

Your Guide to HIV Treatment



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Introduction

Simply put, HIV treatment is a lifesaver. There is no cure for HIV but there are medications that can keep the virus under control and allow you to stay healthy for a long time.

If left untreated, HIV weakens the body's defences against infections and some cancers. But by taking HIV medications every day, most people can control the virus, protect their immune system and prevent infections from developing. With proper treatment and care, most people with HIV can stay healthy and live a long, full life.

We also know that taking HIV medications every day and maintaining an undetectable viral load (while getting proper HIV care) is a highly effective way to reduce the risk of HIV transmission.

If you've just picked up this booklet, maybe you were recently diagnosed with HIV and are about to start treatment. Or maybe you're already on HIV treatment and would like to learn more about it. Either way, this resource is for you! We hope it will also be useful for those who support people with HIV—partners, family members and friends as well as doctors, nurses, pharmacists, counsellors, educators and other service providers.

What you'll find in this guide

These pages explain what we know about HIV treatment. What is it? How does it work? What has changed? (A lot has changed, and for the better!) We also explore the health benefits of starting treatment early and what we know about how treatment can prevent the transmission of HIV.

Throughout this guide, you will hear from people living with HIV who have walked the path you're walking now. And at the end of the guide, you will find a list of resources you can turn to if you wish to learn more.

What is HIV treatment?

HIV treatment goes by many names: combination therapy, antiretroviral therapy (ART), highly active antiretroviral therapy (HAART) and HIV meds, to name just a few. In this guide we use mostly the term *HIV treatment*.

HIV treatment involves taking a combination of drugs—usually three or more—every day to keep you healthy. Although many people take just one pill once a day, that pill contains several different drugs.

With many HIV drugs and many combinations available, you are likely to find a treatment that works for you, with minimal or no side effects.

Ultimately, effective HIV treatment and care allows people with HIV to live full and healthy lives.

I had read blogs about atrocious side effects and met people from the early days of treatment who told horror stories of a time not-so-long passed. For me, this is what HIV treatment represented....

As time went by, taking my meds became a part of my routine, as second nature as brushing my teeth or going to the bathroom. I realized that all of the fears I had had were no longer relevant, at least not for me.

“

When my viral load became undetectable, it gave me the sense of empowerment I had lost when I was first diagnosed. My fear and anguish dissipated and I felt more like the person I used to be.

”

Five years later, without having missed a dose, I don't view taking my meds as a reminder of something negative but rather as something that gives me control over my health—for maybe the first time ever.

—Jonathan

A better pill to swallow

HIV treatment has come a long way! If you've heard scary stories about the HIV medications of yesteryear—handfuls of pills that need to be taken several times a day and cause unpleasant side effects—rest assured that newer drugs are far more effective, safer, easier to tolerate and much simpler to take. HIV treatment, and what we know about it, has changed dramatically in the past few years. You'll be glad to know it's largely a good news story!

Several **very effective** HIV medications that are **easy to take** and have **few side effects** are **available** for all Canadians.

Not only have the medications themselves improved but so has our knowledge about treatment. In recent years we have learned that it is best for your health to begin treatment as soon as possible after being diagnosed. No more waiting around for the best time to start, no more weighing the pros and cons. Research has clearly shown that starting treatment early decreases your risk of developing serious illnesses. **Starting treatment early is good for your long-term health and your lifespan.**

And there's more good news: We've also learned that continuous care and **HIV treatment that keeps your viral load undetectable prevents the sexual transmission of HIV.** In other words, if you see your doctor regularly and keep taking your HIV treatment so that your viral load stays undetectable (HIV is still in your blood but at levels too low to be detected by routine tests), you do not pass on HIV to partners during sex.

We also know that HIV treatment can greatly lower the risk of HIV transmission from an HIV-positive mother* to her baby during pregnancy and childbirth, allowing HIV-positive women to have healthy pregnancies and give birth to HIV-negative babies. Research has also shown that treatment can help prevent HIV transmission for people who share equipment to use drugs.

So HIV treatment is good for you and for the ones you love. As someone living with HIV, starting and staying on treatment is one of the best things you can do for your health.

* We have used the words *mother* and *woman* in this guide but we recognize that some people who can get pregnant and have babies do not identify as women.



Knowing your status is a good thing.... You're still the same person you were before you were diagnosed. Get your meds and health in order and you'll be doing better than the average person.



—Jon



1. The benefits of HIV treatment

HIV treatment helps people who are living with HIV stay healthy. It does this by suppressing HIV's ability to make copies of itself. When you take HIV medications every day as prescribed, see your doctor regularly and maintain an undetectable viral load, treatment:

- can control the virus and allow your immune system to rebuild itself—the benefits are especially significant if you start treatment early
- can prevent the transmission of HIV to your sex partner(s)
- allows women living with HIV to have healthy pregnancies and give birth to HIV-negative babies
- can dramatically reduce the chances of passing HIV when sharing equipment to use drugs

It's good for your health!

