

You can have a
healthy pregnancy
if you are **HIV positive**



In this booklet



- 3** You can have a healthy pregnancy if you are HIV positive
 - 6 You can have an HIV negative baby
 - 7 Building a relationship with your healthcare providers
- 9** Getting pregnant
- 12** Staying healthy while pregnant
- 15** HIV treatment options
 - 15 What anti-HIV drugs are recommended during pregnancy?
 - 16 When should you start anti-HIV drugs?
 - 17 You're already on anti-HIV drugs
 - 18 Stopping or changing your anti-HIV drugs
 - 18 What if you haven't taken anti-HIV drugs during your pregnancy?
- 19** Other treatments while pregnant
- 22** Delivery
 - 23 You have been circumcised
- 24** Your baby's health
 - 24 Does your baby have to take treatment?
 - 25 How will the medications affect your baby?
 - 25 How will you know whether your baby is HIV positive?
 - 26 What if your baby is positive?
- 27** Breast-feeding
- 29** Building a support network

You can have a healthy pregnancy if you are HIV positive

Are you HIV positive and pregnant or considering having a baby? You are not alone. Living with HIV does not necessarily take away your desire or your ability to have children. The good news is that advances in HIV treatment have allowed many HIV positive women to have healthy pregnancies and healthy babies.

“HIV positive women should know that they can get pregnant.”

Let's be honest. Dealing with HIV can be difficult, and dealing with pregnancy can be difficult. But having the facts about how to get pregnant safely and how to prevent your baby from becoming HIV positive may help you overcome some of your fears and make you feel more confident in your decision about whether or not to have a child.

You probably have many questions. Asking questions is an important step in making choices. This booklet is meant to help you make informed decisions about your health during pregnancy as well as the health of your baby.



4 You can have a healthy pregnancy if you are HIV positive

As well, it includes words of support and inspiration from HIV positive women from across Canada.

“I must have asked a million questions—most of them over and over again. My healthcare providers didn’t mind. I liked that.”



Maybe you are pregnant and have just found out that you are living with HIV. That can be a lot to deal with at once. In addition to the information provided in this booklet, you may want more information about HIV and its treatment, as well as whom to tell about having HIV. The most important thing right now is to find a doctor who can help you get this

information and support your choices around your pregnancy and your HIV. The resources listed at the end of this booklet can link you to services in your area.

“I found out I was pregnant and HIV positive at the same time. It was scary not knowing what to do.”

You may be thinking about ending your pregnancy because you may feel you cannot care for a child right now, or maybe there are other reasons. Having an abortion is a very personal choice. Only you can decide whether or not to continue your pregnancy. No one can force you to have a baby or force you to end your pregnancy. You may want to know more about abortion. You can discuss your options with a doctor or nurse. Some women worry that having an abortion will make it harder to get pregnant again, but most women go on to have normal, healthy pregnancies after an abortion.

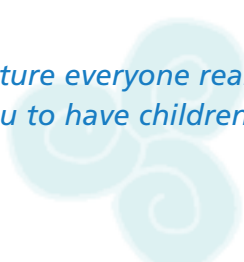
Some HIV positive women face stigma and discrimination because of choices they make about having children. Stigma is the negative judgment some people make about you because they think your choice is wrong. Stigma about HIV can limit the services available to you. This is called discrimination. Stigma and discrimination are often based on fear and can happen when people don't know all the facts about HIV and pregnancy.

You may face stigma because you choose to have a child.

"I was told it wasn't my right to have a child."

You may face stigma because you choose to not have a child.

"In my culture everyone really pressures you to have children."

