



PRIVACY AND DISCLOSURE FOR YOUTH LIVING WITH HIV OR HEP C

Questions & Answers

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TABLE OF CONTENTS

1	Introduction
4	My health record
6	With my health care provider
8	At school
9	At work
11	With my partner(s)
16	Additional resources

INTRODUCTION

Who is this guide for?

This guide is for youth between the ages of 15 and 29 and focuses on some of the factors at play when young people living with HIV or hepatitis C (Hep C) are thinking about telling others about their HIV or Hep C status.

This guide gives you legal information, not legal advice

This guide provides information about different laws that may apply to young people living with HIV or Hep C. This guide does not provide legal advice about your particular situation. If you want or need legal advice, you should talk to a lawyer. If you are living with HIV and in Ontario, you can contact the HIV & AIDS Legal Clinic Ontario (HALCO). There is information at the end of this guide about where to get legal help.

The information in this guide is based on an understanding of the laws around HIV and Hep C in Canada at the time of publication. One of the things you will notice in this guide is that each case is different. People living with HIV or Hep C will almost always benefit from getting more information about their individual circumstances. The resources at the end of this guide can help.

General information about disclosure

The term “disclosure” refers to telling another person your HIV or Hep C status.

As a general rule, **you have the right to keep your health information private.** Whether this includes how much you weigh, when you last saw a doctor, or your HIV or Hep C status, in most cases at work, school or home you do not have to disclose health information to other people. This document gives some answers to questions you may have about telling others about your HIV or Hep C status under different circumstances.



Are those of us living with HIV or Hep C legally required to disclose our status?

In most cases, there is no legal obligation to disclose your HIV or Hep C status. It is your choice whether or not to tell your parents, family members or friends your status. Many reasons affect your decision to share or not share your status. You may decide to tell someone who you think might be able to help, whether that person is a representative of an organization, a friend or someone else who has HIV or Hep C.

In some situations, you are legally required to tell your sexual partner(s). These situations are described in more detail later in this guide.



I am afraid of other people's reaction if I disclose my HIV or Hep C status.

Telling others that you are living with HIV or Hep C can bring up many feelings, and may be understandably difficult and stressful. You may face judgment, discrimination, stigma or violence when people are uninformed about HIV or Hep C and rely on hurtful stereotypes, or believe that conversations about issues related to sexuality are taboo. People may also react with love and support.

Deciding if you want to tell others, or when and how to tell others, can be stressful because it's often hard to tell how people will react. If you are worried about how your friends, co-workers or others are going to react, contacting your local HIV or AIDS service organization (ASO) or a support organization for people living with Hep C can be a good first step. Many ASOs also have young people on staff or as volunteers who can support you. In some cases, you may want to seek legal advice before deciding whether to disclose your status.

What do I do if someone is discriminating against me because of my HIV or Hep C status?

Discrimination based on HIV status and other aspects of identity is all too common in Canada. There are laws in place that make it illegal for people to discriminate on the grounds of a health condition you may have, including your HIV or Hep C status. Using the law to help in an individual situation you are facing can be hard. If you are trying to protect yourself through legal means, the first step is to keep a record of all documents with relevant details of the discrimination (such as dates, descriptions of the incidents, names and contact information of any witnesses, copies of all relevant documents and correspondence). Sometimes your school or workplace, or the professional body that regulates your health care provider, may have policies and procedures to address discrimination, harassment or bullying. So your teacher, school principal, employer, work supervisor, human resource manager (at work) or an ombudsperson at your school may be one of the first people for you to speak with.

Additionally, you may contact your provincial human rights commission (or the Canadian Human Rights Commission, if your employer is regulated by the federal government) and file a claim free of charge. Note that there is usually a "limitation period." This means you must file your complaint within a certain period of time (usually a year) after the discrimination takes place. Check with the relevant commission to find out the limitation period.

If you want personalized legal advice, you will need to hire a lawyer. You are responsible for paying the lawyer's fees unless you are able to find someone who may help you for free.

What do I do if I am being harassed online due to my HIV or Hep C status?

Online harassment can leave you feeling upset and alone. And it can be very hurtful. But in most cases, online harassment is not criminal under the law.

