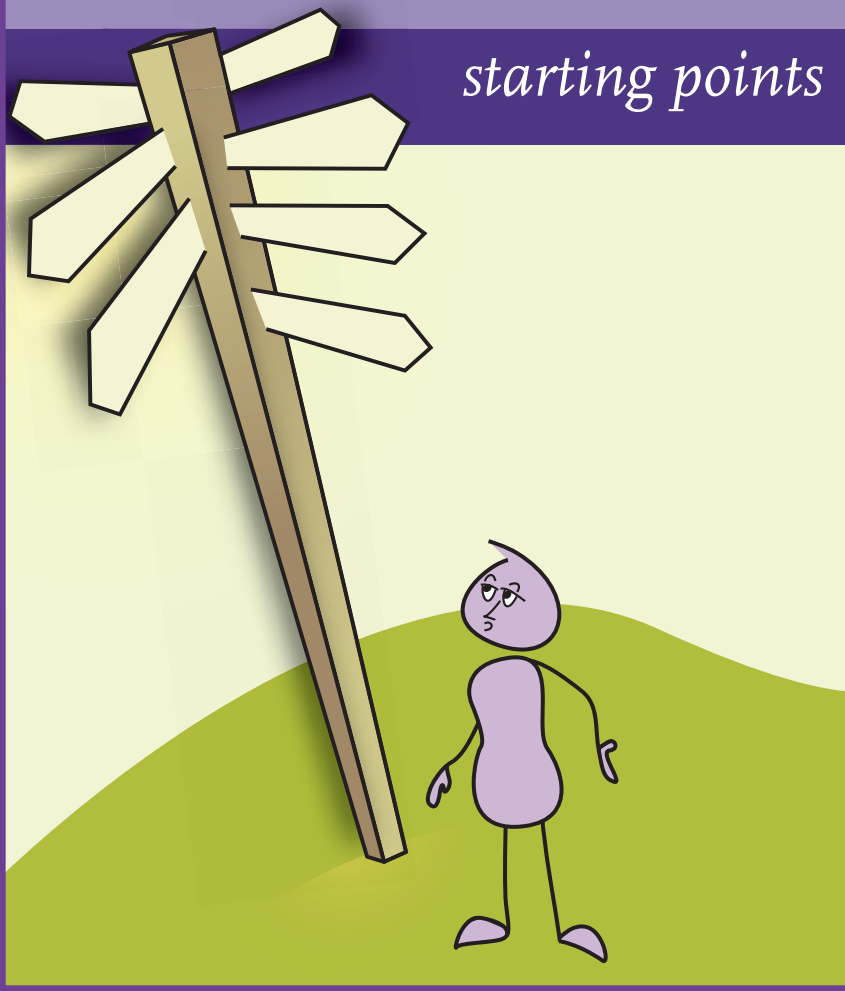



Living with HIV

starting points



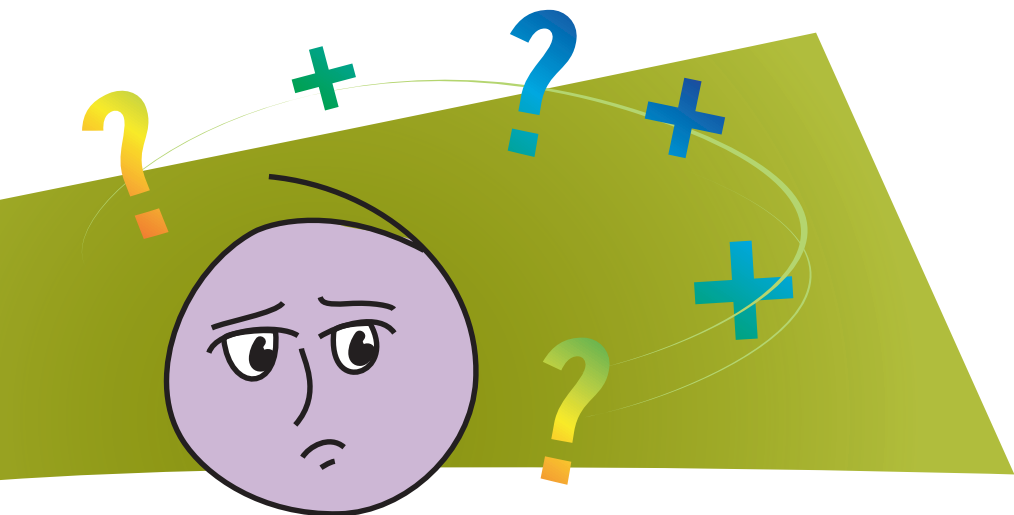
toronto
PEOPLE WITH AIDS
foundation





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:

