



*for women
aging with grace*



Positive Women's Network
Pocket Guide on Aging
for Women Living with HIV

Disclaimer

This booklet has been reviewed by health care professionals and community advocates, but it cannot replace medical, counselling, or legal professional services provided to individuals. Readers are encouraged to seek appropriate professional advice based on their individual needs and circumstances. Readers accept full responsibility for their use of this guide, as well as for any costs, loss, damage, or other consequences suffered from use of the information.

THIS GUIDE provides simple, basic information about HIV and the changes it may bring to your life.

This guide is designed to support

- women who have been living with HIV for ten years or more
- women with HIV going through perimenopause
- women over 40 newly diagnosed with HIV
- care providers and communities supporting women with HIV



HIV and Aging

New Expectations, New Changes

Contents

HIV and Aging	3
HIV Basics	6
HIV Progression	12
The Shift to Menopause.....	17
Bone Health	23
Heart Health	28
Treatment for Life	33
Changing Shape	40
Sexual Well-Being	44
Abuse in Relationships	50
Brain Health	54
Spiritual Health and Community Connections.....	57
Resources	61
Index	62

WOMEN WITH HIV are living longer than ever expected. The number of HIV+ women over 40 and 50 years old is rising as positive women age and new diagnoses are made. Heterosexual transmission accounts for almost half of new infections in people over 50 years old,¹ and it's expected that over 50% of people with HIV in North America will be 50 or older within a few years. If you're aging with HIV, you're not alone.

¹ *HIV in Canada: Trends and Issues That Affect HIV Prevention, Care, Treatment and Support* (2010), page 15: http://www.catie.ca/pdf/Canada/HIV-in-Canada_ES.pdf





It's normal to have mixed feelings about getting older—we live in a society that values youth. But you may welcome aging: “I didn't expect to see 40,” says Lori, who was diagnosed in her early thirties. She's now 47 and happily thriving. Sacha says her hands have started looking older. Given that she's had HIV for over sixteen years and didn't expect to live this long, it has come as a welcome surprise.

When HIV (human immunodeficiency virus) first appeared in North America, many people progressed to AIDS (acquired immunodeficiency syndrome) and died within a few years from related complications. Thanks to the introduction of highly active antiretroviral therapy (HAART) in 1996, life expectancies have changed dramatically. The medicines in HAART (also referred to as ARVs, for antiretrovirals) limit HIV's harmful effects on the body, so the immune system can restore itself. Many people with HIV will now live well for decades.

Aging for *everyone* means the possibility of diseases like diabetes, heart disease, kidney disease, and cancers. Smoking, alcohol and drug use, exercise, and nutrition also play a part in aging, especially if you have HIV.

If you know your biological family history, that can help you and your doctor in looking after your health. If you don't know your history (lots of people don't), paying attention to changes in your body and keeping your doctor informed is essential.

This guide can help you know what to expect.





HIV Basics For Newly Diagnosed Women

A DIAGNOSIS OF HIV can come as a shock. Thankfully, good support and treatments can help people live long, fulfilling lives. But that doesn't mean HIV isn't a big deal. It can take a while to adjust, and that's normal. You might feel embarrassed or ashamed that you've tested positive. Heather did, and said, "My kids knew more about HIV than I did!"



You're not alone in having HIV. Women account for about one in five new diagnoses in Canada.² Aboriginal communities are being hit hard: 25% of HIV diagnoses between 1985 and 2009 were for Aboriginal people.³ There are lots of women who have HIV; it's just not something people tend to share.

Don't be hard on yourself. This guide can help you learn more about HIV, and when you're ready, you can connect with other women through a local HIV organization. (See the next page for suggestions on where to look.)

² *HIV and AIDS in Canada: Surveillance Report to December 31, 2009* (2010), page 28: <http://www.phac-aspc.gc.ca/aids-sida/publication/survreport/2009/dec/pdf/2009-Report-Rapport.pdf>

³ *Ibid.*, page 33.





What Can I Do?

Find support that is safe and comfortable

Connecting to an HIV service organization can help. You'll be able to talk about your diagnosis and about adjusting to HIV with people who have done so as well. Many communities have service organizations.

If you live in an area that doesn't, or you want to protect your privacy, you can visit some organizations online. The Positive Women's Network website offers information about HIV and support programs online (www.pwn.bc.ca). If you live in British Columbia, you can call our toll-free line to talk to a support worker (1-866-692-3001). CATIE is Canada's source for HIV and hepatitis C information and has a page listing HIV organizations across the country (www.catie.ca).

Figure out when to start medication

Whether you need to start treatment right away depends on your health. Tests will measure the level of immune cells (a CD4 count) and the level of HIV (a viral load test) in your blood. It's normal to have a spike of HIV in your blood during early infection while the virus establishes itself and the immune system hurries to catch up. The viral load will come down once your immune system kicks into high gear. Your doctor will monitor your system to decide with you when it's time to start treatment (see the "Treatment for Life" section).





Take relationships at your own pace

It's not unusual to feel uneasy about sex and relationships after an HIV diagnosis. You might not want to take the risk of infecting someone, or you might feel you don't deserve to have sex anymore. You can prevent HIV transmission by practicing safer sex, and you *do* deserve to have a pleasurable sex life. Move at your own pace and go ahead when you feel ready.

