



Patients

Women-Centred HIV Care: Information for Women



You are not alone. About 14,500 women in Canada are living with human immunodeficiency virus (HIV).¹ This toolkit was made lovingly in partnership with women living with HIV, to support women like you to receive the care you deserve. We call this care 'women-centred HIV care' (for more information on the Women-Centred HIV Care model see [page 27](#)). The purpose of this toolkit is to give you the information that you need to advocate for and make informed choices about your health care.

Terms used in this toolkit:

- **Women living with HIV** – to refer to all people who are living with HIV and who identify as women. This includes cis, trans, gender non-binary who were assigned female at birth, two-spirit and gender-diverse women
- **Care providers** – to refer to all people who provide care for women living with HIV. This includes family physicians, specialists, nurse practitioners, registered nurses, pharmacists and front-line service providers from HIV service organizations
- **HIV service organizations** – to refer to community-based organizations that provide HIV and AIDS programs, supports and services

You can bring this toolkit to all your appointments. This includes appointments with your main care provider, hospitals and specialists. All parts of this toolkit are important for women living with HIV. However, different parts of this toolkit may be important to you at different times. The information in this toolkit is based on current research. An overview of the toolkit development process can be found at [cep.health/hiv](#). In this toolkit, you will also see quotes from women across Canada who live with HIV. These women are at different stages of their life and healthcare journey. These women share their advice, thoughts and experiences with you to let you know you are not alone.

Living well with HIV



Remember that you can live a long, healthy and happy life with HIV.



Emotional healing takes time. Seeking support for coping through friends, family, care providers or peer supports may be helpful (see [Section F: Peer support, leadership and capacity building](#)).



Set and work towards Specific, Measurable, Attainable, Realistic and Time-oriented (SMART) goals.



I have been living with HIV for over 20 years. You can live long, happy, and very healthy with HIV. — Woman living with HIV



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Section A: Person-centred care

Person-centred care is health care that respects an individual as a whole person. It treats each person as a partner in their care. You have a right to receive person-centred care from your care providers. You have a right to be treated as a unique individual. You have a right to be included in decision-making about your health care. You play an important role in person-centred care.

To help your care providers understand you as an individual, you may choose to share with them the following information about yourself:²⁻⁸



Share this information with your care provider to help them to understand you, your health and your preferences for treatment and self-management.⁶⁻⁸



If your doctor is asking you questions that you don't understand the purpose of, you have the right to ask them, 'Why are you asking me that? I want to understand more about it.' — Woman living with HIV



Section A: Person-centred care (continued)

Build partnerships with your care providers who are trusting and helpful.⁹

Find care providers who:⁹

- Are knowledgeable and up-to-date about HIV. They may be experienced through training or may have other women in their practice who are living with HIV.
- Are respectful and caring. They should be interested in you as a person.
- Are accepting of your lifestyle. They should allow you to be open and honest.
- Listen to your needs. They should give enough time so that discussions do not feel rushed. (Tip: When you have more than one concern, call ahead and ask to book a longer appointment.)
- Acknowledge and address your questions. They should help you to make informed decisions.
- Are efficient. They should follow up with you regularly.
- Protect your confidentiality and privacy.

Contact your local HIV service organization if you have trouble finding care or if your care providers do not meet your needs. It might be hard to access care if there are not enough healthcare services or skilled HIV care providers in your area. It might be hard to find transportation to the care you need. Your local HIV service organization can help you to find a care provider. They also may be able to make a referral on your behalf. If you have a care provider but feel that they are not meeting your needs, there is nothing wrong with finding a new one.



To find your local HIV service organization: contact HIV411 by dialing 1-800-263-1638 or browse their directory at HIV411.ca, or browse the [Canadian AIDS Society's membership website](#). Peer navigators can also help you to navigate the healthcare system (see [Section F: Peer support, leadership and capacity building](#)).



I find it SO HELPFUL to keep a record or journal of my side effects and bring it with me to my doctor's appointment. I record everything I can, and then we use it together to address my concerns. — Woman living with HIV



Questions you may want to ask your care provider to feel informed, safe and comfortable:¹⁰

- What are you going to do with my information? Who in my circle of care should know about my HIV status?
- Will you talk to my partners/family?
- Who else will see my results?
- Is your clinic/organization a welcoming space for people living with HIV? What makes it safe and welcoming?
- How do you plan to include me in decision-making about my treatment and care?
- How will you support me in my goal of _____? (e.g. getting to undetectable, finding a peer navigator)
- What support can I receive to help me pay for my health care expenses?
- Are translation/interpreter services available?

You can use the space below, an audio recording or the [MyHIVTreatmentOptions](#) website to make a list of questions to ask your care provider at your next appointment.

Questions:

Section A: Person-centred care (continued)

Bill of rights for women living with HIV

You have the right to:^{9,10}

- Be treated with dignity and respect
- Ask questions
- Honesty
- A second opinion (advice from a second expert) from another care provider
- Say “no” to your care provider
- Confidentiality
- Up-to-date and balanced information
- Refuse any therapy
- Start, change or stop taking medication
- Have all tests and treatments be done with your full informed consent
- Your care providers’ full attention
- Have your personal information kept private
- Have children
- Bring a peer navigator, an advocate or a translator to your appointments (see [Section F: Peer support, leadership and capacity building](#)).
- Trauma- and violence-aware care and a care provider that provides this care
- Decline the presence of a student/trainee in the room during your appointments

Be considerate and respectful of your care provider⁶

Remember that the relationship with your care provider is a partnership, which means you have responsibilities as well. Be sure to:

- Make your appointments and be on time
 - If you need to cancel, do so as soon as possible. Providers can offer the time to another person
 - Ask your care providers if they can set up appointment reminders for you
- Prepare a list of your questions and the things you need before your appointment
- Be open and honest (as much as you feel comfortable) about your circumstances and experiences (e.g. priorities, preferences, health beliefs, lifestyle, access to housing and food)
- Share information (as much as you feel comfortable) with all members of your care team⁹

Section B: Trauma- and violence-aware care

If you have experienced trauma or violence, you are not alone. It is estimated that 79% of women living with HIV in Canada have experienced a form of trauma or violence.¹¹ This is 13 times higher than among all women in Canada.¹² Therefore, it is recommended for care providers to practice trauma- and violence-aware care with all women living with HIV. Trauma- and violence-aware care is an approach to health care in which care providers understand the impacts that trauma and violence can have on one's physical, mental and emotional health and wellbeing. Trauma- and violence-aware care acknowledges all forms of violence. It aims to provide women living with HIV with a safe space and to equalize the power imbalances that can exist in care provider-client relationships. Trauma- and violence-aware care acknowledges women living with HIV as equal experts in their care and respects their priorities and preferences.¹³

“Don't be ashamed to get the help you deserve. — Woman living with HIV”

Trauma can be ongoing, and reactions to trauma can be different across individuals. But there is help. There are steps that you can take to recognize and heal from trauma.

What is trauma?

Trauma is an experience that overwhelms an individual's capacity to cope. It can be the result of a specific event, multiple events or circumstances that an individual experiences as emotionally or physically threatening.¹⁴ Trauma can happen at any age, and it can result from:^{14,15}

- **Single incident trauma** – trauma from experiencing a health diagnosis, accident, natural disaster, abuse, assault, sudden loss or witnessing violence
- **Complex trauma** – trauma from experiencing prolonged or multiple traumatic events, including psychological maltreatment, ongoing abuse, domestic violence, war, ongoing betrayal, displacement, resettlement, being trapped emotionally or physically
- **Developmental trauma** – trauma experienced before the age of 18 years, including neglect, abandonment, physical abuse or assault, sexual abuse or assault, emotional abuse, witnessing violence or death, coercion or betrayal
- **Intergenerational trauma** – psychological or emotional effects of trauma that are passed down from generation to generation
- **Historical trauma** – psychological or emotional effects of being part of a community that has experienced a large group trauma such as genocide, residential schools, slavery or war
- **Institutional trauma** – traumatic experiences that happen due to how institutions function (e.g. inadequate medical care, lack of mental health support) and how an individual was treated in an institution¹⁶
- **Stigma trauma** – trauma from experiencing discrimination related to an aspect of one's identity^{17–19}

Section B: Trauma- and violence-aware care (continued)

What is “trauma- and violence-aware care”?

Trauma- and violence-aware care means that your care provider knows that your traumatic experiences may affect you. Your experiences of trauma and violence may affect your development, mental and emotional health, substance use and physical health. Care providers can help you with these effects by sharing information on coping strategies, triggers and reactions. They put your choices and safety first.¹⁴

Trauma- and violence-aware care is about:²⁰

- | | | | | |
|---|---|---|--|--|
| 1. Empowerment – use your strengths to improve your wellbeing. Your care provider can help you to identify your strengths. | 2. Safety – your care setting should feel safe. This means that it feels safe physically, emotionally, psychologically, culturally and for all areas of your life. | 3. Collaboration – you are a part of your care team. It will take time to determine the best care plan for you, and you have the right to be a part of the decision process. | 4. Choice – you have the right to be told about all care options and make your own choices. You can choose the care option that will work best for you. | 5. Trustworthiness – your care provider should explain what all care options will involve, who will provide the care and how it will be provided. |
|---|---|---|--|--|

Please note: Not all care providers have the training to provide trauma- and violence-aware care. Think of this when talking to your team. Understanding each team member's strength is helpful.