- What HIV and AIDS are
- How you can stay healthy if you have HIV
- What your “CD4 count” and “viral load” tell you
- What you can do next



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

Hopefully, you've already heard that people with HIV are usually able to live long and well these days, thanks to huge improvements in treatment. (If not, we're telling you now.)

Even so, finding out you have HIV is stressful. No matter how much good news there is, you still have to work through the shock of your diagnosis 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!

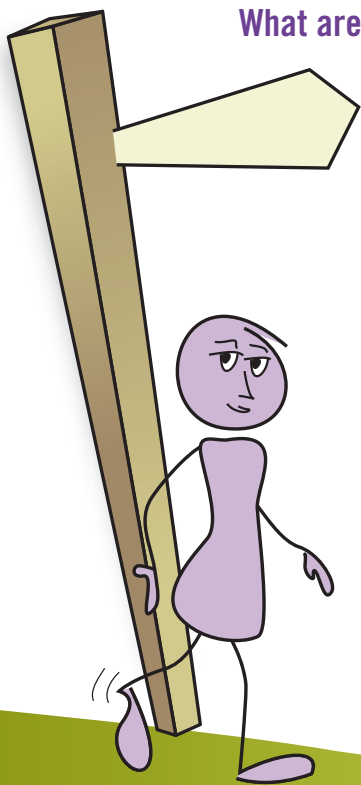
Let's take it one step at a time. You don't need to become a medical expert overnight; just knowing some of the basics about HIV can help you a lot. Understanding more about your condition allows you to take charge of your health. And it helps you work better with your doctor.

HIV

HIV stands for Human Immunodeficiency Virus. (Immunodeficiency means a weakened immune system.)

People who have been infected with HIV are called HIV positive (or HIV+).

What are HIV and AIDS?



HIV is a virus that weakens your **immune system**, your body's built-in defense against diseases. Although your immune system is supposed to protect you from infections, HIV can sneak past it. HIV then attacks your immune system from the inside. If your immune system gets weak enough, you can get very sick from other infections. Generally, if you get sick with one of these infections you are considered to have AIDS.

Just because you have HIV does not mean you will get sick. Most people with HIV can stay healthy for a long time when they get proper care and treatment.

AIDS

AIDS stands for Acquired Immune Deficiency Syndrome. If HIV is not treated, it usually leads to AIDS over time.

How can I stay healthy with HIV?

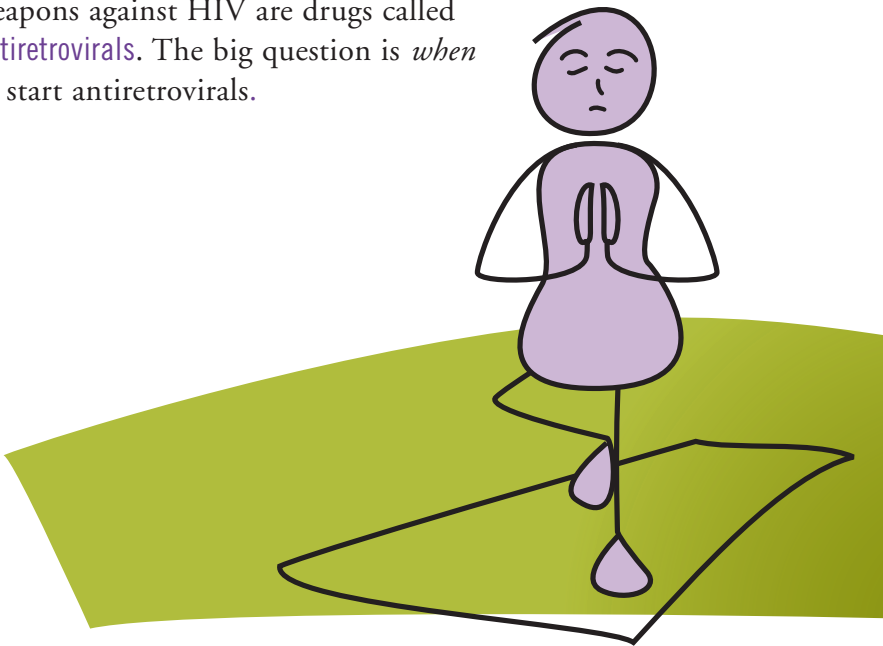
First and foremost, get a **good doctor**. Try to find a doctor who has experience with treating HIV-positive people. You also want someone you can talk to openly and honestly.

