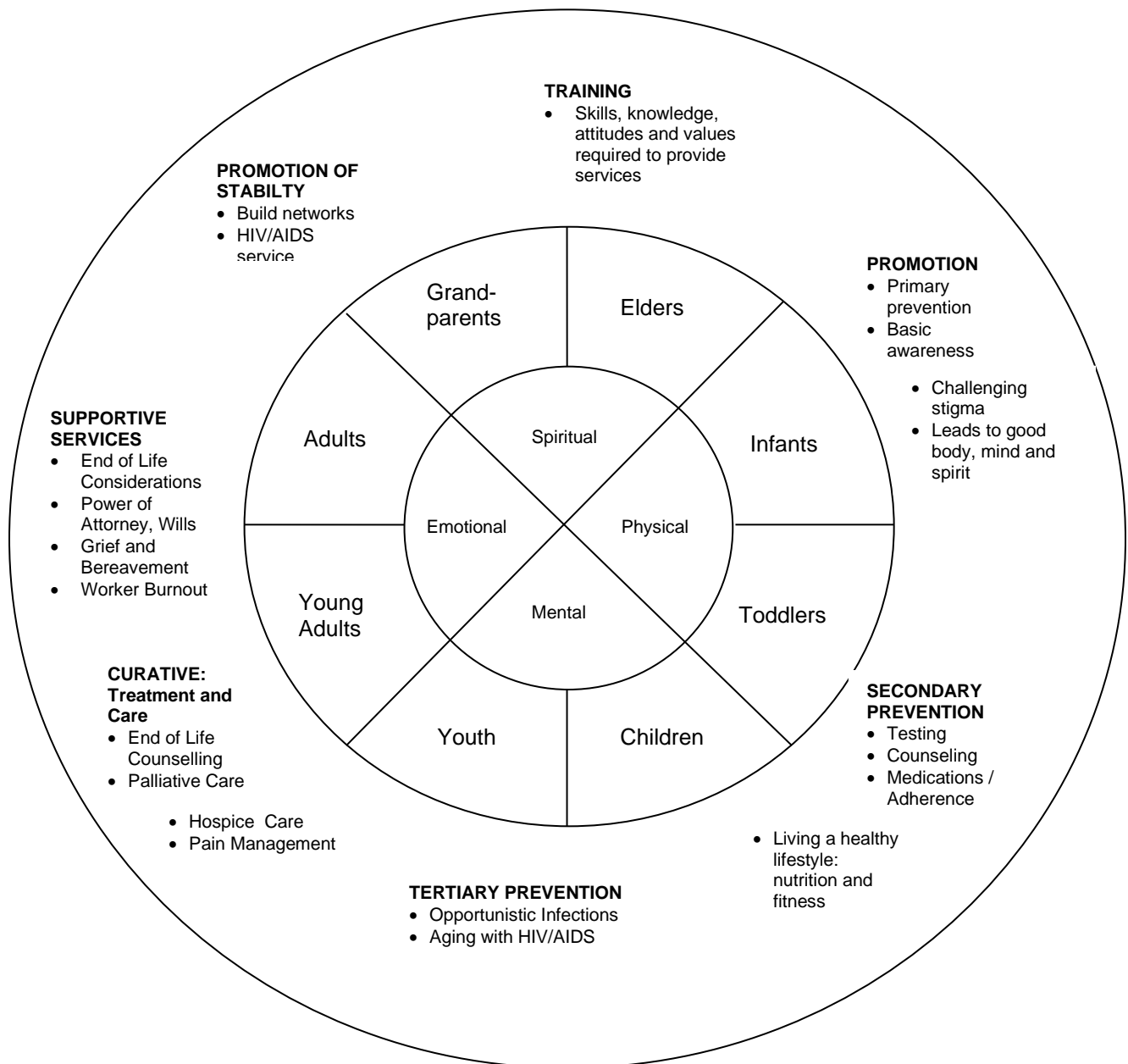
In 2008, PHAC surveillance data demonstrated that Aboriginal people make up a growing percentage of positive HIV test reports and reported AIDS cases, with injecting drug use being a key mode of transmission in the Aboriginal community, especially for women (Aboriginal female cases attributed to IDU: 65.8%, compared to 54.4% for Aboriginal male cases). Aboriginal women also make up a larger portion of positive HIV test reports. For all Aboriginal positive HIV test results between 1998 and 2008, women made up 48.8%, compared to only 20.6% of all non-Aboriginal positive test results being women. In addition, the age that Aboriginal people are testing HIV positive tends to be lower than for other ethnic groups. Between 1998 and 2008, almost a third (32.6%) of positive test results among Aboriginal people were youth aged 15-29, compared to 20.5% among other ethnic groups.

Clearly, HIV and AIDS is still a growing concern for Aboriginal people, especially for women and youth. The First Nation communities need to not only focus their efforts on HIV prevention, but also to support people living with HIV/AIDS to live longer, healthier lives.

¹ PHAC uses the term Aboriginal to represent First Nations, Métis and Inuit. The figures provided in the Preface are derived from the HIV/AIDS *EPI Update*, PHAC, July 2010. "HIV/AIDS Among Aboriginal People in Canada".

The Healing Continuum of Care

The continuum of care wheel demonstrates the holistic nature of First Nation health and healing, addressing the physical, mental, emotional and spiritual needs of human beings, representing all stages of the lifecycle, and a full spectrum of programmes and services. The goal when using the wheel for HIV/AIDS service delivery is to improve the health of people living with HIV/AIDS by strengthening all promotion, prevention and supportive services, while promoting the stability of services. Training is a key element of achieving this goal.



For the purpose of this manual, the continuum of care wheel will be used to present HIV/AIDS information and to suggest the roles and responsibilities of frontline workers in providing programmes and services to people living with HIV/AIDS.

A Holistic Approach to HIV Education and Prevention

Like all things, HIV does not exist in isolation; there are many social issues that may exist in the First Nation community that make individuals more susceptible to HIV infection. This is why a holistic approach to HIV education and prevention is necessary. For example, in mainstream society violence is incidental but in First Nation communities it is a systemic problem that has resulted from collective and intergenerational trauma brought on by state interventions such as residential school and the child welfare system. According to the Ontario Native Women's Association, 80% of Aboriginal women in Ontario have experienced family violence which is eight times the amount experienced by all other Canadian women. In addition, a study by the Alliance of Five Research Centres found that in their sample, 75% of the Aboriginal women under the age of 18 had experienced sexual abuse.

These statistics suggest that sexual violence is occurring in First Nation communities, which suggests that many women do not have control over their sexual health and may be coerced into sexual acts or drug use that puts them at a higher risk of becoming infected with HIV. To further emphasize the connection between violence, substance abuse, and HIV, one study conducted in northern Ontario with Aboriginal women found that experiences of residential school and other state interventions put them at a higher risk of entering abusive relationships and the women linked their abuse experienced as children with their present substance abuse problems, low self esteem, and vulnerability to remaining in and being exploited in abusive relationships.

Poor socio-economic conditions often place Aboriginal women on the streets of Canada's cities. Women living on the streets, homeless, risk being either forced into sex work, or trade sex simply as a means for survival. Sex trade and/or sex is a harsh environment with high risk factors for HIV infection and harsh outcomes - sexual violence, sex work-related rapes, heavy drug injection practice, and unprotected sex.

Incarceration is another HIV exposure risk factor for Aboriginal people. While Aboriginal people comprise 2.7 percent of the adult Canadian population, approximately 18.5 percent of offenders now serving federal sentences are of Aboriginal ancestry. Aboriginal women are even more overrepresented than Aboriginal men in the criminal justice system, representing 30 percent of women in federal prisons. Both men and women in prison have a higher risk of exposure to HIV because of injection drug use, needle sharing and risky sexual behaviour. Although the harsh realities of street life and incarceration may seem removed

from the First Nation communities, Aboriginal people often return to their home communities and may unknowingly place others at risk for exposure to HIV through behaviours such as unprotected sex and sharing of needles.

Aboriginal youth are also particularly vulnerable to HIV infection. According to the Canadian Aboriginal AIDS Network, many Aboriginal youth are sexually active before the age of 15, when they do not have the knowledge, the means, or the maturity to practice safer sex. At this stage in the life cycle, youth tend to experiment – to engage in high risk behaviours such as using drugs and alcohol, and when these substances are abused, these behaviours can lead to unplanned or non-consensual sex, often unprotected. Youth are also vulnerable given their tendency to think that they are “invincible” – that nothing bad can happen to them. This misconception can also lead to unsafe sex and drug injection practices.

Although the above-mentioned experiences primarily focus on Aboriginal women and youth, men are also vulnerable to HIV exposure for reasons such as alcohol and substance abuse as a coping strategy to deal with past trauma.

The following is a summary of social issues in communities that are directly and indirectly linked to increased risk of HIV transmission:

- Substance abuse (alcohol, injected and non-prescription drugs, solvents)
- Sexual violence
- Other forms of violence
- Poverty and lack of economic independence (unemployment and low levels of education attainment)
- Lack of access to services
- Fear of accessing services because of lack of reassurance of confidentiality

From this information, it is evident that it is just as important to raise awareness about preventative methods as it is to help women and men access counseling for some of the trauma they are dealing with, to help them find other coping mechanisms rather than substance abuse, and to help women in poverty access economic programming and support so they do not have to rely on abusive partners.

It is difficult to reach these individuals and provide them with the support they need. As previously explained, in a First Nation community, it may be a family member or friend who is providing the counseling. There have been breaches of confidentiality reported in studies where clients have faced stigma in the community for accessing the services and for revealing information to frontline workers that was supposed to remain private but did not. It is crucial for frontline workers to build trust and to ensure confidentiality despite the relationship one may have with the client outside of the service.

Finally, some of Ontario's First Nation communities have developed protocols – a set of guidelines – that outline how the First Nation will provide services to First Nations people living with HIV/AIDS. To determine whether your community has developed a Protocol, you may have to conduct a search, asking several long-term staff. If not, perhaps you can take a leadership role and begin developing a Protocol and lead your community into the future.

HEALTH PROMOTION

Health promotion is the process of empowering people to make healthy lifestyle choices that will maintain their good health and well-being. These strategies are referred to as primary health prevention and are directed at keeping people from becoming infected with HIV. This section will include basic knowledge about HIV/AIDS that can be used for educational initiatives, as well as breaking down myths and stigma that surround the topic, suggestions for prevention, and other social issues that must be addressed to fully tackle the rising prevalence of HIV.

Basic HIV/AIDS Community Awareness

According to the National Aboriginal Health Organization (NAHO), Aboriginal people are disproportionately affected by HIV/AIDS in comparison to the rest of the Canadian population. For example, even though the Aboriginal population in Canada only represents 3.3% of the total population, Aboriginal people account for 16.4% of AIDS cases and 7.5% of HIV infections. This overrepresentation may be attributed to issues such as poverty, poor access to health care, substance abuse, discrimination and violence. This reality sheds light on the need for education and awareness raising initiatives in Aboriginal communities. Although educating First Nation communities with basic knowledge about HIV/AIDS is not enough of a preventative measure, it is a good starting point.

What is HIV?

HIV is an acronym that stands for *Human Immunodeficiency Virus*. It is a virus that attacks and weakens the body's immune system leaving the body more vulnerable to opportunistic infections which are those illnesses that a healthy body would normally be able to fight off such as pneumonia or the flu. Once a person has been living with HIV for an uncertain amount of time, their immune system will be weakened to the point that they will be diagnosed with AIDS. By "uncertain amount of time" it is meant that people can live up to and beyond twenty years with HIV before developing AIDS. This depends on nutrition, availability of medication, age, prior health status and many more factors.

AIDS is an acronym for *Acquired Immune Deficiency Syndrome*. Once an HIV positive individual progresses to the AIDS stage, medical intervention is usually needed to help them fight off opportunistic infections. AIDS is usually diagnosed when the T4 white blood cell count (a vital component of the immune system) is very low or after acquiring an AIDS indicator illness.

How is it transmitted?

HIV is transmitted by way of body fluids such as blood, vaginal secretions, and semen. Although HIV can be transmitted by saliva, it is almost impossible because it would require gallons of saliva to infect another person. The most

common ways to transmit the virus are by unprotected sexual contact (vaginal, anal, or oral intercourse), sharing needles and therefore passing trace amounts of infected blood between people, and by mother to child transmission (MTCT)². A pregnant woman can infect her child during the pregnancy, during child birth and by breastfeeding. Since 1992, HIV transmission through contaminated blood transfusions has become extremely rare in Canada.

What are the symptoms?

There are usually no physical symptoms experienced during the earlier stages of HIV infection which is why it is so important to encourage testing. Potential symptoms include:

- Frequent experience of flu like symptoms
- Fever
- Unexplained weight loss
- Diarrhea
- Fatigue
- Pneumonia
- Swollen lymph nodes

Whether symptoms are present or not, it is important to always encourage HIV testing.