We now know that there are huge benefits to starting HIV treatment early, before the virus has had a chance to do much damage to your immune system. The earlier you are diagnosed with HIV after infection and the earlier you start treatment, the better. This is true whether your CD4 count is high or low.

A large study, called the START trial, confirmed this. Researchers enrolled 4,685 participants from 35 countries. The study participants were randomly assigned to two groups: The first group started treatment immediately while the second group waited until their CD4 counts dropped to below 350 or until a serious illness developed. (A CD4 count is one measure of how strong a person's immune system is. A blood test is used to measure how many CD4 cells a person has in their blood.) The participants who started treatment immediately significantly cut their risk of developing serious illnesses, such as cancer and life-threatening infections. This was true regardless of the sex, age, race and ethnicity of participants.

These findings confirm that the benefits of starting treatment early clearly outweigh the possible risks.

As a result of this groundbreaking research, Canadian treatment guidelines now recommend that HIV treatment be offered immediately to all people diagnosed with HIV.

“

What I try to tell my patients is that an HIV diagnosis is significant—it's not something to trivialize—but if you get on effective antiretroviral therapy and we work on this together, you'll be around well into old age. We'll both be hobbling around my office together when we're 102!

”

—Dr. Lisa Barrett,
Infectious diseases specialist



Preventing sexual transmission

Another huge benefit of taking HIV treatment and maintaining an undetectable viral load is that it can prevent HIV from being passed to the people you have sex with. The science we have to back this up is solid.

Two large studies, called HPTN 052 and the PARTNER study, showed that when HIV-positive people who maintained an undetectable viral load had sex with HIV-negative people, **not a single transmission occurred.** (All of the study participants went for regular healthcare appointments to check their viral load, get tested for other STIs and receive adherence support.)

The HPTN 052 study followed 1,763 heterosexual mixed status couples (one partner was HIV-positive and the other HIV-negative), at 13 sites in nine countries. These couples were having mostly vaginal sex. No HIV transmissions occurred between partners when the HIV-positive partner was on treatment and had an undetectable viral load.

The PARTNER study followed 888 mixed-status couples, at 75 research sites in 14 European countries. This study included both gay and straight couples. All of the HIV-positive participants were on treatment and had an undetectable viral load. Although the couples had unprotected sex—meaning, they did not use condoms, PrEP (pre-exposure prophylaxis) or PEP (post-exposure prophylaxis)—at least 58,000 times, no HIV transmissions occurred between the couples enrolled in the study.

Neither the presence of sexually transmitted infections (STIs) nor possible viral load blips between tests enabled transmission.

Although a small number of people were infected with HIV in both studies, these infections either came from a sex partner outside of the relationship or occurred when the HIV-positive partner had a detectable viral load.

Because of these findings and results from other studies, we can confidently say that **taking HIV treatment and maintaining an undetectable viral load is a highly effective way to prevent HIV transmission during sex**. With or without condoms, if you're undetectable, you won't pass HIV to your sex partners. For many people, this is life-changing—transforming the way they feel about sex, their relationships and themselves.

PrEP: HIV-negative people using treatment as prevention

HIV-negative people who are at high risk for HIV transmission can take certain HIV medications to dramatically lower their risk. This prevention method is called PrEP (pre-exposure prophylaxis). PrEP involves taking Truvada before exposure to HIV and continuing afterwards. Research shows that when used as prescribed, it is extremely rare for an HIV-negative person to become HIV positive when using PrEP.

Once on PrEP, it's important to see a healthcare provider every three months to get tested for HIV and other sexually transmitted infections (STIs) and to check for side effects. The healthcare provider will also monitor kidney and bone health.

Many people who take PrEP experience no side effects. For those who do, the side effects tend to go away as their body adjusts to taking the medication. Because the use of Truvada for PrEP is relatively new, we do not yet know the long-term side effects.

Preventing mother-to-child transmission

HIV treatment can also prevent the transmission of HIV from a mother to her fetus or child during pregnancy or when giving birth.

Before effective treatment was available, about one in four babies born to HIV-positive mothers was born HIV-positive. But now, with proper treatment and care, the chance of a child becoming HIV-positive is less than 1%.

Canadian treatment guidelines recommend:

- HIV medicine for the mother during pregnancy and labour
- HIV medicine for the baby for a short period after birth
- vaginal delivery for most pregnancies, and in some cases a C-section (surgery to remove the baby from the uterus)
- feeding the baby formula and not breastfeeding

Breastfeeding still carries a small risk for HIV transmission even if the mother's viral load is undetectable. If you're pregnant or thinking of getting pregnant, talk to your doctor about safe alternatives to breastfeeding (subsidized baby formula is available for mothers living with HIV in some parts of the country). You and your doctor should discuss all decisions about your treatment, pregnancy and delivery.

