



Version 1.3



Positive Women's Network



Pocket Guide For Women Living With HIV

This Guide will provide you with simple, basic information about HIV and the changes it could bring to your life. For more information, there are resources listed at the back of this booklet.



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Disclaimer: This information cannot replace information provided
by a medical doctor and/or legal professional.



Where Do I Start?



1

What Is HIV?

HIV is a virus that can be passed from person to person. (Its full name is Human Immunodeficiency Virus). The body has a natural defense system called the immune system that fights illness and infection. HIV slowly attacks the immune system, making you vulnerable to illness and infection. You can have HIV and still live a long, healthy life.





How do people get infected with HIV?

HIV is passed from person to person through blood, semen (cum), vaginal fluids (wetness) and breast milk. Common ways of passing HIV:

- Vaginal or anal sex without a condom.
- Sharing needles (rigs) or other drug injecting equipment.
- Any activity that puts you at risk for exchanging these body fluids. This might include rough sex, tattooing, or piercing with a dirty needle.



HIV-positive mothers can pass HIV to their babies through pregnancy, childbirth and breastfeeding. If you are HIV+, you have come in contact with the HIV virus. You carry HIV in your body, and can pass it on to others for the rest of your life, even if your viral load (the amount of virus in your blood) is low. You can also have HIV but not know it.

What does HIV do?

- HIV kills healthy immune cells in the body.
- HIV makes new copies of itself and keeps on attacking healthy cells.
- As HIV makes more copies of itself, you have fewer healthy immune cells and more HIV. This is what makes you open to infection and illness.





If I'm HIV+, do I have AIDS?

Being HIV+ does not mean you have AIDS. You are diagnosed as having AIDS when these two conditions apply:

- 1 You are HIV+.
- 2 You have been sick with one or more AIDS-defining illnesses or infections.



Where Do I Start?



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How does HIV affect women?

Having HIV does not mean you are going to get sick all the time, and it does not mean you will die tomorrow. But over months and years, HIV will weaken your immune system. This means your body won't be able to fight infections as it used to. Below are some common changes you may experience:

1. Changes in Your Period

Many HIV+ women notice changes in their periods. They find:

- More pain when they bleed.
 - More periods or fewer periods.
 - Changes in menstrual flow (less or more blood).
- If you experience these symptoms, let your doctor or health care provider know.





2. Vaginal Yeast Infections

Yeast infections are very common. They usually cause itching and burning around your vagina. Some women see a white discharge on their underwear. Yeast grows faster when you eat sugar, so try to cut down on sugar and alcohol. See a health care provider if yeast is an ongoing problem, because constantly fighting yeast infections stresses and weakens your immune system.

3. Sexually Transmitted Infections other than HIV

Sexually transmitted infections, or STIs, weaken the immune system, leaving you open to other infections. STIs and vaginal infections include:

chlamydia	gonorrhea	syphilis
genital warts	herpes	hepatitis B

STIs can cause pain, discharge, or itching (or even no symptoms). It is important to see a doctor or



nurse immediately if you have symptoms. To take care of your sexual health overall, see a doctor regularly (the schedule they suggest) and have regular Pap smears too. Nobody likes them, but they're important.

If left untreated, STIs can lead to a serious illness called pelvic inflammatory disease, or PID. Some symptoms of PID are pain in the lower belly with a fever. If you have these symptoms, see a doctor right away.

4. Pap Tests

Women with HIV may be at a higher risk of changes to the cells of the cervix (the lower part of the uterus or womb) due to infection with Human Papillomavirus (HPV). HPV can cause changes on your cervix or anus. These changes are usually easy to treat if they're found early. Talk to your doctor about the best schedule of Pap smears for you.





Most doctors recommend that you have a Pap every 6 months.

How do I care for myself?

If you have an infection or illness that lasts more than a few days, see a doctor or nurse. To stay as healthy as you can:

- Find a doctor you like and see him or her when they advise (usually every 2-3 months).
- Eat a variety of whole foods such as beans, fish, meat, tofu, cheese, rice and other grains, whole grain breads, vegetables and fruits.
- Try to lower your stress level: stress can over-work your immune system.
- Decrease your use of alcohol and drugs.
- Find support: you are not alone with this.