If you are experiencing harassment online or through text messages, you may want to document the harassment to create a permanent record. Try not to get engaged in abusive threads. Keep screenshots of offensive comments and record the dates and times as best as you can.

If you are experiencing any kind of harassment online, you have a few different options to prevent it from continuing to happen. Depending on what platform the harassment is happening (i.e., social networking site, blog, online forum, or chat), there may be an option to report it. You may want to ask others to report it as well, an approach that increases the likelihood that the platform will respond.

INTRODUCTION

Documenting the harassment that you are experiencing to create a permanent record may be important evidence if the harassment escalates. For some people and in some situations, getting the police involved may be helpful. The police can start a file to document the harassment, and the report could also lead to a police investigation and possible criminal charges.

Talking to someone you trust, or someone who works in an HIV or Hep C organization can also be helpful. Some of these organizations have young people who are staff or volunteers and may be able to relate. These organizations may also be able to refer you to in-person or online groups for youth living with HIV or Hep C.



MY HEALTH RECORD

What is my health record?

Health records are created by health care providers (e.g., doctors, nurses, dentists, psychiatrists) and facilities that provide care (e.g., clinics and hospitals). They contain health information that these providers and facilities have collected and stored. This can include information about your physical and mental health; family health history; copies of your test results, prescriptions, doctors' notes, or X-rays; and information related to payments or eligibility for insurance coverage.

This information may be stored physically or electronically. Information may also be included in centralized province-wide databases (sometimes called Electronic Health Records or EHRs), which can be accessed by many different health care providers across Canada.

Can I access or change my health record?

It is your legal right to ask to see your medical information, and health care providers must assist you and respond to your request without delay. You might need to make a request in writing or complete a particular form. Contacting your health care provider or the relevant health care facility is the first step to find out what you need to do.

You cannot make changes to your medical records, but you can ask a health care provider to correct or complete your information if you think it is inaccurate or incomplete. You may have to make the request in writing.

If a health care provider refuses to let you see your records, the health care provider must explain why and indicate that you have the right to file a complaint against the decision with the relevant privacy commissioner. You also have this right when you are unhappy with how a health care provider responds to a request to correct your medical record.



Who is informed of my status when I take an HIV or Hep C test?

When you take an HIV or Hep C test, the person who provided you with the test and informed you of the results, as well as the laboratory that analyzed your blood, will know the results. Depending on the type of test, your name may not necessarily be identified (more information below). If you take an HIV test through your family doctor, your doctor will also likely know your results.

HIV and Hep C are reportable illnesses in all Canadian provinces and territories. That is, when a person tests positive for HIV or Hep C, the result is also reported to the provincial or territorial public health authorities. The type of information that gets reported to the public health authorities, and perhaps stored in a database, depends on the law and practice in a given province or territory.

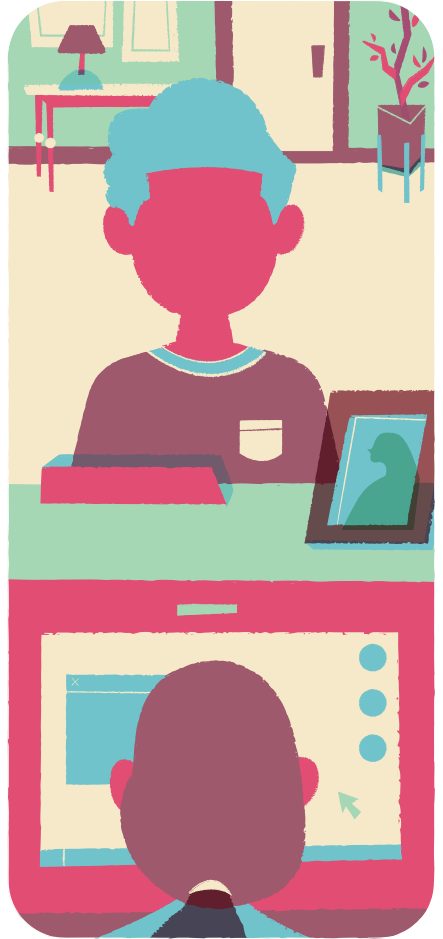
In some provinces, anonymous tests may be available (only your test result and non-identifying information will be reported to public health authorities and no one besides you will know that you took the test). In places without anonymous testing, you might be able to take what is referred to as a “non-nominal test,” meaning that your blood sample is sent to a laboratory with only your initials or a code, and your name is not reported to public health authorities. If, however, you take a “nominal test,” the testing laboratory will report your HIV- or HCV-positive status, your name, date of birth, gender, and contact information to public health authorities.

