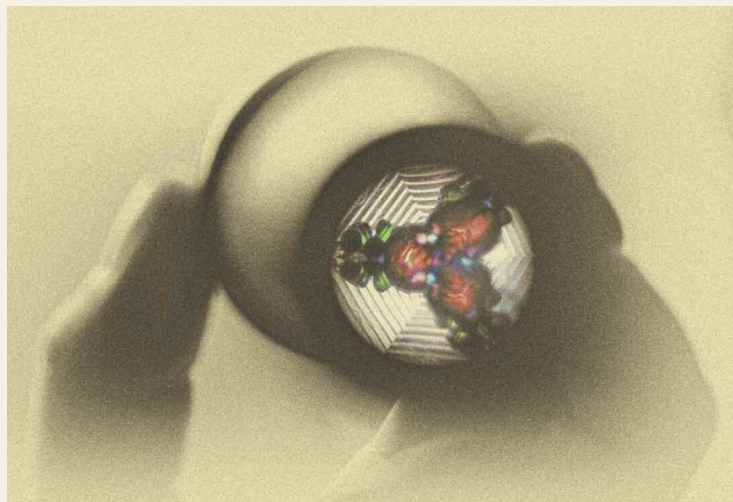




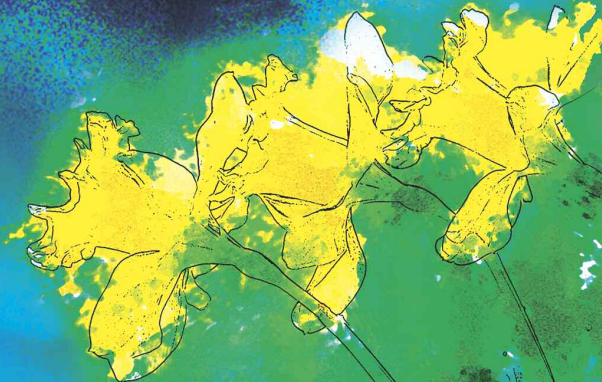
Your support for a healthy future with HIV.



Funding provided by the **Provincial Health Services Authority**

Disclosure

Telling someone you are living with HIV





Introduction

Knowing how to talk to others about our HIV status is important. Our health information is personal and, in most situations, remains private unless we choose to talk about it. For people living with HIV (PLHIV), this choice can be complex. Being open about living with HIV helps us get the care and support we need. However, the idea of someone finding out about our HIV status can also be scary or stressful.

Talking to others about your HIV status will be an on-going process throughout life. This process of telling someone you are positive is often referred to as “disclosure” or “disclosing” your HIV status. The purpose of this guide is to help PLHIV with this decision, whether they are newly diagnosed or have been living with HIV for years. It also provides some useful tools and resources for those that choose to tell others about their HIV status.

This guide is based on the experiences of PLHIV and has three sections:

- **Page 3 > BENEFITS & RISKS OF DISCLOSURE—**
Why disclose? Who needs to know? What could happen?
- **Page 9 > PLANNING FOR DISCLOSURE—**
Am I ready? What do I say? When is a good time?
- **Page 15 > PROVINCIAL RESOURCES—**
What else should I know? Who can help?

Disclosure is different for everyone. How you feel about it can change over time and will depend on many factors. Being in control of the decision to share your HIV status might be challenging, but it is also an important part of taking care of yourself. For some people, that might mean keeping their personal health information private. While for others, being open about being HIV-positive is part of living a healthy lifestyle. Either way, making that decision from a place of self-acceptance is vital to our wellness as PLHIV.

WHY DISCLOSE? BENEFITS & RISKS OF DISCLOSURE

In most cases, disclosing your HIV status is your choice. It is a very personal decision that can be stressful, but also liberating. To help you decide, you may want to start by asking yourself some questions:

- ≡ **Who do I want to tell? Why do I want them to know?**
- ≡ **How will disclosing affect me? How will it affect the people I tell?**
- ≡ **Am I ready to share? Do I have the support I need?**



Who do I have to tell?