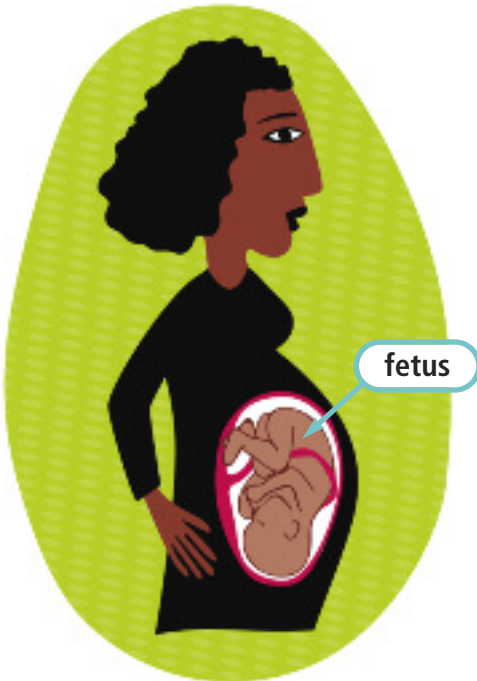


6 You can have a healthy pregnancy if you are HIV positive

Whatever you are facing, you might want to talk with people you trust—friends, family members or healthcare providers. They can give you support while you make your choices. If you decide pregnancy is right for you, your network can also play an important part of helping you to stay healthy and to have a healthy baby.

You can have an HIV negative baby

When HIV passes to a fetus or baby from an HIV positive mother, this is called **vertical transmission**. When HIV passes between sexual partners or people who share needles, this is called horizontal transmission.



In the time before effective treatment for HIV, about one in four babies born to HIV positive mothers was also HIV positive. However, we now know a lot about how to prevent vertical transmission, and with proper care the risk of your child becoming infected with HIV can be less than 2 percent. Experts have written treatment guidelines that outline the best practices to reduce the

risk of vertical transmission. These guidelines recommend:

- anti-HIV drugs for the mother during pregnancy and during labour
- delivery by C-section (cesarean section), when appropriate
- a short course of anti-HIV drugs for the baby after birth
- no breast-feeding

Guidelines are a starting point. You and your doctor should fully discuss all decisions about your treatment, pregnancy and delivery.

Building a relationship with your healthcare providers

Some HIV positive women may feel nervous about talking to their healthcare provider about having a baby because they have heard that not all doctors support women with HIV to have babies. While this may be true, know that you have the right to have a child just like any other woman.



8 You can have a healthy pregnancy if you are HIV positive

Some doctors are not experienced with HIV and pregnancy, but you can help them find information about having a healthy positive pregnancy. Let your doctor know that guidelines exist for the care of HIV positive women during pregnancy. CATIE (Canadian AIDS Treatment Information Exchange, www.catie.ca or 1-800-263-1638) can direct your doctor to the most up-to-date guidelines. Some women choose to have their babies closer to large cities where doctors are more experienced with HIV and pregnancy.

You may also wish to have a midwife assist during your pregnancy. In Canada, most provinces have laws that regulate midwife services, but only some provinces cover the cost. You can find more information at www.canadianmidwives.org.

