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Disclosure and HIV

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Image



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Preparing for Disclosure

Disclosure means telling someone that you are living with HIV. Sharing your HIV status can help with the stresses of living with HIV. However, deciding whom to tell and how to tell them can be complicated.

There is no one best way to tell someone. Similarly, there is no sure way to know how those you tell will react or whom they may choose to tell. To prepare, it may help to ask yourself a few questions:

- Whom do I want to tell and why do I want them to know?
- How much am I ready to share? How much are they ready to hear?
- How will disclosing my HIV status affect me and how will it affect the people I tell?

Consider where you want the disclosure to take place. It could be at home, at a friend's house, or in a healthcare setting so that support is readily available. The important thing is that you choose a place that is comfortable for you.

If you cannot meet the people to whom you want to disclose in person, think about the technology with which you are most comfortable (e.g., phone, private chat on social media, virtual meeting). You may also want to consider how secure that technology is – you don't want your social media chat to be made public accidentally.

How Disclosure Affects You and Others

Disclosing your HIV status can be <u>stressful</u>. While you may receive love and support from some of the people you tell, others may not be as accepting. Try to find someone who can support you through this process. If you have not told any family members or close friends yet, turn to your healthcare provider, social worker, counselor, or AIDS service organization (ASO). To find the ASO closest to you in the US, click <u>here</u>. If you would like to connect with other women (cis and trans) in The Well Project community, visit our <u>Connect With Us! page</u>.

Disclosing your HIV status will also have an effect on the people you tell. People will react differently to the news. Some may immediately embrace you and accept your diagnosis. Others may react negatively or need some time to process what you have told them. They may be scared – for you or for themselves – and may need some information in addition to time to adjust.

If you are afraid or embarrassed to tell them yourself, the health department in your area can notify your sexual or needle-sharing partners without even using your name.

Some people, especially sexual partners who may be afraid they have acquired HIV, may react with anger. If you feel threatened or unsafe, it is important that you get safe and stay safe. Call the National Domestic Violence hotline in the US at 800-799-SAFE for support. You can also check our fact sheet about <u>Violence Against Women and HIV</u>.

Just like you, people you tell may need support. Try to leave them hotline numbers, brochures or books about HIV that they can look at later. Give them the addresses of websites that provide information. Also let them know who else is aware of your status, so that they can go to each other for support if they need it.

Who Needs to Know

You do not have to tell everyone that you are living with HIV. It is important that you tell your current and past sexual partners and anyone with whom you have shared <u>drug injection equipment</u>. This way, they can be tested and seek medical attention if needed. If you are afraid or embarrassed to tell them yourself, the health department in your area can notify your sexual or needle-sharing partners without even using your name.

You also need to tell your healthcare providers to ensure you receive appropriate care. Your health care provider may ask questions to determine if you are vulnerable to (at risk for) other diseases, such as <u>hepatitis C</u> or other <u>sexually transmitted infections (STIs or STDs)</u>.

Disclosure to Non-HIV Providers: Which providers do you tell that you're living with HIV; how do you start that conversation; and what is helpful to be prepared for? On this episode of A Girl Like Me LIVE, host Ci Ci Covin explores these questions and more along with The Well Project CAB member Bridgette Picou, a licensed vocational nurse and a woman living with HIV who shares her expertise on both sides of the client-provider relationship.

View other episodes in the <u>A Girl Like Me LIVE series</u>

Disclosure and Relationships

Sharing your HIV status ought to be a personal choice in every case. However, in the case of sexual relationships, it can be a legal requirement. Whether or not a partner acquires HIV, and whether or not prevention methods were used or the person living with HIV meant any harm, they may face criminal charges if a partner accuses them of not disclosing their HIV status in a sexual relationship.

Most states in the US have laws requiring people living with HIV who know their HIV status to disclose before "exposing" someone else to HIV – what counts as "exposure" varies and may not account for current scientific evidence. Penalties vary from state to state. In many states, you can be found guilty of a felony (a serious crime) if a sexual partner brings charges against you for not telling them that you are living with HIV before you had intimate contact with them. Many other countries also have laws on HIV disclosure.

These laws are unfair for many reasons. For one thing, it is difficult to prove disclosure, and many people living with HIV, particularly women, have been taken to court by partners who claim they did not disclose when they say they did. For another, a person may have not intended any harm, and yet their punishment if convicted is much worse than the harm done to the complainant (person bringing the charges).

Nevertheless, the laws exist. The US Centers for Disease Control and Prevention (CDC) provides a map with information on HIV-related state laws, and a leaflet from the Sero Project tells you how to protect yourself, if you are charged with not disclosing your HIV status. See the Additional Resources section for links. For more information, also see our fact sheet on <u>HIV Criminalization and Women</u>.

Serious Relationship

If you are in a serious relationship, telling your partner is one of the first things you will probably think about. Many people turn to their partners for comfort and support. However, some people worry that they will lose their partner's love when they disclose. It is normal to feel nervous, embarrassed, or even fearful of your partner's reaction.

Since you and your partner may have a sexual relationship, it is important to practice <u>safer sex</u>. If you have already had sex without <u>condoms</u>, <u>pre-exposure prophylaxis</u> or <u>treatment-as-prevention</u> methods, it is important to let them know that they may have been exposed to HIV and should get <u>tested</u>.

