



for women ...



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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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.

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



How do people get infected with HIV?

HIV is passed from person to person through blood, semen (cum and precum), vaginal fluids (wetness), anal fluids 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, or tattooing or piercing with a used needle.

HIV can pass from mother to baby during pregnancy, childbirth or 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 continues to attack your immune cells, you have fewer healthy immune cells to protect you from infections. Medication can help to slow this process and you can live a healthy life. See page 20 (*How is HIV treated?*) for more information about HIV treatment.

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:

- You are HIV+, and
- You have been sick with one or more unusual infections that only occur when your immune system is weak (*AIDS-defining illnesses*).

You may hear the term '*advanced HIV disease*' which is sometimes used instead of AIDS.



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 years, if you don't get treatment, HIV will weaken your immune system. This means your body won't be able to fight infections as it used to.

As a woman living with HIV, you might notice that you get infections more often or that there are changes in your period.



Changes in Your Period

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

- Changes in menstrual flow (less or more blood).
- More pain when they bleed.
- More periods or fewer periods.

These changes could be related to stress, body weight changes or other health factors. It may also be related to *perimenopause*, the years leading up to the end of menstruation. Talk to your doctor or health care provider about what's "normal" for you, and about any changes to your periods. We still have much to learn about HIV's effect on women's cycles.



Vaginal Yeast Infections

Yeast infections are 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.

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.

STIs can cause pain, discharge, or itching (or even no symptoms). It is important to see a doctor or nurse if you have symptoms. To take care of your sexual health overall, see a doctor regularly (the schedule they suggest) and have regular Pap tests 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.



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 and in your anus. Pap tests can help find these changes and they are usually easy to treat if they're found early. Talk to your doctor about the best schedule of Pap tests for you. It is recommended that you have a Pap test every 6 months to a year.

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 can trust 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 overwork your immune system.
- Decrease your use of alcohol and drugs.
- Find support: you are not alone with this.





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 HIV/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.



For the best care, tell your doctor about:

- Your complete health history.
- Any changes in your health.
- Alcohol and/or drug use.
- Any plans to have children (yes, you can do it with HIV).

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 HIV/AIDS organization.

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



How is HIV treated?

Can treatments 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 complementary therapies to help your immune system.

How does HIV treatment work?

HIV is a virus that spreads in the body by making copies of itself. HIV treatment slows down the copying process. This gives the body a chance to fight HIV. Your immune system gets stronger, and your health improves.

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

HIV can adapt to HIV treatment over time, and then the treatment stops working. The drugs are made to target different stages in the HIV life cycle. If you take more than one type of HIV treatment at the same time, HIV cannot adapt. Taking more than one drug at a time is called *combination therapy*, or *antiretroviral therapy (ART)*. This treatment is very effective at slowing down and even stopping HIV from copying itself.





Are there possible problems with 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 medication schedule too hard to keep up with. The good news is that there are many options and you should be able to find a treatment that works for you.

It can take time to adjust to treatment. Side effects may only last a week or can last a month or two. Talk to your doctor if you have a difficult time with a particular side effect because he or she may be able to help treat it or help you choose a different HIV treatment to take.



Why is it so important to stick to a medication schedule?

It is important to try to take all your doses at the right time and in the right way; every missed or late dose leaves time for HIV to adapt. With too many missed doses, your treatment may stop working and you will need to choose a new combination.

Ask your doctor for the simplest drug schedule possible, as it will make it easier to stick to it. Many HIV treatments are taken only once a day.





Are there alternatives to antiretroviral therapy?

Antiretroviral therapy (ART) treats HIV. To help keep your immune system strong, you can use complementary and alternative medicines.

Complementary and alternative medicines can't treat HIV, but they may support your immune system in its fight against the virus.

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

The body has natural ways of eliminating drugs and other toxins from the body, often through the liver. The more drugs you take (both variety and amount), the harder your liver works.

Both street drugs and HIV treatment can change the way that the liver deals with drugs. Some street drugs (and methadone) can *increase* or *decrease* the amount of HIV drug in your body. The change can be enough to make your HIV treatment toxic (which could harm you) or to stop it from working (meaning you'll need to choose a new combination). Similarly, HIV drugs can *increase* or *decrease* the amount of street drug (or methadone) in your body, leading to hallucination, psychosis, seizure, overdose, withdrawal symptoms, or death.

The most important thing is to be honest with your doctor about what drugs you are using and how often.





Complementary therapies 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, especially herbs, can have side effects or negative interactions with other medications. These interactions can be very serious and dangerous. Your medications could stop working or might become harmful to you. Tell your doctor about all the herbs and supplements you are taking.

To find out about complementary therapies, you can do some research through the nearest HIV/AIDS organization. Talking to a treatment information counsellor 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 a big difference.

- 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.
- Treat health problems as soon as you can. It's recommended that you get vaccinated against common infections like hepatitis A and B.
- 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.

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

You can have a healthy baby if you have HIV. With proper care and treatment during pregnancy, childbirth and early life, only 2 in 100 (2%) babies born to HIV+ women will also be HIV+. Without proper care and treatment, approximately one in four (25%) babies will be HIV+.

Try to see a doctor as soon as you find out you are pregnant. Getting good care during pregnancy will increase the chances of having a healthy baby.



How is HIV passed from mother to baby?

HIV can pass from mother to baby during pregnancy, childbirth and breastfeeding. HIV+ women who are less healthy overall are more likely to have an infected baby.

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 out 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 are taking *antiretroviral therapy* (ART) during pregnancy and childbirth. Treatment is also given to the baby for six weeks after birth. Scientists don't know all the long-term effects of ART on women and their babies, but so far studies show most treatments seem to be safe. They definitely lower the risk of a baby being infected.