How do you know if you have/are experiencing trauma?

Everyone's reactions to trauma and violence are felt differently.¹⁵ Some trauma responses include stress, nervousness, fear, shock, shame, flashbacks, feeling numb or disconnected to the present moment, unwanted thoughts, helplessness or powerlessness.¹⁵

Experiencing trauma or being reminded of trauma in a care setting may be a barrier to accessing needed HIV care.



You can answer questions developed by [WithWomen](#) to help you know if you have experienced or are experiencing trauma or violence

If you are experiencing trauma or violence, you are not alone. Talk to someone or access support. You have the right to feel safe. You have the right to be free from violence and trauma.

What to do if you experience trauma?

1. Get 'right now' support – if you are currently experiencing trauma or violence, seek emergency services by calling 911 or a crisis line to get immediate help to cope with the traumatic or violent situation.

2. Share your experiences with your care providers – your care providers can help you deal with a traumatic or violent situation. They can offer ways to cope with memories of previous trauma or violence. You may prefer to talk to a woman with HIV who has a similar experience. If so, refer to [Access peer support](#) below.

- Your care providers may ask you about your experiences with violence or trauma. They may ask how an experience has affected your health and wellbeing.
- Your care providers ask about your experiences so that they can help to support you.
- You can choose what you tell or do not tell your care providers about your experiences with violence or trauma.

3. Access peer support – you can connect with other women who have experienced trauma or violence. You can connect through trauma-specific groups or one-on-one. Both types of peer support can help you to share your experiences and learn how others cope with memories of previous trauma or violence.



To find a crisis line or shelter, you can contact Canada's free government and community-based health and social services information phone line. Dial 2-1-1 or go to 211.ca

To access crisis lines for Indigenous peoples, visit the [Hope for Wellness Help Line](#) and [Talk4Healing](#) webpages

To find more services, look at the [Canadian Department of Justice's Victim Services Directory](#)



To find peer support close to you, you can contact Canada's free government and community-based health and social services information phone line. Dial 2-1-1 or go to 211.ca

Section B: Trauma- and violence-aware care (continued)

- 4. Build skills for coping with a trauma response** – when you talk about your experiences with trauma or violence, it can cause a trauma response, such as stress, nervousness, fear, shock, shame, flashbacks, feeling numb or disconnected to the present moment, unwanted thoughts, helplessness and powerlessness. This can cause you more trauma. Learn how to build skills that help you cope with your feelings when you talk about your experiences. These are called ‘grounding exercises’.



To find grounding exercises to practice, visit the [Blue Knot Foundation's webpage on grounding](#).

- 5. Ask your care provider for a referral to a psychologist, psychiatrist, or psychotherapist** – you can ask for a referral to a specialist who has specific training in trauma if one is available in your community. Please note that seeing psychologists and psychotherapists usually require out-of-pocket payment. Seeing a psychiatrist is usually covered by provincial or territorial health coverage. Psychiatrists also have the ability to prescribe medication, which may be recommended in addition to talk therapy. However, you may require a diagnosed mental health condition to receive coverage, and you may experience longer wait times.

Healing from trauma or violence is a lifelong journey. Healing may require help from women who have experienced trauma or violence or from others who have expertise in supporting women.

Section C: HIV care

HIV is a virus that attacks the cells of your body that help to fight infections. This puts you at risk of getting other infections and diseases. When you start receiving HIV care, your care providers will take steps to understand your current and past health history. They will work with you to lower your risk of getting other infections and diseases. Your care should improve your overall health, longevity and quality of life. Women who are diagnosed with HIV can live long and healthy lives.



For more information on HIV, refer to [CATIE's HIV Basic Facts](#)

Terms used in Section C: ²¹

- **CD4 count** – a measure of how strong your immune system is. It is measured as the number of CD4 cells that are present in each microlitre of blood (cells/μL)
- **Viral load** – the amount of HIV detected in your blood. It is measured as the number of copies of the virus that are present in each millilitre of blood (copies/ml). Viral load ranges from undetectable to millions of copies/ml. At less than 1,500 copies/ml, HIV is considered low; at less than 200 copies/ml, HIV is considered suppressed; and, at less than 40 copies/ml, HIV is considered undetectable. Neither a suppressed or an undetectable viral load means that you are cured of HIV, but it does mean that the virus is under control and cannot be passed on through sexual transmission
- **Antiretrovirals (ARVs)** – medications used to treat HIV by preventing the replication of HIV in your body
- **Combination antiretroviral therapy (cART)** – a combination of antiretroviral medications (either in one pill or in multiple pills) that is the standard of care for people living with HIV to help them to live healthier and longer lives
- **Pre-exposure prophylaxis (PrEP)** – antiretroviral medicines that are taken daily by people who are at risk of getting HIV to prevent becoming infected
- **Post-exposure prophylaxis (PEP)** – antiretroviral medicines that are taken by people to prevent becoming infected after they are potentially exposed to HIV

i. Steps for your HIV care

You and your care providers will work through these steps after your HIV diagnosis.

Initial care^{4,22,23}

- You will have the first assessment with your care providers. It will include a physical exam and questions to help them know about your current health, health history and priorities
 - Remember, you have the right to ask why a question is being asked of you
 - Try to be open and honest with your care providers (as much as you feel comfortable). Information about your experiences will help them.
- You and your care provider will talk about all treatment options
 - Remember, you are a partner in your care. Decisions about treatment options involve both you and your care provider.
- It is important that your care provider offers you counselling and connects you to peer support as well as your local HIV service organization if you want it (see [Section F: Peer support, leadership and capacity building](#))

Follow-up and ongoing care²³

- Your care providers will ask you to come back every 1-2 months* for follow-up appointments and lab tests after your initial diagnosis or after starting cART
- Your appointments may be scheduled less often* (e.g. every 3-6 months) once your HIV viral load is low enough
- Let your care providers know if you have trouble making appointments so that they can help you to set up reminders

* Timelines for follow-up are different for each person (e.g. if you live farther away from your care providers, you may be scheduled for less frequent follow-up appointments and lab tests)

Section C: HIV care (continued)

ii. Treating HIV

Starting cART^{4,22,24,25}


- HIV care has made exceptional gains in the last few years. Effective therapy is now available, and it's called cART
- cART is the standard therapy given to all people living with HIV
- It is recommended that you start cART within 4 weeks of your initial care appointment to receive maximum benefits, but you have the right to decide if and when you want to begin therapy



For information on classes of HIV drugs, visit the [“Different classes of HIV drugs” section in CATIE’s Guide to HIV Treatment](#)

Benefits and side effects of cART

Note: side effects can vary across types of cART. The medications that are now widely used have fewer side effects than in the past.

Benefits ^{26,27}	<p>Benefits:</p> <ul style="list-style-type: none">• Helps you to live a long and healthy life• Decreases your HIV viral load and increases CD4 cell count• Lowers your risk of getting other diseases and infections• Lowers your risk of passing HIV on to your sexual or drug-using partners• Lowers your risk of passing HIV on to your baby during pregnancy and birth <p> For more information on the benefits of cART, visit CATIE's Guide to HIV Treatment</p>						
Possible side effects ^{26,27}	<p>Possible short-term side effects (first few weeks):</p> <table><tr><th>Common</th><th>Less common</th><th>Rare</th></tr><tr><td><ul style="list-style-type: none">• Nausea• Diarrhea, gas and bloating• Fatigue• Headaches</td><td><ul style="list-style-type: none">• Abnormal taste• Dry mouth• Skin rash• Dry skin and cracked lips• Ingrown nails• Hair loss• Hyperpigmentation (darkening patches of the skin) of the palms of the hands, soles of the feet, tongue, nails and occasionally the face• Trouble sleeping</td><td><ul style="list-style-type: none">• Unfocused thinking• Feelings of paranoia and disorientation• Depression• Anxiety• Vivid dreams and nightmares• High levels of lactic acid (acid present in muscles and blood)• Inflammation of the pancreas• Abacavir hypersensitivity (allergic-like reaction) – screening tests are available</td></tr></table> <p>Possible longer-term side effects:</p> <ul style="list-style-type: none">• Weight and body shape changes• Muscle weakness and pain in the back, hips or lower limbs• Decreased bone density• Lipodystrophy (the body is unable to produce and maintain healthy fat tissue)• Increased risk of chronic kidney disease• Increased risk of cardiovascular events <p>If help is needed to cope with side effects:</p> <ul style="list-style-type: none">• Ask your pharmacist if there are ways you can take your medication to reduce side effects (e.g. with meals, at night)• Ask your care provider if you can change to a different type of cART. Remember, you have the right to question or change a care plan that is not working for you• Connect with peer support to discuss how others manage side effects (see Section F: Peer support, leadership and capacity building)	Common	Less common	Rare	<ul style="list-style-type: none">• Nausea• Diarrhea, gas and bloating• Fatigue• Headaches	<ul style="list-style-type: none">• Abnormal taste• Dry mouth• Skin rash• Dry skin and cracked lips• Ingrown nails• Hair loss• Hyperpigmentation (darkening patches of the skin) of the palms of the hands, soles of the feet, tongue, nails and occasionally the face• Trouble sleeping	<ul style="list-style-type: none">• Unfocused thinking• Feelings of paranoia and disorientation• Depression• Anxiety• Vivid dreams and nightmares• High levels of lactic acid (acid present in muscles and blood)• Inflammation of the pancreas• Abacavir hypersensitivity (allergic-like reaction) – screening tests are available
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For more information on the side effects of cART, visit [CATIE’s Practical Guide to HIV Drug Side Effects](#)