Your doctor will likely suggest a **complete medical checkup**. Other medical conditions (like hepatitis, sexually transmitted infections or heart conditions) can affect your care, so you'll want to make sure you've got the whole picture.

Look after your **mental and emotional health**. Stress, depression and anxiety often go hand-in-hand with HIV, and sometimes drugs and alcohol do too. There's no shame in any of this; it's common to need some help coping with an HIV diagnosis. If you need someone to talk to, get hooked up with a counsellor, a therapist or a buddy. Many people also use mind-body practices such as yoga or Tai Chi to help relieve the stress.

There are many other things you can do to keep yourself healthy. **Eat well** (include a good-quality daily multivitamin and mineral supplement if you can), **exercise** and get enough **rest**. A lot of people with HIV also use **complementary therapies** (like herbal treatments, naturopathy and massage) along with their "standard" medical treatments.

Sooner or later, you'll need to talk to your doctor about medications. The main weapons against HIV are drugs called **antiretrovirals**. The big question is *when* to start antiretrovirals.



ART & HAART

Antiretroviral treatment is often called ART, for AntiRetroviral Therapy, or HAART, for Highly Active AntiRetroviral Therapy.

Will I have to start medications right away?

Having HIV doesn't necessarily mean you have to take medications right away. As long as your immune system is still healthy enough on its own, you may not need to take antiretrovirals.

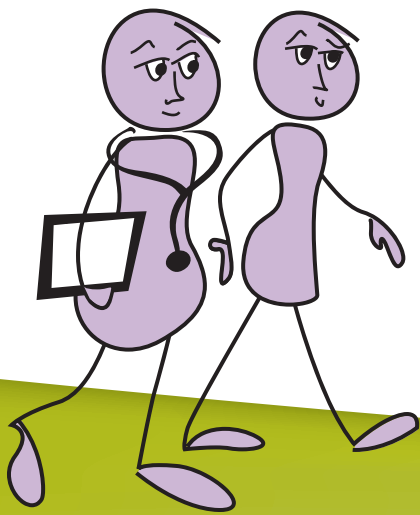
However, most HIV-positive people have to start medications at some point, to avoid getting AIDS. How long you can wait depends on a lot of things. Everyone is different, and some people can be HIV positive for a very long time (10 years or more) without being in danger of developing AIDS.

You and your doctor will make the decision to start treatment based on your blood test results and your symptoms.

Your blood can tell you a lot about what's going on in your body. If you've tested HIV positive, you'll be having blood drawn from your arm at a lab for testing. Your regular blood work will check for many things, but two of the most important factors are your **CD4 count** and your **viral load**.

What is a CD4 count and what does it tell me?

CD4 cells are the "bosses" of the immune system. They organize the battle against invading germs and viruses. Your CD4 count tells you how many CD4 cells you have: a "normal" CD4 count is anywhere from 600 to 1,200 cells/mm³. That's how many CD4 cells are in a "cubic millimetre" of blood (about the size of a grain of rice).



If you have HIV, your CD4 count will probably be lower than normal. That may be OK—your immune system can still keep you healthy even with a CD4 count below normal. But a count of 200 or lower means a much greater danger of getting sick. Staying healthy means keeping your count well above 200.