Where Do I Start?



3

Finding a Doctor

You deserve good care. To get that care, it's important to find a doctor you feel comfortable with. Try to find a doctor who knows a lot about HIV. If you don't know of one, call the nearest AIDS organization for help. Contact information appears at the back of this booklet.





Your health is important

You have the right to:

- Be treated with respect.
- Be listened to.
- Have things explained to you.
- Ask questions if you wish.
- Be treated by a doctor who knows about HIV.
- Bring someone with you to appointments if you wish.



You are responsible for telling your doctor about:

- Your complete health history.
- Any changes in your health.
- Alcohol and/or drug use.

If you're nervous or worried, it's hard to focus. Before your appointment, you might want to write down any questions. If the doctor is using words that are too complicated, you have the right to say, "I don't understand," or "can you explain that again?" until you do understand. You can bring someone along to help you remember what the doctor says.





If you are not happy with your doctor, you have the right to:

- Talk about what isn't working.
- State how you think things could work better.
- Change doctors.

If you want support in talking to your doctor, take a friend or contact an advocate at the nearest AIDS service organization.

**However you choose to see a doctor, GO!
You are in charge of getting care.**



How do doctors treat HIV?

Can treatment cure HIV?

There is no cure for HIV, but there are different kinds of treatment you can take to help your body fight HIV. You can also use alternative treatments to help your immune system. (See page 17: "Are there alternatives to antiretroviral therapy?")

How does HIV treatment work?

HIV is a virus that spreads in the body by making copies of itself. HIV treatment affects the copying process. It slows it down or stops it at different points. This gives the body a chance to fight HIV. As your health improves, your immune system gets stronger, increasing your immune system's fighter cells.





Why do people take more than one kind of drug to fight HIV?

The HIV virus can adapt to HIV treatment over time, and then the treatment stops working. If you take more than one HIV treatment at a time, it takes longer for HIV to adapt. Taking more than one drug at a time is called “combination therapy,” or “Highly Active Antiretroviral Therapy (HAART).” This is the most common and successful treatment.

What if I take HIV treatment and I use street drugs?

Drug companies don't test on illegal street drugs, so we don't know a lot about how street drugs and HIV treatments act together. Because street drugs may be cut with different things, it is difficult to do reliable research. Whether you use drugs every



day or now and then, it can have an effect. We do know that:

- Street and recreational drugs can change how HIV treatment works. This can harm your treatment.
- If you take methadone, your methadone dose may need adjusting because of your HIV treatment.

Everything you take is processed through your liver. The more you take (both variety and amount), the harder your liver works. This alone is important to think about. Be honest with your doctor about what you are using and how often. Your doctor can use the information that is available to give you the best treatment. For more information about HIV medication and street drugs, check out the website of “The Body” (www.thebody.com).





What if I can't take HIV treatment?

In some cases, women can't take certain HIV treatments. They may find a certain treatment makes them sick or they find the medicine schedule too hard to keep up with. It can take time to adjust to treatment. Side effects may last a month or two. Talk to your doctor if you have a difficult time with a particular medicine because he or she may be able to help treat the side effects or help you take a different HIV treatment.

If you can't take them at all, you can still look after yourself in other ways:

- Eat as well as you can afford.
- Drink lots of water.
- Get lots of sleep. Your body fights infection better with rest.
- Take multi-vitamins.
- Ask your doctor for a referral to a dietician.



Are there alternatives to antiretroviral therapy?

Antiretroviral treatment (Highly Active Antiretroviral Therapy or HAART) treats HIV. To assist your immune system in fighting HIV, you can use complementary and alternative medicines (CAM). Complementary and alternative medicines can't treat HIV, but they can support your immune system in its fight against the virus.

They can be used in three ways:

- *Before* starting antiretroviral treatment (HAART).
- *With* antiretroviral treatment (HAART).
- *Instead* of antiretroviral treatment (HAART).





Complementary or alternative approaches may include:

- Bodywork you can do yourself, like yoga, meditation, exercise, tai chi, qi gong.
- Bodywork someone else does for you, like massage, reflexology, shiatsu, acupuncture, reiki.
- Traditional aboriginal healing practices like prayer, smudge ceremonies, sweat lodges, healing circles.
- Mind-Body work (the connection between what you think and how it affects your body) like writing in a journal, changing thought patterns, creative visualization, meditation.
- Vitamins, herbs, health foods, food choices.