Preventative Measures

HIV is preventable³. There are preventative measures that can be taken to decrease the risk of contracting HIV and subsequently passing it on to others.

These measures include:

- Practicing safer sex with the use of a latex condom (or other material if the individual has an allergy)
- Using lubrication during sex to prevent tearing of vaginal or anal tissues
- Not sharing needles for any purposes (drug use, tattooing etc.)
- Using needle exchange programs
- Receiving HIV testing and encouraging sexual partners and/or peers to be tested as well
- Speaking openly about safer sex with partners
- If a woman is pregnant, she should be encouraged to get tested. If the test is positive, encourage her to meet with a health service provider (ie. Community Nurse, Community Health Representative) to explore ways of reducing the risk of infecting the child.

² It is as important to educate community about how the virus cannot be transmitted. See "Challenging HIV Stigma and Breaking the Myths" section.

³ There are situations where the choice to take preventative measures does not exist. For example, when women are sexually abused, they will not likely have control of their lives to make the choice to use condoms.

Challenging HIV Stigma and Breaking the Myths

HIV is capable of being transmitted to anyone yet there remains a lot of stigma attached to the virus and many myths about it being a disease that only affects the two spirited community or deviant risk takers. There are many more misconceptions about the transmission of HIV. For example in one study conducted in First Nation communities in Northern Ontario, one focus group member explained that “There are a lot of kids at my school [who] don’t think it’s possible that it could happen in our community—that it only happens in big cities and that it doesn’t happen here”. (Varcoe and Dick, 2008). In contrast other focus group members in the study believed that HIV/AIDS was a problem that only existed in First Nation communities. These myths about transmission have devastating effects such as convincing individuals that they are immune to HIV and shaming people living with HIV because of the belief that it was bad behavior that resulted in them being infected. This is how HIV came to be thought of as an immoral disease instead of a virus like any other. Some of the following consequences could result from this:

- Higher rates of HIV transmission because of a false belief in immunity (I’m not two spirited, I’m not a drug user, I don’t live in an urban centre)
- Those living with HIV keeping it a secret because of fear of being shamed in the community which could result in them infecting other people
- Community members being unwilling to attend HIV educational workshops because of the belief in immunity and the belief that HIV is an immoral disease.
- Community banishment – punishing a First Nation member living with HIV/AIDS by forcing them to leave their community. Banishment is a result of HIV/AIDS stigma – punishing an individual for their HIV/AIDS status, treating them like a criminal – keeping shame and fear of HIV status alive in the communities. The result of this action is significant – limiting access to health and supportive services, but also negatively impacting the emotional, mental and spiritual aspects of all those affected.

The stigma that people living with HIV experience is further compounded by myths about ways the virus can be transmitted. For example HIV cannot be transmitted by kissing or hugging but despite this individuals continue to believe that it is dangerous to touch those living with HIV. In educational workshops it is not only important to explain how HIV can be transmitted but also how it CANNOT be transmitted:

- By kissing
- By hugging
- By using the same utensils and other everyday objects people use such as phones
- By using the same toilet seat
- By sharing food

Creating activities for educational workshops to expose these myths and to transform beliefs about HIV being an immoral disease would be very beneficial to generate open dialogue in the community, to promote testing and to help community members that do test positive to access the services they need without discomfort and shame.

HEALTH PROMOTION: Roles of a First Nation Frontline Worker

Awareness:

- Raise awareness in the community. Host regular health promotion workshops that include HIV/AIDS information. Provide the needed resources so that community members have what they need to make healthy choices.
- Share information on healthy nutritional and fitness choices that can boost immune systems which can decrease the chances of transmission in collaboration with other preventative methods
- Find an awareness raising method that is culturally appropriate and fits within the cultural and social context of the First Nation community. For example the mainstream *Abstinence, Be faithful, Condoms* (ABC) method creates the misconception that everyone is in control of their lives and making rational choices when there may be substance abuse and violence issues in the First Nation community that make the ABC approach unsuitable.
- Use peer to peer education approaches: youth to youth, women to women, etc.
- Create and sustain on-going social marketing campaigns geared towards reducing the stigma and break down the myths about HIV/AIDS. Involve the youth.

Pre/Post Test Counseling

- Offer pretest counseling to prepare individuals to deal with a potential positive result but also to get a grasp of what is making community members vulnerable to HIV. Confidentiality is absolutely vital since this process can be very embarrassing and private.
- Post test counseling is also important for those who test negative because it is a chance to remind them of preventative strategies that are appropriate for them and to suggest a second test since HIV can take up to 12 weeks to appear after the initial transmission. ***Counseling for those who test positive will be discussed later.***

Preventative Measures

- Encourage those who are injection drug users to seek help and in the meantime seek out needle exchange programs
- Make condoms and other protection available in a confidential and non embarrassing way.
 - Put jars of condoms in the bathrooms of health clinics or community centres so that individuals can take them.
 - Put condoms in health promotion kits that include other items that are less stigmatizing.
 - Needle exchange programs are usually only available in large urban centres so it may be difficult to refer individuals to safer practices for injection drug use and just as difficult to broach the topic and

encourage them to seek help. Nonetheless, proactive communities have taken action to secure funds and implemented successful programs.

In order to discuss such difficult subjects with community members it is important to gain their trust and provide them with a safe and confidential environment. Confidentiality is especially crucial in First Nation communities where clients could be friends, family members, or neighbours. When a community is small and ties are close, the fear among clients that their information will not remain confidential is increased

Health Promotion References

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PREVENTION

Prevention strategies are referred to as secondary or tertiary and are directed at people infected with HIV. The goal of secondary prevention is to prevent/delay progression to disease and disability, avoid re-infection and spread to others, and to keep the person healthy over time. While tertiary prevention is to improve disease severity & disability, thereby enhancing quality of life and preventing death.

SECONDARY PREVENTION

Testing

Making the decision to get an HIV test is not easy, especially given the stigma associated with HIV/AIDS in First Nation communities. The preferred type of testing is anonymous testing, but may not be available in many First Nation communities. The decision may also be compounded by mental stress because the individual is admitting that they may have placed themselves at risk for infection. In some cases, the risk-factor may not have been within their ability to avoid. Women living in abusive and violent relationships may have an abusive partner who refuses to wear a condom or poverty limits a women's ability to purchase condoms.

Anonymous Testing

Anonymous testing offers community members a way to be tested without revealing their identity. Names are not requested, recorded or reported. However, the testing site does ask for information about the person's age, gender and risk factors. This information is used to help understand how HIV is spreading.

Although the testing is anonymous, and ordered using a code known only to the person being tested, if the person is diagnosed with HIV and decides to seek treatment, they can no longer remain anonymous. They will have to give their name and health card number to receive health services.

Anonymous HIV testing is offered at 50 anonymous testing sites across the province. Like all other types of HIV testing in Ontario, anonymous testing includes pre- and post-test counseling and referrals to other services and supports. For information on an anonymous testing site near you, call the AIDS Hotline at: 1-800-668-2437

Point of Care HIV Testing (sometimes called Rapid Testing)

Point of care (PoC) testing is done by pricking the finger and testing the blood while the individual waits. The entire process typically takes only 20 minutes,

including counseling. If the blood tests negative – that is, the point of care test says the individual is not infected – they receive their results immediately. If the blood tests reactive – that is, the result of the point of care test is not certain – the clinic will take a blood sample and send it to the public health laboratory for standard testing. It can take up to two weeks to get the final results, and the individual will have to return to the clinic to get their results.

PoC HIV testing is available free at 60 sites across Ontario, including all anonymous HIV testing sites, some public health units' sexually transmitted infections clinics and some community health centres. For information on a PoC testing site nearest to the First Nation community, call the AIDS Hotline at: 1-800-668-2437

Standard HIV Testing

Standard HIV testing is done by taking a blood sample and sending it to the public health laboratory. It can take up to two weeks to get the results, and the individual will have to return to their doctor's office or the clinic to receive the results.

Confidential Testing by Physicians and Nurse Practitioners

Physicians and nurse practitioners can order HIV tests. They can order the test using the individual's name (nominal testing) or using a code (non-nominal testing) that they can link back to the individual.

Prenatal HIV Testing

The Ontario Ministry of Health and Long-Term Care provide a universal voluntary prenatal HIV testing program with informed consent⁴. This program takes an "opt-in" approach where the clinician is required to provide all pregnant women with information about testing and the opportunity to consent. The informed consent process requires the clinician to explain that the test is a standard of care and is recommended to all women, reviews the benefits and risks of testing, discusses the voluntary nature of the test, and documents whether the women consents or declines. Although Ontario offers this approach to prenatal HIV testing, the program is not applied consistently across the province. The prenatal testing experience may be quite different from woman to women, especially for Aboriginal women. As a First Nation service provider, it may be beneficial for you to discuss the women's experience and offer supportive services if required. When pregnant women with HIV are diagnosed early, they can receive treatment for themselves and treatment for their babies.

⁴ Ontario changed its program in December 1998, from targeting HIV testing (based on risk factors) to universal voluntary.

Counseling

Counseling can help people living with HIV to cope with their status and prevent further transmission. It can also help loved ones of HIV positive individuals to become more accepting and supportive. Counseling is an integral part of a secondary prevention strategy. This section will provide information to guide the counseling process for community members who test positive for HIV, but also for those who may be involved in their care. It will also describe some of the physical, mental, emotional, and spiritual stresses that HIV positive individuals and their loved ones will face after testing positive.

A) Individuals who Recently Tested Positive for HIV

Finding out that you tested positive for HIV, a virus that is strongly associated with an early end of life is very stressful. Although many people cope in a healthy way, there will be many fears about life ending early, how to manage the disease, uncertainty about the future, the potential social rejection from loved ones, as well as feelings of anger and depression about having to live with a chronic illness that there is no cure for.

What Can You Do?

If you are not a Counsellor, or a Crisis Intervention worker, making a referral is recommended.

However, as a Frontline Worker, you may be able to:

- Be a supportive listener: Help the individual work through some of the issues. Initially, the individual may want to vent all of their initial feelings of fear, rage, guilt, anger, depression and shock.
- Reassure them that their status will remain confidential.
- If the individual is depressed it is important to make sure that they do not harbour suicidal thoughts.

If you are the Frontline Worker meeting with the individual for the first time, you should:

- Ask the individual what their plans are for the rest of the day. What will they do when they return home? Do they have anyone at home to turn to for support? How or should they approach their loved ones about the situation? Would it be appropriate or safe for them at the time? It might be beneficial to help the individual come up with a plan on who to tell, and what to tell them.
- Plan a follow up session within the next few days after the initial session. This is especially a good plan as you should not burden them with all sorts of facts and information about the disease and how to take care of him/herself while they are trying to cope with the news of being HIV positive. They may not be emotionally ready to take this information in as

they have more immediate concerns. As a First Nation person, they may immediately start to think about their children, their family, and how they will be treated given that stigma still exists in the communities.

However in follow up visits, after the individual has had some time to cope, it is important to inform them about HIV and how to manage their disease. Studies have shown an association between HIV+ individuals and their caregivers being informed about HIV, and coping with and managing the illness better.

B) Long Term Counseling for People Living with HIV

Living with HIV can be just as emotionally and mentally draining as it is physically. Even after initial feelings of anxiety, shock, anger and guilt, there continues to be emotional obstacles to overcome each day. Some of these feelings may include;

- frustration with the complicated antiretroviral cocktail one must take each day and its side effects which can also act as a daily reminder of one's HIV status
- having to deal with access to medication issues, such as delisting from Non Insured Health Benefits (NIHB)
- financial stresses - it can be very expensive to properly care for oneself while living with HIV
- anxiety experienced as they come to terms with their mortality
- anxiety about experiencing stigma and shame in the community

As in Part A above, it is preferable to refer the individual to a Counsellor. However, as a Frontline Worker, you can:

- Be a good listener, be attentive - help HIV positive people cope with their long term stresses. Encourage them to share their concerns and work through their feelings.
- Spiritual support - some studies suggest that spirituality is correlated with low levels of depression for HIV positive people possibly because a person's spiritual beliefs may help them find meaning in life and death and help them accept living with HIV in a positive way.
- Help them find a coping strategy that works for them - For example, Acceptance coping means finding meaning in life with HIV. This strategy is found to be the most successful at keeping an individual physically and emotionally healthy.
- Less positive coping strategies are:
 - Avoidant coping - detaching from one's situation.
 - Realistic coping - accepting the disease but from a more negative place.
 - The two strategies are less associated with positive health outcomes.