Section C: HIV care (continued)



You may or may not experience side effects, and it might be different from what others are getting. Delayed reactions are normal as well. — Woman living with HIV



Selecting types of cART and avoiding drug interactions

To help your healthcare providers pick the best cART for you, tell them if you:

- Are planning to get pregnant or are pregnant
- Have mental, emotional or physical health conditions
- Are taking other prescribed medications (i.e. anything you have a prescription for)
- Are taking over-the-counter medications, such as ibuprofen (e.g. Advil®), acetaminophen (e.g. Tylenol®) or antacid (e.g. Tums®)
- Are taking vitamins or supplements
- Are using recreational substances including cannabis
- Are using complementary and alternative medicines
- If you have an irregular schedule (e.g. work nights, travel for work)

Keep track of this type of information. It helps to have it when needed:

To help avoid a drug interaction, share this information with your care provider. A drug interaction is a reaction between a drug and another ingested substance (e.g. drug, food, supplement). It can cause side effects or lower how well the drug works.²⁸ Ask your care provider about drug interactions. If your main care provider is not available, talk to your pharmacist. Medications that can interact with HIV medication (ARVs and cART) include:

- | | | |
|------------------------|--|---|
| • Antifungal drugs | • Blood thinners | • Medication used to help people withdraw from opiate addiction (e.g. methadone, buprenorphine) |
| • Antibiotics | • Sedatives | • Medication used for treating tuberculosis (e.g. rifampin) |
| • Acid-reducing agents | • Birth control (HIV medication can lower how well it works) | |
| • Anti-seizure drugs | • Medication used to help control heart rhythm | |
| • Antidepressants | | |
| • Antihistamines | | |

Paying for cART

Your options for paying for cART include:

- If you have private health insurance, contact your insurance company to find out which medications they cover
- If you do not have private health insurance, visit [CATIE's Access to HIV and Hepatitis C Drugs: Federal, Provincial and Territorial Drug Access Programs guide](#) and talk to your care provider to learn more about the federal, provincial and territorial drug coverage and benefit programs available to you
- For information about how your legal status in Canada may impact coverage for your medication, visit the [“Services available to immigrants, refugees and non-status individuals with HIV” section of CATIE's Managing your health: a guide for people living with HIV](#)

Adherence to cART

Adherence means taking your medication how it has been prescribed, such as how often and the time of day to take it. Taking your medication how it has been prescribed is important so that it is safe and works as well as possible.

- Adherence to cART 95% of the time is needed to receive its benefits²⁹
- If you miss a dose:
 - It is better to take the missed dose late than to skip it completely. Then take your next dose at the usual time. Taking the missed dose and next dose close together is fine¹³
 - If you miss too many doses, your HIV viral load can become too high. This can make your HIV virus resistant (not respond) to the medication, causing it not to work³⁰

Section C: HIV care (continued)

- If you have trouble remembering to take your medications, let your care providers know (including your pharmacist), so they can help you by:
 - Packaging your medications with labels for each day
 - Setting up reminders to take your medication or to refill your prescriptions (keep track of the amount of medication you have left and make refill requests at your pharmacy at least a few days before you run out to ensure that you do not miss a dose)
 - Setting up automatic refills for your prescriptions (if your pharmacy offers this)
- If you have travel plans:
 - Let your provider know. Be sure that you have the medication refills and any vaccinations you may need while you are away
 - Notify provincial or territorial financial support programs about travel plans in advance to avoid issues with income support or prescription drug benefits

iii. Preventing HIV transmission

HIV can be passed on to another person through specific bodily fluids. These bodily fluids are blood, semen (including pre-seminal fluids), rectal fluids, vaginal fluids and breast milk. HIV is passed on when one of these fluids from a person with HIV enters the bloodstream or the mucus membrane of another person. This can happen through an injection, broken skin or a mucous membrane (found in the rectum, vagina, mouth or tip of the penis). Steps you can take to prevent the transmission of HIV to your children and sexual or drug-using partners include:

- Taking your cART consistently to keep an undetectable viral load^{31,32}
 - If your viral load is **Undetectable**, your HIV is **Untransmittable**
 - **Undetectable = Untransmittable** may be written as **U=U**
 - **U=U** applies to sexual transmission, but it is unknown if it applies to other forms of transmission (e.g. breastfeeding, transmission via injection drug use)³³
- Using condoms (female or male condoms) correctly and consistently with condom-compatible lubricants (i.e. use water- and silicone-based lubricants, and avoid oil-based lubricants)
 - Condom use is the only form of birth control that can protect against other sexually transmitted infections
- Using clean needles and avoiding sharing substance-injection equipment, as well as tattoo and scarification equipment
- Talking to your care provider about PrEP and PEP for your sexual partners



For more information on **U=U** refer to the [Women & HIV/AIDS Initiative's Living in the Asterisk resource](#)



For more information on reducing the risk of transmitting HIV to your sexual partners, visit [CATIE's Safer Sex Guide](#). For more information on reducing the risk of transmitting HIV on to your drug-using partners visit [CATIE's What Works Guide](#)

Section C: HIV care (continued)

iv. Disclosure ³⁴⁻³⁷

HIV disclosure is when you tell another person about your HIV status. You do not need to tell everyone about your HIV status, but there are some people that you should tell, if you can do so safely. Sometimes this can be hard. When deciding if you should tell someone about your HIV status, consider the benefits and risks. You should also be aware of the circumstances in which you have a public health or legal requirement to disclose. Speak to your care providers or a peer if you need support to plan how to tell another person (see [Section F: Peer support, leadership and capacity building](#)). You have a right to feel safe when you disclose.



Tips for telling another person:

- Obtain a good understanding of HIV transmission so that you can explain it during the conversation (e.g. U=U)
- Let someone (e.g. peer support, friend, care provider) know ahead of time that you plan to tell another person so that they can provide support after if needed
- Be clear about whether the person you tell can tell others. Tell the person if you do not want this information shared with others (keeping in mind that you can never guarantee this)
- Bring some materials (e.g. this toolkit or informational pamphlets) to share with the person you are telling
- Choose a time when the conversation is not rushed. Make sure that you, or the person you are telling, are not tired, hungry or upset
- If you are worried about a person's reaction, but want to tell them your status, you can choose a semi-public place to tell them or have another person with you (e.g. peer support, friend, care provider)

Benefits and risks to telling another person



It can feel good to be open and honest with a partner, friend or family member and can bring you closer together³⁸



It can lead to rejection, stigma, violence or abuse¹⁰
It can be a traumatizing, isolating and painful experience³⁸

Requirements about who you do and do not need to tell about your HIV status:

You do not have to tell your HIV status to:

- Casual contacts, such as employers, teachers, coworkers, sport coaches, roommates, family members or friends
- Sexual partners if you maintain a low viral load (i.e. less than 1,500 copies/ml) and use a condom*
- A provider at a walk-in clinic, unless your reason for accessing the clinic is HIV-related**

It is recommended that you tell your HIV status to:

- Dentists**
- All other care providers (e.g. emergency room care providers)**

Public health and the law require you to tell your HIV status to:

- Sexual partners, if you do not maintain a low viral load (i.e. less than 1,500 copies/ml) and do not use a condom***
- Previous sexual partners following your diagnosis
- Drug use partners before you share injection equipment
- Your care providers who care for you during your pregnancy, childbirth and if you choose to breastfeed. They can help you to look after your health and wellbeing and decrease the risk of transmitting HIV to your child

You do not have to tell others how HIV was transmitted to you.

*Even if your viral load is low and you use a condom, telling your partner about your HIV status may be important to you.

**Although you do not have to tell your HIV status to all your care providers, keep in mind that they can support you best if they know. They can provide better care and help you to stay as healthy as possible if they know about your HIV status. If your care provider would like to share your health files or history (including your HIV status) with another care provider, they must have your consent. Unfortunately, women living with HIV have experienced discrimination from dentists, walk-in clinic and emergency room care providers. Ask your care provider for a referral to a dentist who provides experienced care to people living with HIV.

***This is a legal requirement in Canada. The law is far behind the research that supports U=U. Even though the risk of transmitting HIV to a sexual partner when your viral load is low is unlikely, the law requires you to use a condom during sexual activity. Individuals are working to change the law.³⁹

Section C: HIV care (continued)

Other important information about telling someone that you have HIV:

- Laws for HIV disclosure are changing and differ by province and territory.
- Your provincial or territorial public health authority will be told about your HIV status after you are diagnosed. They will contact you to get a list of your past sexual partners.⁴⁰ You will be given the option to contact your past sexual partners or to have your public health authority contact them for you (they will not tell them your name).
- If you apply for permanent residence in Canada, you will need to have a medical exam that includes an HIV test. Your results will be shared with Immigration, Refugees and Citizenship Canada (IRCC). This is not grounds for refusal of your application however, if IRCC estimates that your annual health care costs including medication are more than \$19,812 (i.e. 3 times the cost of the average Canadian's annual health care costs), and you do not have private health insurance, you may not be able to obtain permanent resident status. Also your HIV positive status may be shared with your sponsor if you are in the Family Class or Dependent Refugee Class.³⁵
- If you need support or counselling around disclosure, contact your local HIV service organization. Counsellors at your local HIV service organization have experience supporting others with disclosure and can help you with questions, concerns or fears that you may have.



