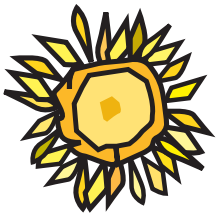
Pregnancy and HIV

life goes on...

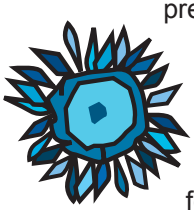
children can be a reason to live

Are you HIV-positive and thinking about pregnancy? You are not alone. Living with HIV does not necessarily take away your desire or your ability to have children. In fact, advances in HIV treatment have many HIV-positive women looking forward to the future and deciding to have children.

This booklet is designed to help you make informed decisions about your health and the health of your baby. Information about HIV and pregnancy is combined with words of support and inspiration from HIV-positive mothers who are members of Voices of Positive Women.



Let's talk plainly. Dealing with HIV can be difficult. And dealing with pregnancy can be difficult. You may not want to consider pregnancy right now. You may not want to consider it at all. Or maybe you have just found out that you are pregnant, but know that this is not a time in your life when you can carry on with it. You may want information about getting an abortion. Whatever your situation, Voices of Positive Women stands firmly behind your right to choose what is best for you. We will support you in your decision-making.



the facts

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

Voices of Positive Women encourages you to seek out other sources of information about HIV and pregnancy, as well as peer support. New treatments that reduce the risk of mother-to-child transmission are available and women are strongly urged to discuss their options with their health care providers.

Facts about HIV transmission from mother to child

Mother-to-child HIV transmission, also known as vertical, perinatal or prenatal transmission, may occur:

- before birth, in the uterus
- during the birth process
- after birth, through breast-feeding

"I wanted to know how much risk my baby was at. But at the time there was no research."

Canadian guidelines have been developed which reduce the risk of HIV being passed from mother to child from approximately 25% to below 2%.

These guidelines recommend:

- reducing the mother's viral load by antiretroviral therapy taken during pregnancy
- delivery by Caesarian section (C-section), when appropriate
- giving the baby a short course of antiretroviral therapy after birth
- not breast-feeding

Decisions about treatment and delivery require full discussion between you and your health care provider.

Will HIV affect my ability to get pregnant?

Research reveals that HIV-positive women may find it more difficult to conceive than HIV-negative women. Although more study is needed in this area, it is thought that HIV, its treatment or co-infection with other sexually transmitted infections, may all contribute to reduced fertility.

Artificial insemination is an option for HIV-positive women. It can usually be done at home, but may require medical assistance.

"I think of how much risk I am putting my HIV-negative partner at by trying to get pregnant. Doctors are not well-prepared to help HIV-positive women through the emotional part of this."

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

If you and your partner are both HIV-positive, you should discuss the risk of re-infection with your health care provider.

How will pregnancy affect my health?

"HIV-positive women should know that they can get pregnant."

Good health continues to be very important while you are pregnant. Your health care provider should provide you with the same standard of care that is available to any woman who is pregnant or considering it.

Research shows that pregnancy itself does not affect HIV progression and HIV does not change how the pregnancy proceeds.

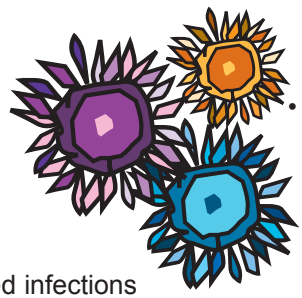
An HIV positive woman who is pregnant should consider taking anti-retroviral therapy for her own health, as well as to prevent mother-to-child transmission of HIV. Your therapy should be tailored to your individual needs and balance the risks and benefits to both you and your child.

"I think getting support from a good doctor and a support group is important for any HIV-positive pregnant woman."

In addition to anti-retroviral therapy, there are many other things that HIV positive women can do to help ensure a health pregnancy. One of the most important is to receive appropriate prenatal care. Try to find an obstetrician who is familiar with HIV care. It is best to do this before you get pregnant, or soon after.