How do I get started?

Using complementary and alternative medicines can be a great way to feel in control of your health. Some natural treatments can have side effects or negative interactions with other medications, so learn about these before you begin. Talk to your doctor about your decisions to ensure you are not harming yourself.

To find out about complementary and alternative medicines, you can do some research through the nearest AIDS service organization. Two good information programs to check out are BC Persons with AIDS Society (BCPWA) and Canadian AIDS Treatment Information Exchange (CATIE). Talking to a treatment information counselor at these organizations can help sort out your questions. Contact information appears at the back of this booklet.





What can I do right now?

Simple things can make big differences.

- Get enough sleep.
- Eat a variety of whole foods such as beans, fish, meat, tofu, cheese, rice and other grains, whole grain breads, vegetables and fruits.
- Drink lots of water.
- Wash your hands after going to the bathroom and wash your hands before eating.
- Take a multi-vitamin daily.
- Learn about HIV and what it does to your body.
- Find someone you trust to talk with.
- Be aware of stressful situations and try to minimize them.

Note: In talking with your doctor, you have the right to decide whether it's time to take treatments or not. If you decide not to take antiretroviral therapy, keep up with your doctor's visits, including regular blood monitoring.



Living With HIV



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I'm HIV+ and pregnant. Will my baby have HIV?

HIV+ women often give birth to children who are not infected with HIV. If women take HIV treatment during pregnancy, approximately 2 HIV+ women in 100 (2%) will give birth to a baby with HIV. Without taking treatment, approximately 25 HIV+ women in 100 (25%) will give birth to HIV-infected babies.





How is HIV passed from mother to baby?

Mothers can pass HIV to their babies during pregnancy, childbirth, and breastfeeding. HIV+ women who are less healthy overall are more likely to have an infected baby. A couple of things can also increase the infection rate:

- Using cocaine, crack, heroin, or other drugs during pregnancy.
- Having unprotected sex during pregnancy, even if you are already HIV+.

If you are actively using drugs, reducing your use will mean a healthier baby who may have a better chance of not getting HIV. Drugs can cause serious damage to a developing baby. But complete withdrawal from some drugs can be dangerous when you are pregnant, so talk to your doctor and a drug and alcohol counsellor about this as soon as you find you are pregnant.



Is there treatment that lowers the chance of infection to my baby?

Transmission from mother to baby can be greatly reduced if women take AZT (an HIV treatment) during pregnancy and childbirth. This is usually offered in combination with other HIV treatments. AZT is also given to the baby for six weeks after birth. Scientists don't know all the long-term effects of AZT on women and their babies, but so far studies show the treatments seem to be safe. They definitely lower the risk of a baby being infected.

If you are thinking of having a baby, talk to your doctor even before you get pregnant. He or she can help you plan how to get pregnant in a low risk way and plan treatment that's pregnancy-friendly. Oak Tree Clinic advises women on all conception and pregnancy questions (see contact information at the back of this booklet).





How will I know if my baby has HIV?

All babies of HIV+ moms are born with their mother's HIV antibodies (fighter cells). This does not mean the baby has HIV. Doctors must test the baby's blood several times before they can tell whether or not the baby is infected. Usually they can tell by the time the baby is a few months old.



How will using injection drugs affect HIV?

HIV weakens your immune system, and drugs are hard for your body to handle. These two factors can make you more likely to get infections or viruses. This is especially true if you don't eat or sleep regularly.

If you use injection drugs and share works (equipment), you can get infections like another strain of HIV, or hepatitis or syphilis. This is hard on your immune system. You can also pass these infections on to someone else if you share works.





Are there other risks to injecting if I'm HIV+?

Other risks to injecting include:

- Infections of the skin and veins around the injection site (abscesses, cellulitis, phlebitis).
- Blood clots in different parts of your body, including your brain.
- Infections that affect your whole body (endocarditis, pneumonia).

Fighting any infection or illness strains your immune system. Blood clots in the brain or endocarditis (an infection of the heart) can kill you. See a doctor right away if you feel numb or dizzy, have blurred vision, speech problems, experience high fever, chest pain and bruising under the fingernails.



