

HIV and aging



HIV and aging

What gives me the most enthusiasm is still being alive and in very good health after more than 16 years. I'm here to say that it's possible to live with HIV and find a path that allows us to live in a positive way.

—Jacques, 63

It's great news that people with HIV are paying attention to issues around aging. It means we are surviving and getting older like the rest of the population! We need to take good care of ourselves, be proactive and pay attention to changes in our bodies as we age.





This booklet is for people 50 or older who are living with HIV, as well as their partners, family members, caregivers and service providers. It looks at some of the issues that older adults living with HIV might face and it recommends ways we can prevent disease and improve our overall health. A healthy body, mind and sex life are important at any age! The booklet also features the insights and advice of men and women in their 50s, 60s and 70s who are living with HIV.

You have only so many options of how you can deal with the disease. But the control you have is in learning everything you can about the disease and the options available to you to stay healthy. Then you can take control of making the right choices for you ...

—Louise, 53

People with HIV are living longer

Thanks to advances in treatment, people with HIV are living much longer than ever before. It is estimated that up to 12 per cent of HIV-positive people in Canada are 50 years of age or older. This number is expected to increase by as much as 20 per cent over the next decade. Unfortunately, the number of people 50 or older who are newly diagnosed with HIV is also growing.

Early diagnosis of HIV is important no matter what your age; however, the older you are, the more critical early diagnosis becomes. This is because HIV progresses more quickly in older people. The good news is that anti-HIV drugs appear to work just as well whether you are 52 or 25 years old. And studies show that age and better control of HIV seem to go hand in hand. If you are HIV-positive later in life, you are more likely to achieve and maintain an undetectable viral load than younger people with HIV, maybe because you are better at following treatment instructions. (An undetectable viral load means that the amount of HIV in your blood is so low that it cannot be detected by tests.)

Treating HIV can become more complicated as we get older. This is because the chances of having other health problems that also require treatment, such as high blood pressure, arthritis or even cancer, also increase with age. Taking several drugs at the same

time can raise your risk of drug interactions, side effects and toxicities. This is why it is especially important to carefully monitor the medications you are taking.

The side effects of anti-HIV drugs don't appear to affect people more as they get older, but they can be made worse by the side effects of other non-HIV drugs. Decreases in kidney and liver function that come naturally with age, changes in hormone levels and metabolism, as well as weight loss associated with aging can all increase the chance of an adverse drug reaction. Make sure your doctor is aware of any conditions you may have and all the medications and supplements you are taking. This will allow you and your doctor to work together to keep your HIV under control and manage any side effects from your medications.



My husband was in the hospital in 1993, very sick with pneumonia ... When [the doctor] looked at my husband's chart, he had the idea my husband might have AIDS. I gave permission for the test. It was positive.... back then he didn't have any symptoms of HIV infection. At our age, no one was even thinking about it ...

—Ana, 77

Is it HIV or is it age?

Many of the health changes that occur with aging can be similar to the symptoms of HIV as well as to the side effects of HIV treatment. Let's take a look at some of the health conditions associated with both age and HIV.

Changes to the immune system

When I tested positive in the '80s, there wasn't much hope. There was no medication available. It was a death sentence. You had maybe a few years. I wish I had known then that researchers were working on medications that would mean that you could one day lead a somewhat normal and productive life. That you could hold onto your dreams ...

—Christian, 53

As you age, your immune system becomes less effective at protecting your body from infection and disease. This is why HIV can progress more quickly in people who are older and why early diagnosis of HIV is so important. HIV also weakens your immune system. Because your immune system is your body's system for fighting off germs, a weakened immune system can make you more susceptible to infections and illnesses. HIV treatment can help strengthen your immune system, so that it is better able to fight off germs and keep you healthy.

Heart disease

Heart disease is a broad term that includes coronary heart disease, heart attack, stroke and other conditions that affect the heart and blood vessels. It is also sometimes called cardiovascular disease.

As you age, the risk of developing heart disease increases, whether you are HIV-positive or not. Women older than 55 and men older than 45 are at higher risk of developing heart disease. If a member of your family—your father, your mother, an uncle, an aunt or a sibling, for instance—has heart disease, your risk of developing heart disease is higher than that of a person who does not have a family history.