Other things you can do include:

- ensure that your health care provider screens and treats you for sexually transmitted infections
- give up smoking, drinking and/or recreational drugs
- find health options for stress reduction
- put together a support network.



treatment options

What drugs are recommended to take while I am pregnant?

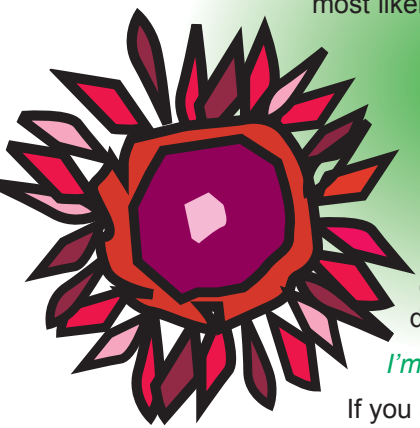
In Canada it is recommended that all pregnant, HIV-positive women take combination anti-retroviral therapy regardless of their CD4 count or viral load. It is also recommended that intravenous Zidovudine (AZT) therapy is given to the mother during labour. A single oral dose of Nevirapine is also sometimes required.

The combination of anti-retroviral drugs you take depends on many factors, including the drugs you have taken in the past and what is currently available. Certain drugs are known to cause side effects in pregnancy and should be

avoided. These include Sustiva, liquid Amprenavir, Delavirdine and the combination of ddI and d4T. Check with your health care provider for up-to-date information.

When can I start anti-retroviral therapy?

Generally your health care provider will recommend starting therapy after 12-14 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 that the antiretroviral drugs could have a negative effect on your baby in the early stages of its development. Another reason for waiting is to avoid the period of pregnancy most likely to include morning sickness.



"Make sure your meds stay down. Nothing is worse than morning sickness right after you've swallowed your meds."

Monthly tests should be done to monitor for the side effects of therapy, including hyperglycemia, anemia and kidney and liver toxicity. Viral load and CD4 counts should be taken at the beginning of your pregnancy and then every 4 to 6 weeks during pregnancy.

I'm already on anti-retroviral therapy!

If you are pregnant and you are already on antiretroviral therapy, you and your health care provider may decide to change the drugs that you are taking. Some drugs are more effective in pregnancy than others. Others can cause serious harm to you and your baby. Seek immediate advice from your health care provider about what is best as soon as possible after finding out that you are pregnant.

"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."

It is not a good idea to come off or change your therapy without seeing your health care provider. If you stop your treatment suddenly, your viral load may rebound, and there may be an increased risk of HIV transmission to your baby. You may also increase your risk of developing drug resistance. This could limit your treatment options in the future.

What can I do if I don't want to take anti-retroviral medication?

While it is strongly recommended that you take medication during pregnancy, it is ultimately your choice. Medication given only during labour and delivery can reduce some of the risk of transmission.