If you are in a relationship, or hoping to meet someone, sharing your HIV status is something you have to think about. If you don't tell a partner that you have HIV before you have sex, you could be criminally charged. The Canadian HIV/AIDS Legal Network has more information about this (www.aidslaw.ca).

Having sex with someone else who has HIV doesn't mean you should forget about safer sex. It's still advisable to have safer sex so you don't get infected with anything your partner might have that could further weaken your immune system.



Understand transmission and prevention

HIV can be transmitted in several ways. It can be passed through direct contact with semen, vaginal fluids, breast milk, and blood. *Direct contact* means the infected fluids have access to another person's bloodstream. This happens most commonly through vaginal or anal sex without a condom, needle sharing, and breastfeeding.

Safer sex involves using condoms when you have anal or vaginal sex. Oral sex is considered a lower risk activity than intercourse, but transmission of HIV and many other sexually transmitted infections is still possible without use of a barrier.

Safer drug use means not sharing needles, spoons, straws, or other equipment.

For more information about living with HIV after a new diagnosis, see Positive Women's Network's *Pocket Guide for Women Living with HIV*.





HIV Progression Inflammation and Disease

UNTREATED HIV slowly breaks down the immune system. Usually, the body's immune cells can stop a virus by killing the viral particles and creating antibodies to protect you in case you're exposed to the virus again. The trick with HIV is that it kills the immune cells themselves. Although the body is always making more immune cells, known as CD4 cells, HIV constantly kills them, creating a vicious circle.

When the immune system is always in response mode because of HIV's ongoing attack, it's working overtime. And it's not just the immune system that's affected. HIV causes inflammation in the whole body. The gut, kidneys, liver, heart, and blood vessels are affected, making you vulnerable to disease. Imagine an engine that's never turned off—parts of it will start to break down.

Women are more likely than men to develop autoimmune disorders, especially as we age. These also cause inflammation. Irritable bowel syndrome, rheumatoid arthritis, and celiac disease are examples of autoimmune disease.⁴ We don't yet know what this means long term, but HIV could complicate the symptoms of autoimmune disease and vice versa.

⁴ For more information, see *Autoimmune Diseases: Overview* (2010), <http://www.womenshealth.gov/publications/our-publications/fact-sheet/autoimmune-diseases.pdf>





What Can I Do?

Make lifestyle changes

Certain things you do every day can contribute to chronic inflammation. Smoking is a big one. Current smokers are far more likely to have a myocardial infarction (heart attack) than non-smokers. If you're a smoker, quitting or at least cutting down will make a big difference (and decrease your risks for cancers too!). Alcohol is another factor. Having more than one drink per day can increase inflammation. Drug use also adds to inflammation.

If you can't quit, at least reduce your use. Smoking cessation programs and treatment for alcohol and drug use can help if you find it hard to go it alone. One online support for quitting smoking can be found at www.quitnow.ca. Your nearest AIDS service organization or your doctor can help find other resources.

Consider HIV treatment

HIV inflammation starts damaging the body even before CD4 counts or viral loads change significantly.⁵ Recommendations about starting treatment balance the benefits (control of HIV) and risks (possible long-term toxicity of treatments). Guidelines can differ province to province, so check with your doctor about what's recommended for you.⁶ Treatment is a lifelong commitment, so start when you are ready for it.

5 "HIV Causes Accelerated Aging: Has AIDS Become Acquired Inflammation Disease Syndrome?" (2010), <http://www.thebody.com/content/art56491.html>

6 *Therapeutic Guidelines* (2011), <http://www.cfenet.ubc.ca/our-work/initiatives/therapeutic-guidelines>



Test beyond HIV

You'll soon be charting your health in more than immune cell counts. Tests to look at bone density, diabetes markers, cholesterol levels, kidney function, and blood pressure may be needed more frequently, as will mammograms, tests for sexually transmitted infections, and cervical and anal (if suggested) Pap tests. If you know your family disease history, share it with your doctor so you can be checked as necessary for cancers and other diseases.



The Shift to Menopause

AS WOMEN AGE, we go through a natural process called perimenopause, the years in which menstrual patterns change. Menopause is reached when a woman has gone a full year without a period. Positive women can experience menstrual irregularities, which might include lack of bleeding, irregular or excessive bleeding, or early menopause (for women younger than 40).





Every woman (with HIV or not) enters perimenopause at a different time. Some women may notice changes starting in their thirties, whereas others may be well into their forties. Timing is influenced by biological family history (genetics), ethnicity, and other health factors. These can include low body weight, chronic infections, immune compromise, street drug use, and hormone levels.

