WOMEN'S COLLEGE HOSPITAL
Healthcare | REVOLUTIONIZED

WCHC Pocketbook

This is the WCHC Model to guide your care – your care, your way:

Contents

Look Out For

? **Sample questions or phrases** you can use with your provider(s).

✎ Sections where you are invited to **write things down**.

! Things that have been **identified by trans and/or gender diverse people as important**. However, much of this information may be important for all women.

📷 The **QR codes** link to websites with more information and toolkits that go into much more detail than this pocketbook. You can access these on your phone by opening the camera and holding it over the code.

Try it out here! To find testing, treatment, and harm reduction services in your area, check out “Where to” by CATIE.

Introduction

Using This Pocketbook

This pocketbook can help you manage your health and communicate with your healthcare provider(s) including doctors, pharmacists, nurses, social workers and more. The content in this book is based on the **Women-Centred HIV Care Model** (see inside cover), which was created by and for women with HIV. **This pocketbook is based on the premise that you have the right to the best care possible.**

This pocketbook contains 6 sections. Each section has 3 parts:

- A summary of important information
- Examples of phrases and questions you can use when talking to your provider(s)
- A reflection or exercise for you to fill out to contribute to your self-care

This pocketbook is for all people who identify, at times, with the term "woman", including those of diverse gender identities (Two-Spirit, trans, nonbinary, intersex, gender fluid, genderqueer, or agender). **You deserve care that supports your identity and experiences.**

You can tell your provider(s) you are using this pocketbook and they can review it with you. You can say something like:

"I am going to be using this pocketbook to help me with tracking my care. It is based on the Women-Centred HIV Care Model. Have you heard of it? They have a toolkit for providers too. It is available at this link or by googling 'Women-Centred HIV Care.'"

Women-Centred HIV Care Provider Toolkit

Getting the most out of your appointments

Here are some things you may want to do before, during and after your appointment to get the most out of your time with your provider(s).

Before →

- Write down your main concerns and number them from most to least important. Sometimes you will run out of time and will not be able to bring everything up in an appointment, but this way you will remember for next time
- Go through this pocketbook and make note of any changes since the last time you saw your provider(s)

During →

- If you are comfortable, show your provider(s) your list
- Make note of any referrals, changes in medications, or suggestions your provider has
- Ask your provider(s) follow-up questions if something they are sharing is unclear or you want more information

After →

- Think about how the appointment went. Do you still have questions? Write them down while it is still fresh in your mind for next time
- If you start a new medication or change your routine, write down any changes you notice over time

Make sure you tell your provider(s) what you think, how you feel, and what you need when you talk to them. Don't wait; say it as soon as you can. Here are some things to keep in mind when going to your appointment:

- Express your needs clearly and be specific
- Ask for what you want, rather than what you don't want
- Ask any questions you have. Your provider is there to assist you, and there's no such thing as a question that's too small or unimportant

Your Care Team

You may have many care provider(s) who help you stay healthy. You can keep track of their details here. This can also help them to know who else is part of your circle of care so they can work together.

PROVIDER NAME(S), TYPE OF CARE THEY PROVIDE

CONTACT INFO

LOCATION

HOURS

PROVIDER NAME(S), TYPE OF CARE THEY PROVIDE

CONTACT INFO

LOCATION

HOURS

PROVIDER NAME(S), TYPE OF CARE THEY PROVIDE

CONTACT INFO

LOCATION

HOURS

Health Self-Advocacy

Another term for standing up for yourself is “health self-advocacy”. Sometimes self-advocacy involves simply sharing your thoughts, feelings, and questions. Other times it means thinking ahead, setting a goal, and making a plan. It can require you to be firm about your wishes and rights.

Here is a list of your rights and ways you can self-advocate with your provider(s).

You have the right to...	To self-advocate, you can say...
Be called by your preferred name and pronouns in all settings	***“Please call me [name] from now on and make a note in my chart about it.”*** ***“The correct way to pronounce my name is...”*** ***“My pronouns are [xx/xx] (e.g., she/her, they/them).”***
Have things explained to you in a way that you understand	***“I don’t understand. Can you explain that again, a little slower and in plain language?”*** ***“Why is that test important?”***
A second opinion from another care provider	***“Before I make a decision, I would like to get a second opinion from another provider. Could you refer me to someone?”***
Take time to consider your options	***“I am not ready to make a decision today. I will book a follow-up with you to talk about this more.”***

Continued →

Bring a family member, friend, peer navigator, advocate, or translator to your appointments (but have your provider(s) talk to you, not the other person)	***“I would be more comfortable if [support person] was here for this conversation.”***
Say no to having a student/trainee in the room during your appointments	***“I would feel more comfortable if it were just us. Could the student wait outside until my appointment is done?”***
Say no to anything that the care provider is asking you to do	***“I don’t want an influenza vaccine this year. I’ll consider it next year.”***
Share as much or as little as you want with your provider(s)	***“Thank you for asking, but I have said all I feel comfortable sharing.”***

There are times when you may not want to self-advocate, like if you don’t feel safe or you don’t feel calm enough to get your point across.
If this happens, there are other options. You can:

- Ask a **friend, peer, or family member** to advocate for you
- Look for a **group (or organization) with experts** who can help you with your issue
- Write down your feelings and **come up with a plan** with a trusted person in your life to talk to your provider(s) about it at another time
- If available in your area, consider finding **another healthcare provider** (a local community-based organization may be able to help you with this)
- Make use of **local organizations** that keep lists of service providers who have supported people well in the past

Section A:

Person-Centred Care

You deserve care that understands, respects, and honours your unique background. The more your provider(s) knows about you, the better they are able to adjust to your wants and needs – this is called person-centred care. Part of person-centered care is making decisions together with your provider(s); this is known as shared-care decision-making.