Spirituality is important for people who have progressed to AIDS. They need to accept and cope with being near death but it is also helpful for people in the earlier stages of HIV dealing with the everyday stresses of having the virus. Spirituality can reduce stress and promote acceptance and therefore extend life. If the individual in counseling participates in traditional First Nation practices, such as ceremonies and having a relationship with the Creator, offer your support as it may be beneficial to their health. Everyone has their own type of spirituality that can help them on their journey.

Empowerment can also mean encouraging positive ways of thinking. For example seeing oneself as a victim of the disease will create a sense of felt injustice and hopelessness. However, seeing oneself as a survivor can foster a sense of strength.

C) Partner Counseling

If the individual has disclosed their HIV status to their partner and has expressed a desire and consented to receiving counseling with their partner, this option should be considered as there are many benefits;

- Giving the information and resources to both partners so that they can take action together in order to prevent transmission of HIV from the positive to negative status partner. For example, information about safe sex practices and misconceptions about the transmission of HIV.
- Having the chance to encourage their partner to get tested and to receive pre test counseling.
- Giving their partner the information and resources needed so that they can support their partner living with HIV to the best of their ability.
- Helping the partner cope with the news of their loved one testing positive. Sometimes it can be just as devastating for loved ones as it is for the individual who tested positive.
- Assessing the situation to make sure there is no emotional or physical abuse that has resulted from learning of their partner's HIV status. In other words, making sure the person living with HIV is safe at home and helping the couple carry on their relationship in a healthy and loving way.
- If they have children, helping them come up with a plan to disclose information to their children.
- If there is a woman in the relationship who is pregnant, there are extra preventative measures you can share with the couple especially if the pregnant woman is the one living with HIV.
 - Help the pregnant woman make a decision about whether to keep the baby or to terminate the pregnancy based on detailed information about mother to child transmission and other complications with having HIV positive children.

NOTE: this is a situation where it is important to consider the cultural values and beliefs of the couple with respect to termination of pregnancy. Ask them to share their beliefs.

In short, there are many health, emotional, social, and economic issues that can be discussed with a couple concerning the impact that HIV will have on their lives. These issues range from the new financial costs of medication that will divert finances from other areas (this is especially devastating for couples living in poverty), to changes in sexual health that need to be made to prevent transmission. In a First Nation community, you may know the couple personally. For this reason, it may take many sessions to gain their trust so that they feel comfortable broaching topics and disclosing information. The importance of keeping their information and visits confidential is just as crucial in group therapy sessions. Shared confidentiality means that any information exchanged between the HIV positive person, you as a frontline worker, and the other individuals invited to the session shall remain private.

D) Counseling Women Living with HIV about Pregnancy

Another misconception is that HIV positive women should not give birth. As First Nations people, bringing life into the world is a women's gift and an honour, and it is also a women's right to choose. To support a woman's right to choose, accurate information is crucial to making an informed decision. In Ontario, there is a marked reduction in prenatal HIV transmission (often called Mother to Child transmission), from approximately 25% to less than 1% when using antiretroviral therapy during pregnancy and not breastfeeding the newborn.

As stated above, there is a risk of mother to child transmission (MTCT) if there are no interventions (ie. medications). Two thirds of babies become infected during labour while the other third of infants become infected during the pregnancy or while breast feeding. Some possible interventions that you can discuss with pregnant women living with HIV are alternatives to breast feeding such as formula or the possibility of having a caesarean section instead of a vaginal birth to reduce the risks of MTCT. Also, be informed about antiretroviral therapies and the benefits of their use.

Many mothers to be have intense fears about possibly transferring HIV to their children so make sure that she has all the correct information. Try to help women understand the risks of delivering their baby. The longer the labour period the higher the chances of MTCT because the infant will spend more time in the birth canal and therefore have more of a chance of coming into contact with their mother's blood through ripping and tearing. Women should also know that infant mortality rates are high among children born with HIV. While adults can live for decades with HIV, most children only live a few years and progress to AIDS very quickly.

With this information, women can make an informed decision, and some may choose to have an abortion. Discuss her options with her in a compassionate and informative way. Also discuss possible barriers to interventions. She may be living in poverty or be living in other circumstances that make alternatives to breastfeeding expensive for her. She may not be able to travel to a larger city to have an abortion or plan a caesarean with a doctor. She may also be anxious about accessing mainstream services where she may experience double discrimination for being HIV positive and for being Aboriginal. You could accompany her when she accesses these services or refer her to someone in the community who acts as an Advocate. They may be able to accompany her.

Finally, whether the choice is that of an expectant couple or of an expectant woman, having to choose between the possibility of transferring HIV to the baby or an abortion is not an easy choice. The couple/woman may be grieving after having to give up the baby. Try to be a compassionate listener and look for signs of depression. It can be a huge loss even if it was a rational choice for them/her.

E) Support for Caregivers

The person caring for an HIV positive person may experience stress, hopelessness, loneliness and exhaustion. Caring for a person living with HIV is demanding and especially hard if the caregiver is living in poverty and resources are strained. In addition, caring for a person living with HIV may mean the caregiver must give up activities they enjoyed such as visiting friends or other obligations such as going to work. They may have to deal with the negativity associated with stigma. This further compromises their mental and emotional health.

Usually the caregiver is a family member or close friend and will be grieving in addition to feeling overburdened with having to care for their loved one. Sometimes they may even keep their feelings inside to protect their loved one who is living with HIV and will experience guilt for harbouring such negative feelings.

Let the caregiver know that they should not feel guilty about the emotions they are experiencing and that you understand how difficult it must be to take care of someone who is HIV positive or has AIDS. Welcome them to discuss what they are going through. Perhaps care-giving for their loved one is an extra stress on top of other issues occurring in the household such as substance abuse.

Suggest possible services and support to help them in their caregiver role and to cope with any other stresses in his/her life. Also remind them that it is okay to ask others for help. When they have adjusted their lives after seeking out support, suggest relaxing and returning to activities that they enjoy. It is important for caregivers to take care of themselves as well.

Caregivers will also likely be inexperienced in dealing with HIV. Offer some tips so that they take care of their loved one in an informed way.

- Suggest that they monitor their loved one's weight and to seek medical attention if it is dramatic.
- Encourage them to eat healthy and remind them of the importance of eating but do not force them.
- Give them small servings if they have a loss of appetite.
- People living with HIV may become depressed if they are dependent and unable to participate in their own care-giving.
 - Suggest that they involve their loved one in planning meals and monitoring their medication. To monitor their medication read the instructions and make sure the person living with HIV understands what not to eat or drink and what the side effects are.
- Make sure the house is hygienic and clean. HIV positive people have poor immune systems and can get sick very easily
- Keep socially active. Social isolation can have negative effects on an individual's holistic health. Go on outings when they have energy.

Mental Health Considerations

The medicine wheel teaches that our physical, emotional, mental and spiritual health is all connected. Being diagnosed with HIV can be a shocking experience for most people and can create an imbalance. As a frontline worker, it is important to see the world through their eyes to have a better understanding of their feelings. Some people feel overwhelmed, and will have strong reactions to all the changes that will happen in their lives. They may have strong feelings such as fear and anger, and often feel helpless, sad, and anxious about the illness. It is a stressful time and it's important to remind the FNPLWA that these feelings are normal.

Sadness is a normal response to HIV infection, but if it lasts over time, the individual may be suffering depression, which is extremely common among people living with HIV. Depression is associated with a rapid progression of HIV to AIDS which suggests that mental, emotional and spiritual health is just as important as physical health. If not addressed, depression can have a major impact on a person's health. People often forget to take their medications and may engage in risky behaviours. Depression can be treated, and as the frontline worker, you can support them to access treatment and to better manage their health through healthy lifestyle changes, such as nutrition, physical activity, and proper sleep.

HIV and some medications for treating HIV may affect your brain. When HIV itself infects the brain, it can cause a condition known as AIDS Dementia Complex (ADC) – a brain disorder that occurs in people with AIDS that causes the loss of cognitive capacity, affecting the ability to function in a social or

occupational setting. Symptoms can include forgetfulness, confusion, slurred speech, sudden mood shifts, difficulty paying attention and clumsiness. ADC can be mistaken for depression because of its symptoms and the person's inability to properly function in their day to day life. As with depression, ADC can be treated with antiretroviral medications.

Suicide is a real issue in the First Nation communities, and for people living with HIV/AIDS, they may be contemplating suicide, even assisted suicide. Understanding the emotional and mental state of a person contemplating suicide is difficult, however, it is key to validate their feelings, recognizing that they have a right to their feelings and their choices. Irregardless of the service they are requesting, establishing confidentiality, trust and a non-judgmental rapport with the individuals is important.

Children Living with HIV

According to the Public Health Agency of Canada's EPI Update (July 2010), 0.8% of 1,891 Aboriginal HIV positive test results are of children 14 years and under. For many of these children, one or both parents are HIV positive. Children require different medications than adults, therefore it is very important that children be in the care of a primary health care provider. Their health is also at risk because of childhood illnesses and disease such as mumps and chickenpox. Although all children face these illnesses, HIV positive children have weakened immune systems, and these illnesses may be more frequent, last longer and may not respond as well to treatment. There are also socio-economic considerations that impact on the health of First Nations children living with HIV. Their health and well-being may be impacted by issues of poverty, violence, substance abuse, and in many cases, their parent(s) may be HIV positive, affecting the parent(s) ability to provide proper care.

For HIV positive parents, and their children, the level of need is great and they may rely heavily on supportive services available in the First Nation community. Service providers can provide an array of support, ranging from counseling to advocacy, to respite for the parent(s).

Co-infection: HIV and Hepatitis C

Hepatitis C (Hep C) is a liver disease caused by the Hepatitis C virus. The virus is transmitted in ways similar to HIV and because of this, many people with HIV also are infected with Hep C. HIV mainly attacks the body's immune system and Hep C mainly attacks the liver. When someone has both HIV and Hep C together it can make it much harder for the body to fight Hep C and HIV. Hep C slows down the rate of increase in T-cell counts during HIV treatment. It does not appear to interfere with HIV medications; however, a damaged liver makes it harder to take HIV medications, which may require adjustments in dosages.

First Nations people with HIV should be tested for Hep C and if infected, should be evaluated for Hep C treatment. Frontline workers can support FNPLHA by providing counseling and education about co-infection. Counseling should include an alcohol and substance use component to promote abstinence and avoid further damaging the liver and affecting the efficiency of the Hep C medications.

Medications: Accessing Highly Active Antiretroviral Therapy

Health Canada's First Nations and Inuit Health Branch provides the Non-Insured Health Benefits (NIHB) programme to status First Nations people under the Indian Health Policy. It is meant to cover the costs of medical drugs that are not covered by the provincial or third party health insurance. The Drugs Benefits List is published annually and updated quarterly. In terms of HIV/AIDS drugs, most are included in the drugs benefits list while a few are included in the limited use benefits list instead. This means that the medication may have a frequency or supply limit or requires prior approval. Approval can be sought with the Limited Use Drugs Request Form. In other special cases an Exception Drugs Request Form is required from a physician to obtain a prescription. In this case, a handwritten prescription slip reading "No Substitution" is also required. If a client is denied the medication they need from NIHB they can appeal this by contacting regional NIHB offices. Clients may ask you to advocate on their behalf.

To access the latest NIHB Drugs Benefits List, or to learn more about treatment and information, visit the Canadian AIDS Treatment Information Exchange (CATIE) website. CATIE hosts the latest update on the list, or visit Health Canada website, www.hc-sc.gc.ca and click on the First Nations, Inuit and Aboriginal Health under the main menu. To contact by telephone or mail:

Non-Insured Health Benefits Directorate

First Nations and Inuit Health Branch
Health Canada
55 Metcalfe Street, Manulife Building
Postal Locator 4005A
Ottawa, Ontario
K1A 0K9 Toll Free: 1-866-225-0709

Ontario Regional Office:

Non-Insured Health Benefits
First Nations and Inuit Health
Health Canada
1547 Merivale Road, 3rd floor
Postal Locator 6103A
Nepean, Ontario K1A 0L3 Toll Free: 1-800-640-0642

There are other options for accessing drugs in Ontario. Ontario's First Nations people, if unable to access Ontario Works or Ontario Disability may be eligible for the Trillium Drug Program which was created for individuals such as those living with HIV with high medication costs in comparison to their income. If the community member living with HIV/AIDS has a Provincial Health Card, they can apply for this. This is especially important for those members of the community that are non status and therefore cannot access HIV anti retroviral medications through the NIHB program. This brings up an essential point; not all people will have equal access to the medications they need. As a frontline worker, you can assist them in acquiring the medications they need.

How to Support Adherence to Western Medications

In acting as a support to First Nations people living with HIV/AIDS, it is important to remember that taking medications is a choice. If the individual is making an informed decision to not take medications, that is their right of choice. However, if the individual chooses to take medications, a First Nations service provider can support adherence to the drug regimen.

