HIV disclosure

Figuring out how to tell ROMANTIC & SEXUAL PARTNERS

This guide is intended to support women with HIV in disclosing to romantic or sex partners.

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FIGURING OUT what's next

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. Women who have been living with HIV for years say that planning and practice can help make things 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 a person doesn't want to deal with HIV. Other women wait before saying anything.

Women have described 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.

Women have also said they fear being rejected or their partner leaving 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.

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

Having HIV doesn't mean you have to give up sex. Safer sex and HIV medication can protect you and your partner from worries about transmission (passing on HIV).

Women respond to an HIV diagnosis in different ways.

You may decide not to have sex for a while until you've sorted through learning about HIV, or you may want to carry on as usual.

Whenever you choose to engage in sexual relationships, take some time to think about how and when you'll disclose to partners.

Worrying about giving HIV to a sexual partner can be stressful. You can reduce your stress by telling your partner that you have HIV and planning for safer sex. This can bring relief and make you feel like a weight has been lifted.

HIV DISCLOSURE and the law

In Canada, people with HIV can be charged with a serious criminal offence if they didn't tell their partners their HIV status before having sex. If found guilty, people can go to jail. This is the case even if their partner doesn't get HIV.

Under the criminal law, you have a "legal duty" to disclose your status if there is what the courts call "a realistic possibility of transmission." What exactly this means can be hard to understand.

Generally it means that if you engage in any sexual act that has more than a negligible risk of HIV transmission, a court could find that legally you should have disclosed to your partner. Note that using a condom does not necessarily mean you do not have a legal obligation to disclose, nor does having a low or undetectable viral load.

The only time you can be certain that there is no legal obligation to disclose before sex is when you use condoms AND your viral load is below 1,500 copies/mL.

Take care when using social media. It's not enough to post your HIV status on a social media site and assume your sex partners will find out because it's online. It isn't the same as telling a person you are going to have sex with. 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.

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 was so low that there was no legal obligation to disclose. These things can be difficult to prove. Your medical records can be used to show 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.

This resource provides legal information. If you want legal advice for a personal situation, speak to a lawyer. A local HIV organization may be able to refer you to free or low-cost services.

DISCLOSURE planning

Disclosing to a partner can be difficult. With some planning, you may find the process a bit easier. Making a plan for yourself, instead of spilling your status under stress, can increase your confidence and lead to better results.

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. This could be a friend, family member, or support person at an HIV organization. You can write out what you want to say if you're worried about forgetting anything.

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?

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 want to be at home? Do you want complete privacy, or do you want a friend or family member close by that you can call on?

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.

Pick a time when you won't be influenced by sex, drugs, or alcohol. Sexual arousal and drug use affect people's choices physically and mentally. They can impact your ways of thinking and your sense of boundaries.

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 have your partner to sign a piece of paper that says you have explained that you have HIV. Positive Women's Network can provide you with a sample document.
- You can tell your partner by email so you have a record that you did. 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 well-written website. 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. **It's 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 your safety might be threatened, talk with someone. 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 may try to make you feel bad about having HIV. If you're in a relationship where 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 afterwards?
- 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? Is it a friend 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 purse, 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?

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.

On the next page are some ways that women try to protect themselves. You can think about them 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.

- Take HIV medicine as recommended by your doctor to keep your viral load low.
- Suggest the use of condoms whenever possible. Maybe you can try telling your partner that you need birth control and that condoms are easy to use. Maybe you can suggest trying condoms worn internally (the "female condom"), which can be put into the vagina up to six hours before sex. Condoms are free at many health units and HIV organizations.
- Use water-based lubricant. Lube prevents friction, so it helps prevent small rips and cuts in the vagina and anus. It also makes it less likely that a condom will break.
- Avoid sharing sex toys.
- Offer to rub your partner using your hands or other parts of your body, instead of having sexual intercourse.
- Offer to perform oral sex on your partner, instead of having sexual intercourse.

SUPPORT
in British Columbia

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

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

Positive Living BC empowers people with HIV through mutual support and collective action.
1-800-994-2437 (toll-free) | www.positivelivingbc.org

Women Against Violence Against Women Rape Crisis Centre (WAVAW) supports all women who have experienced any form of sexualized violence.
24-hour line: 1-877-392-7583 (toll-free)
www.wavaw.ca

HIV organizations across Canada can be located through **www.hiv411.ca**

INFORMATION

Stories about disclosure

HIV disclosure postscript
www.pwn.bc.ca/2012/03/disclosure_postscript

Valentine's Day for women living with HIV
www.thebody.com/content/73844/valentines-day-for-women-living-with-hiv--finding-.html

Safety planning

www.endingviolence.org/need-help/safety-planning/

www.thewomenscentre.org/docs/SafetyPlanVictimsDomesticViolence.pdf

Studies on disclosure

Sex and relationships for HIV positive women since HAART: A quantitative study
www.sti.bmj.com/content/81/4/333.full

Strategies and outcomes of HIV status disclosure in HIV-positive young women with abuse histories
www.ncbi.nlm.nih.gov/pmc/articles/PMC3595953/

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.