



HIV disclosure

Figuring out how to tell
CHILDREN & FAMILY

This booklet is designed to support women living with HIV who are thinking about whether they want to share their HIV+ status with their children and other family members.

Created by

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

Reviewed by

The Teresa Group, le Bureau Régional d'Action sida (le BRAS), 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 978-0-9876816-9-0

Printed and nationalized with assistance from CATIE, 2016.

This booklet is available for order in Canada: CATIE Ordering Centre No. ATI-26527 (Aussi disponible en français, ATI- 26527VF)

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

FIRST STEPS

Finding out you have HIV changes how you look after your health and relationships. Like many women, you may spend a lot of time taking care of others, but this is a time to look after yourself. Talking to someone you trust is a good way to explore how you feel. Many women work on accepting their HIV diagnosis before telling other people.

Connecting with an HIV support organization is a great plan. You can talk with a support worker or connect with other women with HIV. You can also get help figuring out other sources of support—maybe an elder, an old friend, spiritual advisor, or someone else who makes you feel safe.

Learning how to take care of yourself is the first step. But for many women, figuring out how to take care of their families is just as important.

CONSIDERING disclosure

You may be wondering whether you're ready to tell your family you have HIV and whether your family is ready to listen.

Disclosure occurs when you share important and private news with someone. HIV disclosure is when you tell people you have HIV. Sometimes women want to tell their families right away. Other times they want to wait. In some cases they might not be sure they'll ever want their family to know. These are all normal responses. The reality of stigma means that people with HIV need to be selective about who and when they tell. HIV disclosure can be an uncertain and stressful process.

Most parents struggle with the idea of telling their children, even if their children are grown up. Especially if they've kept their status private, they might be worried that a child is too young and may not be able to keep a secret. They may want to protect their children and let them "just be kids." Some are afraid of being blamed by their children for

having HIV. If they have older children, women may worry about their physical safety if their children react strongly to the news. Women who rely on their adult children may be concerned about losing financial support or being kicked out of the house.

In many cases, children already know something is going on. They see things and may overhear adult discussions. They might have noticed you're not feeling well or you're seeing the doctor more often. They may have seen your medication and searched the Internet for information. Being left out of the secret can make children feel anxious. They may imagine that you are very sick and going to die, or that you don't trust them enough to tell them what is going on.

By planning how to tell, you can make sure support is available for your children when they hear the news. Even though they might be sad or concerned at first, disclosure can turn out to be rewarding. Your family may understand better that you need to rest, go to the doctor, and take medications to stay healthy.



Here are some reasons women want to disclose:

- They want to reassure their children that they are okay and looking after themselves.
 - They want to feel free to talk about having HIV.
 - They want to encourage open discussion in the family.
 - They want help to understand and navigate the health care system.
 - They want some help around the house.
-

**Building a strong bond
with your children will
help them feel safe and
promote trust.**

LAYING a foundation

You can start laying a foundation for healthy communication and disclosure even before you're ready to tell your family you have HIV.

By having open discussions about different topics, encouraging questions, and listening closely and respectfully to your children, you can help prepare them for difficult conversations in the future. Developing a strong relationship will help your children trust what you say, and it will also encourage them to come to you when they want to talk.

You may want to indirectly introduce the topic of HIV before you disclose. For example, when your children see or hear something about HIV or illness on TV, talk about it. That way, you can slowly teach your children and figure out what they already know.

Remember that you can't pass on HIV to family members through casual contact such as spending time together, hugging, or holding hands. Don't worry that kissing your children is a problem—it's not!

PREPARING to disclose

When you decide you want to disclose, you can start making a plan. Think about what your family knows about HIV and how they talk about and deal with change. There may not be a perfect way to disclose, but you can use this knowledge to plan your approach.

Figure out what kinds of support and information you can refer your family to. Have resources to give them, such as a brochure with basic HIV information, an up-to-date website such as www.catie.ca, or a phone number for a local HIV organization where they can talk to someone. A support worker can help you prepare for disclosure by talking with you about your concerns and helping you create a plan. Some women may choose to disclose with a support worker present who can answer questions or help the family talk. Contact your local HIV organization about getting the support you need.

Some people suggest starting with your immediate family, or the people you trust the most. Remember that you don't have to tell everyone at once. Weeks or months could pass before you tell anyone else, and that's okay.

WHEN TO DO IT

Sometimes parents wonder at what age their children are ready to learn about HIV. The World Health Organization suggests sharing your HIV+ status when your children reach school age.

When you disclose, try to make sure no other big events or disruptions are going on in your children's lives. You may want to wait until school holidays or the summer break, so they can have more time to deal with the news. Try to choose a time when they feel comfortable and there are no interruptions or distractions. You'll want to be as relaxed and calm as possible to help your children feel the same way.

Plan to spend lots of time with your children before and after you disclose. They may need time to think and ask questions, and you need time to answer patiently.

If your child has HIV, a doctor can support you in teaching them about living with HIV and providing age-appropriate information until the child moves to adult care.

WHAT TO SAY

For younger children, you can keep your message simple by explaining that you have a virus and take medicine to stay healthy.

Pre-teens, teenagers, and adults are usually ready to learn more, such as the difference between HIV and AIDS, how HIV is passed, and how to prevent passing the virus.