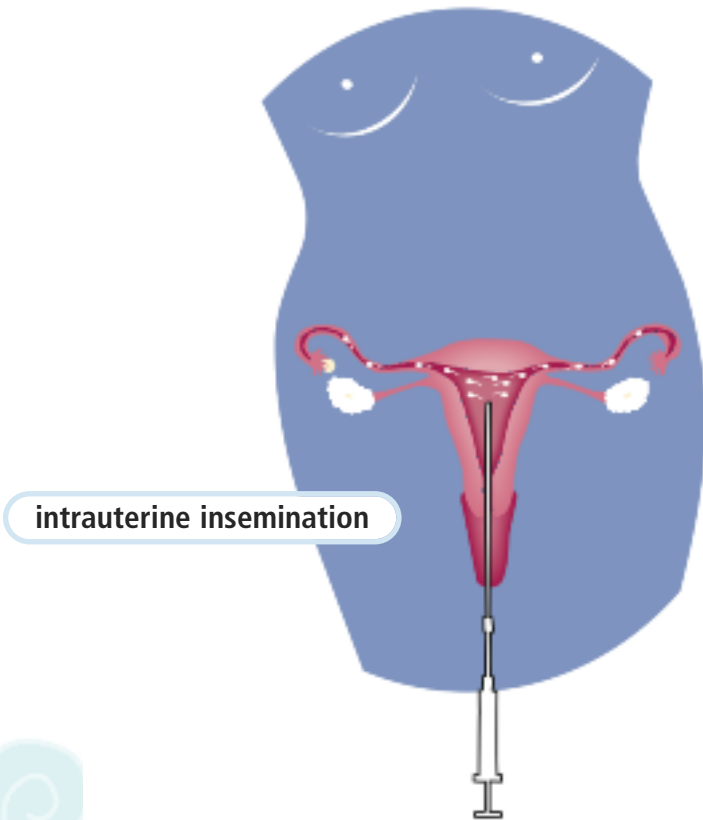
Getting pregnant

Many HIV positive women have no trouble getting pregnant. However, there is some research that shows that HIV disease, anti-HIV drugs or co-infection with other sexually transmitted infections may make it harder for HIV positive women to become pregnant. If you are having trouble getting pregnant, ask your doctor for a referral to a fertility clinic. There are guidelines to assist in the pregnancy planning and fertility needs of people with HIV.



An HIV positive woman can pass on HIV to her male partner(s) while trying to get pregnant. To avoid this, one option is alternative insemination. This can be done at home or may require medical assistance, such as from a fertility clinic. At home, sperm is placed

into the vagina with a syringe or eye dropper. Some women have their partner provide sperm; others use the services of a sperm bank. Medically assisted insemination places the sperm directly into the uterus (intrauterine insemination) and can increase the chance of getting pregnant. This medical procedure is more expensive and is not available in every province and territory. (If you're thinking about using a fertility clinic, be sure to get information about all the services you will need and their costs.)



"I ruled out intrauterine insemination because of the cost, but it is an option."

If you and your partner(s) are both HIV positive, it's a good idea to discuss with your doctor the risk of re-infection (doctors often call it superinfection). Re-infection occurs when you become infected with your partner's virus, or the other way round. Your doctor may recommend a procedure called sperm washing. Sperm washing separates the sperm from the semen. (It is the semen that carries most of the HIV.) The sperm is then used to inseminate the woman. Sperm washing is also an option for HIV positive men who have HIV negative female partners. Sperm washing is done at a fertility clinic and is not available in every province and territory.

Staying healthy while pregnant

Good health is very important while you are pregnant, and there are many things you can do to help you have a healthy pregnancy. Being

pregnant and having HIV needs special medical care, so it is important to try to find a good doctor. As well, there are many things you can do to have a healthy pregnancy.




Getting good medical care is very important. Try to find an obstetrician (a doctor who specializes in pregnancy and childbirth) who is familiar with HIV care. It is best to do this

before you get pregnant or soon after. Your family doctor or HIV doctor can help you. Remember that you have the right to the same level of care that is available to any woman who is pregnant or thinking about having a baby.

Research shows that pregnancy itself does not make your HIV disease worse and HIV does not change how your pregnancy proceeds. Still, doctors say that a pregnancy is high risk if there is any illness or infection, including HIV. This means that you may have more frequent visits to the doctor to monitor your health and the health of the fetus.

Treating your HIV infection and reducing the amount of virus in your blood (your viral load) during pregnancy is one of the most important ways to reduce vertical transmission. Your doctor will talk with you about taking drugs that slow down HIV. These anti-HIV drugs are called antiretrovirals, and you take a combination of them. When choosing your drugs, you should consider a combination that is tailored to your health and needs and that will reduce the risk of vertical transmission.



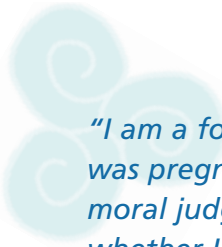
“Getting support from a good doctor and a support group is important for any HIV positive pregnant woman.”

