



HIV disclosure

A GUIDE FOR YOUTH

This booklet is designed to help youth living with HIV who are thinking about whether they want to tell family members, friends, and romantic or sexual partners about their HIV+ status.

Created by

Positive Women's Network (pwn.bc.ca)
in partnership with the BC Women's
Hospital + Health Centre (bcwomens.ca)

Reviewed by

YouthCO, Sexuality Education
Resource Centre Manitoba, MIELS-
Québec, Canadian HIV/AIDS Legal
Network, BC Women's Hospital +
Health Centre, and Positive Women's
Network members and staff

Funding provided by

BC's Provincial Health Services Authority

© Positive Women's Network and
BC Women's Hospital + Health Centre, 2016
ISBN 978-0-9876816-4-5

Printed and nationalized with assistance
from CATIE, 2016.

This booklet is available for order in Canada:
CATIE Ordering Centre No. ATI-26528
(Aussi disponible en français, ATI- 26528VF)

Written by

Janet Madsen
Erin Seatter
Positive Women's Network

Design by

Erin Seatter
Positive Women's Network

Cover photo by

Aretha Munro
Positive Women's Network



Positive Women's Network

**BC WOMEN'S
HOSPITAL+
HEALTH CENTRE**



An agency of the Provincial Health Services Authority



Canada's source for
HIV and hepatitis C
information

FROM FAMILY

to friends and beyond

Getting older often means making more of your own choices and having more independence.

This can be fun and exciting, but sometimes intense. Friendships and relationships are an important part of life. Maybe you're dating, hooking up, or having sex. Maybe you're drinking or trying out drugs.

Living with HIV can make stuff more complicated. You may not know where to start with HIV disclosure, which is when you tell people you have HIV. Who do you tell? When do you tell? And for what reasons?

IF YOU'VE lived with HIV for a while

Your parents or guardians may have told people about your HIV for you—doctors will know, and possibly family members too. Talking to them about why they told the people they did can help you as you start making these decisions yourself. It might feel weird to think about sharing your HIV+ status, and that makes sense if it's been a secret all your life.

Some families want HIV kept secret because they are worried about discrimination or how they will be seen in their community. Although having HIV is nothing to be ashamed of, you will find people who don't know much about it or think it only happens through sex. Not everyone will know, for example, that a person can be born with HIV or that it can be transmitted through sexual abuse or assault, but this can happen.

You might be used to living with HIV, but it will be news to the people you're going to tell. So choose carefully and pick people you trust.

IF YOU'RE


newly diagnosed

Getting tested and taking charge of your health is a good step. Now that you have a diagnosis, give yourself time to adjust. Find a doctor you trust, and learn about what you should know.

You can live a long and healthy life with HIV. Get connected with an HIV organization to find out what services and support are available. If you are in BC, you can connect with YouthCO. Check out www.youthco.org to learn more and find resources. For organizations in other areas, visit www.hiv411.ca, which has info on HIV services across Canada.

Some youth tell their parents or guardians that they've been tested. Others decide not to tell. Keep in mind that disclosing your HIV+ status may lead to questions about other parts of your life, for example:

- whether you're having sex
- what your sexual orientation and gender identity are
- whether you've been partying, using drugs, or drinking



Maybe you don't want your parents or guardians to know any of this stuff because it doesn't feel safe. If this is the case, talk to a local HIV organization for support and suggestions on where to go from here.

As for living at home, HIV is not passed through casual contact. You can't pass HIV by spending time with people, hugging, or holding hands. You also can't pass it by sharing dishes or glasses. HIV can't be spread through air and water, or through your sweat, tears, or saliva. For a refresher on how HIV is transmitted, read the next section.

Your parents, guardians, and other family members can live safely without knowing you have HIV.

TRANSMISSION FACTS

Sharing information about how HIV can and cannot be passed might help people feel more comfortable with you. HIV is passed when body fluids that have a high level of the virus find direct access to the bloodstream. These body fluids include blood, pre-cum/semen, vaginal fluids, anal/rectal fluids, and breast milk.

Here are some activities where HIV can be passed:

- having genital sex (penis in a vagina) without a condom
- having anal sex (penis in a bum/ass) without a condom
- sharing needles used to inject medicine, hormones, or drugs
- sharing equipment for tattooing or piercing
- sharing a sex toy between partners without properly cleaning it or covering it with a condom
- being born to a person with HIV—transmission can occur during pregnancy, birth, or breastfeeding

Worrying about giving HIV to a partner can take away the pleasure of sex. Take precautions to protect yourself and your partner. Use condoms and barriers. If you inject drugs, use a new needle every time.

PLANNING to disclose

Every disclosure situation is different, and having emotional support is important.

Think about who can support you before, during, and after the disclosure process. This might be a friend, a family member or support worker at an HIV organization. You can practise disclosing beforehand with this person. This can help you feel ready.

You are living with a virus that can be treated, and you can live a healthy life. Think about choosing to tell people who know about HIV or are willing to learn.


Some people wait until they've felt the urge to tell someone a few times before they actually tell. For example, consider waiting until you've wanted to tell them three times or more. This way you can be certain that you really want to share your HIV+ status with them, and you can think about the consequences of telling them.

You can also test the situation before disclosing. When you're with the person you're thinking about sharing your HIV+ status with, you might want to find out what your partner knows and thinks about HIV. For example, you can say that you watched a TV show about people living with HIV. The person's reaction can help you decide whether it would be helpful and safe to disclose.