CD4 counts are one of the biggest factors in deciding when to start treatment. When your CD4 count dips too low, your doctor will likely talk with you about your treatment options. You'll also talk about treatment if you've already got serious HIV-related symptoms, no matter what your CD4 count is.

It's a good idea to keep track of your CD4 counts on your own so you can see the patterns over time. You might want to ask your doctor for a copy of your blood test results.

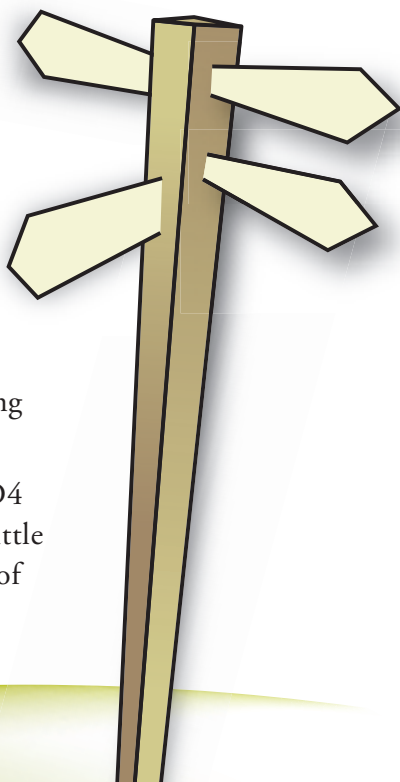
Why would my CD4 count fall?

We mentioned that CD4 cells are the “bosses” of your immune system. The reason HIV is so serious is because it actually attacks the CD4 cells—the very thing your immune system depends on to stay strong and keep you healthy.

During infection, HIV enters your CD4 cells. HIV then turns these cells into little factories that make lots of new copies of the virus. The CD4 cells are killed in

CD4 count

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



the process, and this happens over and over again. Over time, your body can't produce enough CD4 cells to replace the ones killed, and so your CD4 count falls.

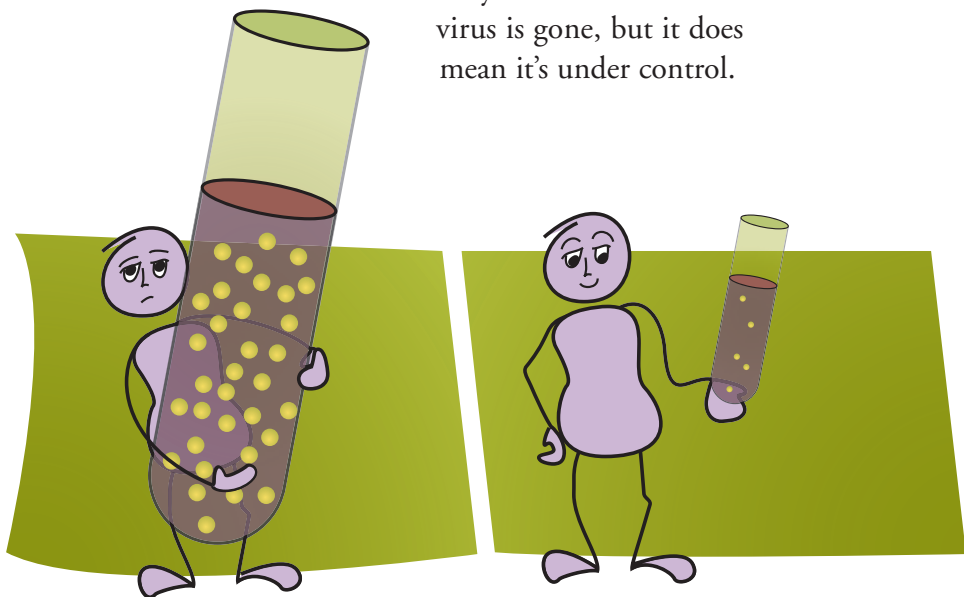
What is a viral load and what does it tell me?