In past studies it was thought that HIV would bring early menopause, but many of the women studied already had advanced HIV disease.⁷ A study from the New York State Department of Health found that women who are on treatments and have higher CD4 counts are less likely to experience a lack of periods, but also noted that more research is needed to understand the relationship between menstruation and HIV.⁸

Perimenopause symptoms can include the following:⁹

- *shorter or longer times between periods*
- *heavier or lighter menstrual bleeding*
- *a change in the number of days of bleeding*
- *sleep disturbances*, including insomnia
- *hot flashes*
- *memory changes*, such as fogginess, forgetfulness
- *less vaginal lubrication*, which can contribute to painful sex
- *sex drive changes*
- *emotional changes*, including mood swings, anxiety, depression

⁷ “Menstruation, Menopause and HIV” (2007), <http://www.thebody.com/content/art40771.html>

⁸ “Menstrual Disorders in HIV-Infected Women” (2010), <http://www.hivguidelines.org/clinical-guidelines/womens-health/menstrual-disorders-in-hiv-infected-women/>

⁹ “Perimenopause: Symptoms” (2010), <http://www.mayoclinic.com/health/perimenopause/DS00554/DSECTION=symptoms>



What Can I Do?

Follow your patterns

Not all menstrual patterns follow standard monthly cycles. You might be like Sidney, who was diagnosed with HIV almost 15 years ago. Even before diagnosis, her periods were never monthly. What's important is *your* normal. Night sweats or sleep disturbances are common in perimenopause, but could also relate to HIV or treatment.

Use a diary to note patterns and changes, so you can share them with your doctor. Changes may be caused by the natural process of aging, HIV, or treatments.

Once you've hit menopause (a year without periods), tell your doctor if you have any spotting or bleeding, cramping, or pelvic pressure, which could indicate other issues.¹⁰ Regular Pap smears, breast exams, and mammograms are still needed. Ask your doctor about the best schedule for you according to your age, menstrual status, and HIV.

¹⁰ "The Significance of Bleeding after the Menopause" (n.d.), http://www.obgyn.net/women/women.asp?page=/women/articles/bradley/banter_0803



Use lubricant

Hormonal changes can bring changes in your sex drive. You may notice a decrease in vaginal lubrication, and while you can't see them, the vaginal walls become thinner. This can make sex a bit uncomfortable and make the vagina more likely to tear. Use personal lubricants to help you rev up when your body's response is slower than you'd like and to make penetration easier and safer. Safer sex is still key, so use condoms and dental dams to prevent the transmission of HIV and other sexually transmitted infections.

Look into hormone treatment

Women may also benefit from taking testosterone, a naturally occurring hormone. It plays a part in bone health, lean body weight, and sex drive.¹¹ Talk to your doctor to see if hormone treatment is recommended.

For more on sexuality, see the "Sexual Well-Being" section of this guide.

¹¹ "Testosterone treatment has benefits and few risks for women with HIV" (2009), <http://www.aidsmap.com/page/1434520/>



Monitor depression and anxiety

Mood swings are common during perimenopause. One month you're rattling with nerves, the next you're down in the dumps. Although these sensations stink, they can be a normal part of shifting hormone levels. Carol says she tries not to schedule anything big in the days leading up to her period. She also reminds herself that it's an effect on her body and doesn't have to affect her spirit.

If anxiety or depression is changing how you lead your everyday life, it could be a sign of something bigger. Talk to your doctor if you have an ongoing lack of interest in life or lack of appetite, or if you are crying a lot (especially if you have a history of abuse or trauma), sleeping more than normal, or thinking of harming yourself. There are strategies and medications to help.



Bone Health What Keeps You Strong



AGING NATURALLY LEADS to a decrease in bone density, and HIV does too, for both women and men.¹² This can mean brittle, more easily broken bones. Postmenopausal women are at risk for lower bone density due to hormonal changes.

¹² "Low Bone Density in HIV-Positive Men" (2009), http://www.aidsmeds.com/articles/hiv_bone_men_1667_17627.shtml





Other factors also influence bone loss:

- *hormonal changes*—In general, postmenopausal women are more likely to have lower bone density than premenopausal women.
- *lifestyle factors*—A study found that HIV was not as much a risk factor for fractures in premenopausal positive women as smoking and drug use.¹³
- *smoking*—Studies have shown a direct link between smoking and bone loss.¹⁴
- *excessive alcohol and drug use*—Alcohol¹⁵ and opioids contribute to bone mineral density loss.¹⁶

13 “Study: HIV Doesn’t Increase Bone Fracture Risk in Women” (2010), http://aidsmeds.com/articles/hiv_bone_fracture_1667_19137.shtml

14 “Smoking and Bone Health” (2009), http://www.niams.nih.gov/Health_Info/Bone/Osteoporosis/Conditions_Behaviors/bone_smoking.asp#b

15 Alcohol Alert, 62, “Alcohol: An Important Women’s Health Issue” (2004), <http://pubs.niaaa.nih.gov/publications/aa62/aa62.htm>

16 “Prospective study of bone mineral density changes in aging men with or at risk for HIV infection” (2010), <http://www.natap.org/2010/HIV/Prospective.pdf>

- *body mass index* (how heavy you are for your frame)—Bone tissue needs pressure to stimulate growth. If you are too thin, there isn’t enough pressure on your bones to maintain their density.
- *lack of exercise*—Walking, running, weight lifting, and other exercise put pressure on the bones needed to stay healthy.
- *HIV medications*—We’re still learning how HIV meds might add to bone loss. HIV treatment plans need to take this into consideration.
- *ethnicity*—This may also play a part. Bone mineral density varies for people with different ethnic backgrounds. A Canadian study found that Aboriginal women had lower Vitamin D levels than non-Aboriginal women,¹⁷ which meant an increased risk for fracture.¹⁸