Antiretroviral therapies are effective only if there is a 95% adherence rate which highlights the importance of discussing adherence with the individual. Adherence means taking the drugs exactly as prescribed, on time, and following any dietary restrictions. If the treatment instructions are not followed, it is likely that the drugs will not be absorbed properly in the body. This can have serious short and long term consequences, such as an increase in viral load and a greater risk of developing drug resistance.

Adhering to the drug regimen can often be difficult, due to side effects or the frequency of dosage. It can be stressful taking up to 30 pills per day at a certain time and in a certain sequence and it is a constant reminder of one's HIV status. The side effects such as nausea and diarrhea can put the individual of routine/adherence as well.

Living with HIV While Leading a Healthy Lifestyle

Nutrition

Highly active antiretroviral therapies (HAART) have made it possible for HIV positive people to live longer lives. HIV strategies are therefore becoming more focused on lifestyle changes so that HIV positive people can enjoy healthy and fulfilling lives. There are also changes in health problems that need to be addressed. Where before the main concerns were wasting and opportunistic infections, now because life is extended and HIV progresses into later stages, people living with HIV are now susceptible to diabetes, heart disease and other chronic diseases. HAART side effects have also created new health problems while extending life.

The model of health care discussed in this manual is centred on empowering HIV positive people to improve their health through fitness, nutrition, and other lifestyle changes. Living with a disease can make a person feel as if they have lost control of their lives but by helping people set their own goals to improve their health it will help them regain that sense of control that is strongly associated with good mental and physical health. For example setting healthy lifestyle goals has been associated with less depressive symptoms in HIV positive people.

Nutritional Planning

Encouraging the individual to improve their dietary habits is important because good nutrition is associated with HIV positive people enjoying longer and more productive lives. In addition, good nutrition will allow medications to work more effectively. The first step to reaching the goal of a healthy lifestyle in terms of better nutritional intake is to do an assessment of the individual's current health status.

The main goals of nutritional planning are;

- To help the person strengthen their immunity and therefore prevent opportunistic infections;
- To slow down the progression to AIDS;
- To help the person maintain a healthy body composition by improving nutrition and exercise;
- To help the person live a long and meaningful life; and
- To ease discomfort and severity of symptoms.

The Impact of HIV on Nutritional Intake

HIV decreases the body's ability to properly absorb nutrients because the virus attacks cells in the stomach and intestines but also because HIV increases the frequency of opportunistic infections that result in nausea and diarrhea which expels nutrients out of the body before they can be absorbed. Nausea and diarrhea can also be a side effect of antiretroviral therapies. In addition, when the immune system tries to fight the virus it uses essential nutrients thereby diverting the nutrients needed to perform other functions.

The reality is that most people do not consume the right amount of nutrients that their body requires to be healthy so with improper absorption of the nutrients that are consumed, this can result in malnutrition for HIV positive people. Other explanations for malnutrition or under eating include mouth sores that may make it painful to eat, a lack of funds to purchase the food they need due to increasing medical expenses, and depression or a lack of energy to prepare meals for themselves.

Malnutrition is a serious issue for people living with HIV because it reduces the functioning of the immune system which results in slower recovery from infections and faster progression from HIV to AIDS. If infections are prolonged this could result in muscle wasting. It also leads to vitamin and mineral deficiencies. The economic and social costs are high as well. With more health problems there are more medical expenses, a loss of independence, and a loss in income due to inability to work. Family members or friends may also need to take time off from work to care for their HIV positive loved ones if their health is degenerating. Fortunately, lifestyle changes can improve the health of HIV positive people tremendously allowing them to take care of themselves, stay involved in activities they enjoy and continue working and spending time with loved ones.

The information provided in this section can be used as a resource to educate and empower HIV positive people to improve their lifestyle. A good nutritional diet will not only improve lifestyle but will strengthen the immune system to fight off infections, prevent malnutrition, prevent wasting of lean tissue, and improve the effectiveness of medication.

Dietary Basics for People Living with HIV

Each individual will have different needs and should follow a unique nutrition and fitness plan. Here are some **basics** about nutrition that can be useful for creating a dietary plan. For optimum care and support, seek the advice of a Dietitian or Nutritionist.

Dietary Component	Tips
Protein	For most people living with HIV the regular amount of protein (0.8 gr./ kg of body weight) should suffice but if the person is experiencing lean body mass weight loss they should consume 1-2 grams of protein per kg of body weight per day. Good sources: soy beans, nuts, beans, fish, eggs, poultry and meat.
Energy (calories and carbohydrates)	The daily recommended intake is sufficient. It is good to get energy from a variety of energy rich foods. If the person is experiencing muscle wasting they should increase their energy intake 10-20%. In addition, if carbohydrates are not consumed the body will begin to use up protein that is supposed to be used to build muscle and strengthen the immune system.
Fat	The regular daily recommendation for fat intake should suffice for HIV positive people. However this may change depending on infections, obesity or mal-absorption problems related to certain medications. It should also be noted that individuals should not be encouraged to consume more fat because of their HIV status.

Micronutrients/ Vitamins	Consume a diet that is high in micronutrients. Studies indicate that vitamin A supplements reduces diarrhea, improves lung, stomach and intestinal lining and improves the immune system. Skin conditions can also result from lack of vitamin A. Good sources of Vitamin A are dark green, red, yellow and orange vegetables and fruits. Vitamin B12 improves the immune and nervous systems. Good sources include fish, chicken, avocados, and leafy vegetables. Vitamins C and E reduces viral load and helps fight and recover from infections. Good sources of Vitamin C are tomatoes, and citrus and Vitamin E can be found in leafy vegetables, and vegetable oils.
Iron	It is important to have good sources of iron in the diet because a deficiency results in anaemia. Iron can be found in red meat, liver, fish and leafy vegetables. However too much iron is not recommended either because it can increase the activity of bacteria when the person has an opportunistic infection.
Zinc	Zinc boosts the immune system and a lack of zinc can result in loss of appetite. Good sources of zinc include dairy products, meat, fish, beans and peanuts, and whole grain cereals.
Selenium	Selenium also boosts the immune system. Good sources include whole grains, yogurt, milk, cheese, meat, fish, poultry, and eggs.

Extra Nutritional Tips:

- Do not boil, fry or steam vegetables for too long because they can lose all their nutrients in the process.
- Whole grains are recommended over starchy bread products
- Soluble rather than insoluble fibres are better for a person experiencing diarrhea
- Although it is better to get nutrients from food, supplements are valuable for the diet if the person is not getting all the nutrients they need from their diet. Encourage individuals to be consistent with taking vitamins, take them on a full stomach, and do not take more than recommended on the bottle. Vitamin supplements can never replace a good diet, only complement one.
- Take precautions when preparing food. HIV reduces the effectiveness of the immune system so contamination can make the person very sick. Healthy food preparation is basic yet important. Encourage frequent washing of hands, covering up open sores, washing vegetables thoroughly, keeping cooking surfaces sterile and handling meat carefully.
- Avoid medications that you do not necessarily need because they may have unwanted side effects and interfere with nutrient absorption.
- Avoid smoking or consuming alcohol as this will diminish the positive impacts of healthy eating. Alcohol will also decrease efficiency of some antiretroviral medications.

- Studies have shown a correlation between stress levels and metabolism in that stress increases loss of lean muscle tissue. For this reason it is important to do daily activities that reduce stress. This is different for everyone, it may be spending time with family, listening to music, meditating, attending ceremonies etc.
- Deal with infections right away to avoid the possibility of the infection interfering with nutritional intake.
- Avoid spicy, sweet or hot foods that cause you irritation.
- Avoid unpasteurized dairy products, undercooked meat, raw eggs and expired food. These things can cause infection.
- Drink lots of water and get extra rest.

As already discussed, antiretroviral drugs and opportunistic infections can have side effects that make it difficult to eat, digest food and absorb the nutrients. These are a few tips on how to make eating easier and more pleasant;

- **Diarrhea** is a common symptom of opportunistic infections. It removes poisonous materials from the stomach and intestine while also removing the nutrients that are essential for the person's health. It can also be an uncomfortable experience and suppress appetite. A person should drink lots of fluids to avoid dehydration and to continue eating foods that will not unsettle the stomach such as soups, fruit juices, soft or moist foods such as porridge, mashed potatoes or other vegetables, bananas, and rice. Milk, spicy foods, coffee, tea, alcohol, and acidic fruits and vegetables should be avoided while experiencing diarrhea.
- **Nausea** and **vomiting** is another common side effect of medications and a symptom of opportunistic infections. Nausea will also decrease appetite. It is important that the person continues eating and giving the body the nutrients that it needs. It is recommended that an individual experiencing nausea should eat while sitting up, drink lots of fluids after eating, ask someone else to prepare their food so they do not have to expose themselves to pungent smells that will induce nausea. If they do not have anyone else to prepare their food a trick is to smell orange or lemon peels to suppress feelings of nausea. Dry salty or soft foods are recommended while fatty or greasy foods should be avoided.
- **Loss of appetite** is a frequent experience for people living with HIV for a variety of reasons. Ways to cope with this is to keep trying new foods until they find something they enjoy, eat small meals often rather than large meals a few times a day. Other ideas include washing out their mouth to make food taste fresher, avoiding foods such as broccoli, beans or carbonates drinks that will make the stomach feel bloated and drinking lots of water.
- Some opportunistic infections lead to a **sour mouth**. Eat soft foods such as creamed vegetables, minced food, avocados, and mashed potatoes. Food can also be moistened by adding water. If the person cannot brush

your teeth because of the pain you can rinse your mouth out with bicarbonate soda.

- If **muscle wasting** occurs, increase protein and starchy foods in the diet. They should eat frequently in small quantities, high quality meals (lots of nutritional value). Gradually increase the size of meals.
- If the person has **tuberculosis**, they should eat foods with protein, iron, vitamins, calories and carbohydrates.

Exercise

It was previously believed that exercise would increase wasting and slow down the immune system by decreasing CD4 cell count for people living with HIV/AIDS. In fact, exercise is extremely beneficial for people living with HIV for the following reasons;

- Moderate exercise delays progression to AIDS
- Exercise prevents wasting and improves the immune system
- Weight training increases strength and preserves muscles for people experiencing wasting and builds muscle for people who are not.
- Decreases fatigue while also improving sleep
- Improves blood circulation which reduces neuropathic pain
- Improves digestion and bowel movements
- Improves mental and emotional health, that is, improved confidence and perceived quality of life
- It normalizes body composition for people experiencing lipodystrophy (a side effect of wasting where fat is redistributed from face, arms and legs to the abdomen, neck and breasts)
- Aerobic exercise helps manage weight and prevents heart disease
- Exercise decreases stress and improves mood

It is recommended by many sources that people living with HIV should exercise three times a week if they can. Two types of exercise are important: aerobic exercise and weight training.

Weight Training	Aerobic Exercise
<ul style="list-style-type: none"> ✓ Examples include push ups, chin ups, lunges and squats. For more effective results use free hand weights or weight machines ✓ Start with machines and move to free weights. Be sure the person knows how to use the weights correctly ✓ Work on every muscle ✓ Do weight training three times a week for about an hour each workout - allowing one day (break) between trainings. ✓ Start with low weights and increase the intensity and number of sets over time. A set is 12 repetitions. If the person can do this easily, they can increase the weight but do not push themselves as this could result in injury. ✓ Make sure to warm up the muscles by stretching or doing cardio for 5-10 minutes before weight training. ✓ Working out for more than an hour can cause overtraining which will destroy muscles. ✓ Between sets only rest 20-30 seconds for the best results 	<ul style="list-style-type: none"> ✓ Aerobic exercise should be moderate not high in intensity ✓ Start with 15 minutes each workout and slowly move up to 40 minutes three times a week. ✓ If the person feels weak, they should try walking a couple of times a week to increase strength ✓ Do not jog or run unless you have strong joints ✓ Refrain from aerobic exercise if they have an illness or are experiencing involuntary weight loss ✓ To stay motivated, they should try different aerobic exercises and change their routine whenever they feel bored ✓ Sports such as soccer or hockey can be part of their routine. If they are injured and are bleeding there is a low chance of transmission but still, they should bandage the wound before returning to the game

Other considerations to share with individual;

- Warm up by stretching before and after exercising
- Make sure to recommend that the person consults their doctor before exercising if it was not part of their lifestyle already. A doctor can measure their blood pressure, heart rate, weight, cholesterol, blood sugar and body composition in order to give them the best advice for exercising.
- Best results can be achieved with a 30-40 minute exercise routine 3-4 days per week. As already mentioned exercising for more than an hour leads to break down in muscles and decrease in strength.
- If the individual experiences vomiting, diarrhea, open sores, foot or hand pain, oozing lesions, severe dizziness, or severe pain due to neuropathy, they should discontinue working out.