All of these new findings about the benefits of HIV treatment have huge implications for living well with HIV. If you have questions about HIV treatment, its role in prevention and what this means for you, talk to your HIV doctor or call CATIE toll-free at 1-800-263-1638.

2. How does treatment work?

HIV treatment keeps you healthy by suppressing the amount of HIV in your blood.

When left untreated, HIV infects CD4 cells and other types of cells in the body. It uses these cells to make millions of copies of itself, which then go on to infect other cells. This process, called viral replication, eventually damages your immune system, lowers your CD4 count and leaves you vulnerable to serious infections and diseases. The goal of HIV treatment is to stop this process and reduce your viral load.

How does it do this? There are several different groups, or classes, of drugs and each class attacks the virus in a different way. Your treatment will include drugs from different classes, to fight the virus on different fronts.



Soon after a person starts taking HIV treatment, viral replication slows down dramatically. The assembly line for producing more HIV essentially slows to a crawl. Since very few new copies of the virus are now being created, the amount of HIV in your body—your viral load—drops. Most people’s viral loads fall to undetectable levels within three to six months of starting treatment.

Suppressing HIV in this way allows your immune system to regain its strength. Your CD4 count rises, the risk of serious infections drops, and any symptoms of HIV infection that you may have experienced diminish or disappear.

Undetectable≠cure

An undetectable viral load (viral load is the amount of HIV measured in a person’s blood) does not mean that the virus is completely gone. Soon after a person becomes infected with HIV, the virus finds its way inside cells deep in the immune system and in certain organs such as the brain.

Current HIV treatments have difficulty penetrating the brain and other organs, as well as the immune system, and HIV can remain dormant or replicate there at very low levels. However, early diagnosis of HIV followed by immediate treatment means that HIV has less opportunity to penetrate deep into the immune system and establish these reservoirs.

Despite scientists’ best efforts, they have not yet found a way to eliminate HIV from deep within the immune system and from certain organs. Much research toward a cure for HIV focuses on this challenge. But, for now, HIV is a lifelong infection and HIV treatment is a lifelong commitment.

Different classes of HIV drugs

Two of the drugs used in many HIV treatment combinations belong to a class of drugs called **nukes** (nucleoside analogues, or NRTIs). Because the two nukes in a combination usually need to be taken at the same time, drug manufacturers have produced several co-formulations—that is, two or more nukes in a single pill, such as Truvada (tenofovir + FTC) and Kivexa (abacavir + 3TC).

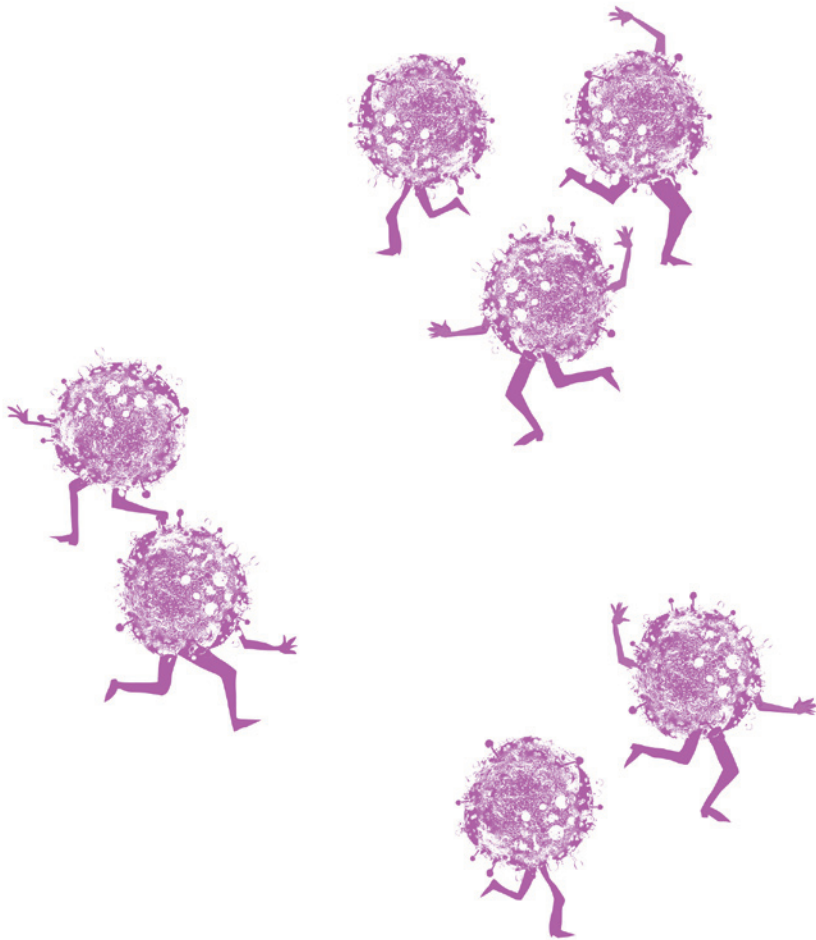
A third drug from a different class is added to these two to create an effective combination that attacks HIV at different points.