Talking about person-centred care with your provider(s)

With a new provider:

"As we are getting to know each other, there are some things I want you to know about me. You can take a look at this page I have filled out."

With a provider you have known for a while:

"I realized there are some things about me you may not know. Can you take a look at this page, so you have a better idea of things that matter to my health and care?"

About You

Use this section to record the details about yourself!

MY NAME AND PRONOUNS:

THREE WORDS TO DESCRIBE ME:

IMPORTANT PEOPLE/SUPPORTS IN MY LIFE *(partners, children, friends, pets)***:**

MY GENDER:

MY SEXUAL ORIENTATION:

MY RELIGION AND/OR CULTURE:

HOW I USUALLY SPEND MY DAYS:

MY IMMIGRATION JOURNEY:

MY ACCESS TO HEALTHCARE AND MEDICATION COVERAGE:

I LIKE WHERE I LIVE:

Strongly Disagree		*Neutral*		*Strongly Agree*

I FEEL SAFE WHERE I LIVE:

Strongly Disagree		*Neutral*		*Strongly Agree*

I HAVE RELIABLE TRANSPORTATION FOR WORK, APPOINTMENTS, GROCERIES, ETC.

Strongly Disagree		*Neutral*		*Strongly Agree*

I USUALLY HAVE ENOUGH MONEY TO PAY FOR RENT AND OTHER BILLS:

Strongly Disagree		*Neutral*		*Strongly Agree*

I HAVE ENOUGH FOOD FOR ME AND MY FAMILY:

Strongly Disagree		*Neutral*		*Strongly Agree*

MY MEDICATION COVERAGE FULLY MEETS MY NEEDS:

Strongly Disagree		*Neutral*		*Strongly Agree*

IS THERE ANYTHING ELSE YOUR CARE TEAM SHOULD KNOW ABOUT YOU?

What to look for in shared-care decision making

In an ideal healthcare partnership, it's a two-way street where you and your providers collaborate for your well-being. They empower, support, and guide you, clarifying options, respecting your preferences, and assisting in decisions aligned with your best interests. Likewise, it's important for you to communicate openly and follow the treatment plan your provider(s) create for you.

Questions to ask your provider

You may want to ask these questions to feel informed, safe, and comfortable.

- ***"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 achieving my health-related goals?"***
- ***"Do you have clients who are trans, nonbinary, and/or gender diverse? How comfortable are you with providing care to them?"***
- ***"Have you prescribed gender-affirming hormone therapy before?"***

For more examples of questions to ask, scan the QR code and scroll to page 3.

Section B:

Trauma and Violence Aware Care

If you have experienced trauma and/or violence, you are not alone. You have the right to provider(s) who understand and keep this in mind when providing care to you, as trauma can affect people in unexpected ways; this is called trauma- and violence-aware care.

TRAUMA is a response to an event or circumstance resulting in physical harm, emotional harm and/or life-threatening harm. The event or circumstance has lasting adverse effects on the individual’s mental health, physical health, emotional health, social well-being and/or spiritual well-being.

VIOLENCE encompasses the deliberate use of force or power, either threatened or actual, against oneself, others, or witnessing it happen to someone else. This can take various forms, including physical, emotional, verbal, sexual, controlling, or financial harm.

Your safety and well-being matter. **If you are experiencing violence, know that you are not alone—help is available to support you in staying safe and cared for**. Scan the QR code to discover the **iHEAL app**. This resource is here for you, offering personalized support to help women who have experienced abuse from a current or past partner find ways to stay safe and thrive.

Talking about trauma- and violence-aware care with your provider(s)

- ***"I have faced trauma and violence that have affected my health. While I am not ready to share all the details, I would like us to talk about how these experiences may be impacting my well-being."***

- ***"I have been feeling unsafe at home. Could we talk about my situation for a few minutes in private?"***

- ***"Doing physical exams can make me feel uncomfortable because of experiences I have had in the past. Can you please make sure to tell me before you touch me, and why you need to?"***

- ***"I have heard about the Women Abuse Screening Tool. Could I fill that out and we can talk about my answers together?"***

Woman Abuse Screening Tool (WAST)

- ***"I would like to explore counselling/therapy/peer support. Can you please refer me?"***

Coping with trauma

If you are ever feeling overwhelmed because of trauma, you can do a “**grounding exercise**” like the 5-4-3-2-1 method. Working backward from 5, use your senses to list things you notice around you – this clears the mind from racing thoughts and brings you back to the present moment.

