

FIRST
NATIONS
AND
INUIT
PEOPLE

Living with HIV

FIRST NATIONS AND INUIT PEOPLE LIVING WITH HIV

When we face adversity and serious threats, like the one AIDS poses to Aboriginal people, it is important that we are together and we remain physically and spiritually strong.

Joe Crow, Elder and FSIN Senator

HIV is a growing reality in First Nations and Inuit communities, with infections increasing among Aboriginal people at a rate three times faster than the general population. This booklet is an attempt to give First Nations and Inuit people living with HIV a tool to use in looking after their own health.

To begin, you will need to have basic information about HIV/AIDS and how it works in the body. The first section, "HIV: The Facts – Plain and Simple," is designed to give you that information.

As a First Nation or Inuit person, you will also need to know how you can get special access to treatments. Along with medications that may by prescribed by your doctor, treatment for HIV includes taking care of yourself through healthy living. Many First Nations and Inuit people have found that consulting a traditional healer and adopting traditional practices can play an important role in maintaining physical and spiritual health. You will find the information on accessing medication and traditional healing in the second part of the booklet: "Living with HIV/Accessing Treatments."

In the "Helplines" section at the end of the booklet you will find contact numbers for government agencies and HIV/AIDS service organizations that should be able to answer any further questions you might have. The treatment and referral organizations can also put you in touch with someone knowledgeable about HIV who can offer individual counselling, which can be of great assistance when you are newly diagnosed, and as you continue with your treatments.



HIV: THE FACTS - PLAIN AND SIMPLE

What is HIV?

HIV is the virus that causes AIDS. Only people who have HIV get AIDS.

A virus is a kind of germ that can make you sick. Some can give you a cold. Others can give you the chickenpox, the flu or a cold sore.

HIV stands for Human Immunodeficiency Virus.

AIDS stands for Acquired Immune Deficiency Syndrome.

What is CD4?

CD4 refers to a kind of cell in the blood. Your body is made up of many different kinds of cells. Each cell has its own job to do. CD4 cells help keep you healthy. They protect you from some germs.



What HIV does

HIV attacks and kills CD4 cells. When there are not enough CD4 cells, it is easier for germs that attack the body to make you sick. And the more HIV you have in your body, the greater chance you have of getting sick.

How your body Fights HIV

HIV kills CD4 cells. Your body fights back by making more CD4 cells. This starts as soon as the virus gets into your body.

Even when you are feeling fine, HIV is attacking CD4 cells. When the number of CD4 cells goes down too much, your body can't protect itself. Then you can get sick from other germs more easily.

How doctors keep track of HIV

Doctors and healthcare professionals can know how many CD4 cells are in the blood by requesting a lab test. This is called a "CD4 count". A blood sample is taken from you to do this. Doctors can also measure how much HIV is in the blood. This is called "viral load". These and other tests can help the doctor identify appropriate treatment options for you.





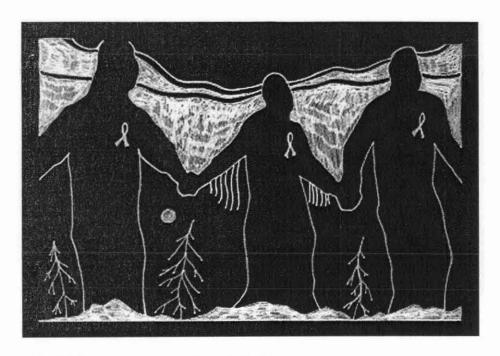
HIV can be very tricky to fight

HIV is a tricky virus. It keeps changing. Because it keeps changing, it's hard for your body to fight HIV only one way. Sometimes, the virus is changing in a way that lets it escape from a drug treatment. This virus is then called a drug-resistant virus.

Keeping HIV levels down may help you live longer

Caring about yourself through healthy living, eating right, and exercising can help you fight HIV. And in some patients, new treatment options are reducing the amount of virus in the blood to levels so low they can't be counted. If you reduce the amount of virus, you may live a longer, healthier life.

While there is still no cure for HIV, making the right choices about healthy living and treatment options can help you stay healthy as long as possible.



Combining treatment options is better

Today there are many new ways to treat HIV that can make it harder for the virus to make you sick. New treatments can be used together in many ways. Some may work better for you. Others may fit better with your lifestyle. You and your doctor should decide what works best for you.