- Remind them to drink lots of water while working out. Aim for eight cups a day.
- It is important that the individual knows the correct forms for weight lifting and other resistance exercises so that they do not injure themselves. Injuries will take longer to heal because of HIV
- People living with HIV may tire sooner than others from working out
- Working out with a partner can keep them committed to their routine and more motivated. Also they can support (spotting) each other while lifting weights to prevent injury
- Eating a small meal high in carbohydrates such as fruit before the workout and then consuming protein afterwards gives the best results. Eating a meal high in protein before a workout will slow the person down because the body is trying to digest.
- Rest after each workout

Barriers to Healthy Living

First Nations people are a marginalized group in Canada who experience barriers to accessing the resources and services they require to live optimal lives. Therefore, First Nations HIV positive people may be diagnosed later than others, may find it difficult to access the medications they need, receive the support they deserve, and place more significance on everyday needs such as taking care of their families, and making ends meet at the expense of their own health needs.

Northern and isolated communities may face additional challenges to accessing nutritional foods. Even when nutritional foods, such as fresh fruit and vegetables, are available, they can be too expensive to purchase. Other barriers are related to socio-economic conditions in a First Nation community. The experience of violence can limit the availability of safe spaces for people to access the services they require for healthy living.

The information provided in this section is useless to these individuals living with HIV if they are not able to overcome the obstacles to taking care of themselves first. As a frontline worker, you should discuss all these issues with the individual and listen to their concerns very closely.

PREVENTION: Roles of a First Nation Frontline Worker

Testing

- As a frontline worker, you can support the individual's decision by listening in a non-judgmental and caring manner and providing information about anonymous testing locations close to your community. If they are unable to travel to the clinic, consider providing transportation or the funds required to get them there.

Counseling

- A Counsellor is a compassionate person who can provide supportive advice, can encourage people living with HIV to make informed decisions, can be an active listener, can provide a safe and non judgmental environment and can refer clients to proper services if it is outside of their mandate. Although the frontline worker may not be a Counsellor, they can be supportive, informed, listen and refer them to a Counsellor in their community.
- There are several roles that a frontline worker can do in terms of supportive counseling. Please refer to previous section on Counseling.

Medications

- Assist the individual to access required medications.
- Assist them to complete all required forms, such as NIHB.
- Adherence to medications:
Remember these tips while supporting the person with HIV:
 - Discuss the different medications with the person, go over the side effects of each and how they should be consumed (on an empty stomach, with water, avoid certain foods etc.) and stored. Some medications, such as Ritonavir, must be refrigerated.
 - As mentioned above, it is important that the individual understand any food restrictions that may affect drug absorption. For example, protease inhibitors must be taken with food.
 - Be a compassionate listener and allow the individual to vent. Sometimes certain therapies will not work for some people. For example men and women may react differently to certain medications because of enzyme and hormonal differences. This can be really stressful and frustrating for them. People may be dealing with accessing new drugs and dealing with the side effects of new drugs as the others did not work. It is a struggle and they will need support.
 - Perhaps caregivers or family members can get involved in counseling sessions so that they can support and encourage the individual to take their medications
 - If the individual is keeping a journal of their nutrition, fitness, successes and/or emotions, suggest that they include keeping track of their medications as well.

Healthy Lifestyles: Nutrition

- Seek the support of a Dietitian, Community Health Nurse, Nutritionist, or Healthy Lifestyles Worker to create a nutritional plan that will work based on the person's needs, their current socio-economic circumstances (ie. income, demographics), cultural attitudes, stage of the infection, and past eating habits. Every person will have unique needs.
- Discuss the person's medical history with them. Do they have health issues other than HIV?
- Ask about their usual weight, eating habits and level of fitness.
- Find out what medications the client is currently on and look into the impacts that these medications have on nutritional uptake (does the medication inhibit uptake of iron or other vitamins for example?)
- Find out if the client has opportunistic infections and assess how the symptoms of the infection are creating obstacles to healthy living. For example, mouth sores or nausea will make eating all the right foods less than desirable.
- Take body measurements. How much of the client's body is composed of lean muscle? Fat? Is this within a healthy amount for a person of their sex and age? Have the person keep track of their weight. A 10% loss in body weight or 6-7 kg in one month is a sign of unhealthy weight loss. Keeping track of the circumference of the waist, thighs, hips and mid-upper arms is also a good indicator. Sometimes fat can accumulate behind the neck. This is referred to as buffalo hump. It is a mal-distribution of fat and a sign of wasting. It is usually a side effect of antiretroviral medication and is important to measure as well.
- Assess barriers a person may face in obtaining the nutritional foods they require. It may not be that they do not have transportation to purchase healthy food, or they have an abusive partner that they have to rely on. Malnutrition and food insecurity is already an issue in First Nation communities due to demographic location (isolation) and poverty. Funds may also be diverted from food to medications needed to live with HIV.
- Once barriers are assessed, help them come up with solutions or you may have to refer them to other services in the community that will help them overcome barriers to healthy living.
- If the person is experiencing weight loss, evaluate whether this is because of poor nutrition, poor nutritional uptake or because of anxiety or depression.
- To support the development and adherence to a nutritional plan, the person should keep a journal.

NOTE: If possible, refer the person to a Community Health Nurse (CHN), Nurse Practitioner, or Dietician to conduct a more in depth assessment of their nutritional intake and body composition. A CHN will be able to monitor the person's medication and health status more effectively.

Healthy Lifestyle: Fitness

- Discuss the benefits of physical activity and help the individual make a plan that they can adhere to – make it reasonable and achievable.
- If available, refer them to a program within the community or a worker responsible for fitness activities/programs.
- If your First Nation does not have a gym or fitness centre, or if the person cannot afford membership or has no mode of transportation, help them form a plan using available resources. For example: for exercising at home, check out <http://weboflife.nasa.gov/exerciseandaging/toc.html>

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TERTIARY PREVENTION

This section discusses health and self care for people living with HIV over a long period of time. When people are first diagnosed with HIV they are more susceptible to common infections than usual and it takes a longer time to recover because of their weakened immune system. As the immune system becomes even weaker, people living with HIV or AIDS become susceptible to more opportunistic infections, some that are not common in the general population. At this stage of the illness, it is still important to incorporate healthy lifestyle strategies into day to day living, such as healthy foods and physical fitness.

Opportunistic infections (OIs) are infections that take advantage of a weakened immune system that results from HIV. These germs exist or try to attack everyone's bodies but usually fail when the immune system is functioning normally. The following chart is a list of common opportunistic infections, how they relate to HIV/AIDS, symptoms, and common treatments (medical advances happen daily – to have an accurate diagnosis and treatment plan, an individual must consult a medical practitioner / physician).

Opportunistic Infection	Description	Symptoms	Infection Treatment
Tuberculosis	A bacterial infection that infects the lungs and sometimes other organs. People with CD4 counts below 200 are especially susceptible.	Hard lumps in the lungs Can increase HIV viral load and worsen the immune system Can cause other opportunistic infections	A combination of antibiotics that must be taken for six months. If the TB is not active in the body but still present, the antibiotic isoniazid must be taken for six months
Pneumocystis pneumonia (PCP)	It is a fungal infection that develops into a fatal pneumonia due to a weakened immune system. It is the most common opportunistic infection. This fungus is called <i>pneumocystis jiroveci</i> .	First Symptoms: ➤ Difficulty breathing ➤ Dry cough ➤ Fever ➤ Chills ➤ Fatigue Left untreated: ➤ Death	Common drugs used include Dapsone, Pentamidine, Atovaquone, and the most effective drug TMP/SMX which combines two antibiotics.
Mycobacterium Avium Complex (MAC)	A bacterial infection that usually infects the lungs, intestine, bone marrow, liver, and spleen. The bacteria is found in water, dust, food and soil. MAC will frequently cause disease for individuals with CD4 cell counts below 50 but almost never for people with cell counts above 100.	Pneumonia Diarrhea High fever Weight loss Stomach aches Fever Fatigue Hepatitis Anaemia	Azithromycin or clarithromycin are common antibiotics used. Sometimes drugs are used for specific localized infections Medication must be taken for life or the disease will return .

Herpes Simplex	A common virus that causes painful bumps on the mouth (HSV1) or genitals (HSV2). Although it is common, for HIV positive people outbreaks are more frequent, painful and longer lasting.	<ul style="list-style-type: none"> ➤ Itching and tingling pre break out ➤ Increases HIV viral load ➤ Painful sores 	<ul style="list-style-type: none"> ➤ Acyclovir: an oral pill taken five times a day ➤ Famciclovir ➤ Herpes cannot be cured but medication can make the outbreaks shorter and less painful.
Candidiasis (referred to as thrush for infection of the mouth)	A fungal infection of the mouth, throat or vagina. It is an overproduction of a yeast called candida which creates a white cottage cheese build up or red spots. It can spread to bones or joints if not treated	<ul style="list-style-type: none"> ➤ Sore throat ➤ Pain when swallowing ➤ Nausea ➤ Loss of appetite 	Amphotericin B is a drug used for serious cases but for most cases anti fungal creams are applied to the infected area. The best way to avoid this infection is to strengthen the immune system with antiretroviral therapy.
Cytomegalovirus	A viral infection that can infect organs and cause retinas which leads to eye disease and blindness. It commonly infects individuals with CD4 cell counts under 50.	<ul style="list-style-type: none"> ➤ Blindness ➤ Eye disease ➤ Floating black spots on the eye 	<ul style="list-style-type: none"> ➤ Vigorous antiretroviral therapies that can increase CD4 count to above 100 ➤ Intravenous ganciclovir which is not preferred because it adds 12 pills a day to a person's cocktail
Toxoplasmosis	An infection of the brain caused by a parasite called <i>toxoplasma gondii</i> . It can be found in raw meat, raw vegetables, soil and cat feces. Most people come into contact but a weakened immune system (usually under 100 CD4 count), will lead to infection	<ul style="list-style-type: none"> ➤ Fever ➤ Confusion ➤ Headache ➤ Disorientation ➤ Seizures ➤ Coma ➤ Death 	Pyrimethamine (Daraprim) and Sulfadiazine are used together to treat Toxoplasmosis. Treatment should improve health within 2-3 weeks but the infection can return so the medication should be taken at a maintenance dosage for life.

Some OIs affect only women, or women are more prone to some OIs than men. For example, yeast infections are common to many women. For women with HIV, these problems are harder to treat and can be more serious. As a frontline worker, you can support women with HIV by encouraging them to be aware of their body, to self assess their health and use a variety of self care strategies. Discuss the importance of regular pap tests.

Below are additional OIs that are more common or affect only women.

Opportunistic Infection	Description	Symptoms	Treatment
Bacterial Vaginosis	Caused by an imbalance in the bacteria that are normally found in a woman's vagina. More harmful bacteria than good bacteria.	Odorous, frothy vaginal discharge	BV is treatable with antibiotics. Two different antibiotics are recommended: metronidazole or clindamycin.
Trichomonas	Caused by the protozoan parasite. The vagina is the most common site of infection in women.	Heavy, itchy vaginal discharge (sometimes a greenish-yellow color), usually with a fishy odor; can cause pain and soreness in and around the vagina; can cause extreme itching	Trichomoniasis can usually be cured with prescription drugs, either metronidazole or tinidazole, given by mouth in a single dose.
Vaginal Candidiasis (yeast infection)	A fungal infection (candida). Infection happens when candida, a fungus that is normally found in the body, grows too much in certain areas of the body, including the vagina.	thick, white discharge, pain during sex, pain when you pass urine, and vaginal burning and soreness.	Creams or suppositories, which you can buy in the drug store or get from your doctor. If this treatment doesn't work, other drugs are used to treat the infection
Human Papilloma Virus (HPV)	HPV is a group of viruses that can cause abnormal cells to grow on the cervix that may lead to cervical cancer.	multiple tiny white spots (warts) on the vagina or around the anus; other symptoms include some vaginal discharge or, rarely, pain during intercourse multiple tiny white spots (warts) on the vagina or around the anus; other symptoms include some vaginal discharge or, rarely, pain during intercourse	There is no treatment of cure for the HPV but there have been cases where it went away on its own.

Pelvic Inflammatory Disease (PID)	Bacterial infection of a woman's pelvic organs. Bacteria can move upward, from a woman's vagina or cervix into her fallopian tubes, ovaries and uterus, causing infection. Gonorrhea and chlamydia — bacteria from these STIs are the most frequent causes of PID. After being infected, it can take from a few days to a few months to develop PID	Lower abdominal pain and abnormal vaginal discharge; can also cause fever, pain in the upper-right abdomen, painful intercourse, and irregular menstrual bleeding as well as bleeding during intercourse.	Can be cured with antibiotics. Most of the time, at least 2 antibiotics are used that work against a wide range of bacteria.
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Aging with HIV/AIDS

The reality is that people are living into old age with HIV/AIDS and more people over the age of 50 are becoming HIV positive. There needs to be more of an effort to provide resources and information to the elders in the community so that they can protect and take care of themselves.