5 List 5 things you can see

4 List 4 things you can touch from where you are

3 List 3 things you can hear

2 List 2 things you can smell

1 List 1 thing you can taste *(even if you can’t taste it right now, you can imagine your favourite taste)*

WHAT ELSE MAKES YOU FEEL GROUNDED OR CALM?

See Section E: Mental Health Care (page 37) and Section F: Peer Support (page 41) for more ways to cope with experiences of trauma and violence.

I have the right to be heard and taken seriously; my feelings and needs are valid.

Section C:

HIV Care

The science behind HIV and all the terms may feel overwhelming. The most important thing to remember is science has come a long way and you can now live a long, healthy life with HIV.

Understanding HIV

HOW WOULD YOU RATE YOUR UNDERSTANDING OF HIV?

Low Understanding *Medium Understanding* *High Understanding*

HOW WOULD YOU RATE YOUR UNDERSTANDING OF “U=U” - UNDETECTABLE=UNTRANSMITTABLE?

Low Understanding *Medium Understanding* *High Understanding*

HOW WOULD YOU RATE YOUR UNDERSTANDING OF THE IMPORTANCE OF NOT MISSING HIV MEDICATION DOSES?

Low Understanding *Medium Understanding* *High Understanding*

Your HIV Health Log

Use this section to record important health data.

Viral Load

Viral load is the **amount of HIV in your blood**. An “undetectable” viral load means that the virus is under control and cannot be passed on to others through sexual transmission.

Viral Load	Meaning
Less than 1,000 copies/mL	Low
Less than 200 copies/mL	Suppressed
Less than 40 copies/mL	Undetectable

VIRAL LOAD	DATE

CD4

CD4 count is the **number of a specific type of immune cell in your blood**. A CD4 count over 500 cells/mm3 is considered normal and is strong. A CD4 count of less than 200 cells/mm3 means you have a weaker immune system, and you may get sick from infections more easily.

CD4 COUNT	DATE

Combination Antiretroviral Therapy

Combination antiretroviral therapy (cART) is **a combination of medications that stop HIV from replicating in your body** and can come in pill(s) or injection.

So your provider can make sure you are on the right cART, you should let them know if you:

- Have been diagnosed with other conditions or are taking other medications (including birth control);
- Are taking over the counter or complementary medications, such as ibuprofen (e.g. Advil®), antacid (e.g. Tums®), vitamins or supplements;
- Are taking recreational substances (including cannabis);
- Are having trouble taking your medications on time or are often missing doses;
- Are planning to become, may possibly become, or are, pregnant;
- Are having trouble accessing or paying for your cART.

Adherence (taking your cART as prescribed) is very important.
The medication can stop working if doses are missed, because this allows the virus to change itself (this is called a mutation). If you realize you missed a dose, take it as soon as you realize, then take your next dose at the usual time. Taking the missed dose and the next dose close together is okay.

Tips for remembering to take medication(s) every day:

Package your medications with labels for each day or ask your pharmacy to do this for you (they can make you something called a blister pack which has all your pills for each day separated into compartments)

Set up reminders on your phone to take your medication or to refill your prescriptions

Set up automatic refills and/or deliveries (if your pharmacy offers this)

Keep medication near something you use every day, like your toothbrush

Plan ahead when you go on a trip and refill

U=U Counselling

When you keep an undetectable viral load (by taking your cART on time and as directed), there is zero risk of transmitting the virus to someone else through sex (untransmittable). If you have questions or think other people in your life may need to be tested, talk to your provider(s) using phrases listed on page 21.

If you inject drugs, it is important to use new needles and to not share equipment. There are needle exchange programs that can help you get new needles and safe equipment.

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**, check out the CATIE resource: Safer Sex Guide (sexual partners).

Disclosure

You do not need to tell everyone about your HIV status, but there are some people that would be good for you to tell if you can do so safely. Public Health will be told about your HIV status after you are diagnosed. You will be given the option to contact your past sexual partners or have Public Health contact them for you (they will not tell them your name).

✗ ***You do not have to tell anyone how HIV was transmitted to you.***

You do not have to disclose your HIV status to:

- ✗ **Close or 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. <1,000 copies/ml) and use a condom*
- ✗ **A clinician at a walk-in clinic** unless your reason for accessing the clinic is HIV-related

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

Public Health and the law require you to disclose your HIV status to:

- ✓ **Sexual partners** if you do not maintain a low viral load (i.e. <1,000 copies/ml) and do not use a condom
- ✓ **Previous sexual partners** following your diagnosis
- ✓ **Drug use partners** before sharing injection equipment
- ✓ **Clinicians** who care for you during pregnancy, childbirth and if you choose to breast/chestfeed

It is also recommended that you disclose your HIV status to:

- ✓ **Dentists**
- ✓ **All other clinicians** (e.g. emergency room clinicians)

Disclosure-decision making tool in Women's Toolkit on page 10

Talking about HIV care with your provider(s)

- ***"Recently I have had a life change [fill in the blank with details]. Am I still OK to keep taking the cART I am prescribed, or should I change to a different one?"***

- ***"I am interested in learning about injectable cART. Can we discuss if this is an option for me?"***

- ***"I have been experiencing these symptoms. Can these be a side effect of my medication?"***

- ***"I am having trouble paying for my medication. Who should I talk to about that?"***

- ***"Lately I have been missing doses of my cART. Can we come up with a solution together?"***

- ***"Based on my (age/lifestyle/experience I have recently had), I think I should be tested for (insert condition). Could we schedule that?"***

  Possible conditions include cardiovascular disease, high blood pressure, diabetes. For a full list of other conditions and screening tests scan the QR code and scroll to page 13.