In addition to taking anti-HIV drugs, there are many things you can do to have a healthy pregnancy, such as:

- making sure that your doctor tests and treats you for sexually transmitted infections
- making sure that your doctor tests you for hepatitis B, syphilis, group B streptococcus status and rubella immunity
- making sure you eat well; during pregnancy, your body has special nutritional needs, so you should talk to your doctor about the following:
 - taking a daily prenatal multivitamin (prenatal vitamins are different from regular multivitamins; make sure you get the right one)
 - taking 1 to 5 milligrams of folic acid once a day for one to three months before getting pregnant and during your pregnancy

14 Staying healthy while pregnant

- getting 1,500 milligrams of calcium every day either from foods such as milk, cheese and yogurt or from a supplement
- reducing or stopping smoking, drinking alcohol and using street drugs
- finding healthy ways to deal with stress
- putting together a support network



“I am a former drug user. When I was pregnant, everyone put their moral judgments on my life about whether I should even be allowed to have children. Moral judgments prevent women from getting the chance to learn healthy baby and self-care skills.”

If you are pregnant and drinking alcohol or using drugs, cutting down or stopping will increase your chances of a healthy pregnancy. Some women may not be able to stop completely or without help. Speak to your doctor or someone you trust to help you find the resources you need to keep you and the fetus as healthy as possible.

HIV treatment options

Canadian guidelines recommend that all pregnant HIV positive women take combination anti-HIV therapy. You and your doctor will decide what's right for you based on your particular situation, including the stage of your pregnancy and whether or not you are already on anti-HIV therapy.



What anti-HIV drugs are recommended during pregnancy?

The combination of anti-HIV drugs that you take during pregnancy depends on many factors, including the drugs you have taken in the past. As well, certain drugs are known to cause side effects in pregnancy and others may harm the fetus and so should be avoided.

Drugs to avoid include efavirenz (Sustiva), delavirdine (Rescriptor), nelfinavir (Viracept) and the combination of ddi (Videx) and d4T (Zerit). Also, nevirapine (Viramune) should not be started when your CD4 count is above 250 cells. Fortunately, there are many other options, so check with your doctor for the most up-to-date information.

When should you start anti-HIV drugs?



If you are not already taking anti-HIV drugs, doctors generally recommend starting treatment after 12 to 14 weeks of pregnancy, unless there is a medical reason to start earlier, such as a very high viral load. The main reason for waiting is to avoid any possible

negative effects of the drugs on the fetus during the early stages of its development. Another reason for waiting is to avoid taking pills during the first trimester, when you are most likely to have morning sickness.

“Nothing is worse than morning sickness right after you’ve swallowed your meds.”

Some side effects of anti-HIV drugs, especially high blood sugar, low red blood cell count (anemia) and stress on the kidneys and liver, can be made worse by being pregnant. It is important to monitor for these side effects carefully. Your viral load and CD4 counts should also be tracked. Usually, your doctor will order blood tests one month after you start treatment and then every one to three months.

You’re already on anti-HIV drugs

If you are pregnant and already on anti-HIV drugs, you and your doctor may decide to switch the drugs you are taking. As we mentioned above, some drugs should be avoided during pregnancy. Talk with your doctor about what is best for you as soon as possible after finding out you are pregnant. If you are planning to become pregnant it’s a good idea to discuss drug choices with your doctor in order to reduce the chance of harming the fetus.

“Since I tested positive I have been thinking about becoming pregnant. I have now been on meds for over a year and if I choose to get pregnant I might have to change my meds.”

Stopping or changing your anti-HIV drugs

It is not a good idea to stop or change your drugs without first seeing your doctor. If you stop your treatment suddenly, your viral load will likely increase and there will be a higher risk of transmitting HIV to your baby. You may also increase the risk of developing drug resistance, which could limit your treatment options in the future.

What if you haven't taken anti-HIV drugs during your pregnancy?

Canadian guidelines recommend that all HIV positive women take anti-HIV drugs during pregnancy. If you do not take treatment while you are pregnant, the chance that your baby will be HIV positive is about one in four. If you are diagnosed late in your pregnancy or during labour and delivery, medication can still be given to you and your baby to reduce the risk of infection.