For up-to-date information, refer to the [Canadian HIV/AIDS Legal Network's Criminalization of HIV Non-Disclosure in Canada: Current Status and The Need for Change resource](#)



To find your local HIV service organization: contact HIV411 by dialing 1-800-263-1638 or browse their directory at [HIV411.ca](#), or browse the [Canadian AIDS Society's membership website](#)



Visit "[Categories of Restriction](#)" on the [Global Database on HIV Related Travel Restrictions website](#) for more information on travelling with HIV

Disclosure and travel:

- Some countries have restrictions on travel for those who are HIV positive. You can still travel living with HIV, but it helps to know which countries have restrictions and what types.

v. Keeping yourself physically healthy

Keeping yourself healthy will help you to live well with HIV. It will also help you to reduce your risk of getting other infections and diseases. Sometimes, being able to choose healthy lifestyle options is hard for many reasons.

This section offers general tips for living a healthy lifestyle and specific tips for women living with HIV.

Vaccinations⁴¹⁻⁴³

Certain vaccinations are recommended to help protect you from getting other infections and diseases. These vaccinations are a regular part of health care and aging for everyone. Many vaccines require more than one dose over a few appointments. It is important to have all doses that are recommended by your care provider. Keep track of the vaccines you are given. Tell your care providers about vaccinations that you may still need. Live vaccines should not be given to people living with HIV when their CD4 count is less than 200 cells/ μ L or if they are pregnant.

<input type="checkbox"/> Hepatitis A	<p>It is recommended to get your hepatitis A immunity checked. If you are not immune, it is recommended to get your hepatitis A vaccine.</p> <p>Date of hepatitis A immunity status check: _____</p> <p>Date of vaccine dose 1: _____</p> <p>Date of vaccine dose 2: _____</p>
<input type="checkbox"/> Hepatitis B	<p>It is recommended to get your hepatitis B immunity checked. If you are not immune, it is recommended to get your hepatitis B vaccine and you may require a booster shot.</p> <p>Date of hepatitis B immunity status check: _____</p> <p>Date of vaccine dose 1: _____</p> <p>Date of vaccine dose 2: _____</p> <p>Date of vaccine dose 3: _____</p> <p>Date of vaccine dose 4 (if needed): _____</p> <p>Date of booster shot (if needed): _____</p>
<input type="checkbox"/> Shingles (herpes zoster)	<p>It is recommended to get a shingles vaccine once when you reach the age of 50. It is not covered by provincial or territorial healthcare coverage until you are 65 years of age. You may choose to wait. Only the inactivated (not live) shingles vaccine can be given to people with CD4 counts less than 200 cells/μL.</p> <p>Date of vaccine dose 1: _____</p> <p>Date of vaccine dose 2: _____</p>

Section C: HIV care (continued)

Vaccinations⁴¹⁻⁴³ (continued)

<input type="checkbox"/> Hib (haemophilus influenzae type b)	It is recommended to get a Hib vaccine even if you have had this vaccine before. Date of vaccine: _____
<input type="checkbox"/> HPV (human papillomavirus) ⁴⁴	It is recommended to get the HPV vaccine before the age of 15 or as soon as possible after up to the age of 45 years, depending on the coverage in your province or territory. Date of vaccine dose 1: _____ Date of vaccine dose 2: _____ Date of vaccine dose 3: _____
<input type="checkbox"/> Flu (influenza)	It is recommended to get your flu shot every year in the fall. Only the inactivated (not live) flu vaccine can be given to people living with HIV. Date(s) of vaccine: _____ _____ _____ _____
<input type="checkbox"/> MMR (measles-mumps-rubella)	It is recommended to get the MMR vaccine if you have not already, especially if you were born in or after 1970. The MMR vaccine cannot be given to people with CD4 counts less than 200 cells/ μ L or those who are pregnant. Date of vaccine dose 1 (if needed): _____
<input type="checkbox"/> Meningitis (meningococcal conjugate)	It is recommended to get the meningitis vaccine every 3-5 years. Date of vaccine dose 1: _____ Date of vaccine dose 2: _____ Date(s) of repeated vaccines: _____ _____ _____ _____
<input type="checkbox"/> Pneumococcal infection (pneumococcal conjugate 13-valent and pneumococcal polysaccharide 23-valent)	It is recommended to get the pneumococcal 13 and 23 vaccines. It is recommended to also get booster shots with one of the booster shots given over the age of 65 years. Date of pneumococcal 13 vaccine: _____ Date of pneumococcal 23 vaccine: _____ Date of booster shot: _____ Date of booster shot (received after the age of 65 years): _____
<input type="checkbox"/> Tetanus, diphtheria, pertussis (whooping cough), polio	It is recommended to get a combination tetanus, diphtheria, pertussis (whooping cough) and polio vaccine. Date of vaccine dose 1: _____ It is also recommended to get a combination tetanus and diphtheria booster shot every 10 years and a combination tetanus, diphtheria and pertussis booster shot during each pregnancy. Date(s) of booster shots: _____ _____ _____

Section C: HIV care (continued)

Vaccinations⁴¹⁻⁴³ (continued)

<input type="checkbox"/> Chicken pox (varicella zoster)	<p>It is recommended to get the chicken pox vaccine before the age of 50 if you are not already immune. The chicken pox vaccine cannot be given to people with CD4 counts less than 200 cells/μL or those who are pregnant.</p> <p>Date of vaccine dose 1: _____</p> <p>Date of vaccine dose 2: _____</p>
<input type="checkbox"/> Travel vaccines	<p>Let your care provider know if you have plans to travel out-of-country. Be sure to have the vaccinations you need before you leave. Depending on where you are going, the following vaccines may be recommended:</p> <ul style="list-style-type: none"> <input type="checkbox"/> Cholera <input type="checkbox"/> Travelers' diarrhea <input type="checkbox"/> Japanese encephalitis <input type="checkbox"/> Rabies <input type="checkbox"/> Typhoid (only the inactivated, not live, typhoid vaccine can be given to people living with HIV) <input type="checkbox"/> Tick-borne encephalitis <input type="checkbox"/> Yellow fever (the yellow fever vaccine cannot be given to people with CD4 counts less than 200 cells/μL)



For more information on living healthy with HIV refer to [CATIE's Practical Guide to a Healthy Body for People Living with HIV](#)

Testing

Regular testing for other infections and diseases can help with early detection and treatment. Early detection and treatment are important. Testing for many of these conditions is a routine part of health care and aging for everyone. You may not require all tests listed. Keep track of the tests you have been given. Tell your care providers about the tests that you still may need.

<input type="checkbox"/> Bone health	<p>As you age, your bone density decreases. It is recommended that your risk of getting a fracture is assessed starting at the age of 40. To do this, you may need to complete a questionnaire or have an x-ray.⁴⁵ Some cART can cause your bone density to decrease even more.</p>
<input type="checkbox"/> Breast cancer	<p>If you are over 50 years of age and you have breasts, it is recommended that you get a mammogram (an x-ray of your breasts) every 2-3 years to look for breast cancer.^{44,46,47} Your care provider may recommend more frequent or earlier mammograms if you are at a higher risk of getting breast cancer.</p>
<input type="checkbox"/> Cardiovascular disease	<p>Having HIV may increase your risk of developing cardiovascular disease. It is recommended that your risk of developing cardiovascular disease is assessed at minimum every 5 years if you are under the age of 40 years, and annually if you are 40 years of age or older or starting to have the symptoms of menopause.⁴⁸</p>
<input type="checkbox"/> Cervical cancer	<p>If you have a cervix, having HIV may increase your risk of developing cervical cancer. It is recommended that you get a Pap test every year to look for cervical cancer.⁴⁹</p>
<input type="checkbox"/> Colorectal cancer	<p>If you are between the ages of 50 and 75 years, it is recommended that you give a stool sample every 2 years to look for blood which can be a sign of colorectal cancer.^{50,51}</p>
<input type="checkbox"/> Diabetes	<p>Having HIV may increase your risk of developing diabetes. It is recommended that your risk of developing diabetes is assessed every year. To do this, you may need to complete a questionnaire or have lab tests done.⁵²</p>
<input type="checkbox"/> High amount of fat in your blood (dyslipidemia)	<p>Having HIV may increase your risk of having a high amount of fat in your blood. It is recommended that you get lab tests every 1-2 years to assess the amount of fat in your blood.¹³</p>
<input type="checkbox"/> Hepatitis B and C	<p>Having HIV may increase your risk of getting hepatitis B and C. If you are between the ages of 15 and 65 years, it is recommended that you get lab tests that look for hepatitis B and C antibodies in your blood after you are diagnosed with HIV.⁵³ These antibodies can be a sign of having hepatitis. Your care provider may recommend that you go for a follow-up lab test if hepatitis antibodies are found in your blood. There is a treatment available to cure hepatitis C.</p>
<input type="checkbox"/> High blood pressure (hypertension)	<p>It is recommended that you get your blood pressure checked at least once every year.⁵⁴⁻⁵⁶</p>

Section C: HIV care (continued)

Testing

❑ Kidney impairment	It is recommended that you get lab tests done every 6 months to check your kidney function. ⁵⁶
❑ Liver impairment	It is recommended that you get lab tests done every 6 months to check your liver function. ⁵⁶
❑ Brain function (neurocognitive) issues	Having HIV may increase your risk of developing dementia or HIV-associated neurocognitive disorder (HAND). It is recommended that you have your cognitive ability (brain function) assessed within 6 months after you are diagnosed with HIV. ^{4,57}
❑ Sexually transmitted infections	Having HIV may increase your risk of getting sexually transmitted infections. It is recommended, if you are sexually active, to get tested for chlamydia, gonorrhea, syphilis and trichomonas when you are diagnosed with HIV and every year after that. ⁵³ Your care provider may recommend more frequent testing if you are more vulnerable to getting sexually transmitted infections.
❑ Tuberculosis	It is recommended to get a skin test for tuberculosis when you are diagnosed with HIV. ^{4,13,58} Your care provider may recommend that you go for additional skin tests and an x-ray if you are at a higher risk of getting tuberculosis or if you currently have or previously had tuberculosis.