Integrase inhibitors, another class of antiretroviral drugs, have several advantages: When taken as part of combination therapy they quickly suppress the amount of HIV in the blood. They generally cause relatively few side effects and are less likely to interact with other medicines.

Protease inhibitor (PI)–based combinations tend to involve more pills than other combinations and may have to be taken with food. One advantage of PIs is that if your HIV develops resistance to one PI, other PIs can still be effective, providing future treatment options.

A small dose of another drug—either ritonavir (Norvir) or cobicistat—is almost always added to a PI combination. This is called “boosting” because it boosts the levels of the PI in the blood, and usually allows for once-daily dosing. Note that “boosters” can interact with recreational drugs, such as ecstasy, crystal meth, K, benzodiazepines and erectile dysfunction drugs such as Viagra.

Non-nukes are another class of antiretroviral drugs. Resistance to a non-nuke sometimes develops more easily than to drugs from other classes, and HIV that is resistant to one non-nuke is sometimes resistant to other drugs in this class.



The only **fusion inhibitor** currently available is T-20 (enfuvirtide, Fuzeon). This powerful drug, which has to be taken twice a day by injection, is currently used only rarely—by some people who have developed resistance to many other HIV drugs.

Similarly, **CCR5 inhibitors** are used mostly by people who have previously tried other treatment combinations. A simple screening test can determine whether a person has the strain of HIV against which this class of drug is effective. If so, CCR5 inhibitors may be an option.

Finding a treatment that's right for you

The ideal treatment combo is one that:

- effectively suppresses the virus—that is, reduces your viral load to an undetectable level and keeps it there
- restores your CD4 counts
- causes minimal side effects
- is easy to take (few pills and an easy schedule)

Depending on your health conditions and life situation, some drugs may be more suitable than others. In the section “Starting treatment” (page 26), we take a look at the factors that will help you pick a combination that's right for you.

3. Your healthcare team

Your healthcare team will play an important part in making your HIV treatment successful. You will be seeing your doctor regularly (if you're not already), and together you will chart the course of your HIV treatment and care. If possible, try to find someone who is knowledgeable about HIV, who you can trust and be open with.

Your doctor

Some people see a **general practitioner** (GP) or family physician who is knowledgeable and has experience treating people with HIV. Others see an infectious diseases **specialist** or immunologist to treat their HIV, while their GP deals with other health issues.

Ideally, you will want to choose a doctor who is experienced in treating HIV and takes the time to stay up-to-date on all the latest information. In larger cities, it tends to be easier to find a family physician with HIV expertise. Unfortunately, in some parts of Canada, including some smaller cities and rural areas, it can be more difficult. If you need some help finding a doctor, your local HIV organization is a good place to start. You can also visit HIV411.ca.



If you have the option of choosing between doctors, consider interviewing them and asking them about everything that's important to you. You'll want a doctor with whom you feel comfortable and are able to talk freely, one who will answer your questions respectfully.

When talking with your doctor, remember that there are no stupid questions. If your doctor says something you don't understand, ask her or him to explain things more clearly or use simpler language.

Discuss your treatment thoroughly with your doctor: what kind of results you can expect, possible side effects and how to deal with them, and if there are alternatives to consider. You might want to bring a partner, friend or family member with you to help you recall details of the appointment. You might want to take notes or even ask if you can record the conversation so that you can review it later.

There are also things you can do to keep track of your health between doctor's appointments:

Your Personal Health Record

A Personal Health Record or app can help you keep track of your treatment and any health issues that might arise. You can use it to keep all of your health information together in one place—to have a record of your prescriptions and appointments, to collect and review your various test results, to look for trends over time and ensure that everyone on your healthcare team has the same information. You can record information in case of an emergency, a list of your healthcare providers, your allergies and the questions you want to raise at your next appointment.

You can find a sample Personal Health Record at www.catie.ca. You might want to print off multiple copies. Or feel free to use it as a starting point and adapt it to your needs.

Other healthcare team members

Your healthcare team doesn't end with your doctor. Your clinic may have **nurses** on staff, as well as other professionals, such as **social workers, therapists** and **peer counsellors**. These people all have valuable skills to contribute to your care and can often give advice on practical matters, like paying for drugs or drug adherence. What's more, they may have more time to talk to you. For example, your nurse may be able to answer a question when your doctor is busy.

You will also be seeing a **pharmacist** whenever you go to pick up your medications. Because pharmacists are generally more readily available than doctors, many people with HIV rely on their pharmacists for information about their treatment. Pharmacists can help you keep track of your drugs so that you can avoid allergies or drug interactions. To avoid drug interactions, it's best to get all of your medications from one drugstore, especially if you are filling prescriptions from more than one doctor. Pharmacists can also provide useful suggestions for treatment adherence and on drug payment plans.