While you can't control some risk factors for heart disease, such as your age and family history, there are many risk factors you can control. These include smoking, being overweight, lack of exercise, poor diet, excessive alcohol intake, high levels of cholesterol in your blood, diabetes and high blood pressure (or hypertension).

The relationship between HIV and heart problems is not fully understood but is being studied. Some studies show that certain anti-HIV drugs, such as some protease inhibitors, may increase the risk of heart problems by raising the level of cholesterol and triglycerides in your blood. Other research suggests it may be HIV itself that causes heart problems. In either case, it is clear that the benefits of HIV treatment far outweigh the risks of heart disease.

Healthy heart habits

You can lower your risk for heart problems by making the following lifestyle changes:

- Quit or cut down on smoking.
- Eat a healthy diet.
- Exercise regularly—especially aerobic or cardio exercise.



- Drink alcohol in moderation.
- If you use street drugs, avoid cocaine, crack, crystal meth, ecstasy (E), ketamine (K) and GHB.
- Talk to your doctor about supplements, such as anti-oxidants and B vitamins.
- Keep the stress in your life to a minimum.

Your doctor should monitor your cholesterol levels and your blood pressure. If either is elevated, you may want to consider treatment.

Early menopause

For most women, menopause occurs between the ages of 45 and 55. During this time, the production of the female hormones estrogen and progesterone declines, eventually causing menstruation (periods) to stop completely.

Menopause appears to occur earlier in some women with HIV. Just why is not clear, but there are many possible explanations. They include: a low red blood cell count (anemia), lower levels of the hormones estrogen and progesterone, weight loss, reduced CD4+ cell count, and use of street drugs, such as heroin and methadone.

Many of the symptoms of menopause and HIV overlap. This can make it difficult to determine the cause of symptoms and can result in a missed or late diagnosis of HIV. These symptoms include:

- hot flashes
- night sweats
- skin and hair changes
- trouble sleeping
- forgetfulness
- fatigue
- emotional changes or mild depression



When I'm having a bad day, I don't go anywhere, and this is hard for my grandchildren to understand. They notice that I take a lot of pills, and they know I do that to stay healthy.

More women need to come out and share how they feel. Maybe then, others can better understand what we're going through.

—Brigitte, 56

Menopause brings with it an increased risk of many health problems, such as osteoporosis, heart disease, cancer of the breast, lung or ovaries, and other conditions. Women with HIV may face a greater risk of these if they are taking anti-HIV drugs.

Talk to your doctor if you have concerns about any of these health conditions or menopause symptoms.

Bone loss

Your bones are living and growing. The strength of your bones, or bone density, is determined by the amount of calcium, phosphorous and other minerals they contain.

When you have HIV, your risk of some bone disorders increases, whether or not you are on treatment. Research suggests that up to one-third of people with HIV may have early-stage bone loss, or osteopenia.

As we get older, we are more likely to develop bone problems. Women are at higher risk than men of developing osteoporosis, a condition that causes bones to become thin and fragile, and more prone to breaking, particularly bones in the hip, spine and wrist. This is partly because women have 30 per cent less

bone mass than men. Women are particularly vulnerable to osteoporosis after menopause, when the hormone estrogen—key to maintaining bone strength in women—is no longer produced by the ovaries. On the other hand, HIV appears to cause more bone loss in men than in women, cancelling out or even reversing the advantage that men usually have.

Other risk factors for osteoporosis in both men and women include smoking, getting little or no exercise, and a family history of osteoporosis.

Keeping your bones strong

Since the exact cause of bone loss in people with HIV is not known, preventing bone loss is the best strategy. Here's how:

- Eat a healthy diet.
- Increase your daily intake of calcium and vitamin D₃.
- Do lots of weight-bearing exercise, such as walking, running, hiking or weight training.
- Limit or eliminate your intake of caffeine, cigarettes and alcohol.

If you already have osteoporosis, you can take steps to reduce your risk of fracturing (or breaking) a bone and possibly even build up your bone mass. Many people with osteoporosis live full and active lives.