Mammograms don't hurt as much as you think it does. It's more important to know about your breast health than worrying about it. Just do it! — Woman living with HIV



Living a healthy lifestyle

Eat healthy

Eat plenty of vegetables, fruits, whole grain foods and plant-based protein foods. Drink plenty of water and limit saturated fat, processed foods and sugary drinks.⁵⁹

To eat healthy on a budget, try these tips:⁶⁰

- Only buy what is on your grocery list (avoid impulse buys)
- Check out flyers, coupons, mobile apps and websites for discounts on foods that are on your list
- Look for in-store discounts on foods that are on your list (products getting close to their best before dates and oddly shaped or slightly bruised produce may be offered at a discount)
- Compare prices on the labels to choose the less expensive options
- Choose generic instead of brand name products
- Buy bulk or family-size versions instead of single-serve products (but be careful not to buy more than you need)
- Stock up on canned goods and foods that can be frozen when they are on sale (e.g. fish, fruit, vegetables, bread, meat and poultry)
- Buy fruits and vegetables when they are in season
- Choose plant-based protein foods more often (e.g. beans, lentils and legumes)
- Limit highly processed foods
- Prepare more food at home
- Avoid prepackaged foods (e.g. pre-seasoned meat)
- Set a budget for how much you want to spend on groceries each week or month
- Shop at discount grocery stores and avoid grocery shopping at convenience stores
- Check to see if your grocery store has a senior or student discount day (if applicable)
- Pair up with a peer to grocery shop and meal prep¹⁰
- Speak to peers in your community about where to find culturally-relevant food stores¹⁰




For support accessing food (e.g. food banks, community-based meals) contact Canada's free government and community-based health and social services information phone line by dialing 2-1-1 or going to 211.ca



For more information on eating healthy on a budget refer to [Canada's Food Guide Healthy Eating on a Budget](#)

Section C: HIV care (continued)**Living a healthy lifestyle (continued)**

Consider vitamins or supplements if deficient	If you cannot get your daily recommended amounts of vitamins or minerals from food, your care providers may suggest vitamins or supplements plus eating healthy to keep a balanced diet. Some vitamins or supplements may interact with your cART, so always check with your care provider before taking them.
Exercise regularly	<ul style="list-style-type: none"> Find an aerobic activity that you enjoy. Try to spend 150 minutes each week doing an aerobic activity you enjoy - doing it in sets of 10 minutes or more at a time⁶¹ Also, try to do muscle and bone-strengthening activities using major muscle groups at least 2 days every week⁶¹ Exercise does not need to be done at a gym. It can include going for a walk, walking during your commute, doing physical activities you enjoy, etc.
Practice sleep hygiene	<p>If you are having trouble sleeping, try these tips to get a better night's sleep:⁶²</p> <ul style="list-style-type: none"> Have a regular sleep and exercise schedule (even on weekends) Go to bed only when you are tired Use your bedroom only for sleep and sexual activity (if you are sexually active) Avoid large meals and exercise just before bedtime Limit caffeine, alcohol and nicotine Keep the bedroom dark and quiet Avoid daytime or evening napping Remove bedroom clock from sight Avoid light-emitting devices or bright lights in the hours before bedtime (e.g. e-books, cell phones, television), or use a blue light filter
Avoid/quit smoking	<p>Smoking can double the risk of death for those living with HIV and taking HIV medication.⁶³ Let your care providers know when you are ready to stop smoking so that they can offer support to help you quit.²³</p> <p> Visit the Government of Canada's You Can Quit Smoking website to learn more about the free provincial and territorial supports available to help you quit smoking</p>
Maintain healthy bones	<p>Be sure that your diet has enough calcium and vitamin D:</p> <ul style="list-style-type: none"> Daily calcium requirement = 1,000 mg/day for women 50 years of age or younger and 1,200 mg/day for women over the age of 50 years^{45,64} Daily vitamin D requirement = 400-1,000 IU/day for women 50 years of age or younger and 800-2,000 IU/day for women over the age of 50 years⁶⁴ <p>If you think you may not be getting enough calcium and vitamin D, talk to your care provider. They can tell you how to increase your calcium and vitamin D through diet and supplements.^{45,65}</p>
Look after your mental health and wellbeing	See Section E: Mental and emotional health care
Practice good oral hygiene	<p>To prevent tooth decay and gum disease:⁶⁶</p> <ul style="list-style-type: none"> Brush your teeth for 2 minutes twice a day Floss daily Avoid tobacco See an oral health professional regularly
Avoid drug interactions	<p>Check with your care providers before taking any new:</p> <ul style="list-style-type: none"> Prescribed medications (i.e. anything that you have a prescription for) Over-the-counter medications, such as ibuprofen (e.g. Advil®), acetaminophen (e.g. Tylenol®) or antacid (e.g. Tums®) Vitamins or supplements Recreational substances, including cannabis Complementary and alternative medicines <p>Your care providers will tell you if there could be an interaction with your cART.</p>

Section D: Women's health care

You deserve care that acknowledges and prioritizes your sexual and reproductive rights.

Terms used in Section D:

- **Sexual and reproductive health rights (SRHR)** - is the concept of human rights as applied to women's sexuality and reproduction
- **SOGIE** - sexual orientation, gender identity and expression
- **Pre-exposure prophylaxis (PrEP)** - antiretroviral medicines that are taken daily by people who are at risk of getting HIV to prevent becoming infected
- **Post-exposure prophylaxis (PEP)** - antiretroviral medicines that are taken by people to prevent becoming infected after they are potentially exposed to HIV

For information on sexual health (e.g. cervical and breast cancer, human papillomavirus, sexually transmitted infections and diseases), please see [v. Keeping yourself physically healthy](#)

i. Sexuality and sexual rights

- Sexuality comes in many forms
- Women of all ages and SOGIE have a right to a safe, healthy and fulfilling sex life
- You have the right to the sex life you desire (including if you do not want to engage in sexual activity)
- You have a right to care providers and services that support your SOGIE, experiences, preferences, desires, occupations, social and cultural norms, as well as values and networks¹³

If you are experiencing reduced sexual desire/libido, you are not alone. Many women living with HIV report low sexual desire/libido due to many factors, including medication side effects, fears about disclosure and HIV criminalization laws.⁶⁷ Creating safe, supportive relationships and finding coping strategies that work for you can help.

Coping with stigma from SOGIE

You may face prejudice, discrimination or other forms of stigma due to your SOGIE. This may even include violence. If stigma affects your physical safety, find a safe space or call 911 if needed. Ways that you can cope with stigma from SOGIE include:⁶⁸

- Counselling or therapy
- Peer support (see [Section F: Peer support, leadership and capacity building](#))
- Self-affirmation (you can affirm your identity by hearing others that share your SOGIE tell their narratives and sharing yours if you want to)
- Support groups



For more information specific to the health care of trans women, please refer to [Rainbow Health Ontario's website](#)



To access LGBTQTS-friendly programs and services, contact Canada's free government and community-based health and social services information phone line by dialing 2-1-1 or going to [211.ca](#)



For more information or resources to support you in exploring your sexuality and sexual rights, refer to:

- [The Life and Love with HIV website](#)
- [The Genderbread Person website](#)
- [The Human Rights Campaign's Resource Guide to Coming Out](#)



You can have a good relationship and a great sex life with HIV. — Woman living with HIV



Section D: Women's health care (continued)

ii. Reproductive health

Women living with HIV can conceive children who are born HIV free and without transmitting to an HIV-negative partner. In Canada, approximately 98% of children born to women living with HIV who take cART consistently are born HIV free.⁶⁹ Ask your care provider to support you (and your partner, if you have one) in planning for pregnancy. Let them know as soon as you are pregnant so they can help you have a child born HIV free.