Other treatments while pregnant

Some drugs and vaccines for the treatment and prevention of certain conditions that are common in HIV positive women are safe to use in pregnancy, while others are not. Talk with your doctor about the risks and benefits of these treatments to you and the fetus.



It is safe to use preventative medication for *Pneumocystis pneumonia* (PCP), *Mycobacterium avium* complex (MAC) and tuberculosis (TB). You may also take treatment for active tuberculosis when you are pregnant. As well, it appears to be relatively safe to take acyclovir to prevent or treat herpes outbreaks, though you should talk with your doctor about the risks and benefits of this drug.

Methadone is safe to use during your pregnancy, but be aware that your baby may be dependent on (addicted to) methadone and will need to be weaned off. If you are on methadone and become pregnant, you should not stop taking methadone without first speaking with your doctor.

Some HIV positive women use medicinal marijuana. There is no evidence that marijuana causes birth defects, however, smoking of any kind is not recommended during pregnancy. The risks and benefits of smoking marijuana should be weighed carefully.

You should avoid drugs like fluconazole, itraconazole and ketoconazole, which are used to stop candidiasis and other fungal infections. Other medications you may be taking for depression, pain,



diabetes or other conditions might not be safe during pregnancy. Speak to your doctor and pharmacist about which drugs are safe for you and the fetus.

You may need to have some vaccines if you have not already received them. After the first three months of your pregnancy, it is safe to receive pneumococcal, tetanus-diphtheria, hepatitis A, hepatitis B and flu vaccines. However, you should avoid live virus vaccines such as those for measles, mumps and rubella, varicella zoster (chicken pox) and yellow fever.

For women who have hepatitis C virus (HCV) alone, there is a small chance of passing on HCV to the baby. Having both HIV and hepatitis C can increase the risk of vertical transmission of HCV. There is no known treatment to prevent vertical transmission of HCV; however, studies have shown that there is a lower risk of HCV transmission if a co-infected woman is on HIV treatment during pregnancy. This is because a high HIV viral load stimulates HCV to make more copies of itself and leads to a higher HCV viral load.

It is important to be aware that some of the drugs commonly used to treat hepatitis C and hepatitis B can cause severe birth defects and should not be taken during pregnancy. Women should stop taking these drugs for at least 6 months before they become pregnant and during pregnancy. Male partners should also not use these drugs for at least 6 months before they decide with their partner to get pregnant. Speak with your doctor and pharmacist to find out more about which drugs are safe and which are not.

Delivery

During labour and delivery, there are ways to reduce the risk of vertical transmission, including taking anti-HIV drugs and choosing the type of delivery. In many cases, natural (vaginal) delivery is safe and preferable.



Most HIV positive women give birth in a hospital, where they can receive appropriate care. For mothers with HIV, Canadian guidelines recommend that during labour and delivery, the anti-HIV drug AZT (zidovudine, Retrovir) be given to the mother to reduce the risk of vertical transmission.

There are two types of delivery: 1) natural (vaginal) delivery and 2) a surgery to remove the baby from the mother called a C-section (cesarean section). If your viral load is less than 1,000 copies, a C-section is not likely to further reduce your risk of transmitting HIV

to your baby. If your viral load is over 1,000 copies or you are not on anti-HIV drugs at the time of your delivery, a C-section may reduce the risk of infection. It is your choice whether to have a C-section, though sometimes C-sections are performed as emergency surgery because vaginal birth is not possible.

“As for the C-section, I found it so strange and weird. But now that I think about it, it was just a moment of discomfort leading to a long, wonderful life with my beautiful boy.”

In women with risk factors, like a high viral load at delivery or co-infection with hepatitis C, the chance of vertical transmission can be further reduced with the following precautions: limiting the use of forceps and vacuum, no use of fetal scalp electrodes and no fetal scalp sampling. Doctors can explain these precautions in more detail.

You have been circumcised

Some women were circumcised as girls or young women. This means that the clitoris and/or the inner and outer labia have been partially or completely removed. Depending on the severity, this cutting of the genitals can cause great difficulties during intercourse, pregnancy and childbirth.