*In 2012 the Supreme Court of Canada decided that an HIV-positive person has a **legal duty** to disclose their HIV status to a sexual partner before having any sex that poses a “realistic possibility” of HIV transmission. The Court decided that vaginal sex does not pose a “realistic possibility” of HIV transmission when **(1)** a condom is used AND **(2)** the person living with HIV has a low (including undetectable) viral load.*

*Therefore, in this particular circumstance, HIV disclosure is not legally required. However, this also means that there is a legal duty to disclose before **(A)** having vaginal or anal sex without a condom OR **(B)** having vaginal or anal sex if viral load is higher than 1,500 copies/ml, even if you use a condom.*

Based on the Court's decision, it is unclear how “realistic possibility” of HIV transmission would be defined in other sexual contexts, such as oral sex or anal sex with a condom and low viral load. The law about HIV and disclosure—including what terms like “realistic possibility” or “low or un-detectable viral load” mean—is complex and open to ongoing interpretation by the courts.

For more information about the criminal law and HIV disclosure, talk to your local HIV organization or public health nurse. See pages 15/16 for resources.

PLHIV often tell others about their HIV status when doing so seems worthwhile. Maybe you are tired of keeping it a secret or desire to be honest with someone you care about.

Potential **benefits** of disclosure include:

- Peace of mind & relief from stress
- Better emotional support & care
- Strengthened relationships
- More opportunities to meet other PLHIV
- Taking control over your own disclosure
- Feeling empowered & having more choices
- Builds confidence & self-esteem
- Facilitates safer sex or drug use
- Educates & inspires others
- Challenges societal stigma

Some PLHIV find it difficult to talk about their HIV status because of feelings of guilt or shame. Such feelings are a normal response to HIV stigma and discrimination, but they can also have a negative effect on our well-being. Stigma of PLHIV is common in many communities and can lead to negative judgements, misinformation, and rejection. Coming to terms with feelings of guilt and shame helps build resilience and makes it easier to face rejection and

protect yourself from stigma. It can also be a political act; when people learn to live openly and confidently with HIV, it challenges assumptions and fights against societal stigma.

“Disclosure facilitates surrounding yourself with caring, non-judgemental people and weeding out those who aren’t. This is much the same benefit that many LGBT people experience after coming out.”

Many PLHIV experience a sense of freedom following disclosure. However, being nervous or scared about how someone may react is very common.

Potential **risks** of disclosure include:

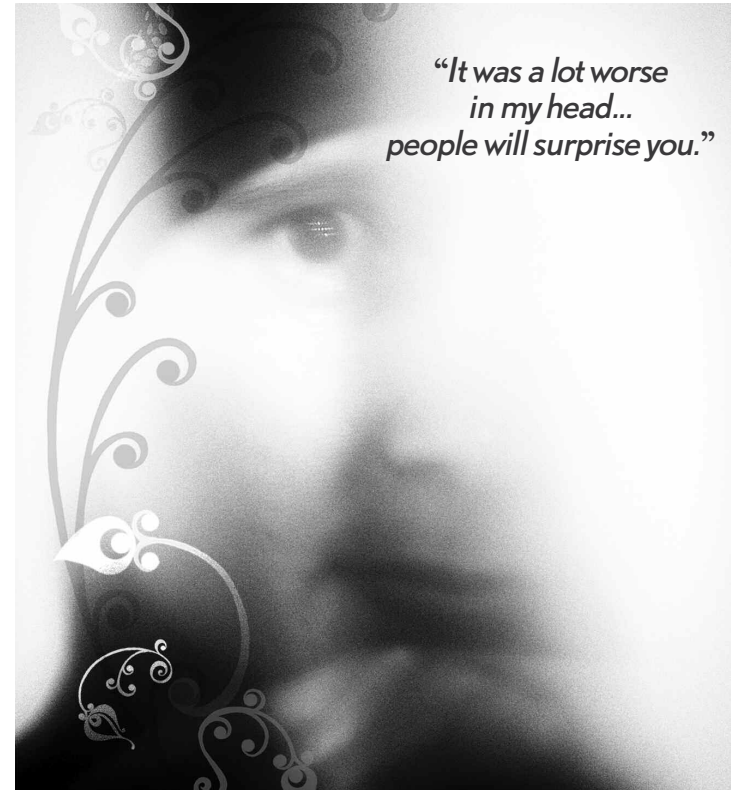
- Negative reactions such as rejection, harassment, or physical violence
- Stigma & discrimination - i.e. loss of home, job, friends, family
- Causing distress to yourself or others
- Needing to educate others about HIV or provide them with emotional support
- Loss of control over your disclosure or being “outed” as HIV-positive