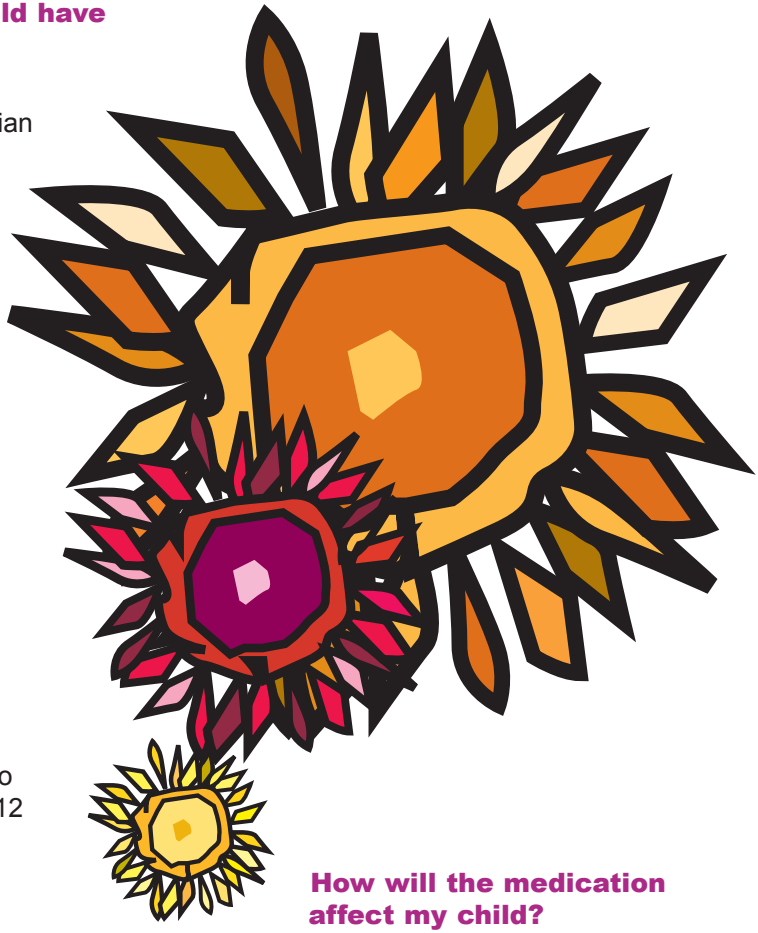
Treatment given to newborns can lower the risk of transmission to babies born to mothers who received no treatment at all.

Does my child have to take treatment?

Current Canadian guidelines recommend that if the mother did not receive antiretroviral therapy during pregnancy or delivery, Zidovudine and Nevirapine therapy should be given to the baby as soon as possible after birth.

If the mother received antiretroviral therapy, Zidovudine is given to the baby within 6 to 12 hours after delivery and is continued for 6 weeks.

While your baby is developing inside of you, you have the right to choose whether you take antiretroviral therapy. Once your child is born, authorities may intervene to ensure that your child receives antiretroviral treatment if they believe it is in the best interest of the child.



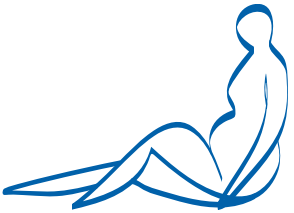
How will the medication affect my child?

"There still isn't research speaking to the long-term effects of the medications on HIV-positive children. My child is HIV-positive. What will her health be like in the future?"

Very few HIV medications have been thoroughly studied for use in pregnancy. Short-term side effects of these drugs are generally limited to mild anemia, but little is known about the long-term effects. A new Canadian study is looking at this issue. Research is ongoing to develop shorter-course therapies that will minimize the exposure of the developing fetus to drugs.

What are my delivery options?

There are two types of delivery: Caesarian section (C-section) and vaginal delivery. If your viral load is less than 1,000, 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 or you are not on treatment at the time of your delivery, a C-section may reduce the chances of transmission. It is your choice whether you have a C-section.



"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."

To further reduce the risk of HIV transmission during delivery, it is recommended that unnecessary rupture of the membranes, use of fetal scalp electrodes and fetal scalp sampling be avoided. Use of forceps or vacuum should also be limited.

Can I breast-feed my baby?

Since a baby can be infected through breast milk, it is important not to breast-feed. If you cannot afford baby formula, Voices of Positive Women can help connect you to a program that provides it free of charge. Donor breast milk is an alternative to formula, but may not be affordable or available in your area.

Some women may need extra support on this issue, especially if breast-feeding is expected in their culture.

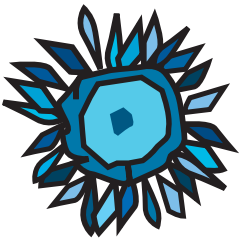
"I found that I could still bond with my son by letting him sleep on my chest. He took really quickly to bottle feeding, which kept his weight in check too."

How will I know if my baby is HIV-positive?