Especially for HIV positive women who have had all outer genitals removed (infibulation), a vaginal birth can increase the risk of transmitting HIV to the baby. A C-section is safer for both you and your child.

Your baby's health

Babies born to mothers with HIV usually get special care during the first few months of life. Your baby will likely receive anti-HIV drugs to further reduce the risk of vertical transmission of HIV. Doctors will also regularly test the HIV status of your baby during this time.

Does your baby have to take treatment?

Treatment during pregnancy is the best way to reduce the risk of HIV transmission to your baby. Giving medicine to the baby after it is born can further reduce the risk of vertical transmission. If you take anti-HIV drugs during pregnancy, AZT will likely be given to your baby within 6 to 12 hours after delivery and be continued for 6 weeks. If you did not receive anti-HIV drugs during pregnancy or delivery, or if your viral load was high before delivery, your doctor may recommend combination anti-HIV therapy for your baby.

You might not want to think about it, but it's important to know that if you refuse to treat your baby with anti-HIV drugs, the authorities may intervene. If they believe the baby's health is in serious jeopardy, they may take your baby away from you.




How will the medications affect your baby?

Many women worry about how the HIV medications they take during pregnancy will affect their children as they grow. The Antiretroviral Pregnancy Registry, a program run by US health authorities, has been monitoring children born to HIV positive mothers since 1994. So far, they have found no evidence of long-term side effects in children of mothers who took anti-HIV therapy during pregnancy.

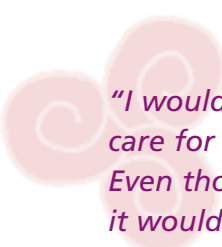
How will you know whether your baby is HIV positive?

In most regions of Canada, tests such as PCR (polymerase chain reaction), which look for virus in the blood, are used as a rapid and very accurate way of finding out the HIV status of your baby. These tests are typically done at birth, 1 to 2 months, and 2 to 4 months of life. With this test it is possible to be fairly certain whether or not your baby has HIV by the age of 2 to 4 months.



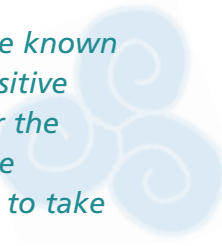
"I can't tell you how scary it was waiting until I found out my child was negative. I could have used some emotional support for that."

What if your baby is positive?



"I would like to know how to care for an HIV positive baby. Even though it scares me sometimes, it would prepare me to adjust my routine so it was all basic and normal."

Very few children are now born HIV positive in Canada to mothers who take anti-HIV drugs. But rest assured that most children who are born HIV positive can lead healthy, active lives. Much of their care is the same as for other children. If your child is HIV positive, it will be necessary for you to make decisions about his or her health, as well as your own. This can be stressful and it is important that you build a strong support network that includes knowledgeable healthcare providers and social and community services, as well as emotional and practical support. The resources listed at the end of this booklet can link you to services in your area.



"I would have liked to have known how to support my HIV positive child. I wasn't prepared for the endless blood work and the medication he would have to take while growing up."

Breast-feeding


In Canada, doctors recommend that you do not breast-feed your baby if you are HIV positive. Since there is a 25 to 50 percent chance that a baby can be infected through breast milk, guidelines strongly encourage HIV positive mothers to use baby formula.



If you cannot afford baby formula, some provinces provide it free of charge. It is important not to feed your baby both formula and breast milk. Feeding both can increase the chance of your baby becoming HIV positive. Donor breast milk is an alternative to formula, but it may not be affordable or available in your area. As well, you must be certain that the woman donating the breast milk is not infected with HIV or other germs.

Several studies are underway to find ways to reduce the amount of HIV in breast milk. These studies are especially important in places where women cannot afford formula or do not have clean water. Although research has shown that it is possible to *reduce* the amount of HIV in breast milk by heating it or by having the mother stay on anti-HIV drugs for 6 months after birth, these methods do not eliminate HIV and are therefore **NOT** safe and are **NOT** recommended in Canada.

You may need extra support, especially if breast-feeding is an expectation among your family, friends and community.