You can access more information on pregnancy from the [HIV Pregnancy Planning Guidelines website](#)

For more information on your SRHR, refer to the World Health Organization's Consolidated guideline on sexual and reproductive health and rights of women living with HIV [Implementation Checklist](#).⁷⁰ This checklist also helps you build the skills to help others (e.g. care providers) offer health care that supports women's SRHR



Do you have thoughts or plans about parenting?⁷¹

No

If you want birth control, ask your care provider to tell you about your options



For more information about birth control options, visit the [Society of Obstetricians and Gynaecologists of Canada's It's a Plan website](#)

Yes, in the near future

If you want to get pregnant, tell your care provider so they can help you to prepare for a safe and healthy pregnancy:

- It is recommended that you take folic acid supplementation 3 months before pregnancy and for at least 3 months into your pregnancy⁷²
- Avoid the use of recreational substances, alcohol and smoking
- Check that you are on medications that are safe for pregnancy^{72,73}
- Talk about methods of conception with your care provider (See [Methods of conception](#))

I am/my partner is pregnant now

Tell your care provider so that they can help you to have a safe and healthy pregnancy:

- It is recommended that you take folic acid supplementation for at least 3 months into your pregnancy⁷²
- Avoid the use of recreational substances, alcohol and smoking
- Check that you are on medications that are safe for pregnancy^{72,73}
- Eat a healthy and balanced diet
- Talk to your care provider about finding secure and affordable housing, food, infant formula/baby food or childcare supports

Talk to your care provider about the delivery process and infant feeding options:

- Women living with HIV do not have to have elective caesarean sections if their viral load is undetectable
- All children born to women living with HIV should take oral antiretroviral medication after birth. This gives them the lowest possible risk of HIV transmission.
- In Canada, it is recommended that women living with HIV feed their child infant formula. Breastfeeding is not recommended. Even with an undetectable viral load, it is not known if HIV transmission can result from breastfeeding.⁷⁴
 - If you have questions or are thinking about breastfeeding, tell your care provider. Your care provider can provide you with up-to-date evidence to help you make informed decisions. If you decide to breastfeed, your care provider and your infant's care provider will help you reduce the risk of transmitting HIV to your child through your breastmilk. This may be done with: medication and testing for the infant, making sure that you take cART consistently and that your viral load is suppressed, as well as discussing your preference for breastfeeding and your plans for weaning.^{74,75} The decision to breastfeed should be made together with your care providers.⁷⁶

Talk to your care provider about post-partum depression:

- In the first months following childbirth, you may have symptoms of depression
- Ask a care provider about post-partum depression if feelings of sadness do not go away after 2-3 weeks of rest, sleep or support from others



For more information on nutrition during your pregnancy, visit the [Government of Canada's Guide to Healthy Pregnancy](#)



To find secure and affordable housing, food, infant formula/baby food or child care supports, you can also contact Canada's free government and community-based health and social services information phone line by dialing 2-1-1 or going to [211.ca](#)



For more information on breastfeeding and the transmission of HIV, visit [Drs. Mona Loutfy and Sean \(Ari\) Bitnun's blog on the CATIE website](#)



It is because of my child I gain motivation and strength to live healthy and create lasting memories. Being HIV positive didn't take away my right to be a mother. — Woman living with HIV



Section D: Women's health care (continued)

Methods of conception

General recommendations:

- Talk to your care provider about ways you can conceive and about pre-conception counselling with your partner if you have one
- Take cART for at least 3 months and have a suppressed viral load for ideally 6 months (meaning 2 viral load tests that are less than 200 copies/ml at least 1 month apart) before trying to conceive^{72,73}
- If your partner does not have HIV, talk to your care provider and partner about PrEP⁷²

Methods:⁷²

- Condomless sex timed with ovulation (recommended method of conception) – this method requires the partner with HIV to be on cART and for their viral load to be less than 200 copies/ml twice in a row and at least 1 month apart. Then the partners have sexual intercourse without a condom 1-3 days before the day of ovulation and on the day of ovulation (or every other day around ovulation if menstruation is irregular).
- Condomless sex – this method requires the partner(s) with HIV to be on cART and for their viral load to be less than 200 copies/ml twice in a row and at least 1 month apart. Then the partners have sexual intercourse without a condom.
- Home sperm insemination with a syringe – this method requires the collection of sperm from a partner or donor (who does not have HIV) in a clean container or a condom. Then the sperm is drawn into a needleless syringe and inserted into the vagina as close to the cervix as possible. This method should be used 1-3 days before the day of ovulation and on the day of ovulation.
- Sperm washing with intrauterine insemination – this method requires a referral to a fertility clinic or a care provider who specializes in fertility. In this method, the care provider will collect sperm from a partner or donor, 'wash it,' and insert it into the uterine cavity with a catheter 1-3 days before the day of ovulation and on the day of ovulation.
- Other – in vitro fertilization, intracytoplasmic sperm injection, sperm donation, egg donation or surrogacy, adoption



For more information on PrEP access and government drug plan coverage, visit [CATIE's PrEP Access and Coverage guide](#)

Coping with stigma during and after pregnancy

Ask your care providers for referrals to peer or counselling support. This support may help you to cope with the stigma or discrimination you may face from people who are less informed about the risks of HIV transmission. These people may question your right to have a child or your decision to breastfeed or not breastfeed.⁷⁴

iii. Aging with HIV

Women with HIV are living longer and healthier lives. Improvements in cART have had a great effect. As you age, you will have many care providers within different areas of health care. You may even move between healthcare systems within Canada. You have an important role in keeping track of information about yourself as you age. Use this toolkit, even more so when there are changes in your healthcare team. You can share your information with all new members of your care team as needed.



iv. Menstruation and menopause

Menstruation

Having HIV or using cART may be linked with irregular menstrual periods in women living with HIV.⁷⁷

Irregular menstruation^{13,77}

What is it? Irregular menstrual periods can mean having bleeding between expected periods. It can also mean having bleeding that is painful, heavy or lasts longer than usual, as well as having bleeding after intercourse or after menopause. It can even mean having no periods, but which is not related to menopause.

How can it affect me? If you have ovaries, abnormal or irregular periods can lower the number of red blood cells in your body (i.e. anemia) and affect fertility. It may also have an impact on your quality of life and mental wellness.

What can I do about it? Let your care providers know if you have abnormal or irregular menstrual periods so that they can talk with you about options. Try to reduce, limit or quit smoking, eat healthy and try activities that lower your stress. These changes may improve abnormal or irregular menstruation.

Section D: Women's health care (continued)

Menopause

If you have ovaries, you will likely go through menopause around the age of 48 years.⁷⁸ This is 3 years earlier than women without HIV.⁷⁸ The higher rate of premature or early menopause may be because of HIV or it may be a side effect of cART. The risk of early menopause can be higher if you have a history of substance use, smoking or hepatitis C. It is important to talk to your care provider if you have any of these risk factors. Your care provider can help you to manage them.⁷⁸

The phases of menopause and management options are explained below. Let your care providers know if you are going through menopause symptoms, so they can help you manage them.

Phases and definitions related to menopause		
Phase	Definition ⁷⁹	Possible symptoms ⁷⁹
Perimenopause	The time leading up to menopause. You will experience changing hormone levels. It can last up to 8 years	Hot flashes and irregular menstruation for up to 8 years
Premature menopause	When menopause occurs before the age of 40 years	Hot flashes, night sweats, pounding/racing heart, sleep disturbances, anxiety attacks, difficulty concentrating, fatigue, irritability, memory loss, mood swings, weight gain, joint aches and pains, skin changes, vaginal dryness and discomfort, incontinence (lack of control over urination or defecation), reduced sexual desire/libido, changes in eye and oral health and increased risk of co-morbidities such as osteoporosis and cardiovascular disease
Early menopause	When menopause occurs before the age of 45 years	
Menopause	The point in time when a woman has had no menstrual period for 12 straight months after the age of 45 (and they are not pregnant and are not on male transitioning hormone therapy or opioid replacement therapy)	

Note: if you have a hysterectomy (uterus removal), you may experience symptoms of menopause if you still have your ovaries.

Menopause management	
Management strategy	Details
Lifestyle changes	Use a fan, dress in layers, drink cold drinks, meditate, exercise, quit smoking, lose weight to lessen hot flashes and night sweats ⁸⁰
Hormone replacement therapy	May be used if you are under the age of 60 years to help lessen hot flashes and night sweats, skin changes, vaginal dryness and discomfort, incontinence (lack of control over urination or defecation), reduced sexual desire/libido ⁸¹
Venlafaxine, paroxetine and fluoxetine, gabapentin or clonidine	May be used to manage hot flashes and night sweats ⁸⁰
Iron replacement	May be used during perimenopause to manage anemia (low iron) from irregular menstrual periods ¹³
Low-dose vaginal estrogen therapy	May be used to lessen vaginal dryness and discomfort, incontinence or reduced sexual desire/libido ⁸¹
Bioidentical hormone therapy	Government-approved bioidentical hormone therapy may be used. They have a similar effect as menopause hormone replacement therapy on the symptoms of menopause. Compounded hormone therapy should be avoided due to risks and lack of evidence ⁸¹



For more information on menopause refer to [CATIE's HIV and Menopause Guide](#)



I was diagnosed with HIV when I was forty four years of age at a time when, fortunately for me, new medicines were being developed to control the virus so menopause and dealing with HIV medicines and their side effects became intermingled. The worst part of this period were the night sweats, which I did not know were caused by menopause or HIV and the medicines I was taking. Otherwise menopause was a very easy transition for me.