Cancer

Before more effective anti-HIV drugs (called highly active antiretroviral therapy, or HAART) were introduced in the mid-1990s, the most common cancers in people with HIV were HIV-related cancers, such as Kaposi's sarcoma, non-Hodgkin's lymphoma and cervical cancer. Now, thanks to more effective HIV treatment, these cancers are less likely to occur when you have HIV.

On the other hand, the chances of developing both HIV-related and non-HIV-related cancers increase as you age. For example, both men and women 50 or older are at greater risk of developing colon and rectal (colorectal) cancer. People with HIV, especially people with a weakened immune system, can become more vulnerable to certain types of cancer.

Maintaining a healthy immune system with anti-HIV drugs and going regularly for screening tests lowers your chances of getting certain cancers. Fortunately, most cancers are not common and can often be successfully treated if they do occur in people with HIV who maintain healthy immune systems with anti-HIV drugs.

Diabetes

Diabetes occurs when your pancreas cannot make enough insulin. Insulin is a hormone produced by the pancreas to control the amount of sugar or glucose in your blood.

Are you at risk of diabetes?

- I am older than 45.
- I am overweight.
- I get little or no exercise.
- I have a parent, brother or sister with diabetes.
- I am of Aboriginal, African, Latin American or Asian ancestry.
- I have high blood pressure (hypertension).
- I have high levels of cholesterol and/or triglycerides in my blood.
- I am co-infected with hepatitis C.
- I take anti-HIV drugs.

If one or more of these risk factors applies to you, it is important that you get tested for diabetes.



If you have already been diagnosed with diabetes, your doctor will need to monitor your blood glucose levels closely, especially if you are taking anti-HIV drugs. There appears to be a link between treatment with anti-HIV drugs and a rise in blood sugar levels leading to diabetes.

Maintaining a normal blood sugar level

To help keep your blood sugar levels within the normal range:

- Limit the amount of sugar and starchy foods in your diet, such as desserts, soft drinks, white rice and potatoes.
- Choose whole grains, such as barley, brown rice and oats, and unprocessed foods that contain fibre.
- Eat smaller portions.
- Eat a balanced diet, including healthy protein-rich foods, such as lean meats and at least two servings of fish per week.
- Exercise as often as possible, ideally every day.

Depression

Depression is quite common in people with HIV of all ages. Finding out you have HIV can take a toll on your mental health and sense of well-being. This may be compounded by the social isolation, stigma, health conditions and financial difficulties that some people experience as a result of aging or of living with HIV.

If you feel depressed—have trouble sleeping and feel unexplainably fatigued, sad or hopeless—talk to your doctor. Some of these problems may be caused by anti-HIV drugs or other medications, such as those used to treat hepatitis C. Feelings of depression can also be connected to physical causes that can be treated, such as low levels of iron (anemia), testosterone, vitamin B₁₂ or thyroid hormone (especially in women); and hormonal changes in women due to pre-menstrual syndrome (PMS), pregnancy or menopause.



Getting help

No one should face emotional problems alone. There is help available. If you are feeling depressed, it's important to see your family doctor or your HIV specialist and get treatment and support. Many doctors do counselling themselves, and many HIV specialists work with social workers or counsellors available to people with HIV who have emotional problems.

There are different kinds of counselling and psychotherapy available. Some of these are one-on-one (where it is just you and a therapist) and some are done in groups (where you and other people are seen together by a therapist). Sometimes counselling or psychotherapy is provided in a private office, and other times in a clinic, hospital or AIDS service organization. The setting and type of service you receive will depend on the problem you need help with and which services are available in your community.

In the beginning, when I spoke to my friends and family about what I was feeling physically and emotionally, their reactions often began with words like "You should..." or "If I were you..." Inside I was thinking: "How clueless!" How could they truly feel what I was feeling? I knew their intention was to reassure and encourage me, but how could anyone who isn't infected truly understand what it is like to live with HIV? ...

My participation in support groups taught me the importance of listening to people with HIV, including those with points of view different from my own. I discovered how important it was to pay attention to experiences that I had not lived myself, as well as the stages of denial and acceptance that varied from one person to the next.