4. Starting Treatment

For the sake of your own sense of well-being and the success of your treatment, it is important to be prepared—practically, mentally and emotionally.

Before starting treatment, your healthcare provider will recommend blood tests to check for drug resistance and hypersensitivity. He or she will ask you about other drugs and supplements you are taking, to help ensure that the drugs you take all play well together. The HIV drugs you and your doctor decide on will also be influenced by other health conditions you may have.

Drug resistance

Drug resistance refers to HIV that is resistant to certain HIV drugs and stops those drugs from working properly. Drug-resistant forms of HIV can sometimes be transmitted from person to person—so a person who has never taken HIV medications before can become infected with drug-resistant HIV. A person's HIV can also change and become drug-resistant. If a person who is on treatment misses doses, the virus can mutate and become resistant to the medication.

All people living with HIV should have a resistance test done before they start treatment, and, in most cases, before switching to a new treatment. Resistance testing can identify medications that may not work against the HIV in your body. Drug-resistance testing can help you and your doctor determine which medicines to include in your HIV treatment regimen.

Hypersensitivity

You may be allergic, or hypersensitive, to certain drugs. For example, some people are hypersensitive to abacavir (Ziagen, ABC, also found in Kivexa, Trizivir and Triumeq). A simple blood test, done before you start treatment, can determine whether you're likely to have a potentially dangerous reaction to abacavir. If your test result is positive, you can cross that drug off your list of choices. If your test result is negative, a reaction is still possible but the risk is low.

Ask your doctor about the signs of a hypersensitivity reaction so that you can seek medical help should you have such a reaction to abacavir or another HIV drug.

Drug interactions

When one drug alters the effect of another drug—intensifying the side effects or producing new side effects or making the drug less effective—this is known as a drug interaction. It is important to choose HIV medications that do not interact with other drugs you take.

Talk to your doctor(s) and pharmacist about all the different drugs you're taking—including prescription drugs, over-the-counter drugs, street drugs, herbal and nutritional supplements—so they can advise you about possible interactions. In some cases, there are drugs that cannot be used together. In other cases, it may be possible to use certain drugs together provided you make certain adjustments (for example, change the time when you take one of them).

Pregnancy

If you are pregnant or hoping to get pregnant, be sure to let your doctor know, so that this can be taken into consideration when choosing the best HIV treatment for you.

Other health conditions

Be sure to let your doctor know...

- if you have any risk factors for cardiovascular disease (such as smoking, high cholesterol levels, obesity, a parent or sibling who has had heart disease, or you use street drugs such as cocaine or amphetamines) because HIV and some HIV medications can increase your risk of heart disease. A good combination for you will avoid these drugs.
- if you have hepatitis B or C or other liver problems, kidney injury, tuberculosis, depression or other mental and emotional health issues, as certain drugs may not be recommended.

Side effects

With the newer HIV medications, many people experience no side effects whatsoever. Plus, we now know that the sooner you are diagnosed with HIV and the sooner you begin HIV treatment (in other words, the shorter the time between infection and starting treatment), the less likely you are to experience major side effects from your medications.

Still, side effects are to some extent the luck of the draw: You may get them, you may not. If you do experience side effects, they may go away in a short time on their own or you may be able to manage them with an over-the-counter treatment, such as acetaminophen for headaches or an antihistamine for rashes. Each drug in your HIV combination is associated with various side effects, some more common and some very rare, but that doesn't mean you will experience all or any of them.

I had the worst side effects from my [old] meds.... I started my new meds in August 2012. Thank goodness HIV meds have improved. I experience no side effects whatsoever. My meds and I are now getting along just fine.

—Gladys



When deciding on my first combination, I was lucky because I had several options. I was worried about changes to my body and I wanted something that was simple to take.... In the beginning, I had weird dreams and my mood changed. Those side effects come back from time to time, but mostly I'm happy with my choice.

—Ladidee



Ask your doctor about the most common side effects for the drugs in your combination. Discuss ways you might be able to minimize some of these side effects, should you experience them. Pharmacists are also a good source of information.

Other things to consider when starting treatment include: What will help you stick to your pill-taking schedule? When and where will you take your medications? And how will you pay for treatment?

Adherence

To keep your treatment working, you will need to consistently stick to your pill-taking schedule. It can be a challenge at first to get used to taking medications every day. Think about your daily routine and whether you'll have to make any changes to accommodate your pill-taking schedule. Knowing about the benefits of treatment can help inspire you to pop your pills. There are also many tips, tricks and supports out there that can help you (see "Adherence is key" on page 35).

Work and social situations

Do your family, friends, co-workers or roommates know your HIV status? Could taking meds or having them around your home or workplace be a problem? If so, think about strategies to avoid having to disclose your HIV status to people with whom you are not comfortable sharing this part of your life. Where you will keep your medications? When and where you will take them?