Some of the myths that need to be broken include;

- The idea that older adults and elderly people are not sexually active
- The idea that since older adults and elderly people can no longer get pregnant that they no longer need to use protection
- The idea that only the younger generations are at risk of contracting HIV

In fact, all generations are at risk of contracting HIV. People over 50 are especially at risk because:

- there are no promotion efforts directed at their age group,
- they did not become adults at a time when using protection was popular (many older adults and elderly people do not use protection and have not been tested for HIV),
- they do not perceive themselves to be at risk, and
- their bodies are aging so their immune systems are weakened and with age, vaginal and anal tearing is more common during sex.

When older adults and elderly people are newly infected with HIV they often develop AIDS within a year and only live on average three years when younger people can live for decades with HIV. This emphasizes, as a frontline worker, the importance of considering the topic of HIV and aging.

Older adults and elderly people aging with HIV/AIDS have unique circumstances that should be considered;

- They are more likely to adhere to their antiretroviral medications than younger people.
- Studies have shown that this age group feels that they can handle the mental, emotional, and spiritual stresses of being diagnosed and living with HIV because they have more life experiences and developed abilities to cope with life's challenges.
- They are less physically capable of dealing with the physical problems and stresses brought on by HIV.
- Older adults and elderly people feel that others are less sympathetic with their diagnosis because they are older.
- They have less social support than other age groups and sometimes live alone making it difficult to live with HIV. This social isolation is worsened if they experience depression and lose motivation to maintain their social ties to their family and community.
- Elderly people already have less of a CD4 count than younger people and develop these cells more slowly. So the immune system is already weaker to begin with therefore more vulnerable to damage brought on by HIV.
- Elderly people have weaker bone, muscles, and organs making their bodies less resilient to infections and other problems brought on by HIV

Keeping these circumstances in mind, a frontline worker should tailor the support they give to their older adult and elderly clients whether they are newly infected or are aging with HIV. Elderly people may be less willing to discuss sexuality or other related topics with a frontline worker, so handle these discussions with respect and care. In First Nations communities, elderly people are generally respected as keepers of knowledge and experienced in life. Suggest to them, if they are comfortable and willing to extend a confidential relationship to others, that they work with younger people living with HIV who are having a harder time coping. Most importantly, there is hope for older adults and elderly people aging with HIV. They can continue to live fulfilling lives despite aging if they continue eating nutritiously, exercising and taking care of their bodies in ways that are suggested for their age group.

TERTIARY PREVENTION: Roles of a First Nation Frontline Worker

Awareness:

- Be informed. Understanding the common OIs will enhance your effectiveness as an advocate and a support to the individual as they plan their self care.
- Understand the special considerations of aging with HIV. In some ways,, older adults are better able to cope with HIV/AIDS, but in other areas, such as adherence to medication and access to social networks, they may need extra assistance from you.

Advocacy:

- Assist individuals with their care plans, and that they have the medications they need to treat OIs.
- Support women with HIV by encouraging them to be aware of their body, to self assess their health and use a variety of self care strategies.
- Discuss the importance of regular pap tests with women

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CURATIVE: Treatment and Care

Palliative Care

Palliative care is focused on treating pain, making the client comfortable, improving the quality of life, and offering emotional and spiritual support. It is not necessarily something that is offered to a person at the end of life but can be combined with efforts to extend life. However it should be noted that despite antiretroviral therapy that has successfully extended life for individuals living with HIV/AIDS, the need for end of life considerations has not become obsolete.

Palliative care respects the autonomy and choices of the client while also welcoming all the people the client cares about to participate in the decision making and care. Palliative care is based on an interdisciplinary team model. That is, it includes a wide range of people who can bring together their skills and support to give the client the best possible care. Nurses, Community Health Reps, Traditional Healers, social workers, family members, community members, and Elders can work together, with the individual, to create an enriching care experience. It involves team work, shared goals, trust, and shared information. Frequently it is the case that health care workers see themselves as the providers of care while the individual living with HIV or AIDS is the recipient. The best model of palliative care is one where the individual is one of the members of the interdisciplinary team providing and planning their own care.

There is a misconception that medical attention focused on extending life will end once palliative care begins. As a frontline worker, you can reassure the individual that you will demand the best care for them and that they could be missing out on pain management and comfort because of the misconception that medical care ends where palliative care begins. Medical care and palliative care should be complementary throughout the whole process.

Respite Care

Respite is a much needed service for people providing care to loved ones living with HIV and AIDS. It provides a break for caregivers- allowing someone else to temporarily take over some of their caregiving duties. When provided on a regular basis, respite care helps prevent caregiver burnout, by relieving some of the caregiver's workload and stress.

Hospice Care

Hospice care is a place or service for people in the final days of their life to live comfortably and peacefully, surrounded by the things and people that matter most to them. Hospice service can also be offered at home. Many clients may prefer hospice at home because they do not want to be isolated from their family

and friends, even when there is a hospice on reserve. Explore all options for your client and ask them what they prefer based on their options.

Supporting the Client with Hospice Care

The following is a list of questions that you could ask the person living with HIV or AIDS in order to get an idea of what kind of care and assistance they need;

- 1) Are you experiencing pain? How often are you in pain?
- 2) Does the pain stop you from doing what you normally enjoy?
- 3) What kind of assistance would make you life more comfortable?
- 4) What activities are most meaningful to you? Do you have goals that you feel you need to achieve in your life? How can I help you reach your goals?
- 5) What would you like to happen if your condition gets worse? Would you like to focus on pain management, be in the hospital to receive medical care etc?
- 6) What are you worried about leaving behind? What would you like me and other workers to do for your loved ones?

These questions should give you a better idea of what community resources you need to help the individual access care, whether they want to receive care at home or somewhere else and what personal matters they need to sort out. The next section will discuss the management of pain so that the individual can live the rest of their life comfortably.

Universal Precautions

Universal precautions protect both service providers and those people being provided with care, in this context, First Nations people with HIV/AIDS. When universal precautions are adhered to, in any care setting, it eliminates the need to make assumptions about people's lifestyles and how much of a risk they present. Care providers have the right to protect themselves against infection, whether it is HIV, hepatitis C, or other transmittable infection.

The following universal precautions are advised by the World Health Organization to help protect health care workers from blood-borne infections, including HIV, when they are providing care where exposure to blood may be possible:

- Hand washing after direct contact with HIV positive individuals.
- Use of protective barriers such as latex gloves for direct contact with blood and other body fluids.
- Safe collection and disposal of needles and sharps, with required puncture- and liquid- proof boxes.
- Preventing two-handed recapping of needles.

- Covering all cuts and abrasions with a waterproof dressing.
- Using a safe system for health care waste management and disposal.

Appropriate waste disposal is essential to prevent used and potentially contaminated medical equipment being recycled. However, this is reliant on the necessary disposal facilities being in place within the First Nation community. The use of sharps boxes for used needles prevents health workers from injuring themselves or re-using them. It also protects members of the community from exposure to needles, which can easily occur if medical waste is disposed of alongside normal refuse.

Pain Management

Pain management is not only important for improving quality of life but it can improve adherence to antiretroviral therapies that have painful side effects. If the side effects are minimized, people living with HIV will be less reluctant to take their medication. Pain is experienced by the majority of individuals living with AIDS but is severely undertreated when clearly it should be complementary to antiretroviral therapy. The goal of pain management is to relieve pain for clients with the least side effects so they can carry on living their life how they desire to.

Not only is pain management treated as if it is insignificant compared to medical treatment, there are also many misconceptions about the medications available to manage pain that creates barriers to accessing them and minimizing the pain. Opiates are the most common form of pain medication for people living with AIDS. Opiates are used because they effectively block the nervous system from detecting pain. These medications are also considered addictive and have a stigma attached to them.

Since 2001, Health Canada has granted access to marijuana for medical use to those who are suffering from grave and debilitating illnesses, including HIV positive individuals suffering severe pain, cachexia, anorexia, weight loss, and/or severe nausea due to HIV/AIDS infection. The program is called Marijuana Medical Access Regulations (MMAR) and to access the program, two application forms must be completed by a family doctor or specialist and submitted to Health Canada. Although some people may not approve of these regulations and the program, it is a viable treatment to pain that some First Nations members may want to consider.

Health Care providers have barriers to properly treating pain such as lack of knowledge about HIV/AIDS, misconceptions and fears about addictions (i.e. Aboriginal people have addiction problems so it is best not to give them morphine) or (morphine is always addictive), and fear of legal sanctions if the patient becomes addicted. Studies show that marginalized groups such as Aboriginal people have less access to medications to treat HIV/AIDS pain related problems probably because of stigma attached to opiates and discrimination

against these groups. As an advocate for the person living with HIV or AIDS, you can help them access the drugs they need to manage their pain by challenging some of the misconceptions and stereotypes.

The Person living with HIV/AIDS also faces barriers such as fear of becoming addicted; especially if they were previously or still injected drug users. They may be worried about the stigma they would face in the community because of using opiates for pain management. Caregivers may also have the same concerns. There are barriers to accessing these drugs, especially opiates because of the additional costs. For someone already having to divert finances from food and other important needs in order to pay for the costs of treating HIV/AIDS, these costs can be impossible to cover. Familiarize yourself with what opiates and non opiate pain medications are available through NIHB, in what amounts, and if there are special regulations that will make them hard to access.

Although it is up to health care providers (physicians, nurses, nurse practitioners) to prescribe medications and their dosages, you can still be an advocate for ensuring that the individual is living pain free.

In addition to medication to manage pain, other therapies such as massage, music or traditional medicines/ methods can help reduce pain by relaxing the mind, body, and spirit. The individual may already have a preferred method that they would like to rely on to complement their medication.

Understanding Chronic Pain in People Living with HIV/AIDS

Having a general understanding of what types of chronic pain people living with HIV/AIDS experience can help you advocate on their behalf to access the drugs and health care treatment they need. Pain can result from HIV/AIDS itself, from the various medications and their chemicals, and also from other chronic diseases that can form during the life span of a person living with HIV/AIDS such as diabetes.

There are different types of pain an individual can experience;

- Neuropathic pain involves damage to nerve tissue. The sensations that are common to this sort of pain are pain produced by stimulus such as light sensitivity, tingling, burning, shooting pains, and a sensation that feels like an electric shock.
- Headaches can result from light sensitivity, stress, muscle tension and/or infections in the nervous system.
- Chest pain can result from opportunistic infections such as tuberculosis.
- Gastrointestinal pain such as nausea, diarrhoea, vomiting, or sores on the mouth or throat can result from medication side effects, or opportunistic infections and it can making eating difficult.

Although you are not responsible for diagnosing the pain, you can use this information to assist individuals when they are trying to describe the pain and the symptoms to health care providers. This way you have the knowledge to be an informed advocate for the individual.

End of Life Counseling

It is difficult for anyone to raise the topic of dying. You will first have to confront your own discomfort about the topic before offering counseling to your client. End of life counseling in this context has several purposes;

- 1) To help the individual find peace and meaningfulness at the end of their life and to also help the individual to confront and work through their fears.
- 2) To assess the client and their family member's desires and plans for end of life care.
- 3) To help the client access the resources they need to find meaning and dignity in end of life care.
- 4) To support and advocate on behalf of the client and their family since there will be interactions with mainstream health workers and services. You can help them articulate their needs so they are properly met.

People living with advanced stage AIDS can experience many concerns and fears including fear of death, the agony of being separated from their family and friends, fear of leaving their loved ones behind without their care and support (this could be especially challenging for parents leaving behind young children), depression from continuing stigma and isolation, and fears about the meaning of life and death (whether their life was purposeful).

When providing supportive counseling, you should be open to helping your client cope with these fears. Your client may not bring up these concerns with you and instead keep their fears buried inside, feeling isolated and scared. Try to be compassionate and find a quiet, private and cozy space to discuss these issues. All of the qualities a person should have to counsel someone living with HIV also applies to end of life counseling. It is important to be an attentive, non judgemental listener, to keep all information confidential, and to never do anything that would compromise the trusting relationship that you have built with your client.