  Women's Toolkit

- ***"Can you help me arrange an HIV test for my partner?"***

- ***"Can you help me explain HIV and U=U to my partner?"***

- ***"As I am getting older, I am noticing changes with my (balance, mobility, memory) and I thought I should let you know."***

Vaccine Tracker

Vaccines make sure you are protected from getting other infections or diseases. Some vaccines need more than one dose over a few appointments and some need to be repeated. **Ask your provider for your vaccine record to fill this out.**

Vaccine	Tracker (date of vaccination)	Recommended
☐ **Flu** *(influenza)**	Date(s) of repeated vaccines:	For everyone annually
☐ **Hepatitis A**	Immunity status check: Dose 1: Dose 2:	For everyone
☐ **Hepatitis B**	Immunity status check: Dose 1: Dose 2: Dose 3: Dose 4 (if needed): Dose 5 (if needed):	For everyone
☐ **Hib** *(haemophilus influenzae type b)*	Dose 1:	For everyone in some provinces
☐ **HPV** *(human papillomavirus)*	Dose 1: Dose 2: Dose 3:	For everyone under the age of 45
☐ **MMR** *(measles-mumps-rubella)***	Dose 1: Dose 2:	For everyone
☐ **Meningitis** *(meningococcal conjugate)*	Dose 1: Dose 2: Date(s) of repeated vaccines:	For everyone, every 5 years
☐ **Shingles** *(herpes zoster)**	Dose 1: Dose 2:	For people over 50

This list aims to be as thorough and up-to-date as possible; however, vaccine recommendations change frequently. Please consult the latest NACI guidance to ensure accuracy.

➔ ***Note:*** *In this table, we share vaccine recommendations for those with HIV. "Everyone" refers specifically to individuals living with HIV, as recommendations may vary for those without HIV.*

For the most up-to-date vaccine recommendations for people living with HIV, visit this website.

Vaccine	Tracker (date of vaccination)	Recommended
☐ **Pneumococcal infection** *(pneumococcal 20- or 21- valent conjugate)*	Dose 1:	For everyone, if full series of pneumococcal 13 and pneumococcal 23 are not completed
☐ **Tetanus, diphtheria, pertussis** *(whooping cough)*, **polio**	Dose 1: TD Booster(s):	For everyone, booster every 10 years, during each pregnancy
☐ **Chicken pox** *(varicella zoster)***	Dose 1: Dose 2:	For those who are not immune
☐ **Travel vaccines**	☐ Cholera/Travelers' diarrhea: ☐ Japanese encephalitis: ☐ Tick-borne encephalitis: ☐ Meningitis: ☐ Rabies: ☐ Typhoid*: ☐ Yellow fever**:	Depending on travel plans
☐ **COVID-19 Vaccines**	Dose 1: Dose 2: Other dose(s):	For everyone
☐ **Mpox Vaccine******	Dose 1: Dose 2:	For those at risk
☐ **RSV Vaccine**	Dose 1:	For people over 60 and some over 50

** Only the inactivated (not live) vaccine can be given to people with CD4 counts < 200 cells/µL*
*** Cannot be given to people with CD4 counts < 200 cells/µL*

Medical Conditions Related to HIV

Some medical conditions are more common with HIV (e.g., cardiovascular events, bone mineral loss, cervical dysplasia, hepatis B and C). It is important to have regular testing for these conditions for early detection and treatment.

For a **list of medical conditions** to consider and their tests and treatment, scan the QR code and scroll to pages 13 to 14.

Cervical Cancer

One related condition that is very important for people with HIV with a cervix to monitor is cervical dysplasia (abnormal changes in cells) and cancer. They are more common in people with HIV. The ongoing monitoring is done usually by Pap testing but varies by province and territory and is to be done once every 1-3 years.

Keep track of your Pap tests here:

PAP TEST DATE	**RESULT**
PAP TEST DATE	**RESULT**
PAP TEST DATE	**RESULT**
PAP TEST DATE	**RESULT**

Your General Physical Health

Use this section to consider your health overall.

HOW WOULD YOU DESCRIBE YOUR PHYSICAL HEALTH IN 5 WORDS?

DO YOU HAVE ANY GOALS RELATED TO DIET, EXERCISE, SLEEP, SUBSTANCE USE, OR WEIGHT THAT YOU WANT TO DISCUSS WITH YOUR PROVIDER(S)?