Because HIV can pass through breast milk, breastfeeding is not recommended. Ask your doctor or nurse whether free baby formula is available for HIV+ moms in your area.





How will using street drugs affect HIV?

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

If you are thinking of having a baby, it can be helpful to connect with a clinic or doctor who is informed about prenatal care for HIV+ women. They can help you plan how to get pregnant in a low risk way and plan treatment that's pregnancy-friendly. Connect with your local HIV/AIDS organization for a referral (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. Through special tests they can tell by the time the baby is a few months old.



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 (such as abscesses, cellulitis, phlebitis).
- Blood clots in different parts of your body.
- Infections that affect your whole body (such as endocarditis, pneumonia).
- Drug overdoses.

Fighting any infection or illness strains your immune system. Pneumonia, blood infections 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 or bruising under the fingernails.

How can I make using safer?

- Use less.
- Use less often.
- Avoid sharing equipment.
- If you inject, 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 street 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 street 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 *CD4 cells* (fighter 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.

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*.

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 have HIV it's a good idea to get tested for hepatitis C, so both viruses can be managed effectively.**

What kind of treatment is available for hepatitis C?

There are drug treatments for hepatitis C. Some people are treated successfully, but not all. Hepatitis C treatment can affect your HIV treatment, so check with your doctor to find the best treatment plan for you.

Some herbs and supplements may help the liver, but they cannot cure hepatitis C. Research herbs carefully and talk to your doctor before using them, as some herbs could be harmful and affect other medicines that you take.



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 that you can get help in case anything goes wrong. Don't fix alone.





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

Try to stop drinking alcohol, as it damages the liver. If you are using injection drugs, don't share needles. Some drug store medications, like Tylenol, can also cause liver damage, so check with the pharmacist before using anything. Tell all your 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.

For more information about hepatitis C, visit www.hepcinfo.ca.

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 and try to eat 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: Try colourful fruits and vegetables and experiment to find 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 (provide 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 affect many parts of the digestive system. Stomach aches, diarrhea and constipation are not uncommon. Adjusting your diet may help.

If you have problems with diarrhea:

- In the short term, the BRAT diet (Bananas, Rice, Applesauce, Toast) is a common approach.
- Limit high-fat foods, sweet drinks, caffeine and stimulants.
- Talk to your doctor if it's an ongoing issue.





If you have problems with constipation:

- Drink lots of water (8 to 10 cups per day).
- Eat more fibre, including raw fruits and vegetables, whole grains, high-fibre cereals, legumes (beans and peas), and dried fruits (figs, prunes, dates).
- Increase your activity level, try going for a walk after a meal.
- Ground flax seeds, senna tea and psyllium are options available in health food stores.

If you just don't feel hungry:

Lack of appetite is common and may be caused by illness, fatigue, depression, drug side effects or addiction. Eat smaller portions and eat more often. Talk to your doctor about your reduced appetite.

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.

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.

Should 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.



However, 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 risks. To learn about sex and HIV transmission, see page 49 (*How do I have "safer sex"?*). To learn more about legal questions, contact the *Canadian HIV/AIDS Legal Network* or talk to an advocate at the nearest HIV/AIDS organization.

Do I tell my other 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 well you know your family and what is the safest and healthiest choice for you.



Should I tell my children?

Some moms who tell their children are glad they did, 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 understand what this means?
- Do my kids have another trusted adult to talk with about this?
- 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 certain body fluids. HIV is transmitted from person to person through blood, semen (including pre-cum), vaginal and anal 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 the vagina, anus, urethra, open cuts). For more information, see page 6 (*How do people get infected with HIV?*) and page 49 (*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 or pre-cum), blood, or vaginal or anal 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.

HIV is spread when:

a **body fluid** with high concentration of HIV
(*semen and precum, blood, vaginal or anal 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,
injection site*)



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

Remember, you can be charged with a criminal offense if you have unprotected sex with someone and you don't tell them you are HIV+. See page 45 (*Should I tell my sex partners?*) for more about the law and the risk of HIV transmission.

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 (type) 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 a cut-up polyurethane condom or even non-microwavable plastic food wrap.

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 and precum), vaginal and anal 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 during pregnancy, childbirth and breastfeeding. For more information, see page 6 (*How do people get infected with 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.





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

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 HIV/AIDS organization nearest you for suggestions on the best way to make a will.

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

- Is it a place that's easy to get to in case of emergency?
- Do the workers protect against passing infections that may harm your child's health? This includes wearing latex gloves to change diapers and using bleach when they clean up spills of blood or bathroom accidents.
- If your child is 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 (cum and precum), vaginal and anal fluid and breast milk. For there to be a risk, the infected body fluid must pass directly into the bloodstream of another. The chance of your child spreading HIV to another child in a daycare or school is small.



What if my child tells someone she or he is HIV+?

Your child may tell someone she or he has HIV. It can be too much pressure for kids to keep it a secret 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.



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Where to get help

In B.C.

Positive Women's Network

Web: www.pwn.bc.ca

Phone: 604.692.3000

Toll free (in BC only): 1.866.692.3001

Oak Tree Clinic

(Treating HIV+ women and their families.)

604.875.2212

Nationally

ASO 411 - www.aso411.ca

CATIE - 1.800.263.1638, www.catie.ca

Canadian HIV/AIDS Legal Network -

www.aidslaw.ca

Hepatitis C (CATIE) - www.hepcinfo.ca





Positive Women's Network

*Challenging HIV.
Changing Women's Lives.*

Vision Statement

Action and Leadership on Women and HIV/AIDS

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.





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