Scheduling doses

It is important to choose a treatment that fits well with your schedule. For example, many HIV drugs do not have food requirements but some should be taken with food and others, on an empty stomach. Talk to your doctor about how your treatment can fit with your lifestyle. Today HIV treatment is easier to take than ever before. Many people take only one pill a day.



Know your lifestyle and habits and don't be afraid to talk about them with your doctor. This could help identify the treatment that will best fit your life. And don't lose sight of why you are taking HIV treatment. The pleasures of the days and years to come make the little hassles worthwhile.

—Ken



Paying for treatment

To cover the cost of HIV drugs, most people with HIV rely on drug insurance plans—either private plans (usually through work) or provincial or territorial plans. Some people are covered under plans from the federal government. These people include refugees, members of the military, federal government employees and retirees, federal prisoners and designated Indigenous people who are living on reserves.

Which drugs are eligible for coverage varies from plan to plan. If you have private insurance, contact your insurance company to find out which antiretroviral drugs are covered under your plan and ask about the terms of coverage. To find out about provincial, territorial and other drug benefits, talk to your doctor.

Each province and territory has a list called a *formulary* that includes all the drugs covered under its plan. Most antiretroviral drugs are covered on most provincial and territorial formularies. However, there may be special conditions or restrictions—for instance, certain drugs may not be covered unless you have tried other drugs first. Also, it may take some time for a newly approved drug to be included on a formulary.

There are ways you can get financial assistance even if certain drugs are not covered by your private, provincial or territorial plan, so don't despair. Your doctor, pharmacist or local HIV organization can give you more information about paying for HIV drug treatment.

What should your first combination be?

The group of possible drugs for your first combination is fairly well defined. Currently, treatment guidelines recommend several possible initial (or first-line) combinations.

But new HIV treatments are constantly being developed and treatment guidelines change. For the latest recommended treatment combinations, visit aidsinfo.nih.gov/guidelines and click on “Guidelines for the Use of Antiretroviral Agents in HIV-1-Infected Adults and Adolescents”, call CATIE toll-free at 1-800-263-1638 or talk to your doctor.

5. Making treatment work

Once you've started taking HIV medications, you will want to make sure your treatment is working well. In this section, we discuss some things that will help you do this. Taking your pills as prescribed (adherence) is crucial to the long-term success of your treatment. We offer some tips and tricks that others have found useful. You and your doctor will also monitor your health to make sure your treatment is doing its job.

Adherence is key!

Nowadays HIV treatments can be very simple: Many people need to take just one pill a day to keep their virus under control. But one thing that hasn't changed is the reality that HIV treatment is a lifelong commitment that requires taking medication every day, exactly as prescribed. This is called adherence.

Your treatment will only work if you take it each and every day. Sticking to your pill-taking schedule is important because these drugs leave the body quickly and you need to have a certain amount of HIV medication in your blood to keep the virus suppressed. If you miss taking too many pills and develop resistance to these drugs, they will no longer be able to control your HIV. While there are other combinations that might work for you, it's best to keep your current treatment working for as long as possible.

Your doctor and pharmacist should be able to help you adhere to your pill-taking schedule, so be sure to discuss this with them.

Here are some tips you might find useful:

- Take your medication at the same time(s) each day.
- Set the alarm on your cell phone or watch to remind you to take your pills. This can be especially useful when you are travelling. Or carry a small medication “beeper” (talk to your pharmacist about getting one). There are also many apps out there that can remind you it's pill time.
- Keep your medications near your bed, in a kitchen cupboard you open frequently or somewhere you are likely to see them and remember to take them.
- Keep a small supply of medications in places you frequently visit—at your family's or partner's house, and possibly at your workplace.
- If you're taking a trip, plan ahead. Pack the number of pills you'll need for the time you will be away plus a few extra doses in case your plans change. When flying, always take your pills and your prescription carry-on. Do not pack them in your checked luggage. If your luggage were to get lost, you'd be without your meds.
- Use plastic pill boxes (“dosettes”) for storing a week's worth of your pills. Some pharmacies will package your pills in blister packs according to your daily dosing schedule.
- Make sure you don't run out of your medications.
- Talk to other people living with HIV and learn from their experiences.
- Develop a network of people who can support you and help remind you to take your medications.

All my patients know my pill-taking mantra: “If you take this, it will work, and it will probably work forever. So let's work together to get you (or keep you) taking your antiretrovirals every single day. Text reminders, apps, alarms, stickie notes, whatever it takes.” I tell people that most of us have bigger commitments than taking a pill once a day and going for regular checkups. With effective treatment and ongoing care, HIV can be very manageable.