WHAT ARE TYPES OF PHYSICAL MOVEMENT YOU ENJOY? *(e.g., biking, walking, dance)*:

WHAT ARE GO-TO, READY-TO COOK, HEALTHY MEALS YOU ENJOY?

Staying Healthy and Strong While Aging

As you age with HIV, small steps can make a big difference in staying healthy and strong:

- **Medications:** Regularly review your medications with your healthcare provider to explore new options and avoid side effects or interactions.
- **Bone Health:** Keep your bones strong with screenings, weight-bearing exercise, and foods rich in calcium and by taking vitamin D.
- **Heart and Brain Health:** Stay active, eat a balanced diet, and challenge your mind with puzzles or hobbies to support heart and cognitive health.
- **Social Connections:** Build and maintain meaningful relationships—they're vital for your mental and emotional well-being.
- **Preventive Care:** Keep up with regular check-ups, screenings, and vaccinations to stay ahead of health challenges.
- **Cancer Screening:** Start breast and colon cancer screening based on your age and risk.

You're not alone in this journey—these small steps can help you age with strength and confidence.

WHAT IS IMPORTANT TO ME FOR "SUCCESSFUL AGING"? *(e.g. feeling healthy enough to spend time with loved ones)***:**

Learn more about **how to age well with HIV, with personalized tips, recommended screenings, and care options** to support your health and happiness.

Section D:

Women’s Health Care

Women’s health care is a growing field. This section will help you communicate your wants and needs related to your sexual and reproductive health care. We focus specifically on sexual and reproductive health care because these are often reported as conversations that are hard to have with health care providers.

Sex, sexuality, and gender

You have the right to the sex life you want (including the choice to not have sex) and to provider(s) that support your choices.

To read more about **sexuality, relationships, pleasure for women, partners, and couples living with HIV**, visit the Life and Love with HIV online community.

If you feel comfortable, telling your provider(s) about your sexual orientation, gender identity and expression can help them provide you with better care.

Use this section to talk to your providers about your sex life.

Your Sex Life/History

Fill out or talk through the 8P questionnaire below with your provider(s). This will give them information about your sex life and history. Make sure to let your provider(s) know if any of your answers change over time. Before beginning the questionnaire, it is important to know that one of the Ps is about violence.

① Preferences

WHAT WORDS DO YOU USE TO REFER TO YOUR BODY/GENITALS? ARE THERE ANY TERMS YOU DON'T LIKE?

ARE YOU CURRENTLY SEXUALLY ACTIVE?

WHAT KINDS OF SEX DO YOU ENGAGE IN?

② Partners

ARE YOU DATING AND/OR SEXUALLY ACTIVE WITH ONE PARTNER OR MORE THAN ONE?

HOW WOULD YOUR PARTNER(S) IDENTIFY THEIR GENDER?

IN RECENT MONTHS, HOW MANY SEX PARTNERS HAVE YOU HAD?

3 Practices

WHAT KINDS OF SEX DO YOU TYPICALLY HAVE?

WHAT PARTS OF YOUR BODY ARE INVOLVED WHEN YOU HAVE SEX? DO YOU USE TOYS IN YOUR GENITALS OR ANUS, OR DO YOU USE THEM ON YOUR PARTNER(S)?

4 Pleasure

DO YOU FEEL YOU ARE ABLE TO BECOME PHYSICALLY AROUSED DURING SEX?

DO YOU HAVE ANY PAIN OR DISCOMFORT DURING OR AFTER ORGASM?

IS SEX FUN?

ARE YOU HAVING SEX FOR PLEASURE OR ARE THERE OTHER REASONS?
(e.g. survival sex/transactional sex)

5 Partner Violence

HAS ANYONE EVER FORCED OR COMPELLED YOU TO DO ANYTHING SEXUALLY THAT YOU DID NOT WANT TO DO?

If your answer is yes, consider referring to "Section B: Trauma and Violence Aware Care" (page 11).

6 Pregnancy Intention

See "Reproductive Health" (page 31).

⑦ Protection from sexually transmitted infections (STIs)

IF YOU USE PROTECTION, WHAT METHODS DO YOU USE AND HOW OFTEN?
(e.g. external or internal condoms, dental dams, etc.)

HAVE YOU EVER BEEN TESTED FOR STIS? WOULD YOU LIKE TO BE TESTED?

⑧ Past history of STIs

HAVE YOU BEEN DIAGNOSED WITH AN STI IN THE PAST? WHEN? DID YOU GET TREATMENT?

HAVE YOU HAD ANY SYMPTOMS THAT KEEP COMING BACK?

For more information on sexual health, testing, and STIs other than HIV, scan this QR code.

Reproductive Health

You have the right to know about your reproductive and birth control options. You and/or your partner(s) can become pregnant without passing on HIV to each other and your children if your viral load is undetectable or low (remember U=U).

Pregnancy and Parenting

Family-building choices are personal and vary for everyone. If pregnancy is being considered, it is recommended you take cART and keep a suppressed viral load for 3-6 months before attempting conception. Also, starting at least 0.4 mg of folic acid daily 2 to 3 months before pregnancy is important for supporting healthy neural tube growth in your baby. **Breast- or chest-feeding** is maybe an option. If you meet current recommendations and are interested, ensure you speak to your care providers as soon as possible in pregnancy.