How can I make using safer?

- Use less.
- Use less often.
- Avoid sharing equipment.
- Look after your veins. They'll last longer if you do, and getting health care will be less frustrating if you have a healthy vein to use for blood tests.
- Get off drugs when and if you can. Complete withdrawal can be dangerous if you do it without medical help, so talk to your doctor and a drug and alcohol counsellor.





How do I get medical care if I'm still using?

Try to find a doctor who is used to seeing people who use drugs. He or she will need to take blood sometimes to see how your body is doing in its fight against HIV. The tests include checking your viral load (how much virus is in the blood) and your fighter cells (cells that help your immune system stay strong). If having blood drawn makes you want to fix, ask the doctor or nurse to take it slow. Some doctors will even let you draw your own blood if that's the best way for you.



How does Hepatitis C affect HIV?

What is hepatitis C?

Hepatitis C destroys cells in the liver. The liver plays a key part in cleansing your body of toxins (poisons) and in making proteins used throughout the body. Hepatitis C scars the liver so it can't work properly. A lot of scarring is called cirrhosis. Hepatitis C is the leading cause of liver transplants in North America.

How is it spread?

Hepatitis C is spread through blood-to-blood contact, most often by sharing needles.





What are the symptoms of hepatitis C?

Early signs of hepatitis C are tiredness that doesn't go away, aching body, night sweats, no appetite, or feeling like you have the flu. But it doesn't always produce symptoms. If you or your partner has a history of using injection drugs, it's a good idea to get tested.

What kind of treatment is available for hepatitis C?

There are drug treatments for hepatitis C. Some people are treated successfully, but not all. Check with your doctor or an AIDS services organization for up to date information on treatments.

Herbal treatments may help as well, but they cannot cure hepatitis C. Research herbs carefully and talk to your doctor before using them, as some herbs could be harmful.



How will using street drugs affect hepatitis C?

Street drugs are hard on the liver. If your liver is damaged by hepatitis C, street drugs strain it even more. Street drugs may affect you differently than they did before you got hepatitis C. Find somewhere where you can get help in case anything goes wrong. Don't fix alone. If you're on methadone, talk to your doctor to make sure you are getting the right dose.

How can I look after myself if I have HIV and hepatitis C?

Hepatitis C can adapt and you can become re-infected with another strain (type). This can make you sicker. If you are using injection drugs, don't share needles. If you must share, use bleach to clean needles between injections and then rinse three times with clean water to reduce your risk of getting re-infected.





Try to eliminate alcohol use, as it damages the liver. Some drug store medications, like Tylenol, can also cause liver damage, so check with the pharmacist before using anything. Advise all health care providers that you have hepatitis C.

A healthy diet is the most important thing you can do to feel better, so eat as well as you can.



Should I eat differently if I have HIV?

Food provides energy in the form of calories. HIV causes your body to burn more calories than you did before, so even though you eat the same amount you may find you are losing weight. Eat as well as you can from a variety of foods. This will help you fight infections and stay healthy.

It's important to eat on a regular basis. This can be tough, especially if you have to eat on a schedule so you can take your HIV treatment or if you're using street drugs. If you don't have a stove or fridge, you can still eat good food.



Good nutrition is based on eating a variety of foods.

Try to eat from these food groups every day:

- Protein: Includes cheese, meat, fish, chicken, nuts, milk, yogurt, rice with beans, soybeans, tofu.
- Fruits and vegetables: Experiment with what you like.
- Grains: Bread, pasta, cereal, rice, millet. Eat whole grains whenever possible.



Good food that you can buy on the run for little money:

- Milk or soy milk
- Pizza slices (provides protein, vegetables and grain)
- Bread
- Pieces of fruit
- A bag of peanuts or sunflower seeds

Sometimes I get an upset stomach. Is this because of HIV?

HIV can make it hard for your stomach to digest food, so you may get less benefit from the same amount of food. You also may find that infections make it difficult to eat. Eat smaller portions and eat more often.





I have problems with constipation...

If you have problems with constipation, try

- Lots of water
- Prune juice
- Orange juice
- Senna tea (available in health food stores)
- Shredded wheat and bran cereals
- Ground flax seeds
- Raw fruits and vegetables (wash thoroughly)
- Psyllium husks

Where can I get free food?