*Cultural differences matter a lot when considering the risks of HIV disclosure. Sharing your status may seem more beneficial if you are part of a community that has some experience with HIV. In some communities, religious views or cultural attitudes about sex, sexuality, and drugs may make it harder to talk about living with HIV. Find **support** where you can. See pages 15/16 for resources.*

Many PLHIV have had their HIV status shared by others without their consent. **Involuntary disclosure** can cause feelings of anxiety, fear, mistrust, and betrayal. Deciding whether to stand up against such a breach of your privacy will depend on a variety of factors, including the support available in your community or if there are legal remedies available. See pages 15/16 for resources.

*Unfortunately, HIV stigma means that PLHIV do experience various forms of **discrimination**. It can be very difficult to challenge such discrimination, even when it is illegal. However, it is important to know that human rights laws in Canada and BC do protect people against discrimination based on disability. For example, it is considered discrimination to refuse to hire or to fire someone because of a disability, including HIV. See pages 15/16 for resources.*

People will react differently to being told about your HIV status. Some people may immediately accept your diagnosis. Others might need more time or information in order to adjust to the news. Just like you, people may need support.



AM I READY? PLANNING FOR DISCLOSURE

PLHIV who have been dealing with the process of disclosure for a long time suggest that it's important to understand ahead of time why you want to disclose and what you expect in return. Then we can decide whether we're ready to face the possible challenges of sharing our HIV status.

There are lots of ways PLHIV can **prepare** for telling others about their HIV status. Consider the following:

- Choose someone you trust and think can be supportive and non-judgemental, especially if you are disclosing for the first time. *Will they be able to cope with their own feelings about your disclosure?*
- Think ahead of time about how the person you're telling may react. *Are you ready for the range of possible responses you're likely to receive from different people?*
- Learn about how HIV impacts your health. *You don't need to be an expert, but will you be able to answer questions about how you're doing?*
- Know where to refer people for information or support. *Are you ready and willing to respond to possible questions or misconceptions about HIV?*

- Select a time and location where you will be comfortable. *Will there be enough privacy? Do you need to be in a safe place with immediate support available?*

“I am going through a hard time right now and could use your support. I was recently diagnosed with HIV.”

How you approach sharing your HIV status will make a difference to how it is received. If you are calm and confident, others will be more likely to match your emotions. When it comes to deciding what to say, it can be hard to strike the right balance between being honest and straightforward and being too blunt. The experiences of PLHIV tell us that being overly direct—such as saying “I have HIV”—can cause others to feel fear or sadness. Instead, a **simple message** that lets others know you are seeking support can bring people closer together.

“I'm HIV-positive and I'm telling you because you are important to me.”

Whatever your personal reasons for disclosure are, it is important to let the person know what you're telling them and why.

Finally, make sure people understand that your health and HIV status is confidential information.

“What I've shared with you is really personal. I told you because I trust you not to tell anyone without my permission.”

Some PLHIV find it helpful to tell two or more people that know one another. This creates a closed circle of support that gives those that have been disclosed to someone to talk to while still respecting your privacy.

There is no best way to disclose your HIV status. What you need to think about when planning for disclosure depends a lot on the context.

*In preparing to disclose your HIV status you may want to **role play** with a friend, support group, or support worker. Write down what you want to say and practice ahead of time to help you feel more calm and confident.*

Dating & Intimate Relationships

Disclosing your HIV status to current or potential sexual partners is complicated, with different personal, practical, and legal considerations depending on the nature of the relationship (i.e. casual or committed). There is no perfect time for revealing your HIV status, but leaving some space between the act of disclosure and negotiating safer sex (or drug use) allows everyone more time to process their feelings and consider their options. This can be especially important when alcohol and drugs are involved, as substance use can impact a person's ability to make informed decisions or consent to sex. Support groups can be a great place to talk to other PLHIV about their strategies for disclosure. See pages 15/16 for resources.