Ovulation occurs when an egg is released during the menstrual cycle. For pregnancy to happen, a ***sperm must meet an egg at the time of ovulation.*** *If you want to conceive a pregnancy, you can increase your chances by either planning to have sex timed with ovulation OR you can have sex every few days throughout the month.*

OPTIONS TO CONCEIVE INCLUDE:

- **Condomless sex**
- **Home sperm insemination with a syringe**
- **Sperm washing with intrauterine insemination** (in a clinic)
- **Other fertility care options** (e.g.in vitro fertilization, intracytoplasmic sperm injection, sperm donation, egg donation)

Interested in parenting but not in pregnancy options? Surrogacy, adoption, and/or fostering children may be of interest!

Scan the QR code for simple, helpful information to guide and support you as you explore your parenting journey.

Birth Control

As a person living with HIV you can safely use any form of birth control (also known as contraceptive methods) but there are some things to consider when choosing a method, including personal needs or desires and potential drug-drug interactions. For instance, HIV medication may make some contraceptives less effective, meaning you may be more likely to get pregnant.

Contraception methods include:

- **Barrier Methods** (internal/external condoms) – these are the only contraceptive methods that also reduce the risk of HIV and/or STI transmission
- **Intrauterine devices** (IUD, a hormonal IUD or copper IUD is inserted by a provider through your vagina). The hormonal IUD is the recommended contraceptive by experts in Canada
- **Daily-use oral hormonal contraceptives** (birth control pills)
- **Hormonal contraceptive patch** (worn on skin)
- **Hormonal contraceptive ring** (inserted into vagina)
- **Hormonal contraceptive implants** (Nexplanon, inserted in upper arm by a provider)
- **Quarterly hormonal contraceptive injection** (Depo-Provera, or DMPA, injected in butt or upper arm by a provider)

Visit this website to read more about the **pros and cons of each method**.

Menstruation

Menstruation is not often talked about, but it can tell you and your provider(s) a lot about your reproductive health. Research has shown that women living with HIV more commonly have menstrual irregularities. If this is an issue for you, consider talking to your care provider(s) about it. Fill out the box below and show to your provider(s) as a starting point.

HOW WOULD YOU DESCRIBE YOUR PERIOD?

There are usually ________ days between my periods (bleeding).

Bleeding usually lasts ________ .

- ☐ I have bleeding between expected periods.
- ☐ I have painful periods.
- ☐ I have heavy bleeding.
- ☐ My periods have recently changed in length, amount of bleeding, or something else.
- ☐ I have no period (not related to menopause).

Menopause

You should begin talking about menopause with your provider(s) around age 40, and you may notice symptoms around or after then. Menopause is when a person has no period for over 12 months. Perimenopause can start 8 years before and have similar symptoms. There are several ways to manage your menopause symptoms, including medications and lifestyle changes.

There are 2 types of menopause medications:

- **Menopause hormone replacement therapy** (medication that replaces the estrogen that your ovaries stop making during menopause to help reduce menopause symptoms; can take the form of creams, pills, or patches - if one has a uterus, progestin has to be also taken to prevent uterine cancer)
- **Non-hormonal medication to help with symptoms** (medication that does not contain hormones but can help with symptoms; usually oral pills)

Lifestyle changes that can help reduce symptoms:

- **Dressing in layers**
- **Drinking cold drinks**
- **Meditating or doing mindfulness activities**
- **Exercising**
- **Quitting smoking and/or reducing alcohol intake**
- **Using lubricants during sexual activities**

For in-depth information around menopause for women living with HIV, scan the QR code here.

Menopoz and You

Talking about women's health care with your provider(s)

- *"I am hoping we can talk about birth control today."*
- *"I have had changes to my sex life/history. I filled out this questionnaire (on page 28), can you take a look at the results?"*
- *"I am interested in getting pregnant. What should I do to prepare?"*
- *"I recently found out I am pregnant. I am feeling (insert feelings) and have questions about (insert questions/concerns). Can we create a pregnancy plan together?"*
- *"Based on my age/symptoms, I was hoping we could talk about menopause today."*
- *"I am interested in learning about (hormone therapy/non-hormone therapy/lifestyle changes) to manage my menopause symptoms."*
- *"I am interested in gender-affirming care and transitioning. Can you help me with that? Do you know about the excellent Rainbow Health Ontario guidelines?"*

Do you know about the excellent Rainbow Health Ontario resources?

Other Notes

Section E:

Mental and Emotional Health Care

Having good mental and emotional health is important for everybody. Just like you need to exercise to stay physically healthy, it is equally important to put effort into maintaining good mental health. Like all aspects of health, mental health needs may change at different times in your life.

Common Mental Health Conditions

The most common mental health conditions include: depression, generalized anxiety disorder, panic disorder, post-traumatic stress disorder, and substance use disorder.

For full **definitions and symptoms,** scan the QR code and scroll to page 22.