You can explain that health is a personal and private matter and discuss with your children who they can and cannot tell. It is important to let them know whom they can turn to if they have questions or simply want to talk about HIV. It could be you, a supportive family member who knows you have HIV, the nurse or doctor at an HIV clinic, or a support worker at an HIV organization.

If there are other adults in your family's life that your children can trust and turn to, let your children know they can approach these grownups with any questions about HIV.

When some children hear difficult news, they worry that somehow they're to blame. Let your children know that your health status is not their fault and they haven't done anything wrong. They should also know that they don't need to step into the job of looking after you.

Disclosing your status may lead to a discussion about sex. Some parents worry that talking about sex will encourage children to have sex too early in life. But research has shown that learning about sex empowers children with important knowledge they can use later in life. Children who know about sex are less likely to have sex in their adolescence or before they're ready to than those who don't get sexual health education.

When you tell your children about HIV, they may feel sad or scared at first, but as they learn more those feelings can change for the better. Some older or adult children might worry about you and have expectations about your behaviour. This can be difficult, but remember your health choices are up to you. **You and your family will need time to adjust.**

STARTING a discussion

Parents can respond to children in positive ways that encourage them to open up:

- “What do you think about that?”
- “How are you feeling?”
- “That’s a good question.”
- “Does that answer your question? I can find out more if you’d like.”
- “Thank you for sharing that with me.”

Some answers can make children feel uncomfortable and shut down discussions. Here are some comments that can be discouraging.

- “You don’t need to know that.”
- “You’re too young for that.”
- “We’ll talk about that when you’re older.”
- “Why would you ask me that?”
- “That’s a stupid question.”

ANSWERING questions

Be prepared for questions such as these:

- “How did you get HIV?”
- “Will it go away?”
- “Are you going to die? How long will you live?”
- “Can you give it to someone else? Can I get it?”
- “Who got it first?” (if another parent has HIV)
- “Do I have it? Does anyone else in the family have it?”

Try to make your answers age-appropriate. For example, you can say, “I am not sure how I got it, but we can ask the doctor or nurse at the clinic to explain how people can get HIV” or “We come from a country where a lot of people have HIV.” If both parents have HIV, you can say, “We are not sure who got it first.”

A support worker can help you prepare to answer these questions by role-playing the questions and responses with you.

FAMILY PRIVACY

When you tell your family you have HIV, think about how to protect your privacy.

You don't want your HIV+ status shared with everyone, but making it a family secret may not feel right.

Some parents use the idea of “good secrets” and “bad secrets” when talking to their children. Good secrets keep families healthy and confident. Bad secrets make people feel uncomfortable, unsafe, and worried. Explaining how secrets can be good can help your family understand the importance of keeping them.

You have to be realistic when planning to tell your children you have HIV. Do they understand privacy? Will they be able to keep your HIV+ status a secret? Children of different ages will have different skills. Young children may not understand that your HIV+ status is something you don't want to share, so simply saying you have an illness may be the best bet: “Mommy takes medication to help her feel well.”

Often when you tell people you have HIV, they will want to talk to someone about the news. Connecting your children with adults you trust can help. These can include a close friend, family member, doctor, nurse, or support worker. You can also ask your children to get permission from you before they talk to anyone about your health.

**You deserve to live
with dignity.**

SAFETY PLANNING

It is normal to have worries about disclosure. Think about what you want in place before, during, and after you tell. Even if you haven't experienced abuse from older children or other family members, it can be a good idea to develop a safety plan. Support workers at an HIV organization or a women's anti-violence centre can help you.

Here are some questions to consider:

- Where is a safe location to disclose?
- Who can be with you when you disclose? Or who can you share your disclosure plan with so they can check on you afterwards?
- If you have younger children, is there someone you trust that you can leave them with? Do you think a safety plan specifically for them would be helpful?

HIV is never an excuse for threats or violence. Your family may try to control you by making you feel bad about having HIV. If you're in a situation like this, know that there are support workers you can talk to.

WHAT TO DO

after disclosing

If things were perfect, you would tell people you have HIV, get fantastic support, and feel great. It doesn't always go that way. After disclosing, you might find yourself in a position where you have to answer difficult questions and support others as they try to process the information. Some people might pull away from you. Know that you are not to blame for someone else's reaction.

Keep in mind that disclosure is a process; this is especially important with children. Let your children know that it is okay to keep sharing their thoughts or feelings with you and that they can keep asking you questions.

Have someone you can call and who will check on you after you disclose. This may be a worker at an HIV organization, a friend, or a family member. It is helpful to talk about how you're feeling. Self-care is important too. It can reduce stress, help you balance your life, and strengthen your health and overall well-being. Some ideas for self-care include doing physical activity, making art, socializing, treating yourself, and engaging in spiritual practices. **Remember to take time for yourself.**

WHEN SOMEONE shares your status

Everyone deserves privacy about their HIV status. Unfortunately, there are times when someone may tell another person you have HIV.

This is called involuntary disclosure. It's understandable that this feels awful. Talk to someone you trust about what happened, how it feels, and what you want to do.

Speaking to the person who betrayed your trust won't change what happened, but it might help you feel stronger. If it was someone in a professional position (such as a health care or social service provider), there may be formal steps you can take so that it doesn't happen again.

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.