Your viral load tells you how much HIV is in each “millilitre” of your blood (about the volume of a kidney bean). If you're not on treatment, your viral load could vary widely—anywhere from a few thousand or less to a million or more. Although a lower viral load usually means you stay healthier longer, this link varies a lot among people.

If you're on treatment, your viral load is a surefire way to know whether the drugs are working. If your treatment is successful, your viral load will fall to “undetectable”—too low for tests to measure. This doesn't mean you're cured or that the virus is gone, but it does mean it's under control.

Viral load

Your viral load shows how active the virus is in your body: the lower the number, the better.



What are opportunistic infections?

We said before that you can get serious diseases if HIV goes untreated long enough. Maybe you found out you have HIV in the first place because you had one of these diseases. There are too many to list here, and they tend to have tongue-twisting names like *Pneumocystis jirovecii* (or they go by mysterious short-forms like PCP and MAC). Don't feel dumb if you haven't heard of them (or can't pronounce them)—they were uncommon until HIV showed up.

Such diseases are rare because people with healthy immune systems can usually fight them off. However, these diseases can strike if they have the opportunity; that is, they infect people with weakened immune systems. For that reason, they are called **opportunistic infections** (OIs for short).

A lot of HIV-positive people used to die from OIs, and some still do if they can't get treatment. But OIs are much more rare than they used to be, simply because HIV treatments have gotten so much better. As long as you are diagnosed early and get proper treatment, you shouldn't have to worry about OIs.

If you found out about your HIV infection because you had an OI, you might consider learning more about the infection and what you can do to stop it from coming back.

What can I do next?

There is, of course, plenty more to learn and plenty more to do. But knowing the basics about HIV disease should help you tackle the things that come next.

There's so much information out there about living with HIV that keeping up with it could almost be a full-time job. 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 your "next steps," you can break them down into a few major areas:

Keep yourself healthy. Start learning about the ways you can take control of your health, from eating well to managing your stress. Protect yourself from other infections by practising safer sex and safer injecting. Finally, learn about antiretrovirals so that when it comes time to start treatment, you can make choices that are right for you.

Keep the people around you healthy. Learn how HIV is transmitted so you know how to avoid passing on the virus to other people. Practise safer sex and safer injecting.

Get connected. Find out about services for people with HIV in your area. If you picked up this brochure at an AIDS service organization, talk with someone there. These places offer support and information and can help connect you with

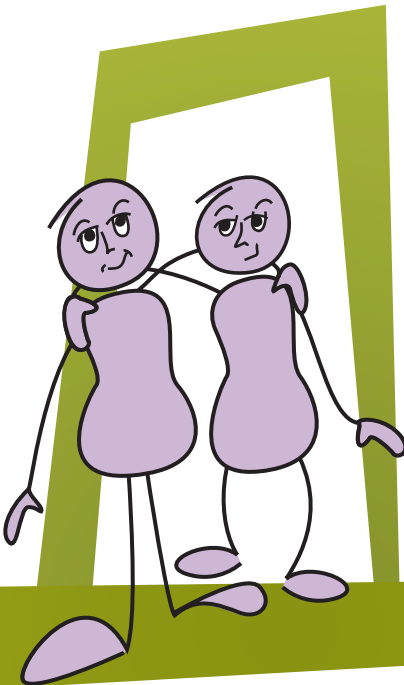
more info

There are many good sources of information about living with HIV: your doctor, your local AIDS service organization and CATIE (www.catie.ca).

other HIV-positive people if you want. Talking to someone who is HIV positive can be a good way to deal with the stress of living with the virus.

There are many ways to find your local organization: you can contact CATIE, Canada's source for HIV and hepatitis C information, at www.catie.ca or 1-800-263-1638. You can also visit www.aso411.ca or www.cdnaids.ca, the Web site of the Canadian AIDS Society.

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 forget about being HIV positive for a little while.



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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 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 the Toronto People With AIDS Foundation or CATIE, however, is not to be considered medical advice. We do not guarantee the accuracy or completeness of any information published by the Toronto People With AIDS Foundation or CATIE. Users relying on this information do so entirely at their own risk.

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