Check with your local food bank for a list of places where you can get free food. Most communities have at least one or two programs.



HIV and relationships

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I just found out I'm HIV+: Who do I tell?

When you are HIV+, sharing your status can be hard. Disclosure is a lifelong process for everyone with HIV.

How do I tell my sex partners?

Telling your sex partners you have HIV may seem impossible and unsafe if you:

- Have a partner who can be abusive or violent.
- Have a partner who won't talk about or practice safer sex.
- Have sex in exchange for money or drugs.





If you don't tell your sex partners you are HIV+ you could face criminal charges if they are at risk of infection. Different sexual activities carry different chances of transmission. To learn about sex and HIV transmission, see page 41 (How do I have "safer sex"?). To learn more about legal questions, visit the Canadian HIV/AIDS Legal Network's "Disclosure of HIV Status after Cuius" report on their website www.aidslaw.ca or talk to an advocate at the nearest AIDS organization.

Do I tell my family members?

Some women choose to tell family members as soon as they learn they have HIV. Others don't tell them for a long time. It depends on how you feel with your family and what is the healthiest choice for you.



Should I tell my children?

Some moms who tell their children are glad, because then they don't have to worry about hiding their HIV. Other women feel that telling their kids might upset them. There is no right answer.

Ask yourself...

- Would it make things better or worse?
- Are my kids old enough to get what this means?
- Do my kids have another trusted adult to talk with?
- Will my kids sense something is wrong and worry if I don't tell them?





Can I pass HIV to someone in a shared living situation?

Sharing a home with someone is not a risk unless you are doing things that could exchange body fluids. HIV is transmitted from person to person through blood, semen, vaginal fluids and breast milk. Transmission of HIV can occur when a body fluid with high concentration of HIV (semen, blood, vaginal fluid, breast milk) enters the body of someone else through an activity (like intercourse, sharing needles) that provides access to the bloodstream (through vagina, anus, urethra, open cuts). For more information, see page 1 (What is HIV?) and page 41 (How do I have “safer sex?”).



How do I have “safer sex”?

“Safer sex” does not pose a high risk of passing HIV from one person to another.

Any activity that passes semen (cum), blood, or vaginal fluid from one person into the bloodstream of another (usually through the vagina, anus, or urethra) is called “unsafe sex” or “high risk sex.” An example of unsafe sex is vaginal or anal sex without using condoms.



If you're not sure if what you're doing is safe, use this formula:

HIV is spread when:

1. a body fluid with high concentration of HIV (semen, blood, vaginal fluid, breast milk)
2. enters the body of someone else through an activity (like intercourse, sharing needles)
3. that provides access to the bloodstream (through vagina, anus, urethra, open cuts).

If this happens, there is a risk for HIV to pass from one person to another.



Do I have to tell my sex partners I'm HIV+?

You may be charged with a criminal offense if you have unprotected sex with someone and you don't tell them you are HIV+. Different sexual activities carry different chances of transmission. To learn more, visit the Canadian HIV/AIDS Legal Network's "Disclosure of HIV Status after Cuius" report on their website www.aidslaw.ca or talk to an advocate at the nearest AIDS organization for more information.

I have HIV and so does my partner. Why worry about safe sex?

Having unprotected sex puts you at risk of getting sexually transmitted infections. This could include a slightly different strain (kind) of HIV. Sexually transmitted infections can weaken your immune system, and make you get sick faster.





How do I protect myself?

Use latex or polyurethane condoms for intercourse and use barriers for oral sex. (To make a barrier, cut a condom up the side). If your partner refuses to wear a condom, can you say no to sex? If this puts you in danger, weigh the risks, and know you are not alone.

I can't use latex condoms! What can I do?

- Polyurethane condoms are an alternative to latex.
- Female condoms are made out of polyurethane and are inserted into the vagina. They are available at many drug stores.
- For oral sex with a woman, use non-porous plastic wrap (like Saran Wrap) or cut up a condom. Don't use the kind of plastic wrap indicated for microwave use; there are tiny pores in it.



What does being HIV+ mean for me as a mom?

Can I lose custody of my kids if I am HIV+?