To prepare to discuss end of life with your client, keep the following in mind;

- They may not be ready to discuss end of life because it makes the circumstances, and their mortality more real to them
- Act natural around the dying person. It is often the case that people begin to act differently around a person when they are near death.
- Do not be afraid to use humour when appropriate but at the same time when the person wants to discuss serious and emotionally charged issues, do not interrupt them, diminish what they are saying, or try to change the subject out of your own discomfort; they will need your support. Keep in mind that they are losing everything in their life all at once.
- It is likely that the individual has known for a very long time that they are going to eventually die from AIDS. They have probably already worked through the earlier stages of denial, anger, and bargaining after finding out their diagnosis and are now either experiencing depression or acceptance of their pending death.
- They may have questions for you. Be open to answering their questions and to advocating on their behalf
- They may want to have their family members or partners present when they talk about these issues for the support and because they want their family very much involved in end of life decisions. Perhaps they need help to prepare and will also have questions.
- Be attentive to what the client wants. They may want moments of silence or to take a break from discussing these matters because it is too intense. They may want to discuss their fears now and leave some of the legal matters until a later date. It is up to the client.

- Repeat some of what the client is saying back to them in question form to reinforce that you are hearing everything that they say and taking it seriously.
- Respect the client's cultural views, attitudes, and ways of expressing themselves.
- Listen closely. Your client may have final wishes that you did not expect. For example the stigma attached to HIV/AIDS may have created conflict between family members and your client. Perhaps the client wants to make amends before death. Help your client fulfill these last needs if it is possible.

People at the end of life, living with AIDS will be reflecting on the meaning and purpose of life and death. People may have spiritual beliefs that they will turn to for answers. Spirituality is usually culturally specific and both personal and shared. Studies show that people with AIDS at the end of life often want their spiritual needs fulfilled. Spirituality can allow the client to find meaning in death, to experience peacefulness and to reflect on their life and see it from a new perspective. It allows healing and hope when medically there is no more that can be done. Part of end of life counseling and palliative care is supporting and nurturing the spiritual beliefs and needs of the client. This will require cultural sensitivity and respect.

The following should be kept in mind;

- The individual may want to discuss their spiritual beliefs and may want you to be involved. If they do, participate in their rituals whether that is attending ceremonies, spending time with Elders, or praying. Participating lets the client know that you care about and support them.
- On the other hand, they may want to keep their spiritual beliefs and rituals private. Respect that desire as well.
- Try to nurture those aspects of their spiritual beliefs that give them comfort and peace about death but try to comfort them and discourage those aspects that create feelings of guilt or fear.
- If they do have spiritual beliefs, encourage and nurture that but if they do not, do not suggest that they develop a sense of spirituality. Sometimes religion (a form of organized spirituality), in particular is associated with colonization, residential school and past traumas. This will not be the case for traditional Aboriginal beliefs but still it is about the client's personal choices.
- There are other activities that can help the person with self reflection and to find peace and relaxation such as journaling, art therapy, meditation or yoga that you can suggest and/or participate in with your client

TREATMENT AND CARE: Roles of a First Nation Frontline Worker

Advocacy

Palliative Care

- Be informed. Understanding HIV/AIDS, the client and their community, the pain the client is experiencing, barriers to services outside of the community and all the resources available for the client will help you to be an informed advocate
- Making sure the client and his/her family has adequate housing, transportation, food security and access to all the services they need including treatment for related issues such as substance abuse or depression
- Helping the individual and their family make plans for the present and future
- Understanding government services such as disability pension
- Understanding all the social issues surrounding the circumstances of having a family member with a severe illness and potentially close to death
- Making sure that the individual's cultural needs are met in all aspects of palliative care
- Arranging for the best palliative care. This includes referring clients to hospice centres if they desire or accessing the medical equipment and health care workers needed to provide care at home.

Although you may not be able to personally provide **respite care**, you may be able to assist with arranging respite care for the caregiver.

Assist the individual, and their caregiver where appropriate, to arrange **hospice care**. Taking the time to listen to their needs and to be aware of what services are available, will ensure their needs are met.

Pain Management:

- Be an advocate for ensuring that the individual is living pain free.
- Be informed. Familiarize yourself with what opiates and non opiate pain medications are available through NIHB, in what amounts, and if there are special regulations that will make them hard to access.
- If they require assistance to complete forms, you can assist or find someone who can.

Supportive Counseling:

- Be open to helping your client cope with these fears. Your client may not bring up these concerns with you and instead keep their fears buried inside, feeling isolated and scared.

- Try to be compassionate and find a quiet, private and cozy space to discuss these issues.
- Be an attentive, non judgemental listener, to keep all information confidential, and to never do anything that would compromise the trusting relationship that you have built with your client.

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SUPPORTIVE RESOURCES

In addition to all the overwhelming emotions of dealing with end of life, individuals living with AIDS will also likely be experiencing stress over preparing for the end of their life such as preparing a will and making funeral and traditional arrangements. They have to cope with decisions about how their children will be cared for, and by whom. They have fears about leaving their loved ones with all of these legal and financial burdens. This section will provide you with some tools and information so that you can help the individual lessen these burdens.

Furthermore, the death of your client does not mean the end of care. Family and friends will be struggling to cope with their loved ones death emotionally but also financially. This section will also help you give support to the individual's loved ones who are grieving their death.

End of Life Considerations

This section will define some important legal terms so that you can discuss them with your client and their loved ones. The purpose of having this discussion is to reduce stress for everyone involved. Terminal illness can be financially draining and arrangements and legal decisions after death can be stressful and exhausting for bereaved loved ones. A discussion about end of life considerations will ensure your client that their decisions and the decisions of their loved ones will be respected and followed through. The Office of the Public Guardian and Trustee has produced a Power of Attorney Kit that will help individuals appoint the person they want to make decisions for them when they are no longer able to do so for themselves.

Power of Attorney for Personal Care:

This is a written document that delegates the right to a chosen person to make personal decisions on behalf of an individual – decisions such as health care and housing. This may be important in the case that the individual living with HIV/AIDS is hospitalized and cannot communicate their own decisions. It is important that as long as the individual can communicate, they should be in charge of their own decision making. It is recommended that this document get notarised to make it legally binding.

Living Will:

This is a legal document that outlines what an individual wants to happen if they become ill and can't communicate their wishes about treatment. This is quite common in the event where an individual who have advanced to the AIDS stage needs life prolonging medical measures to survive. The Living Will could explain that they do not want to be placed on life support or in certain circumstances do not want life prolonging medications. It might be beneficial to schedule a meeting with a health care provider, the individual, and you as an advocate to discuss all the implications of different decisions that can be made. It is important to have a living will because physicians are ethically bound to do all they can to keep the

individual alive despite the fact that the individual might not want this. Also it communicates the individual's decisions that otherwise their next of kin would be allowed to make. Whoever that is may not properly represent the individual's wishes and their right to chose.

Power of Attorney for Property:

This is a person appointed by the individual to handle their financial matters. If the individual is sick and hospitalized over a long period of time or unable to take care of their own finances at home, the power of attorney would be responsible for paying bills and taking care of bank accounts and assets for example. The written document can have very specific information about what is expected of the power of attorney. When the individual dies the power of attorney's responsibility is transferred to an executor of a will.

Will:

A will is different from a "Living Will", in that it only comes into effect upon the individual's death. It describes the individual's assets and who she/he wants to inherit them. If the individual does not have a will, the biological relatives or spouse will inherit the property while in reality the individual may prefer for an unmarried partner or close friend to inherit some assets. Although a person over the age of eighteen can draw up a will themselves with the signature of two witnesses who are not inheriting assets under the terms of the will, it is probably a good idea to have a lawyer draw up the will. Lawyers can be expensive and may not be available in your community but there are lawyers or legal services (Aboriginal Legal Services, Toronto), where assistance can be acquired for free if the client has a low income.

Frontline workers, as advocates, can have these discussions with the individual and their loved ones when they are ready. These arrangements do not have to be left until the individual is near death; in fact it is better to sort out these issues when the individual is perfectly healthy and has the time and energy to think it over and discuss it with friends and family. As an advocate, try to be informed about the individual's wishes and which legal documents they have or do not have so that you can make sure that health care providers are aware of these documents and follow the wishes outlined in them.

Grief and Bereavement

The grieving process can be very complicated for those who lost a loved one to AIDS. Even though they were likely prepared for the death of their loved one, there are still many emotions and life changes to work through. AIDS is now considered more of a chronic rather than terminal illness so loved ones may feel that death can be prevented and it may still come as a shock when their loved one dies. This section will first define and discuss grief and bereavement and then suggest how you as a counsellor can help family and friends cope with the death of their loved one.

Bereavement is the state of having suffered a loss. *Grief* is the reaction to that loss.

Grief is the process of letting go of the attachment one had to the person who died and the changes in life necessary to live without that person. Grief can be exhibited in many ways. The person can intensely mourn their loved one's death over an extended period of time, deny the loss and put off feelings of grief or move through the painful feelings quickly and find a way to live without their loved one while still remembering and appreciating them. There is no right way to grieve and sometimes it is important to let the grieving individuals know this since they may be surprised by their reaction to the death or feel guilty about the way they are handling it.

Anticipatory Grief is an awareness that one is about to lose their loved one. This is common with HIV/AIDS because it is a chronic illness and death is not sudden but is something that is prepared for over time. Anticipatory grief includes reworking one's relationship with the dying loved one, changing assumptions about the future and at times, feeling anxiety, depression and sadness. It also gives the individual and their family time to make final arrangements and say good bye. This time can be very meaningful for the grieving process.

Mourning is the outward expression of grief. It is culturally determined. Some First Nations people are reclaiming traditional ways of mourning but this is not true in all communities or for all people. Also keep in mind that different Nations have different traditional practices.

The following are some of the physical, mental, emotional and spiritual experiences that bereaved people may go through;

- Anxiety
- Anger about the amount of time they spent taking care of their dying loved one and subsequent guilt over the feelings of relief when that person dies
- Physical and emotional exhaustion
- Depression about watching their loved one slowly die without being able to prevent it or slow it down
- Health problems such as high blood pressure, heart failure, immune suppression, and illnesses
- *Denial* before reality sets in. This way of coping can involve feelings of shock, numbness, sporadic anger, confusion
- Carrying on as if the person is still alive. This is called *searching*. An example would be cooking meals for their deceased loved one.
- Depression which may include sleeping problems, inability to concentrate, and lack of energy. This usually occurs when a person is in *despair*, that is intensely grieving their loss and at times experiencing survivors guilt

- Going back and forth between mourning and feeling energetic and positive about the future. This is often referred to as *reorganization*
- Being able to move on and reinvest in life but still re-experiencing grief at certain periods such as birthdays, family holidays, and anniversaries
- Family disruptions where everyone is experiencing grief and financial changes and it becomes a high stress environment.
- Social Isolation
- Sometimes grieving can take the form of mirroring the symptoms of their loved one that died of AIDS, for example weight loss as a grief response which mirrors the wasting symptom of AIDS.
- Guilt for participating in the activities that increased the risk of transmission of HIV
- Using drug or alcohol as a coping mechanism. This only numbs the feelings of grief and takes away the opportunity to work through those feelings

Grief is a natural process that a person goes through when bereaved. Grief work is a personal journey that will help the person;

1. Accept the reality that their loved one has passed on
2. Inwardly reflect to make necessary changes to their identity
3. Make life changes that reflect the new circumstances of their loved one being gone

As a frontline worker, you can help the person on their personal journey.

Worker Burnout

As frontline workers, sometimes it is emotionally draining to be giving support to individuals with AIDs that are near death and their family members who are bereaved or anticipating bereavement. It is important to take care of your emotional and mental health before you can give support to others. It is challenging to keep a certain amount of distance between you and your clients, especially in a community where you may know your client personally. It can be extra difficult when you lose that client once they pass on but are still expected to remain strong and offer support to their bereaved family and friends. You may not be able to handle the level of the support that you are being asked to give so familiarize yourself with other resources such as bereavement counseling that you can refer bereaved individuals to. With the permission of your bereaved clients you can also ask an Elder to work with you.

Although you may want to give yourself completely to helping others cope, it will not be helpful if you are not healthy yourself. Take care of yourself too!

SUPPORTIVE RESOURCES: Roles of a First Nation Frontline Worker

Support with legal matters:

As an advocate, try to be informed about the individual's wishes and which legal documents they have or do not have so that you can make sure that health care providers are aware of these documents and follow the wishes outlined in them.

Frontline Workers (advocates) should keep the following in mind;

- When the individual is ready, legal and technical issues to discuss include where they want to pass away (hospice, hospital, or at home), where they want to be buried or cremated, who their power of attorney is and whether or not they have a living will.
- Are they traditional? Have they arranged for a traditional ceremony with their Elders? Who are their cultural supports in these matters?
- Listen closely. Your assumptions of what your client would want may be very different from what they actually want. For example they may want a friend or partner to be a power of attorney rather a close family member

Counseling for Anticipatory Grief:

- Suggest, as a way of coping that the individual and their family members spend time looking back on some of life's happy moments with use of pictures or videos.
- Suggest that they engage in spiritual or relaxing activities together such as meditation or traditional ceremonies.
- A final trip together is also a good idea for creating final memories before the end. This could be as simple as a trip to a lake or camping.
- Keep in mind that although people have time to think about death and the consequences of their loss, it is still painful when the death finally occurs

Supporting bereaved individuals:

Now that you understand some of the physical, mental, emotional, and spiritual challenges that bereaved people experience during their grieving process, it is important to know how to support them during that process.