—Albert



To find out about counselling services, support groups, and housing, income and other supports in your area, contact your local AIDS service organization. You can also call **CATIE** toll-free, at **1-800-263-1638**, or visit **www.catie.ca** to find out about support services and AIDS service organizations near you.

Sexual health

It is possible to have a healthy and satisfying sex life when you are HIV-positive and when you are aging. A healthy sex life can reduce stress, express intimacy and simply feel good.

Sexual problems and low libido (low sex drive) can occur in men and women, especially as we get older. This can be a sensitive issue that gets swept under the rug and ignored. A low sex drive can be the result of HIV, the side effects of drugs, hormone imbalances



(including low testosterone in women and men), heart disease, diabetes, stress or depression. It's important to talk to your doctor about sexual problems you may be having because, chances are, something can be done about them.

It is also important that you take steps to prevent getting or passing sexually transmitted infections (STIs). People with HIV are at greater risk of acquiring STIs and, if you get one, the symptoms may be more severe. If you are sexually active, you may want to get tested regularly for STIs, such as gonorrhea, chlamydia and syphilis. Using condoms greatly reduces the risk of passing HIV to your partner(s), and will also protect you from sexually transmitted infections like gonorrhea and chlamydia. Keep in mind, though, that condoms will not protect you from all STIs. Take steps to protect yourself and your sex partner(s).

You can have HIV and have a healthy and satisfying sex life.

Cognitive changes

Over time, some people living with HIV find they have trouble focusing, remembering things and processing information. These are called cognitive changes. If you are living with HIV, you may have noticed some cognitive changes. They may be mild or they may interfere with your activities and your ability to function on a day-to-day basis.

Many people living with HIV experience such problems. At the same time, many people have lived with HIV for decades and experience no cognitive problems at all.

If you suspect that you may have a problem with your cognition—for example, problems with your memory, perception, reasoning or judgement—see your doctor. He or she may do some tests to figure out what the problem is. In addition to medical treatments, your doctor may recommend lifestyle changes, such as changes to your diet, vitamin supplements, physical exercise and exercises for your “brain health.” Your doctor can also refer you to an occupational therapist—someone who can suggest strategies you can use to get around these problems.



Dementia is a brain disorder that can affect your memory and ability to think clearly. It can have a serious impact on your daily activities, quality of life and even your ability to live independently. Fortunately, the rate of HIV-associated dementia has greatly declined since more effective anti-HIV drugs became available in the mid-1990s. Nevertheless, as you age, you may be at risk of developing dementia. It's

important to speak to your doctor as soon as possible if you become aware of early signs of dementia, such as difficulty remembering, concentrating or completing basic tasks.

In a way, it can be a relief to find out that you really do have a problem and it isn't all in your imagination.

*—Dr. Sean Rourke,
neuropsychologist*

Screening tests

While HIV is monitored using routine tests, your doctor may recommend additional tests to monitor your health as you get older. These include:

- **Bone density scan**—A scan of your lower spine and hip that measures your bone density. It is recommended that you have a bone density scan every two years.
- **Fasting blood glucose test**—A blood test for diabetes. It is recommended that you have this test every three to six months.
- **Lipid profile tests**—These blood tests check total cholesterol, LDL (“bad” fats), HDL (“good” fats) and triglycerides. It is recommended that you have these tests one to two times a year, depending on your risk factors for heart disease.
- **Kidney function test**—Because kidney function declines with age and because certain anti-HIV drugs are processed through the kidneys, it is recommended that you periodically have a blood and/or urine test, to check your kidney function.
- **Blood-pressure monitoring**—A blood-pressure monitor measures the force of blood against the walls of your arteries and indicates your risk of developing heart disease.

- **Screening for colorectal cancer**—A few tests can detect cancer of the colon or rectum. Tests include a stool test, a digital rectal exam (where a doctor inserts a gloved finger into the rectum to feel for abnormalities) or a scope inserted into the rectum. Your doctor will let you know how often you should be screened.

For women only

- **Pap test**—A doctor collects cells from the cervix, which are then examined under a microscope. A Pap test is used to look for cell changes that indicate the presence of cancer or changes that could lead to cancer. It is recommended that sexually active women with HIV have a Pap test every six months to a year.