17 “Canadian Aboriginal Women Have a Higher Prevalence of Vitamin D Deficiency than Non-Aboriginal Women Despite Similar Dietary Vitamin D Intakes” (2007), <http://jn.nutrition.org/cgi/content/full/137/2/461>

18 “Bone density and bone area in Canadian Aboriginal women: the First Nations Bone Health Study” (2007), <http://www.springerlink.com/content/d20g127120815706/>



What Can I Do?

Get moving!

During weight-bearing exercise, muscles squeeze on the bones, putting on the necessary pressure to stimulate growth of bone tissue. Brisk walking, running, hiking, aerobics, or weight lifting are all good activity choices. Exercise can also help you manage weight gain and lift your spirits. Talk to your doctor about the best plan for you.

Go smoke free

Quitting smoking is a huge bonus for your bones (and your heart). Smoking interferes with the delivery of oxygen throughout the body, affecting every part. Smokers are at higher risk for heart attacks and have lower bone density than non-smokers, so quitting (or even cutting down) can make a difference.¹⁹ The nicotine patch or smoking cessation programs can help: www.quitnow.ca offers online support.

¹⁹ “Smoking and Bone Health” (2009), http://www.niams.nih.gov/Health_Info/Bone/Osteoporosis/Conditions_Behaviors/bone_smoking.asp#b



Eat well, with supplements

Eat a variety of whole foods, including calcium-rich foods like almonds, dark leafy greens, fortified soy milk, salmon, and milk products if they agree with you. Calcium and Vitamin D supplements might be recommended. In Canada we don't see as much sun as those farther south, so 1,000 IU of Vitamin D per day is recommended. Please note that advice on supplements changes with new research, so always talk to your doctor or a dietician about current recommendations as well as how they might affect your HIV medications.

Test your bone density

People with HIV should have bone density testing done to establish a health baseline. This will tell you whether you are at risk for osteopenia (thinning bones) or osteoporosis (porous bones). Your doctor will recommend a schedule for retesting based on the baseline information, your age, and other health factors.





Heart Health

THE CARDIOVASCULAR SYSTEM is made up of the heart and blood vessels, which circulate nutrients to all parts of the body. Cardiovascular disease affects blood vessels and can lead to thickened arteries, stroke, or heart attack. People with HIV may be at risk for cardiovascular disease at a younger age than people without HIV,²⁰ and that includes women.²¹

²⁰ “CROI 2009 Highlights: A Review of Cardiovascular Disease and HIV” (2009), <http://www.thebody.com/content/confs/croi2009/art51024.html>

²¹ “Lipoprotein levels and cardiovascular risk in HIV-infected and uninfected Rwandan women” (2010), <http://www.ncbi.nlm.nih.gov/pubmed/20796311>



Several factors contribute to cardiovascular disease:

- *chronic HIV inflammation*, which causes arteries to thicken and compromises blood circulation²²
- *biological family history* of heart disease
- *lifestyle*—smoking, nutrition, exercise, drug use, stress
- *diabetes*
- *obesity*
- *high blood pressure*
- *too-high lipid levels*—lipids are naturally occurring fats in the blood, which can be increased to harmful levels through poor diet, obesity, lack of exercise, and some HIV medications (see the section “Changing Shape”)
- *aging*

²² “Chronic Inflammation in HIV: CROI 2010” (2010), http://www.natap.org/2010/CROI/croi_96.htm





What Can I Do?

While family history and HIV have roles in cardiovascular disease risk, your choices can have a big impact on your heart health.²³

If you're a smoker, quit

Smoking is a serious risk factor for heart attacks, HIV+ or not. If “cold turkey” hasn’t worked for you, look into smoking cessation programs, talk to your doctor about the nicotine patch, or check out www.quitnow.ca.

Get active!

Make regular exercise a part of your life. Exercise that gets your heart rate up and makes you sweat can decrease stress, improve your blood pressure, decrease lipid levels, and help you lose excess weight. Talk to your doctor about what’s right for you.

²³ “Heart health: Behaviour trumps genetics” (2010), <http://www.futurity.org/health-medicine/heart-health-behavior-trumps-genetics/>; “HIV and cardiovascular disease” (2009), <http://www.catie.ca/facts.nsf/efob8c264397949f852571700053e30c/78ab93dc461831ea85257680006d5d24!OpenDocument>



Get your lipid levels checked

Knowing your cholesterol and triglyceride levels can help you decide goals in diet, exercise, or medications. (Don’t make changes to medications without talking to your doctor.)

Have your blood pressure checked

It needs to be measured at least twice a year. Headaches can be a sign of high blood pressure.

Explore HIV treatment

If you’re not on HIV medication, is it time to consider it? It can help control the inflammatory damage of HIV. Some medications may contribute to risk, so ask your doctor which meds are best for you.

