



HIV disclosure

Figuring out how to tell
**ROMANTIC & SEXUAL
PARTNERS**

This booklet is intended to support women living with HIV who are thinking about whether they want to tell their 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)

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



An agency of the Provincial Health Services Authority



Canada's source for
HIV and hepatitis C
information

FIRST STEPS

Learning you have HIV certainly changes things.

It affects how you look after your health and relationships. Learning how to care for yourself is the first step. For many women, figuring out disclosure is next.

Disclosure occurs when you share important and private news with someone. HIV disclosure is when you tell people you have HIV. Women who have been living with HIV for years say that planning and practice can help make disclosure go more smoothly. But disclosure of HIV to romantic and sexual partners remains one of the biggest challenges about living with HIV.

THINKING about disclosure

You don't have to tell everyone in your life. Your coworkers, employer, landlord, neighbours, service providers, and so on don't need to know you have HIV. If you are thinking about sharing your HIV+ status, ask yourself why you want to do it and what you want to get out of it. Thinking about these questions can help you make the best decision for yourself:

- What could be good about telling?
- What could be bad?
- What could happen after you disclose?

Women who are dating sometimes want to disclose early on, even on the first date, so they know right away if someone doesn't want to deal with HIV. Other women wait before saying anything.

Many women describe the peace of mind that can come with disclosure. They feel more freedom from fear and stress. Being able to talk honestly about their health and get day-to-day support can be a relief. Very close relationships involve sharing, vulnerability, and listening. Sometimes women find that disclosure leads

to more open discussions and stronger intimacy. It also offers chances to talk about the health of each person and plan for the future.

Some women say they fear being rejected or having their partner leave them. They may be concerned about losing their kids, money, or housing. Some worry about emotional or physical abuse. Women in small communities worry about word getting out. This can be a concern if you live in a rural area or within a distinct population in a city. Women who have migrated and have tight-knit links to family and community in other parts of Canada or in their home country may have the same concerns.

When making decisions about disclosure, connecting with an HIV organization or trusted health care worker is a great idea.

It is important that they are skilled in supporting people through the process of disclosure. You can also get help figuring out other sources of support—perhaps an elder, long-term friend, spiritual advisor, or someone else you feel safe with.

SEXUALITY

after HIV diagnosis

When you find out you have HIV, your feelings about sex might change, even if only for a while.

You may feel a sense of loss, wonder how you will tell people, or feel frustrated that you have to teach your partners about HIV and safer sex. You may worry about how a partner will see you as a woman with HIV. You may feel that HIV is a big deal to talk about.

Many women go through this. In a study in the United Kingdom, 82% of women with HIV had concerns about sex after diagnosis. Their concerns included disclosure, condom use, and the possibility of infecting a partner.

Women respond to an HIV diagnosis in different ways. Some decide not to have sex, some choose to wait until they've learned more about HIV, and some want to carry on as usual. These are all normal responses.

People living with HIV can have healthy sex lives.

There are ways to make sex safer and prevent HIV transmission. One way is to use barriers, such as condoms, which also protect against other sexually transmitted infections. Another way is to consistently take your HIV medication, which lowers the amount of HIV in your body—having an “undetectable” viral load (an amount of HIV in the blood that is so low it cannot be detected by available monitoring tests) significantly reduces the chance of passing on the virus.

A newer option is pre-exposure prophylaxis (PrEP), where the partner without HIV is prescribed HIV medication, before having sex, to prevent transmission. Talk to your health care provider about finding tools that work for you.

When you choose to engage in sexual relationships, take some time to think about how and when you’ll disclose to partners. Worrying about passing on HIV to someone can be stressful. For some women, telling partners brings relief and helps reduce their anxiety.

HIV DISCLOSURE

and the law

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.

Take care when using social media. Posting your HIV+ status on social media or a website and assuming your sex partners will find out is not enough. It isn't the same as telling a person.

If you decide to share your HIV+ status using social media, keep in mind that the information will be permanently out there, even if you delete it. People who see the information can save it by taking a photo or screenshot, and companies save backup copies of content that you remove.

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.

This 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.

DISCLOSURE

planning

Disclosing to a partner can be difficult. Preparation can make the process a bit easier. Making a plan for yourself, instead of sharing your status unexpectedly under stress, can increase your confidence and lead to better results. Having emotional support is an important part of disclosure. Think about who can support you before, during, and after the process. This might be a friend, family member, or support worker at an HIV organization.

How can you test the situation beforehand?

When thinking about sharing your HIV+ status, you might try to find out what your partner knows and thinks about HIV beforehand. For example, you can say that you watched a TV show about people living with HIV. You might even mention that there are long-term relationships where one person has HIV and the other person does not. Your partner's reaction can help you decide whether it would be helpful and safe to disclose. It may also be an opportunity to think about whether you want to continue the relationship.

What will you say?

You can do a few things to feel as safe, comfortable, and good as possible when you disclose. Try practising your “disclosure speech” beforehand with someone you trust. You can write out what you want to say if you’re worried about forgetting anything.

You may also find it helpful to have information on HIV, such as the latest information on treatment and transmission risks. HIV care and treatment have advanced significantly, and many people may not know about these developments. Understanding this information can provide you with reassurance before and during disclosure.