— Woman living with HIV






Section E: Mental and emotional health care

Your mental and emotional health are just as important as your physical health. Talking to your care provider(s) is an important first step so that they can help you. Your care provider(s) can work with you to prevent, identify and treat mental and emotional health conditions. They also can help you to find other services if needed.


i. Maintaining and improving your mental and emotional health

Regulating your mind and your emotions is important. This section gives you some tips that are specific to mental and emotional health. Other tips are repeated from the [v. Keeping yourself physically healthy](#) section. This is because many important lifestyle choices, such as exercising regularly and sleep hygiene, are good for both your physical and mental health.

Living a healthy mental and emotional lifestyle

Get your basic needs met	Let your care provider know if you need help with finding safe, secure and affordable housing, food, financial assistance, employment services, or child/elder care. They can help you to find support.
Exercise regularly	<ul style="list-style-type: none"> Find an aerobic activity that you enjoy. Try to spend 150 minutes each week doing this activity - doing it in sets of 10 minutes or more at a time⁶¹ Also, try to do muscle and bone-strengthening activities using major muscle groups at least 2 days every week Exercise does not need to be done at a gym. For example, it can include going for a walk, walking during your commute or doing physical activities you enjoy
Practice sleep hygiene	<p>If you are having trouble sleeping, try these tips to get a better night's sleep:⁶²</p> <ul style="list-style-type: none"> Have a regular sleep and exercise schedule (even on weekends) Go to bed only when you are tired Use your bedroom only for sleep and sexual activity (if you are sexually active) Avoid large meals and exercise just before bedtime Limit caffeine, alcohol and nicotine Keep your bedroom dark and quiet Avoid daytime or evening napping Remove bedroom clock from sight Avoid light-emitting devices or bright lights in the hours before bedtime (e.g. e-books, cell phones, television), or use a blue light filter
Practice mindfulness	<ul style="list-style-type: none"> Mindfulness can help you to regulate your emotions and to improve your overall mental health⁸² Regular practice can change the structure of your brain. This helps to have a lasting effect on your mood and attention <p> There are many free apps that can be used to guide you through mindfulness practice, including the UCLA Mindful App</p>
Enjoy the company of others	<p>Healthy relationships are important. Invest time with people who support you. Make sure that you always have at least one person or peer that you can rely on. To help build or strengthen your relationships:¹⁰</p> <ul style="list-style-type: none"> Meet up with a friend, family member, acquaintance or co-worker to catch up Get involved in group or one-on-one peer support (this can be support for individuals living with HIV, mental health concerns or both) <p>If you do not have a social support network, contact your local HIV service organization so that they can help you to make new social connections</p> <p> To find your local HIV service organization: contact HIV411 by dialing 1-800-263-1638 or browse their directory at HIV411.ca, or browse the Canadian AIDS Society's membership website</p> <p> If you are looking to meet a new partner, you can use a free dating website that caters to individuals living with HIV or sexually transmitted infections called Positive Singles</p>

Section E: Mental and emotional health care (continued)**Living a healthy mental and emotional lifestyle (continued)**

Find and join organizations or communities that you may identify with	<p>Every person has many parts that make up their identity. Some organizations and communities can connect you to people who you may share identities with. This can include organizations and communities specific to your:¹⁰</p> <ul style="list-style-type: none"> • Spirituality or religion • Race, ethnicity or heritage • SOGIE • Age • Location <p> To find an HIV service organization that shares your identities, contact HIV411 by dialing 1-800-263-1638 or browse their directory at HIV411.ca, or browse the Canadian AIDS Society's membership website</p>
Take part in self-care activities that you enjoy	<ul style="list-style-type: none"> • Self-care is personally-identified. It is about doing what you like and putting your needs and interests first • Examples include: going outdoors for a walk, listening to music or a podcast, singing, taking a bath, doing a personal hobby, making a meal/baking, doing your hair, painting your nails, reading a book or organizing your things
Build your self-esteem and remember your self-worth	<p>For free online tips for improving your self-esteem, visit the Mind webpage on Self-Esteem</p>
Keep a gratitude journal	<p>Take a few minutes a day to think of, write down or draw 3-5 things that you are grateful for. It can help to improve feelings of optimism and your overall emotional wellbeing⁸³</p>
Harm reduction techniques (for substance use)	<ul style="list-style-type: none"> • Try not to go over daily alcohol limits (i.e. 10 drinks a week for women, with no more than 2 drinks a day most days)⁸⁴ • Drink slowly (no more than 2 drinks in 3 hours)⁸⁴ • Eat before and while you are drinking⁸⁴ • Choose the method of use that is least harmful (e.g. smoking instead of injection) • Do not share or re-use substance-injection equipment • Use safe injection sites when available • Try not to use alone • Carry a naloxone kit (available from pharmacies) • Try to plan some days that are alcohol or substance-free or both. Plan activities ahead that can take your mind away from thinking about alcohol or substances that day • Try to buy less as a way to reduce your use
Speak to your care providers about support, services and treatments	<ul style="list-style-type: none"> • For women living with HIV who are also living with mental health conditions, support (e.g. peer support), services (e.g. psychologist, psychiatrist, psychotherapist) and treatments (e.g. medication) can help⁸⁵ • Talk to your care provider(s) about options available to you
Complementary and alternative treatments	<ul style="list-style-type: none"> • Complementary and alternative medicine treatments are a group of practices and products that are not generally considered part of conventional medicine • Some people may prefer them due to fewer side effects and lower costs or the feeling of being empowered by using them • It is important to know that there is limited research available to support their effectiveness • Some examples include: <ul style="list-style-type: none"> • Ingestible (e.g. herbs/herbal medicine, homeopathy, vitamins/minerals) • Physical (e.g. acupuncture/acupressure, chiropractic, massage) • Psychological (e.g. imagery, meditation/prayer/spiritual healing, relaxation/breathing exercises) • Let your care providers know if you are using complementary and alternative treatments

Section E: Mental and emotional health care (continued)

ii. Mental and emotional health conditions

How do you know if you have a mental or emotional health condition?

Everyone has feelings of sadness and stress throughout their life. If these feelings affect how you function at work, school, home, in social settings or other ways, you may be experiencing a mental or emotional health condition.

Everyone experiences mental and emotional health conditions differently. For some women living with HIV, their diagnosis and the stigma that can surround it may contribute to having mental and emotional health conditions. This can be worsened by other issues, such as violence and trauma.



You can use the [Patient Health Questionnaire \(PHQ\)](#) to help you identify whether you have symptoms common to mental or emotional health conditions. If you identify that you may be experiencing symptoms common to a mental or emotional health condition, talk to your care provider. Your care provider can help to connect you with the support, services and treatment options that are best for you.

Some common mental and emotional health conditions:⁸⁶

- **Depression** – involves feeling very sad for at least two weeks. Individuals with depression can experience a loss of interest in activities, difficulty sleeping, weight changes, difficulty concentrating, thoughts of suicide and feelings of hopelessness, worthlessness or guilt.
- **Generalized anxiety disorder** – involves feeling very stressed for at least six months. Individuals with generalized anxiety disorder can experience feeling edgy, restless, tired or irritable and they may have trouble concentrating, muscle aches/soreness and trouble sleeping.
- **Panic disorder** – involves experiencing panic attacks that can be expected or unexpected. Individuals with panic disorder can experience a pounding or racing heart, sweating, trembling or shaking, shortness of breath, chest pain or discomfort, nausea, feeling detached from oneself, fear of dying, numbness or tingling sensations, and chills or hot flashes.
- **Post-traumatic stress disorder (PTSD)** – involves re-experiencing a previous traumatic event as unwanted or upsetting memories, nightmares, flashbacks, emotional distress or physical reactions. Individuals with PTSD may avoid environments or situations that could cause them to re-experience the previous traumatic event (e.g. big groups of people, dark streets or parking lots). Individuals with PTSD may feel irritable or aggressive or very sensitive to their surroundings. They may be easily startled and experience difficulty concentrating and difficulty sleeping. These feelings and experiences last for at least one month.
- **Substance use disorders** – involves using substances (e.g. alcohol, opioids, recreational substances) in a way that leads to impairment or distress. Individuals with substance use disorders use substances over a long period and have a hard time cutting down on their substance use. They spend a lot of time getting, using or recovering from substance use. Individuals with substance use disorders experience cravings for the substance and their tolerance for that substance increases. Individuals with substance use disorders often experience symptoms of withdrawal when they stop using the substance (e.g. sweating, shaking hands, trouble sleeping, nausea, vomiting, hallucinations or illusions, feeling agitated or stressed, having seizures).

What to do if you are experiencing a mental and emotional health condition?

1. **Get 'right now' support** – if you are in crisis, seek emergency services by calling 911 or a crisis line to get immediate help to cope with a current mental or emotional health situation
2. **Speak to your care providers** – let your care providers know if you have any symptoms of mental or emotional health conditions. Also, tell them if your existing conditions change. Your care providers can help you to find support, services and treatments that are best for you
 - Accessing mental and emotional health services can be hard. Let your care provider help you
 - Some symptoms can be due to medication(s) or other illness, not the presence of a mental health condition. Let your care provider help you to rule out other reasons
3. **Access peer support** – connect with other women who have experience living with mental and emotional health conditions or HIV. You can connect through groups or one-on-one meetings. Both can be a helpful way to share your experiences and learn how others cope
4. **Ask your care provider for a referral to a psychologist, psychiatrist, or psychotherapist** – you can ask for a referral to a specialist who has specific training in mental and emotional health if one is available in your community. Please note that seeing psychologists and psychotherapists usually requires out-of-pocket payment. Seeing a psychiatrist is usually covered by provincial or territorial health coverage. Psychiatrists have the ability to prescribe medication, which may be recommended in addition to talk therapy. However, you may require a diagnosed mental health condition to receive coverage and you may experience longer wait times.