Living with a mom who has HIV does not threaten the health of a child. If anyone tries to use your HIV status to threaten to remove your children, talk to an advocate right away.





Can my kids get HIV from living with me?

HIV is not passed through casual contact, so spreading HIV is not likely in day-to-day living. HIV is passed through body fluids: blood, semen (cum), vaginal fluids and breast milk. These fluids must get into the bloodstream to pass HIV to another person. From mother to child, HIV is most often passed through:

- HIV-positive mother giving birth to a baby
- HIV-positive mother breastfeeding a baby

For more information, see page 1 (What is HIV?)



I don't feel sick, and my doctor says my health is good. Do I need to find a guardian for my children?

If anything happens to you, you need someone to care for your kids. It might not even be HIV related! Finding a guardian for your kids while you're well is a good idea, rather than worrying about what might happen if you get sick. It can give you and your kids the security of knowing someone will look after them if you can't. If you don't choose a guardian and something does happen, the government will step in to find care for your kids.

My kids don't know I'm HIV+. How do I explain choosing a guardian?

All parents should choose a guardian. If you are not ready to tell your children you are HIV+, you can still tell them who would look after them if you couldn't.





Who should I choose as a guardian?

Some women choose a family member. Others ask a friend. Some things to consider when asking someone to be a guardian are:

- Do you feel comfortable talking to the guardian about your health?
- Do you want your children to go to a home where there are other children?
- Is it important that they stay in the same school or community?

How do I prepare a guardianship document?

Most people name a guardian for their children in a will. A will also indicates how you want your possessions to be distributed. There are steps you must follow for the will to be legal, so it's best to get help. You can call Legal Aid or the AIDS organization nearest you for suggestions on the best way to make a will.



How do I choose a daycare/school for my HIV+ child?

Here are some questions to ask when choosing a daycare or school to suit you:

- Is it a place that's easy to get to in case of emergency?
- Do the workers protect against passing infections from person to person? This includes wearing latex gloves to change diapers, using bleach when they clean up spills of blood or bathroom accidents. If they do, they are protecting against infections that may harm your child's health.
- Is your child on medication? Do you feel you can tell the workers?
- If your child gets sick at daycare or school, who needs to know?





- Are you on good terms with the daycare or school staff?
- Does your child like it there?

Should I tell daycare workers or school teachers that my child is HIV+?

This can be a tough decision. Telling might make your life more difficult. HIV is passed from person to person through blood, semen, vaginal fluid and breast milk. For there to be a risk, the infected body fluid must pass directly into the bloodstream of another. The chances of your child spreading HIV to another child in a daycare or school is small.



What if my child tells someone s/he is HIV+?

Your child may tell someone s/he is HIV+. It can be too much pressure for kids to keep the secret about HIV and some kids need to talk about it with someone outside their family. If this happens, you may want to talk to a friend or find support regarding what to do about reactions.





Where to get help

In B.C.

Positive Women's Network

Action and leadership on women and HIV/AIDS

Meet us: www.pwn.bc.ca

Find support: www.pwn-wave.ca,

Phone: 604.692.3000 or

toll free (in BC only) 1.866.692.3001

Oak Tree Clinic treating women and their families.

604.875.2212, www.cw.bc.ca/oaktree/home.asp

BCPWA Treatment Information 604.893.2243 or
toll free 1.800.994.2437, ext 243, www.bcpwa.org

Canadian Liver Foundation 604.707.6434 or toll
free 1.800.856.7266



Nationally

Canadian AIDS Treatment Information Exchange

1-800-263-1638, www.catie.ca

Canadian HIV/AIDS Information Centre

1-877-999-7740, www.aidssida.cpha.ca/

Canadian Liver Foundation 1.800.563.5483

Mission Statement

Positive Women's Network, a partnership of women living with and affected by HIV/AIDS, supports women in making informed choices about HIV/AIDS and health. We provide safe access to support and education/prevention for women in communities throughout British Columbia. The Positive Women's Network provides leadership and advocacy around women's HIV/AIDS health and social issues in the national and local health care communities.



**Positive Women's Network –
Action and leadership on
women and HIV/AIDS**

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Support and education:
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Centre at 1.877.999.7740.

This document is available online
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www.aidsida.cpha.ca
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