Combat stress

Exercise helps, as does talking to friends, family, or a therapist or counsellor. There’s no shame in reaching out. It will do you good, as ongoing stress increases the strain on the heart.



Reduce your use

If you use drugs, cut down or quit if you can.

Talk to your doctor

If you know heart disease has been an issue for someone in your family, let your doctor know. You can't change it, but if you know to monitor it, you'll be better off.²⁴ Your doctor may suggest some changes to what you eat, or prescribe medications to help with high blood pressure.

Treatment for Life



HIV TREATMENT has evolved a lot from when the only hope was the drug AZT. Since 1996, when highly active antiretroviral treatment (HAART, or ART for antiretroviral therapy) made the news at the International AIDS Conference in Vancouver, treatment has changed the course of HIV infection for many people. For those with access, HAART or ART is very effective at keeping the viral load (the amount of HIV in the blood) under control, slowing HIV progression.

²⁴ "HIV and cardiovascular disease" (2009), <http://www.catie.ca/facts.nsf/efob8c264397949f852571700053e30c/78ab93dc461831ea85257680006d5d24!OpenDocument>





People diagnosed with HIV now may live as long as they would have without HIV, if they take effective medications. Even those who've had HIV for ten years or more are living longer than ever thought possible.²⁵

HIV reproduces itself constantly in the body, destroying immune cells and sapping the strength of the immune system. HIV reproduction is a multistep process, and medications work on different steps in the process. As a result, viral load goes down, and immune strength (primarily measured by CD4 cells) increases. Once you're on treatment, the goal is to keep your viral load at fewer than 50 to 75 copies. (The range depends on the test used to measure.)

You might hear people talk about their viral load as “undetectable.” That doesn't mean they don't have HIV, but it means that the amount of virus is very low. If a viral load test can measure 40 or more copies of HIV in a small sample of blood and a person only has 39, then the HIV isn't gone, but is under the radar of that test. HIV lives in other body fluids too: semen, vaginal fluids, lymph fluid in the brain and spine, breast milk in new moms. Your viral load can go up and down depending on adherence to treatment and other infections or things going on with your body, but the HIV is not gone.

²⁵ “Goals of Controlling HIV in Aging Populations,” Fifth International AIDS Society Conference on Pathogenesis, Treatment and Prevention, Cape Town, South Africa, July 19–22, 2009.





If you've read the section on HIV progression, you know that HIV causes damage through inflammation even when the body appears healthy. Doctors now think treatment is better earlier rather than later, to fight the damage of inflammation. This has to be balanced with long-term side effects or toxicities (negative effects on the body). Women are more likely to go through changes in body shape as a result of HIV treatments, but with improvements to treatments these aren't as dramatic or as likely as they used to be. Going on treatment can extend your life and improve your quality of life. See the section "Changing Shape" for more info on metabolic and body changes.

What Can I Do?

Figure out your overall health

It's becoming clear that HIV treatment has to be tailored to individuals, in consideration of family history of disease and other health conditions. Diabetes, cancers, and heart disease are often related to aging.

Treatment plans will look at your overall health. Viral load, CD4 counts, as well as other health issues like diabetes, hepatitis C, and opportunistic infections, are all considered. If you don't already know it, find out your hep C status through a blood test. Treatment practices vary from province to province, so ask your doctor about what's available where you live.





When side effects get you down, keep your eye on the prize

Side effects from the medication can be discouraging. Many side effects diminish after four to six weeks on treatment, as your body adjusts. You may go through diarrhea, headaches, dizziness, and sleep disruptions. Carol had some really tough side effects and said it was her connections with other positive women that kept her going. Try to focus on the big picture and never stop taking your meds until you see your doctor. If you stop taking them, HIV can develop resistance to those meds and you may never be able to use them again. This gives HIV a chance to damage your body even more and limits what you can do to fight it.

Learn about long-term side effects

Every kind of pill (even Aspirin) can have side effects other than physical discomfort. Research on the long-term use of HIV meds is still in the early stages overall. So far, we know that some HIV meds may affect bone health, the kidneys, liver, and the heart. They can also change the way your body looks (lipodystrophy) and change metabolic function, although changes to treatments have improved these outcomes. Treatments help slow the damage of HIV, and for most people, the benefits outweigh the risks. Along with treatment, your doctor should be tracking your kidney function, blood sugar levels (at least every three months), and cholesterol levels, and performing bone scans (see more in “Bone Health”).

Learning as much as you can²⁶ and talking to your doctor is important. What we know changes all the time.

²⁶ TreatmentUpdate (ongoing publication), <http://www.catie.ca/tu.nsf>



Changing Shape

Metabolism, HIV, and Treatment

HIV CAN BRING CHANGES in how your body looks and functions, but it affects everyone differently. It doesn't happen to everyone, or in the same way for everyone.

You might gain weight in some places and lose weight in others. Lipodystrophy is the term for changes in how fat is distributed in the body—more in some places, less in others.