It's important to stay on your treatment plan

Whatever treatment options you and your doctor have chosen, it's important to stay with them as long as you can. Choosing a treatment plan that will work for you is important because stopping treatment, even for a short time, can allow HIV to reproduce. Keeping up your treatment isn't always easy. Sometimes, while they are working, they may make you: feel tired; have headaches; feel sick to your stomach; have diarrhea; break out in a rash.

Ask your doctor about ways to make you feel better.

PART TWO:

LIVING WITH HIV/ACCESSING TREATMENTS

Staying well involves taking my medications, but also taking care of myself. And for that, you can draw on your traditions. They are a great source of guidance and strength.

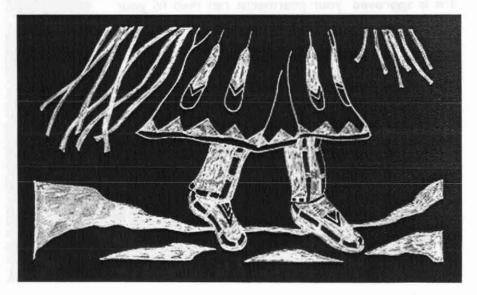
Randy Jackson, Manitoba

Special Health Benefits For First Nations and Inuit

First Nations and Inuit people living with HIV/AIDS have special access to HIV/AIDS treatments through Health Canada's First Nations and Inuit Health Branch (which was formerly the Medical Services Branch). The First Nations and Inuit Health Branch provides prescription and non-prescription drugs for First Nations and Inuit people through its Non-Insured Health Benefit (NIHB) program. These services are free to First Nations and Inuit people and are a First Nation and Inuit right.

Which drugs are covered?

The Non-Insured Health Benefits program will pay for prescription drugs and over-the-counter medicines that are on the NIHB Drug Benefit List and have been prescribed by your doctor.



Accessing the treatments

To access the treatments you will need a doctor's prescription and a status card.

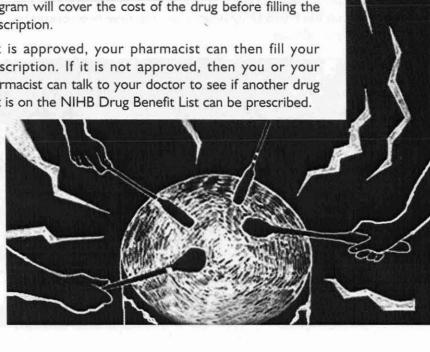
- You will have to present both your prescription and status card at your local pharmacy.
- ? The pharmacist will check to make sure that you are eligible.
- If the drug is included on the Non-Insured Health Benefit (NIHB) Drug Benefit List, the pharmacist will fill your prescription.

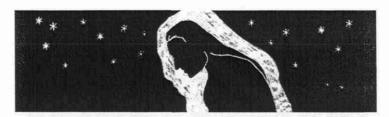
Why there may be delays in filling your prescription Sometimes the pharmacist will not be able to fill your prescription right away. This can happen for a variety of reasons:

- when your doctor has prescribed a drug that is not on the NIHB Drug Benefit List
- 2 the drug is on the list but is only covered by the NIHB program for certain conditions
- when the doctor has written "No substitution" on the prescription

In all of these cases, the pharmacist must ask the NIHB Drug Exception Centre for approval to make sure the program will cover the cost of the drug before filling the prescription.

If it is approved, your pharmacist can then fill your prescription. If it is not approved, then you or your pharmacist can talk to your doctor to see if another drug that is on the NIHB Drug Benefit List can be prescribed.





Appealing a Decision

Should coverage for a drug be denied, you have the right to appeal the decision. Call Health Canada's Non-Insured Health Benefits Regional Office at the number given in the Helpline section of this brochure. They can provide you with a copy of the Appeal Process for NIHB Benefits information sheet, and explain the steps to follow.

Emergency Prescriptions

If the NIHB Drug Exception Centre is closed and you need the prescription urgently, your pharmacist can give you a supply, generally for four days, until the request for prior approval is reviewed.

Dealing with side-effects

If you are encountering side effects from any treatments, you should first consult with your doctor. But you might also want to speak to others who are undergoing the same treatments, or to a traditional healer, who might have suggestions on healthy lifestyle changes or coping mechanisms. You might also contact one of the Treatment Information organizations given in the Helpline section.

