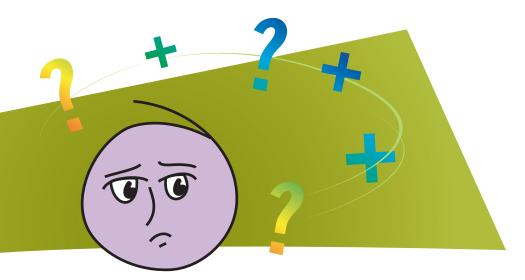


Have you found out you have HIV and are trying to get your bearings? We can help you with the basics of living with HIV. Here's what you'll read about in this booklet:



- How you can stay healthy if you are living with HIV
- What your "CD4 count" and "viral load" tell you
- Starting HIV treatment
- Telling others you are HIV positive
- Next steps



# So you found out that you're HIV positive.

The first thing you need to know is that these days most people with HIV live long and healthy lives, thanks to huge improvements in treatment and care.

Even so, finding out you have HIV can be stressful. No matter how much good news there is, you still have to work through the shock and other emotions you might be feeling, at your own pace, in your own way.

Right now, you may want to know everything there is to know about HIV. On the other hand, learning more may be the last thing you want to do!

Let's take it one step at a time. You don't need to become a medical expert; just knowing some of the basics about HIV can help you a lot. Understanding more about your condition will allow you to take charge of your health. And it can help you work with your doctor.

### What is HIV?

HIV is a virus that weakens your immune system, your body's built-in defence against disease.

HIV (which stands for human immunodeficiency virus) attacks your immune system. If your immune system gets too weak, you can get very sick from other infections.

But just because you have HIV does not mean you will get sick. Most people with HIV can stay healthy and live a long, full life if they get proper care and treatment.

#### How can I stay healthy with HIV?

 Get a good doctor. Try to find a doctor who has experience treating people living with HIV. You'll also want a doctor you can talk to openly and honestly.

Your doctor will likely suggest a complete medical checkup. Other health conditions (such as hepatitis, sexually transmitted infections (STIs), tuberculosis (TB), diabetes and heart conditions) can affect your care, so it's a good idea to get tested for these as well.

- 2) Talk to your doctor about HIV drugs (also called HIV medications or HIV treatment). Today's HIV drugs are easier to take than older ones, and they can help you stay healthy for many years. Effective treatment also lowers your chance of passing HIV to others.
- 3) Take care of your mental and emotional health. Stress, depression and anxiety often go hand-in-hand with finding out you have HIV. Sometimes drugs and alcohol do too. There's no shame in any of this. Talking to your doctor, a counsellor, a therapist or a friend helps many people deal with the news. Some people also use mind-body practices, such as yoga, meditation or Tai Chi, to help relieve their stress.
- **4)** Eat well (include a good-quality daily multivitamin and mineral supplement if you can).
- 5) Exercise.
- 6) Get enough rest.
- If you're a smoker, try to quit smoking, or smoke less. Talk to you doctor, nurse or pharmacist about ways to help you quit smoking.
- Try to reduce or stop using drugs, alcohol or other substances that could be harmful to your health.
- **9)** You may also want to try complementary therapies, such as acupuncture, massage and naturopathy, along with the care you get from your doctor.

When you're HIV positive, regular visits to your doctor will help you stay on top of your health. As part of your regular checkups, your doctor will recommend blood tests to monitor your health. Two of the most important tests check your CD4 count and your viral load.

### What is a "CD4 count"?

Your CD4 count tells you how your immune system is doing. The higher the number, the better.

CD4 cells are the "bosses" of the immune system. They lead the fight against invading germs and viruses. Your CD4 count tells you how many CD4 cells you have in a cubic millimetre (mm<sup>3</sup>) of blood. A "normal" CD4 count is anywhere from 500 to 1,200.

When you received your diagnosis, your CD4 count may have been normal or it may have been below normal. Even if it was below normal, that may be OK in the short term. But a count of 350 or lower means a greater risk of getting sick. CD4 counts usually rise once you start HIV treatment, and many people on HIV treatment have normal CD4 counts.

### What is "viral load"?

Your viral load tells you how much HIV is in a millilitre of blood. The lower your viral load, the better.

If you are on HIV treatment and the treatment is working, your viral load will fall to a level too low for a test to detect. When you have an "undetectable" viral load, it does not mean that you're cured or that the HIV is gone, but it does mean that the HIV is under control. It also greatly lowers the risk of passing HIV to someone else.

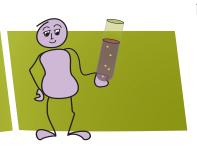
## When should I start treatment?

There is no cure for HIV, but treatment helps you stay healthy by stopping HIV from multiplying in your body. Your immune system can then stay strong (or get stronger if it was weakened when you were diagnosed). HIV treatment can also help prevent other health problems. What's more, having an undetectable viral load greatly lowers the risk of passing HIV to someone else.

Doctors who specialize in HIV usually talk about HIV treatment soon after diagnosis. Experts now think that starting treatment early is better for long-term health. Research suggests that people who start treatment soon after diagnosis and get good care can expect to live a nearnormal lifespan.

You need to take HIV drugs every day as prescribed by your doctor. If not, the virus in your body can develop resistance and the drugs will stop working. If this happens, you'll have to change your drugs, which may leave fewer options for the future.

Newer HIV drugs are more tolerable than older drugs, but some may still cause side effects. These often go away after a few weeks. Your doctor, nurse or pharmacist can help you learn how to cope with side effects. If the side effects make it difficult to keep taking your drugs, your doctor might be able to recommend other drugs that would be easier for you to take.