You might gain weight in your breasts, on the neck and back, and in the belly (lipohypertrophy). You may lose it from your face, arms, or legs (lipoatrophy). Fatty cells, including cholesterol and triglycerides, can increase in your blood (dyslipidemia or hyperlipidemia). Both men and women can have lipodystrophy, but it develops in a higher percentage of women.²⁷ Treatment combinations have improved over time, with the added benefit that body changes are not as extreme as they used to be.

It's not entirely clear what causes these changes in the body: Is it HIV? Is it treatment? Or a mix of both? It's been identified that protease inhibitors can play a part in both lipodystrophy and diabetes risk.²⁸ Treatment combinations are always being fine-tuned to reduce the incidence of side effects like these, and as people live longer with HIV, we're learning more.

²⁷ "Lipodystrophy and Women" (2005), <http://www.thebody.com/content/art5101.html>

²⁸ *Managing Your Health: A Guide for People Living With HIV*, "Chapter 18: HIV and aging" (2009), http://www.catie.ca/pdf/myh/MYH_CH18.pdf





Your body's ability to metabolize food can change, leading to a risk of diabetes. Here are some risk factors for diabetes:

- *increasing age*
- *lack of exercise*
- *obesity*
- *poor nutrition*
- *co-infection with hepatitis C*
- *high blood pressure*
- *biological family history* of the disease
- *Aboriginal heritage*—Aboriginal women are more likely to have diabetes than non-Aboriginal women²⁹
- *use of protease inhibitors*

²⁹ *Pathways to Healing: 2nd Report on Health and Well-Being of Aboriginal People in British Columbia* (2009), <http://www.health.gov.bc.ca/pho/pdf/abohlth11-var7.pdf>



What Can I Do?

None of these issues means that you shouldn't take HIV medications.

Talk to your doctor about your concerns. Ensure that tests measure the success of HIV treatment, but also potential changes in lipid levels and glucose tolerance.

Dealing with body changes can be difficult. Women are raised to measure a degree of our worth though our looks. Body image, self-esteem, and sexuality can all be affected by changes in how we look. Some women who have lipodystrophy can feel self-conscious about their gains and losses, worrying it might identify them as living with HIV.

Talk to other women experiencing body changes—you'll find you're not the only one. Connect with women through Positive Women's Network, an AIDS service organization near you, or online. One woman said that finding a friend who was also dealing with lipodystrophy was life changing, because each knew what the other was going through.

You are always more than how you look.





Sexual Well-Being

AGING MEANS CHANGES in menstruation and for lots of women changes in sexuality. Sexual enjoyment doesn't end when your periods do, and sex can be defined in many ways. While orgasm can feel great (and is good for you physically), it doesn't have to be the goal all the time. Feeling good is what it's about, whether you're pleasing yourself or with a partner.

With age, vaginal walls become thinner and less elastic. You'll probably notice a decrease in regular vaginal secretions and feel drier than you used to, due to changes in hormone levels. These changes can make sex less comfortable and make you more vulnerable to infections.³⁰

Don't be surprised if you notice your sex drive change too. It may go up and down, affected by hormonal changes. Taking testosterone, a naturally occurring hormone in our bodies, may help improve body mass, depression, bone health, and sex drive.³¹ It's available through prescription, so ask your doctor if it's a good choice for you.

Your self-image may also change as you age. Don't underestimate your thinking: a recent study found that attitude about sexuality was as influential as hormones. How you see it matters!³²

³⁰ "Sex and Menopause" (2009), <http://www.webmd.com/menopause/guide/sex-menopause?page=2>

³¹ "Testosterone treatment has benefits and few risks for women with HIV" (2009), <http://www.aidsmap.com/page/1434520/>

³² "Negative Perceptions of Menopause Contradicted by New Study" (2010), <http://www.sciencedaily.com/releases/2010/07/100706112557.htm>





What Can I Do?

Honour what you want

If you're dealing with vaginal dryness, hot flashes, painfully dry itchy skin, grumpiness (for some, in the extreme!), and depression, sex just might not be on the list of things you want to do. But changing your ideas about sex can help.

You're in charge of defining "good sex." Respect what you want: more sex, less sex, solo sex, or partner sex. If you have a partner, talk to that person about what feels good. Understand that changes in desire and response are normal. Orgasm is good for the body (bringing blood flow to the vagina and strengthening pelvic floor muscles), but if you're having a tough time getting there, give yourself a break. If you've experienced sexual trauma, the ups and downs of perimenopause can make it come to mind more often. Be as kind to yourself as you can. If you're feeling extremely traumatized, consider talking to someone you can trust with your tender emotions as you try to realize your strength.



When you do it, make it slick

If you haven't tried personal lubricant yet, now's the time: it's great. It makes sex play of all kinds easier and it can make it more fun. Some lubes heat up, some are flavoured, and there are lots of options available at the drugstore. If vaginal dryness is an ongoing discomfort even with lube, there are lubricating suppositories you can buy over the counter. Your doctor may also suggest a prescription cream.

Remember that safer sex still counts

Changes to vaginal walls and lubrication levels make you more vulnerable to sexually transmitted infections, so in addition to lube, keep up the safer sex. Use latex condoms, dental dams, and gloves as part of your safer sex routine, whether it's vaginal and anal penetration or oral sex. Although oral sex is a lower risk activity for HIV transmission, it's possible to transmit HIV that way. Other infections can also be transmitted through oral sex.