To find a crisis line close to you, contact Canada's free government and community-based health and social services information phone line by dialing 2-1-1 or going to 211.ca



To find peer support close to you, you can contact Canada's free government and community-based health and social services information phone line by dialing 2-1-1 or going to 211.ca

Section F: Peer support, leadership and capacity building

You have the right to take part as an active and equal member of your health care. You also have the right to participate in the design, delivery and evaluation of health care for all women living with HIV.⁸⁷

Terms used in Section F:⁸⁸

- **Peers** – to refer to individuals who have lived experiences that are similar to yours and therefore can understand your life circumstances
- **Peer support** – to refer to individuals who have lived experiences that are similar to yours and can provide you with emotional, cultural and social support
- **Peer navigators** – to refer to individuals who have lived experiences that are similar to yours and can help guide, connect, refer, educate and accompany you throughout your journey in the healthcare systems
- **Peer leadership** – to refer to women living with HIV who take roles that recognize and use their knowledge and expertise about HIV

i. Peer support

Peer support can happen one-on-one or in groups. Peer support can happen in-person, on the phone, over text, over email or through the internet. Peers can be helpful to you by sharing information, providing mutual social support and helping you to feel empowered.⁸⁹ As mentioned throughout this toolkit, peer support can be helpful when coping with your HIV diagnosis, trauma and violence, disclosure and stigma.



It helped to discuss these issues with a peer because we are on the same plane. There is a common understanding about what it means to live with HIV. It helps to talk to someone in the same situation and this was a good opportunity to discuss living with HIV. — Woman living with HIV

It was helpful connecting with peers because it felt comfortable to talk about HIV openly. I didn't feel alone. — Woman living with HIV



If having peer support or a peer navigator seems like it would be helpful:

- Tell your care providers. They can help you to find a local peer support or a navigator
- Look for peer support or a navigator for yourself through:
 - Other women living with HIV (informal networks of support can be as helpful as peer support or navigators referred by care providers)
 - Online support
 - Online or local support communities (HIV or non-HIV specific)



For free online peer support visit the [HIV/AidsTribe wellness community](#)

It is okay if you do not want peer support right now or at other times in your life. Just remember it is there if you do want it.

ii. Peer navigators

Peer navigators can help by providing:¹³

- Practical assistance
- Healthcare appointment support
- Support to ensure that your voice is heard during healthcare appointments and in the community
- Emotional, cultural and social support based on a common understanding of the experience of living with HIV
- Education and information
- Referral support
- Healthcare system navigation support
- Immigration system navigation support
- Support to find transportation, secure and affordable housing, food, financial assistance, employment services, child/elder care and other services
- Support communicating with your care providers, including interpretation and translation
- Support to help you take part in your health care and to learn about self-care maintenance
- Shared aspects of their lived experiences that may be helpful to you



I was scared to go places... A HIV positive woman held my hand to different medical appointments & support groups. My confidence sprung, knowing I wasn't alone. — Woman living with HIV



Section F: Peer support, leadership and capacity building

iii. Peer leadership and capacity building

Peer leadership

As a woman living with HIV, you are an expert in your own experiences. This can offer care providers, researchers and policy makers valuable information.⁹⁰ Using your expertise to help care providers is called peer leadership. Women living with HIV who become peer leaders often look after themselves first - even for a few years - before getting involved. Once they feel ready, these women have so much to offer. Becoming a peer leader has been shown to improve the health and wellbeing of women living with HIV.^{70,87,91}

Leadership positions can be paid or volunteer, and they can vary because of factors such as your role and time commitment. Being a peer leader is an option. Remember, it is also okay to use services without becoming more involved.

Being a peer leader can be an empowering experience. It can increase your support network, knowledge, confidence and can make a positive impact in your community.⁹²

Recognizing the contribution people living with HIV can and do make in response to HIV/AIDS is called GIPA (Greater Involvement of People living with HIV/AIDS) and MEWA (Meaningful Engagement of Women living with HIV/AIDS).

- If you are interested in a leadership role to use and share your expertise, ask your care providers and other women living with HIV about opportunities in your community, such as:⁹³
 - Boards or steering committees
 - Mentors
 - Peer navigators
 - Peer group and program coordinators
 - Local, regional, national and international health committees
 - Research
 - Organization leaders
 - Advocates
- If you have a leadership role in your community, let your care provider(s) know. They can help connect other women living with HIV who are interested in getting involved.



It is hopeful for people who are recently diagnosed to see us long-term survivors. Don't lose hope. It's not a death sentence anymore.
— Woman living with HIV



For more information on GIPA/MEWA, refer to the [Canadian AIDS Society's One Foot Forward training toolkit](#)



Being a peer leader has helped in many ways, the most important being to pay forward the help that I received in the past and present.
— Woman living with HIV



Capacity building

To become a peer leader, you may require training to build your capacity to use your expertise in a leadership role.

- To find training opportunities to help you build your capacity as a leader:
 - Ask your care providers about leadership skills training in your community
 - Look online for workshops or other educational opportunities



To find workshops or other educational opportunities, check the following organizations' websites:

[Pacific AIDS Network's Positive Leadership Development Institute](#)

[Ontario AIDS Network's Positive Leadership Development Institute](#)

[AIDS Bereavement and Resiliency Program of Ontario's Turn To One Another \(TTOA\) Forum](#)

[Ethno-racial Treatment Support Network \(ETSN\) Peer Treatment Counselor Training](#)

[Canadian AIDS Society's Jobs and Volunteering Board](#)

[Canadian AIDS Society's annual People Living with HIV Forum](#)

[CATIE's Career Opportunities](#)

- Talk to your local HIV service organization and join their mailing lists to receive information about opportunities⁹⁴



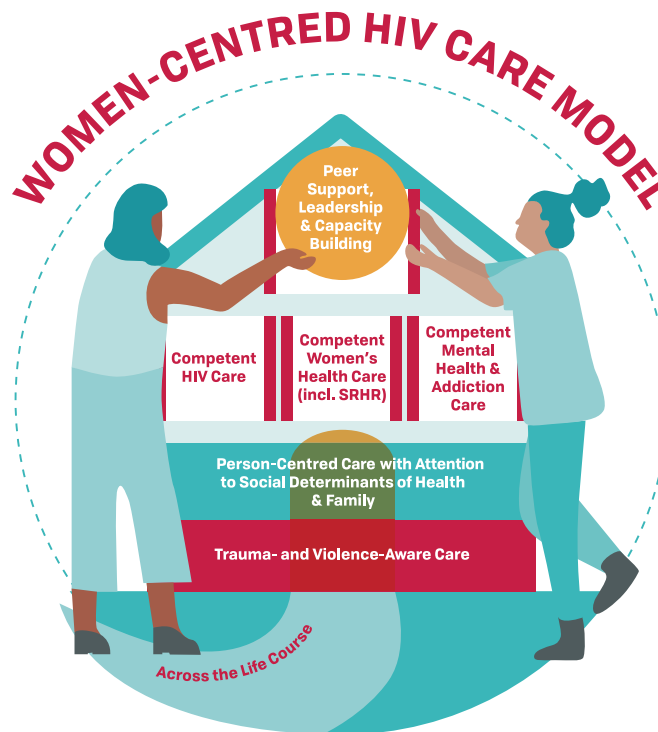
To find your local HIV service organization: contact HIV411 by dialing 1-800-263-1638 or browse their directory at [HIV411.ca](#), or browse the [Canadian AIDS Society's membership website](#)

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The model is in the shape of a 'house' to represent safety and stability – essential aspects of care delivery. Trauma- and violence- aware care is the 'foundation' to acknowledge the alarmingly high rates of violence, trauma and intersecting oppressions* women living with HIV face. Person-centred care, with attention to social determinants of health and family, make up the 'first floor'. For many women, ensuring their family is cared for is as essential to their care as ensuring adequate housing, livable income and other social determinants of health. The 'second floor' contains three rooms: competent HIV care is integrated with women's health (including sexual and reproductive health and rights) and mental health and addiction care. This is important as many women living with HIV do not see any other care providers other than their HIV care provider. The 'roof' contains peer support, leadership and capacity-building, which are integral to the model.

The woman herself is the most essential component of the model and emphasizes the shared-care decision-making principle of person-centred care. The woman is often supported by a peer to enter the house, and together, the women are holding up the glowing piece about peer support. Importantly, the model is meant to be provided to all women, in all their diversity. Finally, women will be of different ages at different stages of their lives, so all components of women-centred HIV care are to be delivered across the life course.

*Intersecting oppressions refers to disadvantages experienced by an individual based on their multiple and overlapping social identities including gender, race, ethnicity, class, sexuality, and HIV status. These identities are also shaped by history including colonization and slavery, and impact many aspects of one's life, including health status and wellbeing.

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