Talk to your doctor about when is the best time for you to start treatment. Starting is a big step, but you are not alone. Your doctor, nurse, pharmacist or staff at your local communitybased HIV organization can give you information and support.

## What about other infections?

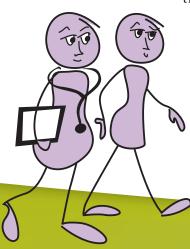
If HIV is not treated, your immune system eventually becomes weakened and other kinds of serious infections, called opportunistic infections, can develop. Maybe you found out you have HIV because you were sick with such an infection. By keeping your immune system strong, you'll be better able to fight off infections.

There are also other kinds of infections. Some are passed through sex without a condom—for example, syphilis and gonorrhea. Some are passed when sharing needles and other equipment to inject drugs. And some infections, such as hepatitis B and C, can be passed through sex without a condom or sharing drug use equipment.

To learn more about how to prevent these infections, talk to your doctor, nurse, staff at your local community-based HIV organization or CATIE (1-800-263-1638).

## Who should I tell I'm HIV positive?

Telling someone that you're HIV positive can be stressful. You may not be sure who you can trust or how a person will react. But it can also be isolating to keep it a secret. To help you decide who to tell, ask yourself: Who can I



trust to listen and not judge me? Who can I rely on to give me the support I need and deserve? Who will respect my privacy?

Most of the time, telling someone (disclosing) you have HIV is your decision. You don't have to tell your family or friends, although if you think they might be supportive it could help you. In most cases you don't have to tell your landlord, employer, coworkers or school. You do not have to tell your dentist or other healthcare workers, but if they know, they might be able to provide you with better care.

The law is different when it comes to sex. In Canada you can be charged with a serious crime if you do not tell your sexual partner about your HIV status before having certain kinds of sex.

The law may evolve, but at the time of publication, it suggests you have a legal duty to tell your sexual partner about your HIV status before having:

- Sex without a condom regardless of your viral load (this includes vaginal, frontal\* or anal sex)
- Sex with a condom if your viral load is higher than low (this includes vaginal, frontal or anal sex)

However, you do not have a legal duty to disclose before sex if you both use a condom AND have a low viral load (at least before vaginal sex).

There's a lot to know and think about when it comes to disclosing your HIV status. Talk to a staff member at your local community-based HIV organization or the Canadian HIV/AIDS Legal Network (www.aidslaw.ca or 416-595-1666). If you need legal advice, talk to a lawyer. The Canadian HIV/AIDS Legal Network may be able to refer you to a lawyer.

Talking to another HIV-positive person can also be helpful. If you don't know another HIV-positive person, contact CATIE or your local community-based HIV organization and ask if they can connect you to an individual or group.

<sup>\*</sup> The term "frontal sex" is sometimes used by trans men instead of "vaginal sex."

# Next Steps

There is, of course, plenty more to learn and plenty more to do. But knowing the basics about HIV can help you tackle what comes next.

For now, it's a good idea to learn enough so you feel comfortable and can be involved in your own care.

As far as "next steps" go, let's break them down into a few main areas:

Keep yourself healthy. Learn how you can take control of your health, from eating well to managing your stress. Protect yourself from other infections by getting vaccines, practising safer sex and (if you use drugs) safer drug use. Learn about HIV drugs and talk to your doctor about your options so that you can make choices that are right for you.

Learn how HIV is transmitted so you know how to avoid passing the virus to other people. Condoms, HIV treatment and treating STIs are just some of the ways you can lower the risk of passing on HIV during sex. If you use street drugs, don't share drug use equipment.

Get connected. Find out about services for people with HIV in your area. Services for people with HIV are in a variety of community organizations. For some organizations HIV is their main focus. These are often called AIDS service organizations or ASOs. In other places, HIV services are part of a larger organization. If you picked up this brochure at a community-based HIV organization,

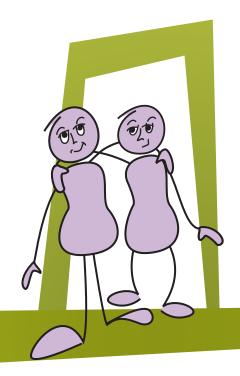


talk to someone there. These places offer support and information and can help connect you with other people living with HIV. Talking to someone who has HIV can be a great way to deal with the stress of living with the virus.

To find a community-based HIV organization near you:

- visit HIV411.ca
- call CATIE at 1-800-263-1638
- email CATIE at questions@CATIE.ca

But before you get into all of that, you're totally allowed to take a break. Go ahead, grab some popcorn and a good movie. And know that there are people and resources out there to support you as you learn to live long and well with HIV.



This publication, originally developed by the Toronto People With AIDS Foundation, has been updated and printed in partnership with CATIE.



#### 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.

Toronto People With AIDS Foundation and CATIE provide information resources to help people living with HIV who wish to manage their own healthcare in partnership with their care providers. Information accessed through or published or provided by Toronto People With AIDS Foundation and CATIE, however, is not to be considered medical advice. Toronto People With AIDS Foundation and CATIE endeavour to provide the most up-to-date and accurate information at the time of publication. Users relying solely on this information do so entirely at their own risk. Any opinions expressed herein may not reflect the policies or opinions of Toronto People With AIDS Foundation and CATIE or any partners or funders.

Information on safer drug use is presented as a public health service to help people make healthier choices to reduce the spread of HIV, viral hepatitis and other infections. It is not intended to encourage or promote the use or possession of illegal drugs.

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