—Dr. Lisa Barrett
Infectious diseases specialist

If you are having trouble taking your drugs as prescribed, don't be afraid to ask for help. Maybe you're feeling down and depressed, maybe you travel a lot, maybe your life isn't so stable these days or you use substances, or maybe it is not safe to keep your pills out in the open in your home... These things can all affect your adherence. Or maybe you just find it hard to remember your meds every day! You are not the only one. Talk to your doctor, nurse or pharmacist and to people at your local HIV organization to figure out how they can support you.

Adherence can be challenging! Missing an occasional dose is not the end of the world, so don't panic. Do the best you can to get back on track: You'll keep your drug combination working for as long as possible and do yourself the most good in the long run.

Monitoring your health

Regular visits with your doctor to monitor your health are part of living with HIV. At these visits, you can ask questions and talk about any changes in your body that you may be experiencing. Your doctor may do a physical exam to follow up on specific issues.

You will also get blood drawn at the lab every few months, particularly in the first year of treatment. Your blood will be tested for several things. Two important blood tests will be done to measure your **viral load** and your **CD4 count**. Other routine tests can spot potential health issues even if you have no noticeable symptoms.

How you're feeling – Every time you see your doctor, tell him or her how you have been feeling, especially if you have noticed anything new or unusual. This can also include changes in your mood and mental health: If you've been feeling down or depressed, say so. Your doctor will probably follow up with some questions.

Your viral load – Your viral load is the amount of HIV in your blood. A viral load test measures the amount of HIV in a sample of blood. The results are reported as the number of copies of HIV genetic material (called RNA) in a millilitre of blood (copies/ml—a millilitre is about the size of a pea). Without treatment, a person's viral load can be as high as millions of copies/ml.

The standard tests in Canada can measure levels as low as 40 to 50 copies/ml. Below this level, your virus is considered undetectable. (There are more sensitive viral load tests, but these are used only in specialized labs and in some clinical trials.)

Your viral load is the most important measure of whether or not your treatment is working. The main goal of treatment is to reach an undetectable viral load as soon as possible and to keep it that way.

An “undetectable” viral load does not mean that there is no HIV in your body. It means that the amount of HIV in your blood is too low to measure using routinely available tests. If you miss doses, stop taking your treatment or if the HIV in your body becomes resistant to your antiretroviral drugs, your viral load will once again become detectable (that is, greater than 40 or 50 copies/ml). In this case, you may need to change your treatment.

Your CD4 count – Your CD4 count is one measure of how strong your immune system is—that is, how well you are able to fight off infections. CD4 counts generally drop as HIV does more damage to your immune system and they go up as your immune system regains its strength with treatment.

A normal CD4 count in a healthy HIV-negative person is generally somewhere between 500 and 1,500 cells. The sooner you start treatment, the more likely your CD4 count is to stay high or increase to a high level.

Generally, you should get your CD4 count checked every three to six months. CD4 counts are measured in cells per cubic millimetre (cells/mm³—a cubic millimetre is about the size of a pinhead).

My GP [general practitioner] is a compassionate doctor who spends extra time listening and talking to me, as he knows I've struggled with depression. He's there to help and support me.

—Randy

I feel good when I get that undetectable result every three months. It's always the first thing I ask my doctor about. It means that I don't have to change my treatment and that everything is fine until the next time I get my viral load checked. It's encouraging, a positive affirmation that I'm doing well. I have multiple drug resistance, so not having to change my regimen is a great relief.

—Murray

How to tell if your treatment is working

HIV treatment should bring down your viral load to an undetectable level and it should increase your CD4 count.

Your viral load should become undetectable and it should stay there. For most people, it takes three to six months, though for some people it takes less time and for others it can take longer. Some people see occasional **blips** in their viral load. A “blip” is when your viral load becomes detectable at a very low level on one test and then becomes undetectable again on the next test. A single blip is not cause for alarm, but two detectable measurements in a row may be a sign that your treatment is no longer working. Certainly it is a signal that you and your doctor should talk about why this might be happening.

If your CD4 count had already dropped when you were diagnosed with HIV, it will probably take more time for your CD4 counts to rise than it takes for your viral load to drop. Once HIV is successfully suppressed, your immune system should rally and your CD4s increase.

Your healthcare team can help make your pill-taking schedule manageable, and if you experience side effects, they should be able to help you deal with them.

Many people who felt ill as a result of HIV begin to feel better after starting treatment. And their health improves. People on treatment often feel more confident about their health, their sex lives and as people living with HIV.

Stopping treatment?

In a word: Don't! HIV treatment is an ongoing, lifelong necessity. This is because HIV can stay inside infected cells of the body for a very long time and the whole process of HIV replication speeds up once treatment is stopped.

If for some reason you need to stop treatment for a limited period, your doctor can advise you how to do this so that drug resistance does not develop.

“

I've had a few blips over the years but when we've done a followup I've been undetectable again every time. When there's a blip, I get concerned but I don't worry that we won't be able to manage it. I feel like everything is easier to manage now when it comes to my HIV. My focus now is on living longer and growing older with HIV and all of the issues that come along with that.