WITH MY HEALTH CARE PROVIDER

Do I have a legal obligation to disclose my status to my health care provider?

No. You do not have to disclose your status to health care providers, whether they are dentists, doctors or optometrists. But because HIV and Hep C can affect your health needs, health care providers may be able to give you better care if they have information about your status.

If you do not answer doctors' questions about your HIV or Hep C status or do not tell them the truth, withholding this information should not be used against you. Generally speaking, health care providers should only ask questions that are relevant to the care you are receiving at the time. In other words, they should not ask about your HIV status for the purpose of providing care if this information is not required to examine or treat you. If you have any doubts, you are always entitled to ask your health care providers why their questions about HIV or Hep C are relevant to the discussion.



If I do disclose my HIV or Hep C status to a health care provider, will it be recorded?

Health care providers must keep records of a patient's consultations, medical condition and treatment. So you might not be able to prevent a doctor from including your health information in your medical record. However, if you do not want the information to be shared with others, including other health care providers, you can ask your doctor not to share your information with others or mask the information in your file.

Can health care providers disclose my status to another provider without my consent?

Yes. There are some situations when health care providers can disclose your status to another provider. Consent can either be "express" (i.e., explicit consent that is spoken or in writing: "Yes, you may tell other health care providers about my status") or "implied" (i.e., it is understood that you give consent even though it is not specifically communicated). Generally, health care providers do not need your express consent to disclose your health information to other health care providers for the purpose of providing or assisting in providing care. This practice is called sharing information within the "circle of care," and your consent is considered to be implied in many provinces.

Information shared within the "circle of care" should be limited to what is *necessary for the particular purpose of disclosure*; that is, for providing or assisting in providing health care. You may be able to prevent one health care provider from disclosing your status to other health care providers if you explicitly say you do not want the information disclosed. Within a hospital setting, there may be a specific process in place. If you don't want all members of your medical team to have access to certain information, you may have to fill out a specific request form to block it. This process is different at each facility.



AT SCHOOL

Do I have to disclose my status to my teachers or my classmates?



No. In most cases, you do not have to tell your school that you have HIV or Hep C. Whether or not to disclose your status is entirely your choice. HIV and Hep C are not transmitted through casual contact, vomit, sweat, stool, urine, tears, or nasal secretions. Additionally, there is no risk of transmission from scratching another person or through spitting.

You may choose to disclose your status for many reasons. Sometimes, disclosing you have HIV or Hep C can make it easier if you require frequent time off school for medical appointments or simply if you require support from your teachers, school administrators or your peers.

If I am studying in a health care field, do I have to disclose my status to my college or university instructor, professor, mentor or thesis supervisor?

In a vast majority of programs at university or college, you will not be required to disclose your status. However, you may be required to disclose your HIV and Hep C status if you are training in health professions such as medicine or dentistry where there is very slight possibility of transmission. The administration may either request and expect voluntary disclosure of communicable diseases or require medical documentation that includes the results of a recent HIV or Hep C test. However, you are not obligated to provide information where requests by educational institutions for your disclosure may be overly broad or unjustified.

Will my HIV or Hep C status be kept confidential?

If disclosure is required, school authorities should ensure that only the minimum number of staff members required are made aware of your HIV or Hep C status. If your status is disclosed to a school authority (e.g., principal, teacher, counsellor or administrative staff), that person must keep the information confidential.