Sexual HIV transmission can be simplified to an equation:

Body fluids with high concentration of HIV
(semen, vaginal fluid)

- + **entry point for HIV**
(receptor cells that provide access to bloodstream)
- + **activities that provide HIV entry to bloodstream**
(unprotected vaginal, anal, oral sex;
risk varies depending on activity)

= **risk of infection**
(of HIV or other sexually transmitted infections)

Reduce your risks by using latex and lube to smooth the way. Whatever your partner's gender, condoms, gloves, and dental dams can help protect both of you.

You deserve to be treated well

HIV doesn't make you unworthy of love and kindness, no matter what anyone says or does. If you're in a relationship where you don't always feel comfortable or safe during sex (or any time), you don't deserve it.

If violence is a threat or a reality, there is support out there. See the next section for more information.

You are worthy.





Abuse in Relationships You Never Deserve It

LOTS OF WOMEN experience violence in relationships, whether they or their partner have HIV or not. An abusive relationship isn't just when you get hit, although that's an obvious sign. It's also when your partner tries to control what you say or do, where you go, and who you see. It's also when that person refuses to practice safer sex or forces sex when you don't want it.

Having HIV doesn't mean you have to put up with it. You can get support.

There's more to abuse than physical violence. It's about control, because that's what an abusive person is trying to get and keep. He³³ starts by controlling you through words or actions—limiting your contact with friends or family, and shutting you out emotionally when you do something he doesn't like.

³³ Although women in relationships with women can also experience violence, it's much more often an issue women face in relationships with men; hence, "he" is used to reflect the gender-based nature of this violence.





Abuse can be any of the following:

- *manipulative language*, used to keep you under control, such as “No one will ever love you like I do” or “You’re worthless with HIV and you’re lucky to have me.”
- *mind games*, where he blames his rages on you because of how you look or behave, or says your reactions to things aren’t normal, or undermines your confidence.
- *physical abuse*, including threatening movements and hitting you.
- *sexual abuse*, including any sexual act he insists on.

After things have been really bad for a while, and escalated to some kind of incident, he’ll often say he’s sorry and promise that “it will never happen again.” It will.

What Can I Do?

You never deserve to be abused. Abuse affects your ability to look after yourself. It’s stressful, which compromises your immune system. It can limit your ability to get to a doctor or other supports and seek care. To protect yourself, it’s important to recognize what you can do.

If you want to leave the relationship and don’t have options with friends or family, there are safe houses to help make the transition. If you feel unable to leave the relationship, for financial, family, or other reasons, know that there is still support available to you through crisis phone lines and support centres. You are not alone.

You might feel alone, but you don’t have to be. An abuser will try to convince you that you’re alone and isolated. You’re not. For 24-hour support, you can call the National Domestic Violence Hotline: 1.800.799.SAFE (7233).





Brain Health

HIV IS A SYSTEMIC INFECTION that primarily affects the immune system, but also the whole body, including the brain. The body's blood–brain barrier protects the brain from many bacterial infections in the body, but HIV can enter the brain via immune cells. Research has suggested that HIV causes premature aging in the brain as well as the body. We know HIV treatment greatly improves immune health, but we know less about how HIV treatments affect the brain.

A normal sign of aging in all people is a decrease in blood flow in the brain, but it happens at least a decade earlier in people with HIV. It's believed that HIV infection can influence cognitive function (how the brain works) in terms of memory and learning.³⁴

Before the development of current treatments, dementia was a common sign of HIV progression. While it's not as common now, half of people living with HIV will have some changes in brain function.³⁵

HIV treatments might help reduce viral levels in the brain if the right drugs are used and can be tolerated long term. Not all HIV drugs can cross over the blood–brain barrier. We also need to learn what effect HIV drugs themselves might have on brain function.³⁶

34 "HIV infection causes premature aging of the brain" (2010), <http://www.news-medical.net/news/20100122/HIV-infection-causes-premature-aging-of-the-brain.aspx>

35 "HIV-Associated Neurocognitive Disease Continues in the Antiretroviral Era" (2009), <http://www.iasusa.org/pub/topics/2008/issue2/94.pdf>

36 "HIV infection in the brain: a long-term limitation of HAART?" (2009), <http://i-base.info/htb/1525>

What Can I Do?

Talk to your doctor about any concerns with memory loss or learning and comprehension problems. Some memory fuzziness can be a part of the hormonal changes of perimenopause (see “The Shift to Menopause” section). Don’t panic, but do let your doctor know about changes overall. Also let your doctor know about physical changes, like any difficulty you have controlling how you walk or move around.

Some people say challenging the brain to learn new things is a good way to stay sharp. Challenge your mind through crossword puzzles or learning a new language—Spanish, anyone? If you want to learn something new and have the time and space, go for it. If it puts more pressure on your life, let it go.



Spiritual Health and Community Connections



LIVING WITH HIV has emotional ups and downs in addition to the physical ones. Stigma, isolation, depression, and anxiety are common experiences of people living with HIV. Hitting midlife can add to these. Midlife is a time of looking back and wondering about what’s to come. Some moments you’ll be amazed and grateful you’ve made it this far, and others you may feel depressed. It’s normal to feel a mix of emotions.