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. **If you need a little extra help, your care provider has options** including screening for mental health conditions, brief counselling and treatment, referrals for other counselling options, medications, and more. You do not have to manage this on your own.

Talking about mental health with your provider(s)

- ***"I am not feeling my best mentally lately. Some things impacting my mental health are (fill in the blank from below). Are there mental health tests I could do to get some answers and make a plan, or services I could access to get support?"***
  Examples: HIV stigma, Access to food, Current living environment, Family, friends, other loved ones, Job/workplace, Weight/body image, Physical pain/health, Finances

- ***"I am having a hard time prioritizing my self-care. Do you have any advice on what I should do?"***

- ***"I think I would like to speak to a mental health professional. Can you please refer me to a psychiatrist, psychologist, or psychotherapist? Can you tell me what costs and wait times will be associated with that referral?"***

- ***"Are there any free mental health services/psychotherapy for people living with HIV that you can refer me to?"***

- ***"Rainbow Health Ontario has a list of mental health providers with expertise in working with 2SLGBTQIA+ people. Could you refer me to someone from this list?"***

Rainbow Health Ontario Resource Library

Your Mental Health & Emotional Health Care

HOW COMFORTABLE DO YOU FEEL DISCUSSING YOUR MENTAL HEALTH WITH YOUR PROVIDER(S)?

Not At All Comfortable *Somewhat Comfortable* *Very Comfortable*

WHAT FACTORS AFFECT THIS? *(e.g. upbringing, values, religion, shyness)*

WHEN YOU THINK OF YOUR MENTAL HEALTH, WHAT ARE 3 WORDS THAT COME TO MIND?

WHAT TYPES OF ACTIVITIES “EMPTY YOUR CUP” OR MAKE YOU FEEL TIRED, DRAINED OR MENTALLY UNWELL?

WHAT TYPES OF ACTIVITIES “FILL YOUR CUP” OR MAKE YOU FEEL REFRESHED AND HAPPY? *(e.g. going for a walk, music, a podcast, a personal hobby, reading etc.)*

Mental Health Strategies

These are some strategies you may want to try to keep you mentally healthy. Fill in the chart to start a discussion with your provider(s) about how to make these things more accessible to you.

STRATEGY	Do I use this strategy?	Notes from talking to my provider
Get your basic needs met *(safe, secure, and affordable housing, food, financial assistance, employment services, child/elder care)*	☐ Yes, I do this ☐ No, I need help to do this	
Exercise regularly *(This can look different for everyone. A good goal is to move your body in a way that feels good every day!)*	☐ Yes, I do this ☐ No, I need help to do this	
Get enough sleep	☐ Yes, I do this ☐ No, I need help to do this	
Practice mindfulness	☐ Yes, I do this ☐ No, I need help to do this	
Reach out to others for support/company	☐ Yes, I do this ☐ No, I need help to do this	
Find and join organizations or communities that you may identify with	☐ Yes, I do this ☐ No, I need help to do this	
Reduce substance use *(including alcohol and cigarettes)*	☐ Yes, I do this ☐ No, I need help to do this	

Substance Use

What is Substance Use?

Substance use can mean different things to different people. It exists on a spectrum – **from occasional use with minimal harm to patterns that can negatively impact your life**.

Substance use can develop into addiction, sometimes without you even realizing it. Certain substances can even interfere with ART or lead to missed doses, making it harder to maintain a suppressed viral load.[2]

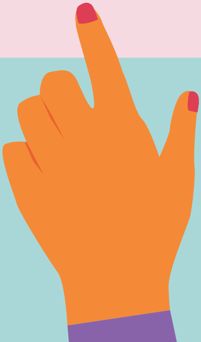
Whether you're looking to use substances more safely, work toward stopping all together, or support loved ones who use, education, support and harm reduction strategies can help.

What is harm reduction?

Harm reduction is a **set of practical strategies aimed at minimizing the negative consequences of substance use**, grounded in respect for the rights and dignity of people who use substances.

Examples of harm reduction programs include:

- **Opioid Agonist Therapy (e.g., Methadone or Suboxone)**
- **Supervised consumption sites/safe injection sites**
- **Naloxone distribution and overdose education**
- **Safer use equipment distribution (e.g., syringes, pipes, and other supplies)**



Getting Help with Substance Use

Asking for help isn't easy. Be patient and kind to yourself as you navigate your options.

Not sure if you need help for your substance use? These two quick **screening questions** can help:

HOW MANY TIMES IN THE PAST YEAR HAVE YOU USED AN ILLEGAL DRUG OR USED A PRESCRIPTION MEDICATION FOR NONMEDICAL REASONS? *(e.g. because of the feeling it caused)*

HOW MANY TIMES IN THE PAST YEAR HAVE YOU HAD 4 OR MORE DRINKS IN A DAY?

You can bring your answers to your next appointment. Based on your responses, your doctor may suggest more screening.

You can also try the TAPS **screening tool** on your own or with a provider.

Tobacco, Alcohol, Prescription medication, and other Substance use Tool (TAPS)

Talking about substance use with your provider(s)

"I'm thinking about making a change and getting help for my drug or alcohol use. I'd like to hear your suggestions on treatment options and what support is out there."