AT SCHOOL

However, in Alberta, Ontario, Nova Scotia, Prince Edward Island and Newfoundland, school authorities are legally obligated to report a student in the school who has HIV to the provincial Medical Officer of Health, who is obligated to keep this information confidential. School authorities may record your HIV status in your student record, but this information should remain exclusively with the required personnel in a secure filing system to protect your privacy. In British Columbia and Ontario, your health information may be kept with your academic record, but access to this information should be very limited.

If you disclose your status to your school's health or counseling services, your status is considered confidential information and shouldn't be shared with other school staff. If you are a minor (under 16, 18 or 19 years old, depending on the province or territory), your medical record cannot be released by school personnel without your parent or guardian's permission.

This legal obligation of confidentiality, however, does not include classmates or any other person at your school who is not acting in an official capacity.

Will my activities be restricted because I have disclosed my HIV or Hep C status?

Because there is no risk of HIV or Hep C transmission through casual contact, there is no legal reason your school can prevent you from participating in activities. Your school has to treat everyone the same when dealing with scrapes, cuts and anything that involves bleeding or contact with bodily fluids.

AT WORK

Do I have to disclose my status to my employer?

In most cases, you do not have to tell your employer that you have HIV or Hep C because your status is private and personal information. Additionally, all jobs except for those in health care pose no real risk of transmitting HIV or Hep C to anyone else. There is some risk of HIV or Hep C transmission in jobs that include performing or assisting with certain kinds of medical procedures that may involve transmission of blood or bodily fluids. Regulatory bodies for different aspects of the medical profession (e.g., the College of Nurses of Ontario in the field of nursing) have specific requirements for HIV and Hep C disclosure. If you are considering a career in health care services, you can contact the relevant regulatory bodies to find out the specific rules that would apply.

Do I have to disclose my status to my co-workers?

Neither HIV nor Hep C can be transmitted through day-to-day contact. As such, you are not legally obligated to disclose your status to your co-workers.

Will my status be kept confidential?

Yes. If you choose to disclose to your employer or to co-workers *acting on behalf of your employer* (for example, a human resources manager), they are obliged to keep this information confidential.

Legally, your employer cannot disclose your medical information, including your HIV or Hep C status, to any third party without your consent. This legal duty of confidentiality, however, does not apply to co-workers who are not acting in an official capacity as a representative of your employer.

If I request special accommodations at work, do I need to tell my employer that it is because I have HIV or Hep C?

No. You do not need to provide a specific diagnosis to your employer to request accommodations. However, you will likely need to provide requisite medical documentation explaining your specific limitations and special accommodations needed in order to perform your job.

For more information, read "Accommodation in the workplace," the second brochure in the *Know Your Rights* series listed at the end of this guide.



WITH MY PARTNER(S)



What do you mean by “partner”?

A “sexual partner” in the context of HIV status disclosure is a person of any gender with whom you have had or are having any kind of sexual contact. It may be a steady partner; a casual partner; a one-time hookup, or any other person you had sex with in the past or are having sex with now, whether one time, occasionally, or regularly.

When do I have to disclose my status to my partner?

For people living with Hep C, it is unclear whether you have a legal duty to disclose to your partners before sex. We are aware of only two cases in which people with Hep C were charged for not disclosing their Hep C status before sex and neither of these cases resulted in a conviction.

For people living with HIV, the current legal rules set out the specific contexts in which you have a legal obligation to disclose your HIV status.

People living with HIV have a legal duty to disclose their status before sex if they are having sex *without* a condom. People living with HIV also have a legal duty to disclose their status before sex if they are having sex *with* a condom **unless** they have a low viral load (less than 1,500 copies/ml).

You do not have a legal duty to disclose your status if you have a viral load under 1,500 copies per ml *and* use condoms during vaginal or frontal-hole sex. The law is not as clear about anal sex. You may also have a legal duty to disclose your HIV status when you are having sex with a condom and your viral load is under 1,500 copies per ml.

When it comes to oral sex, we know that there is no legal obligation to disclose before oral sex if you use a condom and have a viral load under 1,500 copies per ml.

What does “viral load” mean?

The term “viral load” refers to the amount of HIV in your body. A viral load test measures the number of HIV particles in your blood. The courts have decided that viral loads under 1,500 copies per ml are low. People who have an undetectable viral load have a viral load much lower than this number.