Your baby can have an HIV antibody test, like adults do, but it will not necessarily show right away whether your baby is infected with HIV. All babies born to mothers with HIV are born with HIV antibodies. Babies who are not infected lose their antibodies by the time they are about 18 months old. So it is only after your baby is 18 months old that the HIV antibody test will give an accurate result.

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

In Ontario, diagnostic tests such as the polymerase chain reaction (PCR) are used as a more rapid way of finding out the HIV status of your baby.



What if my 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."

Many HIV-positive children 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 health care providers, social and community services, as well as emotional and practical support. Voices of Positive Women can link you to hospital and community-based 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."

What about pregnancy and opportunistic infections?

Some drugs and vaccines for the prevention of opportunistic infections are safe in pregnancy while others are not.

It is safe to continue preventative medication for Pneumocystis carinii pneumonia (PCP), Mycobacterium avium complex (MAC) and tuberculosis (TB). After your first trimester it is also safe to receive vaccines for Pneumoccocal meningitis, hepatitis B and the flu. It also appears to be safe to take small amounts of acyclovir in the case of a herpes breakout.

You should, however, avoid drugs used for the prevention and treatment of candidiasis and other fungal infections, such as fluconazole, itraconazole and ketoconazole. You should also avoid live virus vaccines such as those for measles, mumps and rubella.

What about methadone and pregnancy?

"I am a former addict. 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."

Long-term studies have shown that there is no increased risk of birth defects or developmental difficulties in babies born to methadone-treated women. It is important to be prepared that your baby may be dependent on (addicted to) methadone at first and need to be weaned off. If you are on methadone and become pregnant, you should not stop your methadone treatment without first speaking to your health care provider.

Hepatitis C co-infection

I have Hepatitis C (HCV). Can I infect my child?

HIV increases risk for mother-to-child HCV transmission from about 5% to about 17%. Unfortunately, there is no known treatment to prevent mother-to-child transmission of HCV. It is also important to be aware that Ribavirin, a drug commonly used to treat HCV, can cause severe birth defects. Women should not use it for at least six (6) months before they become pregnant, or during pregnancy. Male partners should not use Ribavirin for at least six (6) months before they decide with their partner to get pregnant.

Where can I find support and information?

Many HIV-positive women face stigma and discrimination because of choices they make about having children. You may face stigma because you choose to have a child.

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

On the other hand, you may face stigma because you choose not to have a child.

"I wanted to have a child – and in my culture everyone really pressures you to have children."

If friends or family are not supportive, look to other HIV-positive women, community workers and health care providers for support.

"I came to Voices and 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."

This brochure provides you with answers to some of the questions you may have about HIV and pregnancy. You may have other questions. Asking questions is an important step in making an informed choice about your health.

"I must have asked a million questions — most of them over and over again. My health care providers didn't mind. I liked that."

The Teresa Group
Toronto, ON

Phone: 416-596-7703

www.teresagroup.org
Practical assistance to families affected by HIV. Provincial formula program provides free formula to HIV-positive mothers in Ontario.

The Miriam Group
Burlington, ON

Phone: 905-681-7157

e-mail: miriamgp@idirect.com

Motherisk – Healthline and confidential counseling to Canadian women, their families and health care professionals about the risk of HIV and HIV treatment in pregnancy

Phone toll-free: 1-888-246-5840

http://www.motherisk.org/hiv/index.php3#Accessing

Canadian Medical Association
Clinical Guidelines on women and HIV, promoted by the Canadian Medical Association can be found at
www.cmaj.ca/misc/service/guidelines.shtml

See also http://www.cmaj.ca/

The Well Project – HIV and Women
An overview of general issues relating to pregnancy.

www.thewellproject.com

Voices of Positive Women
HIV+ peer mentors available for support, information and referral, free vitamin supplements for HIV+ women in Ontario.

Phone: 416-324-8703

Toll-free: 1-800-263-0961

website: www.vopw.org

www.vopw.org

Voices of Positive Women

A community based non-profit organization directed by and for women living with HIV/AIDS in Ontario

Women live strong lives with HIV/AIDS.

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