Think about the kinds of things you’re willing to share. What kinds of questions will you answer? If your partner asks how you got HIV, how do you want to respond? Also, be clear about how you want your partner to handle your privacy. But remember that once people have that information, you cannot control what they do with it.



Where and when will you disclose?

Think about where you want to disclose. What location is secure for you? Do you feel safer in a public location such as a park, or do you feel more comfortable at home? Do you want complete privacy? Do you want to disclose in front of a doctor or a support worker from an HIV organization? Do you want a friend or family member close by so you can call on them?

Another thing is timing. When do you feel at your best? When would be the best time for your partner? Consider what else is going on, and whether you could be interrupted when you're talking. Try to choose a quiet time when you and your partner will have time for discussion and questions. If you have kids, think about where the best place is for them to be.

Pick a time when you won't be influenced by sex, drugs, or alcohol. Sexual arousal and drug use affect the way you think and your sense of boundaries. The influence of drugs and alcohol in particular may lead you to make decisions you wouldn't usually make.

Do you want proof of disclosure?

Because of the law on HIV non-disclosure, sometimes women want proof that they disclosed to a sex partner. Here are some ways you can do this:

- You can ask a trusted person to be with you as a witness. Often a support worker from a local HIV organization can do this.
- You can ask your partner to sign a piece of paper that says you have explained that you have HIV. Positive Women's Network has developed a sample disclosure statement. Visit www.pwn.ca to access this and other disclosure resources.
- You can follow up a conversation with an email so you have a record. Print out the email and your partner's response for safe keeping.
- You can take your partner with you to the doctor to disclose there. Your partner can ask any questions about HIV that may come up. This visit will become part of your medical record.

What kind of HIV information will you provide?

Your partner might want information on transmission, the disease, or what life could be like for you. It's a good idea to have written material on the basics of HIV, such as a brochure, that you can give to your partner to take away and look at later. Your partner can also get information from your doctor (with your permission), a worker at an HIV organization, or even a reliable website, such as www.catie.ca. Ask staff at an HIV organization for suggestions. If you're in a relationship when you find out you have HIV, your sex partner should be tested for it.

Who will you talk to after?

Have someone you can check in with after you've told your partner—maybe a friend or a support worker at an HIV organization. It can be helpful to talk about what happened and how it made you feel. This is also a time to take pride in what you've done—telling someone you have HIV takes a lot of courage.

SAFETY

planning

It's normal to have worries about disclosure. Think about what you want in place before, during, and after you tell. If you feel that your safety might be threatened, talk with someone that you trust. It can be a good idea to develop a safety plan, even if you haven't experienced abuse from your partner. Support workers at an HIV organization or clinic can help you. You may also want to talk with workers at a women's anti-violence centre.

HIV is never an excuse for threats, intimidation, or violence. Your partner might try to make you feel bad about having HIV. If you're in a relationship and this happens, know that there are support workers you can talk to.

You deserve to live with dignity.



Here are some questions to think about as you plan how to disclose:

- Who can be with you when you tell? Or who can you share your disclosure plan with so they can check in with you before, during, and afterward?
- If you have children, is there someone you trust that you can leave them with? Do you think a safety plan specifically for your children would be helpful?
- Where is a safe place to disclose? Which room is safest and can be exited most easily?
- Where will you go if the disclosure doesn't go well? To a friend's or family member's home, a transition house, or another place?
- How will you get away? What doors, windows, elevators, or stairways will you use?
- Where will you keep your medications, wallet, money, phone, and keys in case you need to leave quickly?
- Is there anywhere you can leave an overnight bag to pick up in case you need it?

WHEN SEX is not a choice

Sometimes sex is not a choice. A partner can force sex in many ways, including physical strength, verbal abuse, threats, and blackmail. No one should force you to have sex—it doesn't matter if you are dating or married, or if your partner gives you money or pays for things. If this happens to you, know that it is never your fault.

Relationships are complex, especially for women. Sometimes you cannot easily leave a violent relationship. In these cases, disclosure can be very tricky. You may feel you have no options.

Here are some ways that women try to protect themselves:

- Take HIV medicine as recommended by your doctor to keep your viral load low or undetectable.
- Suggest the use of barriers, such as condoms, whenever possible. Maybe you can tell your partner that you need birth control and that condoms are easy to use. Maybe you can suggest trying internal condoms (“female condoms”), which can be inserted in the vagina or anus up to six hours before sex. Condoms are free at many



health units and HIV organizations.

- Suggest the use of oral dams (small pieces of latex), which can prevent sexually transmitted infections during oral sex. Some stores and health units have them. You can also make one by cutting an unlubricated or flavoured condom.
- Use water-based lubricant, which helps prevent friction and small rips in the vagina and anus. It also makes it less likely that a condom will break.
- Properly clean sex toys and try not to share them.
- Remember, penetrative sex is not the only option. You can also rub your partner with your hands or other parts of your body or engage in mutual masturbation. There's also oral sex, where the chance of transmitting HIV is lower (but you may be at risk of other sexually transmitted infections).

You can think about these ideas and decide what may or may not work for you. You know best how to keep yourself safe—remember to always have your safety plan in your mind and be ready to act on it.

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 comprehensive health care for women and families with HIV.
1-888-711-3030 (toll-free in BC) | www.bcwomens.ca

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.