What happens if I don’t disclose my HIV status when I’m supposed to?

In Canada, not disclosing your HIV status when required is a criminal offence. People living with HIV who are charged in relation to non-disclosure are most commonly charged with a crime known as “aggravated sexual assault.”

If you face a criminal charge of aggravated sexual assault, lawyers representing the government (also known as the Crown) must prove the following “beyond a reasonable doubt”:

- that you are the person who was involved, that you were aware of your HIV-positive status and the potential for sexual transmission;
- that you were “dishonest” to your sexual partner about your HIV status (through lying or silence);
- that the sex you had included a “realistic possibility” of HIV transmission;
- that the person (or people) you had sex with would not have consented to sex if they knew you were HIV-positive; and
- that the sex act “endangered the life of” the person you had sex with.

The criminal law on matters of HIV non-disclosure has been, under some circumstances, very harsh. Unfortunately, the criminal law applies to everyone living with HIV, even youth. Even though the law is scary and hard to talk about, getting information about the law can help you make decisions that are right for you when it comes to your sex life.

If you are 12 years old or older, you can be charged with a criminal offence for not disclosing your HIV status when the law requires you to. A special system of dealing with criminal charges applies to those aged 12 to 17.

The *Youth Criminal Justice Act* sets the rules for prosecution and possibly sentencing for youth aged 12 to 17. Youth in this age group will be tried in youth court. Typically, when judges make a decision about your sentence, they will have a greater focus on rehabilitation and consider that you are young. However, sometimes adult sentences can be imposed on youth too.

Can a court or someone working for a court ever disclose my HIV status without my consent?

Your status can be disclosed without your consent only if you are facing charges related to HIV non-disclosure. Specifically, your parents or guardians must be told the reason for your arrest and be given a copy of any medical or psychiatric report the court may order.

If the court believes you may be a danger to others, the court can authorize the temporary publication of information that identifies you as having committed or allegedly committed the indictable offence of aggravated sexual assault.

A youth worker, the Attorney General, a peace officer, or any other person who provides youth services may disclose your status to other professionals or people who care or supervise you.

In some cases, publication bans may be in place to prevent sensitive media from being shared, but these rules do not apply to young people who have received adult sentences and may not apply if you, even sentenced as a youth, have been convicted of something the court deems to be a violent offence (which includes HIV non-disclosure).



What is a “realistic possibility of transmission”?

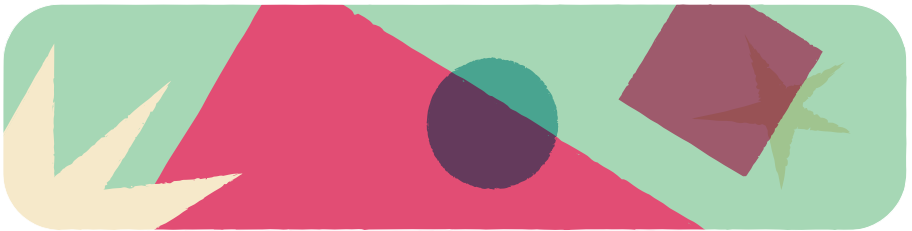
This is an important question. Unfortunately, the court has not provided clear answers. We know that the way the law is currently applied does not reflect the most up-to-date science when it comes to HIV. We also know that the use of the law can take into account the risk factors in each unique situation and adapt to future circumstances. In other words, the law may change as new cases arise.

Are there any contexts in which I am not required to disclose my status to my partner?

The law considers acts such as kissing, mutual masturbation and similar intimate acts to be “no risk.” You are not required to disclose your status to your partner(s) when engaging in these activities. Additionally, as mentioned previously, you do not have an obligation under the criminal law to disclose your status before vaginal or frontal-hole sex **if** you use a condom *and* you have an undetectable viral load because under such circumstances, it is impossible to transmit HIV. This principle likely applies in a similar way to anal sex, but the law has yet to confirm this.

Does my obligation to disclose my status change based on the gender of my partner?