"I'm not ready to stop using, but I want to reduce the risks. Are there any harm reduction services you can recommend?"

Other Ways to Get Help

Detox, Rapid Access Addiction Medicine (RAAM) Clinics, and Rehab Treatment Programs:

Find **detox services** across Canada at canadadrugrehab.ca or call 1-888-245-6887

Find **RAAM Clinics** by searching "RAAM Clinics Near Me"

More support services (including Canada-wide, provincial/territorial and **Indigenous-specific** resources)

Learn how to **recognize and respond to an opioid poisoning** and how to administer naloxone

If you need immediate help, Call 911 or 211.

Other Notes

Section F:

Peer Support, Leadership and Capacity Building

“Peer” is a term the HIV community uses, meaning another person living with HIV who you may relate to. Some people do not like this term because it can disclose HIV status to others. It is used throughout this section, but it can be changed with “community member”, or “friend” if you feel more comfortable with that.

Peer Support Roles

Peer Support can be emotional, cultural, and/or social. It can involve peers sharing information, providing mutual social support, and helping each other feel empowered.

Peer Navigators provide guidance, connection, referrals, education, and can accompany you through the healthcare system. Sometimes peer navigators are people living with HIV and sometimes they are not. This is important to consider before accessing peer navigation – you may need to disclose your status to them.

Talking about peer support with your provider(s)

- *"Can you connect me with someone at the local HIV Service Organization for peer support?"*
- *"Are there any peer navigator programs that you know of? Can you help me access them?"*
- *"I have heard of some Peer Leadership and Capacity Building opportunities. Do you know of any that you can refer me to?"*

Deciding what peer support is right for you

It is okay if you do not want to take part in peer support - just remember it is always an option if you want it at another time. If you are interested in peer support, reflecting on the questions below may help you decide what kind of peer support is right for you.

WHAT TYPE OF PEER SUPPORT INTERESTS YOU?

☐ **In person:** One-on-one, In groups

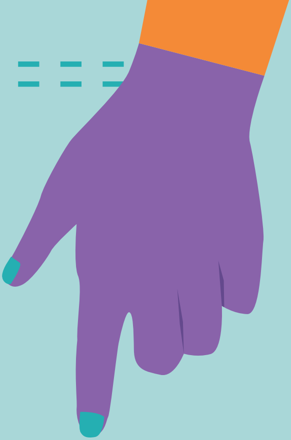
☐ **Virtually:** One-on-one, Through text, Online Group

WHAT DOES YOUR IDEAL "PEER SUPPORT" LOOK LIKE?
(e.g. is it important that the person(s) offering you peer support shares/doesn't share the same gender identity/ethnicity/age/religion/etc. as you?)

If you are **interested in peer leadership or capacity building opportunities**, scan the QR code for free leadership training.

Positive Leadership Development Institute

You have reached the end of the pocketbook!



You can use the prompts on the next few pages to reflect on your care experiences and goals for the future.

How can you advocate for yourself and communicate your needs more effectively during medical appointments? What might you still need to be able to do this?

Are there any aspects of your health or healthcare that you feel more confident about now compared to when you started this journey? What contributed to this increased confidence?

Celebrate your achievements, no matter how small they may seem.

What are you most proud of when it comes to your healthcare journey?

In what ways do you envision your relationship with your healthcare provider(s) improving in the future? What steps can you take to make this vision a reality?

What are some health goals you would like to achieve in the next six months? What steps can you take with and/or without your provider(s) to achieve them?

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We hope this pocketbook has been helpful to you!

If you are **interested in getting involved in future work** with the team that developed the pocketbook, please scan the QR code to contact our team at the WCHC Hub Central.

The WCHC Pocketbook was developed by the **Women HIV and Health Research Program (WHRP)** at Women's College Hospital Research Institute with graphic design support from Loop: Design for Social Good. The WCHC model and toolkits from which the Pocketbook content was derived were developed by a national team of women living with HIV, healthcare providers, community workers, researchers and other expert stakeholders. This project was supported by the WCHAMSG Innovation Fund of the Alternative Funding Plan for the Academic Health Sciences Centres of Ontario (WCH-23-01) and the Canadian Institutes of Health Research (FDN154325).

The WCHC Pocketbook was developed for women living with HIV in Canada as a guide only and does not constitute medical or other professional advice. Women living with HIV are required to exercise their own judgment in using the WCHC Pocketbook. Neither WHRP, the contributors to the WCHC Pocketbook, nor any of their respective agents, appointees, directors, officers, employees, contractors, members or volunteers: (i) are providing medical, diagnostic or treatment services through the WCHC Pocketbook; (ii) to the extent permitted by applicable law, accept any responsibility for the use or misuse of the WCHC Pocketbook by any individual including, but not limited to, women living with HIV, including for any loss, damage or injury (including death) arising from or in connection with the use of the WCHC Pocketbook, in whole or in part; or (iii) give or make any representation, warranty or endorsement of any external sources referenced in the WCHC Pocketbook (whether specifically named or not) that are owned or operated by third parties, including any information or advice contained therein.