What Can I Do?

Connect

A recent study of adults found that connections with others are what we remember most. It's not achievements or failures in school or work or wealth—it's the people. We matter to each other.³⁷

Managing HIV isn't only about your body; it's about your heart and soul. A good friend, support group, or counsellor can help in how you look at things.

A US study of older adults (50 and over) living with HIV found that as people age, more tend to live alone. For some people, being alone can trigger depression, isolation, and even substance abuse.³⁸ Get on the phone, get out, call a friend, visit a community centre.

³⁷ "What makes us happy can make us sad" (2010), <http://www.futurity.org/society-culture/what-makes-us-happy-can-make-us-sad/>

³⁸ Research on Older Adults with HIV (2006), pp. 19–23, <http://www.acria.org/files/ROAH%20Final.pdf>

If you see yourself as a loner, your meaningful connections could be animals or nature. Are you a loner by choice? Connect to what brings you energy. Are you a loner by circumstance? Making the effort to reach out can make a difference, even though it seems tough. One step at a time.

Contemplate

Sacha, who's in her forties, wonders what her life might have been like professionally if she hadn't been so consumed with looking after her health. HIV complications meant she couldn't manage ongoing work even part-time. She volunteers and takes on small projects with acceptance, explaining, "I contribute what I can."

Maybe you decided not to have children because you wondered about the effect of HIV on you and a child. Maybe it feels strange that you've survived when others didn't. It's normal to wonder how things might have been different. Don't beat yourself up though. Focus on what you've overcome and all you're grateful for.

Celebrate

Take comfort in personal rituals, traditions, or spiritual communities. Meaningful ritual can be as simple as a few minutes of quiet each day, or a noisy meeting with friends each week. You might find strength in a formal place of worship. Maybe it's in a sweat lodge, healing circle, sun dance, or pow wow. Kelly says that before she goes to sleep at night, she thinks of two things about herself or her life that she appreciates. "Practice gratitude," she advises.

What brings meaning to your life? What helps you feel a part of the earth? The simple act of greeting another day can be encouraging. Having a connection to rituals of your own or those of a community can help when things get hard.



Resources



Where to go next?

If you want to find an AIDS service organization near you, CATIE (www.catie.ca) keeps a list of organizations in Canada. Check out its "ASO411" feature on the "Find Organizations" page.

For more information specific to women living with HIV, please visit Positive Women's Network at www.pwn.bc.ca

You're not alone, and you can live a long and healthy life!





Index

abusive relationships, 50–53
abusive relationships, getting support, 53
alcohol use, 14
antiretroviral therapy (ART), 33. *See also* treatment for HIV
anxiety, 22
autoimmune disease, 13

body shape, changes in, 40–41, 43
bone density, decrease in. *See* bone loss
bone loss, 23–27
brain health, 54–56

cardiovascular disease, 28–32
cholesterol. *See* lipid levels
condoms and barriers, 47
connecting with others, 8, 58. *See also* support

depression, 22
diabetes, risk factors for, 42
diet, healthy, 27

disclosure of HIV status, legal aspects of, 10
drug use, safer, 11

exercise, 26, 30

family medical history, 16, 32

heart disease. *See* cardiovascular disease

hepatitis C, 37

highly active antiretroviral treatment (HAART), 33.

See also treatment for HIV

hormonal changes, 21

immune system, effects of HIV on, 12–13

inflammation, 13–15

life expectancy, 3–4, 34

lipid levels, 31

lipodystrophy. *See* body shape, changes in

lubricant, 21, 47

medical tests, 16, 27, 31, 39

medication. *See* treatment for HIV

memory changes, 56

menopause, 17

menstrual patterns, 17, 20

midlife, 57, 59

mood swings, 22





new HIV diagnosis, statistics, 7
nutrition. *See* diet, healthy

oral sex, 11, 47

perimenopause, 17–19
perimenopause, symptoms of, 19
periods, changes in. *See* menstrual patterns

relationships, 10, 50–53

self-esteem, 43
sex life, 10, 44–48
sex, safer, 11, 21, 47
side effects of HIV treatment, 38–39
smoking, benefits of quitting, 14, 26, 30
spiritual health, 60
support, 8, 43, 53, 58, 61

testosterone, 21, 45
transmission of HIV, 11, 48
treatment for HIV, 15, 31, 33, 36, 37

vaginal changes, 21, 45
viral load, 34–35

weight changes. *See* body shape, changes in

Many thanks to Dr. Neora Pick for medical review and to positive women and community members who offered valuable feedback on this guide.



Positive Women's Network

614-1033 Davie Street
Vancouver, BC V6E 1M7

604.692.3000

1.866.692.3001 (toll-free BC)

www.pwn.bc.ca

Written by Janet Madsen

Editing and design by Miriam Martin and Erin Seatter

Index by Caroline Helmeczi

Printed with assistance from
Merck Canada, 2012



© Positive Women's Network Society, 2012

ISBN 978-0-9876816-2-1