No. Your obligation to disclose depends only on whether there is a “realistic possibility” of transmission of HIV. Men having sex with men have been charged for not disclosing their status before sex. We are not aware of any prosecutions against women having sex with women.



What if my partner doesn't ask if I have HIV?

In a legal sense, remaining silent about your HIV status is the same as lying about it or not disclosing it. Regardless of whether or not your partner asks for this information, the law requires that you inform your partner about your status.

What happens if I find out I have HIV after I have engaged in sex with my partner?

You will not have committed a criminal offence if, when engaging in sex with your partner, you did not know you had HIV. However, after you become aware of your HIV-positive status, you will have the same legal obligations mentioned earlier if you are having sex that poses “a realistic possibility of transmission.”

How can I reduce the risk of criminal prosecution or conviction for HIV non-disclosure to my sexual partners?

While there is no fail-safe way to avoid being accused of HIV non-disclosure, there are some steps you can take to reduce the risks of being charged criminally for non-disclosure. These include the following:

- Clearly disclose your status when required, and discuss the risk of HIV transmission and prevention during that time
- Conduct this disclosure in front of a witness (such as a health care provider or counsellor)
- Have sexual partners sign a document or agree to a video recording indicating that you have made them aware of your HIV-positive status before having sex
- Keep copies of any documents or correspondence (such as letters, notes, emails, messages, texts or chat-room dialogues) that can be used to show that disclosure took place before having sex, especially before sex that poses a realistic possibility of transmission
- Avoid activities that the court believes pose a higher risk for HIV transmission (specifically, vaginal and anal intercourse without a condom)
- Work with a doctor and care team to maintain a viral load under 1,500 copies per ml

ADDITIONAL RESOURCES

Legal advice and information

HIV & AIDS Legal Clinic Ontario (HALCO)

- www.halco.org/our-services/legal-services
- 416 340-7790
- Toll-free in Ontario: 1 888 705-8889

Canadian Aboriginal AIDS Network

- www.caan.ca
- B.C. main office: 604 266-7616
- Halifax office: 902 433-0900

Coalition des organismes communautaires québécois de lutte contre le sida (COCQ-SIDA)

("Coalition of Québécois community organizations in the fight against AIDS")

- Montréal area: 514 844-2477 ext. 34
- Outside of Montréal (toll-free): 1 866 535-0481 ext. 34
- vih-infodroits@cocqsida.com

The Law Society Referral Service (LSRS)

Online service that provides referrals to lawyers or paralegals for residents of Ontario for up to 30 minutes of free consultation. The service can be accessed by telephone if you cannot access a computer because you are in custody, in crisis, in a shelter or in a remote community without internet access.

- www.lsuc.on.ca/lsrc
- 1 855 947-5255
- Residents outside of Ontario can use the Law Society's Lawyer and Paralegal Directory to find a legal representative:
www2.lsuc.on.ca/LawyerParalegalDirectory/

The criminal law and HIV

Women and the Criminalization of HIV Non-Disclosure, Canadian HIV/AIDS Legal Network, 2012 (updated 2017)
www.aidslaw.ca/site/women-and-hiv-women-and-the-criminalization-of-hiv-non-disclosure

HIV Disclosure to Sexual Partners: Questions and answers for newcomers, Canadian HIV/AIDS Legal Network, 2015
www.aidslaw.ca/site/hiv-disclosure-to-sexual-partners-qa-for-newcomers

Criminal Law & HIV Non-Disclosure in Canada, Canadian HIV/AIDS Legal Network, 2014
www.aidslaw.ca/site/criminal-law-and-hiv

Privacy rights and HIV

HIV Youth Disclosure Project
www.youthco.org/youth_speak_disclosure

Know Your Rights
A series of 8 brochures available in seven languages on privacy rights and disclosure obligations of people living with HIV in a variety of day-to-day contexts.
www.aidslaw.ca/site/kyr

Privacy and Disclosure: Questions and answers on HIV-related privacy and disclosure issues for women's service providers, Canadian HIV/AIDS Legal Network, 2012
www.aidslaw.ca/site/privacy-and-disclosure-questions-and-answers-on-hiv-related-privacy-and-disclosure-issues-for-womens-service-providers/

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