While some people fear being rejected because of their HIV status, others may legitimately fear for their safety or the safety of their children. If you are worried your partner may become violent, consider disclosing in a public setting or in the presence of a friend or health care provider. For more information and resources about staying safe when disclosing your HIV status visit www.pwn.bc.ca.

Friends, Family & Children

Being part of a supportive social network is important to everyone's health, especially when you live with a chronic condition such as HIV. Disclosing to friends and family can be a good way

to get the support we need. However, in some cultures or communities it can be very difficult to talk openly about topics such as HIV, sex, and drug use. If a person was not open-minded or emotionally supportive before finding out about your HIV status, it is unlikely they will suddenly become supportive. Start by telling someone you trust to be able to handle the information and who might be able to help you disclose to others.

Talking to children about HIV is different than talking to adults. For more information about disclosing to children, including age-appropriate resources for families living with HIV, visit www.pwn.bc.ca.

Health Care Providers

Most of the time when PLHIV decide to disclose their HIV status to a doctor, dentist, or other health care provider, it is because they want to receive the best health care possible, not because they have to disclose. For instance, open communication with your doctor and other health care providers reduces the chance of drug interactions or duplications.

Health care providers can be important sources of information and support for PLHIV. For more information about talking to your health care team, visit www.positivelivingbc.org.

Work & School

For many PLHIV, disclosure at work or school may seem unnecessary. However, you may want to disclose to your

employer or school administration if you need special considerations, such as time off due to medical appointments or illness. You may also have to disclose your HIV status in order to receive group benefits. However, your HIV status - like all your medical information - is private and should always be kept confidential.

Be aware of your legal rights, including accommodation for disabilities/health conditions and dealing with discrimination or privacy violations. For more information about your rights at work and school, visit www.aidslaw.ca.

Going Public

Some PLHIV decide to share their stories publicly in order to educate others or act as an advocate or role model. Becoming involved in HIV activism or with a local HIV organization can be very empowering and a good way to connect with other PLHIV. Whether you decide to disclose your status in the media, at a public event, or online (i.e. Facebook, etc.), it's important to think about how much of your story you are ready to share and in which environments.

Talking to others who live openly with HIV in their communities can help you decide when and where to disclose your status publicly. For more information about support groups and other peer support resources in your community, visit www.positivelivingbc.org.

PROVINCIAL RESOURCES SUPPORT SERVICES

▼ Peer Navigator

For information on available support services, including peer/group support, or for a referral to a public health nurse in your area.

navigators@positivelivingbc.org ■ www.positivelivingbc.org

▼ Positive Women's Network

For women living with HIV in BC, and families and service communities supporting them.

www.pwn.bc.ca

[604.692.3000](tel:604.692.3000) ■ [1.866.692.3001](tel:1.866.692.3001) (toll free in BC)

▼ To find a Local HIV organization/service in your community

www.careregistry.ca

▼ GENERAL HUMAN RIGHTS & LEGAL SERVICES

BC Human Rights Coalition

www.bchrcoalition.org

[604.689.8474](tel:604.689.8474) (Lower Mainland) ■ [1.877.689.8474](tel:1.877.689.8474) (BC)

BC Human Rights Tribunal

www.bchrt.bc.ca

[604.775.2000](tel:604.775.2000) (Lower Mainland) ■ [1.888.440.8844](tel:1.888.440.8844) (BC)

DIAL-A-LAW

www.dialalaw.org

[604.687.4680](tel:604.687.4680) (Lower Mainland) ■ [1.800.565.5297](tel:1.800.565.5297) (BC)

PROVINCIAL RESOURCES INFORMATION SERVICES

▼ HIV TRANSMISSION & TREATMENT CATIE

www.catie.ca ■ [1.800.263.1638](tel:1.800.263.1638)

The Body

www.thebody.com

▼ LEGAL RIGHTS & RESPONSIBILITIES

Criminal Law & HIV Disclosure

www.aidslaw.ca/EN/issues/criminal_law.htm

HIV Related Stigma & Discrimination

www.aidslaw.ca/EN/issues/discrimination.htm

Privacy & Involuntary HIV Disclosure

www.aidslaw.ca/EN/issues/privacy.htm