Traditional Healing

The NIHB also provides travel funding if you wish to visit a traditional healer for consultation. Traditional healing and traditional teaching can a play an important role in HIV treatment. To enquire about NIHB support for traditional healing in your region, contact the NIHB office at the number given in the "Helpline" section.

Continuing with the Treatments

It is a good idea to call ahead to ensure that your prescription will be filled on the day it is needed, since HIV treatments must be taken continuously to be effective. A break in the treatments can greatly reduce their effectiveness.

Accessing HIV/AIDS Treatments in Rural or Remote Areas

In rural or remote areas, pharmacies often do not stock expensive medications like those used to treat HIV/AIDS. To have your prescription filled, you must allow at least 3-4 days for delivery to your local pharmacy. So it is important that you order or re-order in advance. If you need transportation, you may also want to arrange for regular rides to pick up your prescription.

Be sure to take your status card with you and to tell the pharmacist the drug is covered through the First Nations and Inuit Health Branch "Non-Insured Health Benefits program."

Respecting your privacy:

You should not have to worry about the confidentiality regarding your HIV status in conversations with pharmacists and doctors, since both of these professions are obliged, by their own codes of ethics, to respect your privacy.



HELPLINES

The following is a list of the government agencies, treatment information and regional referral organizations that can offer you further assistance. The lists are far from exhaustive, but they should provide you with useful entry points in acquiring the information and assistance you may need.

Non-Insured Health Benefits Program Regional Offices

The numbers given below are for Health Canada's Non-Insured Health Benefits Program enquiries. But NIHB personnel should also be able to put you in touch with the Regional First Nations and Inuit Health Branch (formerly Medical Services Branch) HIV/AIDS officer.

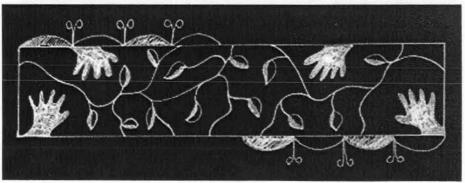
Atlantic Region 800-565-4446 (Halifax) 902-426-2656 Quebec Region 1-877-483-1575 514-283-1575 Ontario Region 613-952-0145

Manitoba Region 800-665-8507 (Winnipeg) 204-983-8886

Saskatchewan Region 800-667-3515 306- 780-8267

Alberta Region 800-232-7301 (Edmonton) 780-495-2694

Pacific Region 800-665-2289 (Vancouver) 604-666-3331 Northwest Territories and Nunavut 800-259-5611 Yukon Region 867-667-3942



Treatment Information Community Resources

Canadian AIDS Treatment Information Exchange (CATIE) 800-263-1638

Exchange (OATTE) 000-200-1000

BC Persons With AIDS Society (BCPWA)

604-893-2243 or 800-994-2437

Regional Referral Resources

Atlantic Canada

Atlantic 1st Nations AIDS Task Force 800-565-4255

Ontario

2-Spirited People 416-944-9300

Ontario Aboriginal HIV/AIDS Strategy (Off-Reserve) 800-743-8851

Ontario First Nations HIV/AIDS Education Circle (On-Reserve) 519-434-2761

Quebec

First Nations of Quebec and Labrador Health and Social Services 800-205-3344 / 418-842-1540

Comité des personnes atteintes du VIH du Québec (CPAVIH)

514-521-8720 or 800-927-2844

Saskatchewan

All Nations Hope AIDS Network 306-924-8427

British Columbia

The Red Road HIV/AIDS Network 800-336-9726

National

Canadian Aboriginal AIDS Network 888-285-CAAN (2226) 613-567-1817

Manitoba

Manitoba Aboriginal AIDS Task Force 888-305-8647 / 204-940-6000

Ce document est disponible en français Date of printing: December 2001

This booklet has been prepared by: National Indian & Inuit Community Health Representatives Organization, P.O. Box 1019, Kahnawake, QC, J0L 1B0, 450-632-0892, www.niichro.com

and has been supported through an unrestricted educational grant by:





n partnership with

Shire Shire BioChem

NIICHRO gratefully acknowledges the Canadian AIDS Treatment Information Exchange (CATIE) for permission to reprint sections of their publication "Get the facts - Plain & simple."

[Artwork & Design by Star Horn Graphics]