As a frontline worker (advocate), the following are ways you can support a bereaved person;

- Help them reconnect with family and community members. Everyone needs a good support system
- Let them know that everything they experience during this process is normal. Everyone has a personal way of grieving and there is no set amount of time they should spend grieving.
- Encourage them to continue to take care of themselves

- Encourage activities and traditional practices (spiritual rituals) that will help them find meaning in being a survivor and in experiencing such as great loss
- Let them know that it is alright to experience intense grief on significant holidays or anniversaries. Let them know that sometimes the most painful time is anticipating this date, not the actual day. Encourage them to plan out the day so they do not dwell on the pain.
- Reassure them that no matter what their relationship was to the person who died, they are justified to grieve and mourn their death however way they want to.
- Acknowledge their loss, share memories and be a compassionate listener
- Acknowledge that it may be extra difficult for those who are denied the opportunity to mourn. An example would be not being invited to the funeral or some other ceremony. Since there is still much stigma attached to HIV/AIDS, there may be conflict and social exclusion of some individuals who are grieving. The stigma attached to AIDS may also mean that the cause of death is not mentioned during ceremonies which can be hard for some bereaved people.

Overall, be a compassionate and caring person and be open to different ways of grieving. Try to support the person according to their way of handling their grief.

Supportive Resources References

Life Long Care Programme. Managing Grief and Bereavement as a Care Support Worker. Ontario Federation of Indian Friendship Centres.

Selwyn, P. Et al. (2003). A Clinical Guide to Supportive and Palliative Care for HIV/AIDS. US Department of Health and Human Services HIV/AIDS Bureau.

Ministry of the Attorney General. Power of Attorney. Retrieved December 13, 2010 from, <http://www.attorneygeneral.jus.gov.on.ca/english/family/pgt/poa.asp>

PROMOTION OF STABILITY

Promotion of stability is about frontline workers creating a network of services that they can use to support the services that they are providing to people living with HIV/AIDS. It is about being equipped to coordinate the services required and supporting individuals to reach out into their community, and the region, to obtain the programs and services they need. In this section, various service organizations/agencies will be listed for quick reference (retrieved from <http://www.ontarioaidsnetwork.on.ca> on October 30, 2010).

2-Spirited People of the 1st Nations

593 Yonge St., Ste. 202
Toronto, ON M4Y 1Z4
ED: Art Zoccole
ED email: art@2spirits.com
Phone: 416-944-9300 Fax: 416-944-8381
Agency E-mail: info@2spirits.com
Website: www.2spirits.com

Ontario Aboriginal HIV/AIDS Strategy

201 – 7 Hayden Street
Toronto, ON M4Y 2P2
A/ED: Doris O'Brien-Teengs
E-mail: doet@oahas.org
Phone: 416-944-9481 or
1-800-743-8851 Fax: 416-944-0541

Canadian Aboriginal AIDS Network

Main Office

6520 Salish drive
Vancouver BC V6N 2C7
Phone: 604-266-7616 Fax: 604-266-7612
Email: kenc@caan.ca

AIDS Committee of Durham

22 King St. West, #401
Oshawa, ON L1H 1A3
ED: Adrian Betts
Phone: 905-576-1445 Fax: 905-576-4610
E-mail: director@aidsturham.com
Website: www.aidsturham.com

AIDS Committee of Guelph & Wellington County

409 Woolwich Street, 2nd floor
Guelph, ON N1H 3X2
ED: Tom Hammond
E-mail: director@aidsguelph.org
Phone: 519-763-2255 Fax: 519-763-8125
Website: www.aidsguelph.org

AIDS Committee of Windsor

511 Pelissier Street
Windsor, ON N9A 4L2
ED: Michele Sharp
E-mail: msharp@aidswindsor.org
Phone: 519-973-0222 Fax: 519-973-7389
Website: www.aidswindsor.org

AIDS Committee of York Region

194 Eagle St. East
Newmarket, ON L3Y 1J6
ED: Radha Bhardwaj
E-mail: edacyr@bellnet.ca
Phone: 905-953-0248 Fax: 905-953-1372
Toll-free: 1-800-243-7717
E-mail: acyr@bellnet.ca
Website: www.acyr.org

AIDS Niagara

120 Queenston St.
St. Catharines, ON L2R 2Z3
ED: Steve Byers
E-mail: sbyers@aidсниagara.com
Phone: 905-984-8684 Fax: 905-988-1921
E-mail: info@aidсниagara.com
Website: www.aidсниagara.com

AIDS Thunder Bay

574 Memorial Avenue
Thunder Bay, ON P7B 3Z2
ED: Lawrence Korhonen
E-mail: lkorhonen@aidsthunderbay.org
Phone: 807-345-1516
or 1-800-488-5840 (in 807 area) Fax: 807-345-2505
E-mail: info@aidsthunderbay.org
Website: www.aidsthunderbay.org

AIDS Committee of London

186 King Street, Suite #30
London, ON N6A 1C7
ED: Brian Lester
E-mail: blester@aidslondon.com
Phone: 519-434-1601 Fax: 519-434-1843
Website: www.aidslondon.com

AIDS Committee of North Bay & Area

269 Main Street West, #201
North Bay, ON P1B 2T8
ED: Stacey L. Mayhall
Phone: 705-497-3560 Fax: 705-497-7850
E-mail: edacnba@vianet.ca
Website: www.aidsnorthbay.com

AIDS Committee of Ottawa

251 Bank Street, Suite 700
Ottawa, ON K2P 1X3
ED: Kathleen Cummings
Phone: 613-238-5014 Fax: 613-238-3425
E-mail: connect@aco-cso.ca

AIDS Committee of Simcoe County

80 Bradford St., #337
Barrie, ON L4N 6S7
ED: Gerry Croteau
Phone: 705-722-6778 Fax: 705-722-6560
E-mail: acscexecutivedirector@rogers.com
Website: www.acsc.ca

Access AIDS Network

111 Elm St., #203
Sudbury, ON P3C 1T3
Phone: 705-688-0500 or 1-800-465-2437
Fax: 705-688-0423
ED: Richard Rainville
E-mail: access@cyberbeach.net

AIDS Committee of Toronto

399 Church St., 4th Floor
Toronto, ON M5B 2J6
ED: Hazelle Palmer
Phone: 416-340-2437 Fax: 416-340-8224
E-mail: hpalmer@actoronto.org
Website: www.actoronto.org

Peterborough AIDS Resource Network (PARN)

159 King Street #302
Peterborough, ON K9J 2R8
ED: Kim Dolan
E-mail: kim@parn.ca
Phone: 1-800-361-2895 or: 705-749-9110
Fax: 705-749-6310
E-mail: getinformed@parn.ca
Website: www.parn.ca

Treatment and Legal Services**Canadian AIDS Treatment Information Exchange (CATIE)**

555 Richmond St. West #505 Box 1104
Toronto, ON M5V 3B1
ED: Laurie Edmiston
E-mail: ledmiston@catie.ca
Phone: 1-800-263-1638 or 416-203-7122
Fax: 416-203-8284 & 416-203-8427
E-mail: info@catie.ca
Website: www.catie.ca

The Ontario HIV Treatment Network (NVM)

1300 Yonge Street, Suite 600
Toronto, ON M4T 1X3
ED: Sean Rourke
E-mail: sean.rourke@utoronto.ca
Phone: 416-642-6486 or 1-877-743-6486
Fax: 416-640-4245
Website: www.ohtn.on.ca

HIV/AIDS Legal Clinic of Ontario (HALCO)

65 Wellesley St. East, #400
Toronto, ON M4Y 1G7
ED: Ryan Peck
E-mail: peckr@lao.on.ca
Phone: 416-340-7790 or 1-888-705-8889
Fax: 416-340-7248
Website: www.halco.org

Government and Other Agencies

Prisoners HIV/AIDS Support Action Network (PASAN)

314 Jarvis Street, Suite 100
Toronto, ON M5B 2C5
ED: Anne Marie DiCenso
E-mail: annemarie@pasan.org
Phone: 416-920-9567
E-mail: info@pasan.org
Website: www.pasan.org

AIDS Bureau

Ministry of Health and Long-Term Care
393 University Avenue, Suite 2100
Toronto, ON M5G 1E6
Phone: 1-800-268-6066 or 416-327-8797

Canadian Treatment Action Council

Box 203, Suite 1109B
555 Richmond St. West
Toronto, Ontario M5V 3B1
Phone/Fax: (416) 410-6538
Email: ctac@ctac.ca

Canadian Working Group on HIV and Rehabilitation (CWGHR)

1240 Bay Street, Suite 600
Toronto, ON
Canada
M5R 2A7
Phone: (416) 513-0440
Fax: (416) 595-0094
E-mail: info@hivandrehab.ca
Website: www.hivandrehab.ca

The Ontario Trillium Foundation

45 Charles Street East, 5th Floor
Toronto ON , M4Y 1S2
Phone: 1-800-263-2887
or 416-963-4927
Fax: 416-963-8781
E-mail: trillium@trilliumfoundation.org

Canadian Mental Health Association, Ontario

180 Dundas Street West, Suite 2301
Toronto, ON M5G 1Z8
Phone: 416-977-5580 or 1-800-875-6213
Fax 416-977-2813
E-mail: info@ontario.cmha.ca

Centre for Addiction and Mental Health

For location and contact information, call CAMH main switchboard:
(416) 535-8501

For information about :

Ontario Disability Support Program

Ontario Works

Go to:

Ministry of Community and Social Services

Website: <http://www.accesson.ca/en/mcss/programs/social/index.aspx>

Anonymous Testing

Anonymous HIV testing is offered at 50 sites across Ontario. HIV testing includes pre- and post-test counseling and referrals to other services and supports.

For information on an anonymous testing site near you, call the **AIDS Hotline:**
1-800-668-2437 Toronto : 416-392-2437

Ontario Provincial Territorial Organizations:

Association of Iroquois and Allied Indians

387 Princess Avenue
London, Ontario
N6B 2A7
Phone: 519 434-2761
Fax: 519 679-1653

Nishnawbe-Aski Nation

100 Back St., Unit #200,
Thunder Bay, Ontario
P7C 4Z2
Phone: 807 623-7730
Fax: 807 623-5193
Toll Free: 1-800-465-9952

Grand Council Treaty #3

P.O. Box 1720

Kenora, Ontario

P9N 3X7

Phone: 807 548-4214

Fax: 807 548-5041

Toll Free: 1-800-665-3384

Union of Ontario Indians

Nipissing First Nation

P.O. Box 711

North Bay, Ontario

P1B 8J8

Phone: 705 497-9127

Fax: 705 497-9135

Toll Free: 1-877-702-5200

To contact the **Independent First Nations**, call:

Independent First Nations Coordinator

1695 Chiefswood Drive

P.O. Box 5000

Ohsweken, ON

Phone: 905 765-2222

TRAINING

Training is a key element for ensuring that First Nation frontline workers are equipped with the knowledge, skills, attitudes and values (SKAV) required to provide effective services to people living with HIV/AIDS in the First Nation communities. In considering the SKAV required, a curriculum developer or trainer must first understand what First Nations frontline workers currently do, or are willing to do, in their jobs and how HIV will change the nature of their work. However, it is important to keep in mind that not all SKAV requirements can be obtained through formal training, or even informal workshops.

Frontline workers should seek culture-based training opportunities and consider spending time with Elders and Traditional people to enhance their cultural teachings, their beliefs and values, such as respect and acceptance. Spending time with their Elders may help them better understand the experiences and needs of people living with HIV/AIDS.

Currently there are various resources developed by Aboriginal organizations that frontline workers can access. The Ontario First Nations HIV/AIDS Education Circle has provided various learning opportunities over the years and will continue to meet the learning needs of their communities. To learn more about these opportunities, contact your Provincial Territorial Organization listed in the Supportive Network section and ask for the HIV/AIDS Educator.

Provincial Conferences and Training:

Annual Guelph Sexuality Conference Communication & Sexual Health
www.guelphsexualityconference.ca

Annual Canadian Association of HIV Research Conference
www.cahr-conference-acrv.ca

Ontario HIV and Substance Use Training Program

(416) 703-7348

1-866-591-0347

For a list of upcoming workshops, go to: www.ohsutp.ca