“My son took really quickly to bottle feeding, which kept his weight in check. I found that I could still bond with him by letting him sleep on my chest.”

Building a support network

Many HIV positive women rely on their friends and family for support. Some look to other HIV positive women, community workers and healthcare providers for information and practical help. You can ask your family doctor or local AIDS service organization for help finding people in your area. Many of the organizations listed here can also help you build your support network.



"I have met so many women who had given birth to children after testing positive. They encouraged me to have a baby if I wanted. That was when things turned around for me."

We encourage you to seek out other sources of information about HIV and pregnancy. Treatment guidelines can change over time and it is important to discuss your options with your healthcare team.

Your local **AIDS service organization** is a good place to start looking for information and emotional and practical support as you make decisions around pregnancy and HIV. The organizations listed

below can help HIV positive women with their pregnancy and fertility needs. You can also contact **CATIE** to find out about treatments or for a referral to an organization in your area. Call toll free **1-800-263-1638** or visit **www.catie.ca**. Finally, for a list of fertility clinics in your province, you can contact the Canadian Fertility and Andrology Society at **www.cfasonline.ca** or by phoning 514-524-9009. (Not all fertility clinics provide services to people with HIV.)

A partial list of AIDS service organizations that help HIV positive women with their pregnancy and fertility needs:



Voices of Positive Women

Toronto, Ontario
416-324-8703
1-800-263-0961
voices@vopw.org
www.vopw.org

The AIDS Coalition of Nova Scotia

Halifax, Nova Scotia
902-425-4882 x225
1-800-566-2437
sc@acns.ns.ca
www.acns.ns.ca

Centre for AIDS Services Montreal (Women)

Montreal, Quebec
514-495-0990
direction@casm-mtl.org
netrover.com/~casm

Ontario Aboriginal HIV/AIDS Strategy

Toronto, Ontario
416-944-9481
1-800-743-8851
info@oahas.org
www.oahas.org

The Teresa Group

Toronto, Ontario
416-596-7703
info@teresagroup.ca
www.teresagroup.ca

Women's Health in Women's Hands

Toronto, Ontario
416-593-7655
whiwh@web.net
www.whiwh.com

Nine Circles Community Health Centre

Winnipeg, Manitoba
204-940-6000
1-888-305-8647
ninecircles@ninecircles.ca
www.ninecircles.ca

Positive Women's Network

Vancouver, British Columbia
604-692-3000
1-866-692-3001
pwn@pwn.bc.ca
www.pwn.bc.ca



Voices of Positive Women

66 Isabella Street, Suite 104
Toronto, ON M4Y 1N3
416-324-8703
1-800-263-0961 (toll-free in Ontario)
www.vopw.org



CATIE

Canadian AIDS Treatment Information Exchange

555 Richmond Street West, Suite 505, Box 1104
Toronto, ON M5V 3B1
1-800-263-1638
www.catie.ca



This publication, originally developed by Voices of Positive Women, has been adapted and reprinted in partnership with CATIE.

Funding provided by the Public Health Agency of Canada.

Cette publication est également disponible en français.

Disclaimer

Decisions about particular medical treatments should always be made in consultation with a qualified medical practitioner knowledgeable about HIV-related illness and the treatments in question.

Voices of Positive Women and CATIE in good faith provide information resources to help people living with HIV/AIDS who wish to manage their own health care in partnership with their care providers. Information accessed through or published or provided by Voices of Positive Women or CATIE, however, is not to be considered medical advice. We do not guarantee the accuracy or completeness of any information published by Voices of Positive Women or CATIE. Users relying on this information do so entirely at their own risk.

Thanks to the many community and medical reviewers who provided input on this booklet.

Author: Shari Margoese

Illustration: Beverly Deutsch

Design and layout:

Quadrat Communications and Metagrafix Design

© 2009 Voices of Positive Women and
Canadian AIDS Treatment Information Exchange

CATIE Ordering Centre Catalogue Number: ATI-26115
(aussi disponible en français, ATI-26116)