Thinking about these questions can help you plan the best time and place to share:

- What do you want to get out of telling someone?
- How will it help you?
- Do you feel pressured to tell?
- Are there possible negative outcomes?
- What can you do if these bad things happen?

Once you decide to go ahead, make a plan for after you tell as well. Self-care is an important part of disclosing. Think about what will make you feel safe and good.



Disclosing is brave. It can also be tiring. You don't have to answer all the questions people might ask. It's a good idea to give them a written resource, such as a brochure with basic information about HIV. You can also refer them to an HIV organization or a trusted, reliable up-to-date website such as www.catie.ca.

When you tell people, they might be surprised, shocked, confused, and even angry you didn't tell them earlier. You are not responsible for how they feel—it's your news to share when you decide to.

Know that they will probably want to talk to someone else about such big news. To protect your confidentiality, you can suggest they talk to a health professional or HIV support worker that you trust. You can also say that you want to be asked for permission before they tell anyone else. Suggesting ways that they can get information and support can help prevent a situation where your privacy is violated.

**It's your news to
share when you
decide to.**

HIV DISCLOSURE

and the law

You don't have to tell everyone that you have HIV, but if you're thinking about having sex, it's a good idea to know what the law says about telling your partner(s). In Canada, people with HIV can be charged with a serious criminal offence if they don't tell their partners their HIV+ status before having sex. If found guilty, people can go to jail—even if they *didn't* transmit HIV to anyone else.

You must tell partners that you have HIV before having sex, according to the law.

Using a condom does not necessarily mean you are not legally required to disclose, nor does having a low or undetectable viral load.

The only time you are not legally required to disclose before sex is when you meet two conditions at the same time: you use condoms AND your viral load is below 1,500 copies/mL.

Keep in mind that posting your HIV+ status on social media or a website and assuming your sex partners will find out is not enough. It is not the same as telling a person.

If you are charged with HIV non-disclosure, in order to defend yourself you will have to show that you did disclose before sex, or that the risk level was so low that you weren't legally required to disclose. These things can be difficult to prove. Your medical records may be accessed to find out what your viral load was at the time.

The legal obligation to disclose applies to all sexual relationships. It is important to know your rights and responsibilities so that you can make informed decisions.

If you want legal advice for a personal situation, speak to a lawyer. A local HIV organization or the Canadian HIV/AIDS Legal Network may be able to refer you to free or low-cost legal support services.

SOCIAL MEDIA

For people who want to go public with their HIV+ status, social media is an easy way to share the news. But for those who want to keep their status a secret or share it with just a few others, social media use requires care.

The privacy settings of social networks can be complicated and change often. Learn how to set strong privacy settings, then regularly check them.

Here are some questions to ask yourself before posting or sharing a message, photo, or video:

- Why do you want to share it?
- Who are you sharing it with?
- What might happen to it?
- Who might see it?

Consider how you would feel if it were shown to other people. Could it hurt you now or in the future?

Once messages or images are out there, you don't know who could end up seeing them. People who see the information can save it by taking a photo or screenshot, and companies save backup copies of content that you remove.

Remember that when you share information (such as your HiV+ status) online, it's permanently out there—even if you delete it.

SAFETY PLANNING

It's normal to have worries about disclosure, because you can't be certain what will happen.

Some people fear rejection. Some people also fear violence and abuse. Even if you haven't experienced abuse, it's a good idea to develop a safety plan.

Support workers at an HIV organization or clinic can help you. You may also want to talk with workers at an anti-violence centre. There are also online resources to help you think about your safety, including safety plans specifically for teenagers and students.

HIV is never an excuse for threats, intimidation, or violence. Someone may try to control you by making you feel bad about having HIV. If this happens to you, know that there are support workers you can talk to. You deserve to live with dignity.

Here are some safety questions to consider:

- Who can be with you when you disclose? Or who can you share your disclosure plan with so they can check in with you afterwards?
- Where is a safe place to disclose? Do you want to do it at home or in a public place, such as a park?
- How will you get out—what doors, windows, elevators, or stairways will you use?
- Where will you go if things go badly—a friend's home or a transition house?
- Where will you keep your medications, wallet, money, phone, and keys so you can leave quickly?
- Is there anywhere you can leave an overnight bag to pick up when you need it?



**You deserve to live
with dignity.**

WHERE TO GET SUPPORT

BRITISH COLUMBIA

Positive Women's Network supports women with HIV and the families and service communities supporting them.
1-866-692-3001 (toll-free in BC) | www.pwn.bc.ca

BC Women's Hospital + Health Centre provides health care for women and families with HIV.
1-888-711-3030 (toll-free in BC) | www.bcwomens.ca

YouthCO seeks to empower young people and reduce the impact that HIV and hepatitis C have on them.
604-688-1441 | www.youthco.org

NATIONALLY

HIV411 is a listing of HIV organizations in Canada.
www.hiv411.ca

CATIE is Canada's source for HIV and hepatitis C information.
1-800-263-1638 | www.catie.ca

The Canadian HIV/AIDS Legal Network promotes the human rights of people living with HIV.
1-416-595-1666 | www.aidslaw.ca

Disclosure occurs when you share important and private news with someone.

HIV disclosure is more than a one-time conversation.

It's an ongoing process.