- **Breast exam**—To detect possible early signs of breast cancer, your doctor will check for lumps or other abnormalities in your breasts, nipples and armpits. It is recommended that women have a breast exam once a year, usually along with a Pap test.



- **Mammogram**—A mammogram uses a low-dose X-ray to examine each breast. It is used to look for different types of tumours and cysts. It is recommended that women over 40 have a mammogram once a year.
- **Pelvic exam**—A pelvic exam is a physical exam of the internal and external pelvic organs. It is usually combined with a Pap test every six months to a year.

For men only

- **Prostate exam**—It is recommended that men over 40 have a manual digital exam of the rectum once a year. Your doctor may also order a PSA blood test, which screens for prostate cancer.

Coping with loss

It is wonderful, and even miraculous, that many people with HIV are now living long enough to experience middle age and beyond. Living with a chronic illness like HIV can be difficult at the best of

times, however, and this can affect your quality of life.

Losses you may have experienced as a result of being HIV-positive—such as the loss of health, employment, income, youthful good looks or the loss of friends who have died because of AIDS—can be devastating.

I've got a new lease on life. I have learned to live with my health issues on a daily basis. You continue to learn—you have to. Everybody goes through it

—Brian, 60

At times, when things feel like they're spiraling out control, I remind myself of the areas where I am exercising control. So, I make sure that I'm taking my meds, doing my exercise and eating and sleeping in a healthy way.

—Louise, 53

Taking care of yourself

Here are some ways to combat isolation and improve your overall quality of life:

- Get involved in your community.



- Create a strong social support network.
- Exercise your mind and stay mentally active.
- Manage stress and depression.
- Eat a healthy diet.
- Sleep well.
- Get outdoors and exercise physically.
- Cultivate a positive outlook.
- Quit smoking.
- Avoid excessive alcohol.
- Have a spiritual practice.
- Have a healthy sexual relationship.

My doctor says I will probably die of old age—that makes me live.

—Ana, 77

Money matters

Your financial security is extremely important, especially when you have HIV. Drug coverage, decent housing and a secure income are crucial to your quality of life.

When you reach 65, you may find yourself with a reduced income. Government disability or private insurance benefits may cease and you may need to live on a stricter budget. This can cause stress and anxiety. It's important to seek support from your local AIDS service organization or elsewhere.

If you are working, you may be eligible for workplace health and disability benefits. For example, many employers provide some form of insurance for a limited time, or for longer periods if their employees become unable to work because of health problems. You do not need to tell your employer about your medical condition—all you need is a doctor's certificate that says you are unable to work due to poor health.

If you cannot continue working at any job on a regular basis for health reasons and if you qualify, you may be able to receive a portion of your Canada Pension Plan or Quebec Pension Plan disability benefits.

To find out about health benefits and social assistance programs available to you, contact your local AIDS service organization.

Need more information?

For more information on HIV and aging, contact CATIE (the Canadian AIDS Treatment Information Exchange). We provide extensive information on the prevention and treatment of HIV. You can call our toll-free phone line at 1-800-263-1638. Your call will be treated as private and confidential. You can also visit us online at www.catie.ca



Canada's source for
HIV and hepatitis C
information

555 Richmond Street West, Suite 505, Box 1104
Toronto, ON M5V 3B1
1-800-263-1638
www.catie.ca

Cette publication est également disponible en français.

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 in good faith provides 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 CATIE, however, is not to be considered medical advice. We do not guarantee the accuracy or completeness of any information published by CATIE. Users relying on this information do so entirely at their own risk.

Acknowledgements

The content of this booklet was originally developed by Kath Webster for *Managing your health: a guide for people living with HIV*. Quotes from *The Positive Side*.

Production of this publication has been made possible through financial contributions from the Public Health Agency of Canada and from ViiV Healthcare in partnership with Shire Canada.

Thanks to the many community and medical reviewers who provided input on this booklet.

Illustration: Julie McLaughlin
Design and layout: Quadrat Communications

© 2010 **Canadian AIDS Treatment
Information Exchange**

CATIE Ordering Centre
Catalogue Number: ATI-40221
(aussi disponible en français ATI-40222)

FSC Logo