—Murray

”

“

Being undetectable gives me hope for more options in the future. It means keeping infections at bay. It lets me focus on things other than the fact that I'm a host to HIV.

—Tracy

”

When I was diagnosed, I had a low CD4 count and a high viral load. It didn't take long before my CD4s were in the high 1,200s and in six months my viral load was undetectable. Besides having to remember to take one pill a day, my life is virtually unaffected by the disease. I've been fortunate enough to fall in love with someone who is negative and our relationship is just fine.

—Jon



6. Changing Your Treatment

Sometimes you may have to, or simply want to, change your HIV treatment. This could be for any number of reasons:

- Sometimes treatment doesn't succeed in controlling HIV—a person's viral load does not drop to an undetectable level or it does drop but then climbs back up to a detectable level.
- A person can't stand some aspect of the treatment—usually a side effect—even though their CD4 count and viral load are both good.
- A newer HIV treatment with fewer side effects and an easier dosing schedule has become available.

You will need to work with your doctor to make the necessary changes to your treatment. Don't stop any medications without talking it over with your doctor first. Suddenly stopping any drug could have consequences you don't expect, including your HIV becoming drug-resistant.

If your treatment doesn't work

Your viral load is the best way to know whether your HIV treatment is working. If your treatment is successful, your viral load should drop to an undetectable level and stay there. If your viral load remains detectable six months after starting HIV treatment, this may mean that your treatment is not working. Or, if you've been on treatment for a while with an undetectable viral load and then your viral load becomes detectable and stays that way, it's likely that your treatment has stopped working.

You and your doctor will have to find out why your treatment isn't working. The most common reason, though not the only one, is that too many doses are being missed. You will also need to know whether your virus has developed resistance to one or more of the drugs you are taking.

Resistance tests can detect changes in the virus and predict which drugs are most likely to work for you.

If these tests show that you have drug-resistant virus, you and your doctor will need to pick a new combination, one that has the highest chance of controlling the virus in your body. For your next combination to be effective, you will need to identify which drugs are no longer working and replace them with drugs that will work against the virus. Ideally, the new combination should contain three fully effective drugs. Your doctor's expertise in these situations is crucial.

If you experience side effects

If your HIV treatment is successfully suppressing your viral load but you experience side effects, talk with your doctor about what you're experiencing.

Many side effects disappear after a few days or weeks. Others can be managed through over-the-counter medications or by changing the time of day when you take your drugs. Your doctor and pharmacist will likely have suggestions. Your doctor may suggest changing your treatment to one that will hopefully give you fewer side effects or none at all.

“

I'm still on my second cocktail and other than a kickass bout of depression... which resulted in me switching regimens, I've had no side effects. My viral load has been undetectable since a few months after starting treatment.

”

—Murray

If a new HIV treatment seems better

Some people take the “if it ain’t broke, why fix it?” approach to their HIV treatment. Others are looking for increased convenience and a treatment that fits well with their lifestyle. So, your HIV treatment may be working perfectly and you may be experiencing no side effects but you have heard about a new treatment that sounds easier to take or better in some way than your current one.

Talk to your doctor about new treatments you are hearing about and ask about new developments in treatment. Your doctor can help you decide whether it makes sense for you to change medications and can tell you how to go about switching treatments to avoid developing resistance.

Resources

HIV treatment information changes regularly. By the time you read this, there may be new information that could affect your treatment choices. When you’re looking for information about current treatment options, always reach for the very latest information—via treatment newsletters, websites, your local HIV organization and, of course, your doctor and healthcare team. At www.catie.ca you will find resources such as

- *The Positive Side* – a holistic health and wellness magazine for people living with HIV
- CATIE fact sheets – a set of up-to-date fact sheets with extensive information on different HIV medications and treatment topics.
- *Treatment Update* and *CATIE News* – In-depth newsletters on developments in HIV and hepatitis C treatment and research.
- *You Can Have a Healthy Pregnancy if You Are HIV-Positive* – An easy-to-read booklet for women with HIV who are pregnant or considering pregnancy.

At www.catie.ca you can also find resources about hepatitis C and sexually transmitted infections.

You can also call CATIE’s free information support line at 1-800-263-1638 to speak with one of CATIE’s knowledgeable educators. They can answer your questions about HIV treatment.

With that, we wish you the best with your HIV treatment. We hope this booklet has inspired you and given you confidence that you can live a long and healthy life with HIV.



Canada's source for
HIV and hepatitis C
information

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Toronto, ON M5V 3B1

1-800-263-1638

www.catie.ca



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.

CATIE provides information resources to help people living with HIV and/or hepatitis C who wish to manage their own healthcare in partnership with their care providers. Information accessed through or published or provided by CATIE, however, is not to be considered medical advice. CATIE endeavours 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 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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