We also now know, after many years of research and evidence, that a person living with HIV who is taking HIV drugs and is virally suppressed (has an undetectable viral load) is <u>unable to transmit HIV to</u> <u>a sexual partner</u> who is <u>not living with HIV</u>. This is an important fact to keep in mind, and to share with your partner(s). For much more information on this development, see our <u>Undetectable Equals</u> <u>Untransmittable</u> fact sheet.

Disclosing your HIV status can put a strain on the best of relationships. It is important for you to think about when and how to disclose. However, keeping the information to yourself for too long is probably not a good idea. If you find it difficult to decide when and how to tell your partner, it may be helpful to get some professional counseling.

It is important to recognize that some partners react to HIV disclosure with anger and even violence. *This is not your fault.* If you are worried that your partner may become violent, try the following to reduce the likelihood of violence:

- Disclose in a semi-public place like a public park with many people around. Find a place that is private enough to have a conversation, but public enough to get help if you need it. It is important to make sure that you can access a way out of whatever space you choose. This may mean making sure the person learning the information is not blocking the exit.
- Consider disclosing with a third person present, such as a friend or a healthcare provider
- Meet only in public with the person to whom you are disclosing until you feel safe
- If possible, avoid intimate contact without disclosing ahead of time. The chance of <u>violence</u> may be greater if a person feels they were vulnerable to HIV or feels they were lied to.

Important: if you are feeling threatened right now, call 911 or the National Domestic Violence hotline in the US at 800-799-SAFE [1-800-799-7233; or 1-800-787-3224 (TTY)], or text START to 88788. You can also search for a safe space online at <u>Domestic Shelters</u>. If you live outside the US, go to the <u>Hot</u> <u>Peach Pages</u> to find help near you.

Dating

Women who are dating have to face the question of disclosure with each new relationship. Some women prefer to get the issue out into the open immediately. Others prefer to wait and see if the relationship is going to develop beyond casual dating.

Although many people know about <u>safer sex</u> and how HIV is <u>transmitted</u>, fear and <u>stigma</u> are still a reality. Your HIV status will prevent some from wanting to see you, but this is their loss. There are others who will not have any problem with this information.

Who May Not Need to Know

In the US, people with disabilities, including HIV, are protected from job discrimination under the Americans with Disabilities Act (ADA). However, it is important that you think carefully before disclosing

your HIV status at work. You do **not** have to tell your employer that you are living with HIV. If you have not had any HIV-related symptoms or illnesses and are not on medications that are affecting your job performance, there is probably no need to tell.

You do **not** have to tell your employer that you are living with HIV.

If HIV or your medications are interfering with your ability to work, it may be a good idea to privately disclose your status to your boss. You can ask for an adjustment in your schedule or workload so that you can continue to do your job. Because the law considers a person living with HIV to be disabled, your employer must adjust your job ("reasonably accommodate your needs") if you can otherwise perform the most important parts ("essential duties") of the job.

If you are planning to disclose at work for employee or benefits purposes (like reasonable accommodation, insurance, disability, or medical leave), contact an employee benefits counselor or an HIV or legal advocate before disclosing. For more information, see our fact sheet on <u>Understanding</u> <u>Your Rights and Responsibilities in the Workplace in the US</u>.

Whom You May Want to Tell

Women often choose to disclose their status to close friends and family members whom they trust. For many, telling those closest to them provides them with both emotional and practical support.

Some people decide to become more public and use their stories to advocate for others with the government or in the media. Others may disclose for educational purposes to neighbors, community and religious groups, schools, other people living with HIV, or healthcare providers. Many women find a sense of purpose and increased self-esteem by telling their story.

"For the first time, I had experienced stigma but it would not be the last. Stigma had wreaked so much havoc in my life that I could not breathe. Every step I took to piece my life back together, stigma would be waiting. The fear of being alone and unloved was something I could not bear... I would live for years without saying a word. As time went by, I moved into a supportive housing complex with people like me. I began to learn through them, how to really come to terms with my diagnosis. I saw life and laughter and although there were some who lost everything, they were still happy. It became contagious. I wanted that kind of life. However, it would entail the sharing of my story. So one day I did just that at an event where I would share to hundreds of bike riders. For the first time in my life, I felt peace and freedom. I received love, hugs and well wishes from people who were not afraid to touch me. It moved me to continue to share my story until this very day."

- msplusamerica2011, from "Why Even Share?" on A Girl Like Me

You may want to consider how much of your story you are ready to tell. Many people will ask you how you acquired HIV. If you decide not to share that information, have a reply ready such as, "Does it really matter?" or simply state that you are not ready to talk about that.

Disclosing to Children

For parents considering telling their children, it is important to ask yourself why you want to tell them:

- Do they suspect something?
- Are you sick?
- Have you disclosed to other people whom the children know?
- Will they be angry if you kept it a secret?

Children can react to the news of HIV in the family in many different ways. Older kids may be upset that

you kept a secret from them. Younger children may just want to go back to their toys. Partial truths can be helpful when telling children. You may decide only to tell them as much as you think they ought to know at their age. You may also want to consider whom your children could tell about your status.

It is important to remember that kids need support, too. If you can, give them the name of another adult they can talk to, perhaps a family member or friend they can trust. There are several books about disclosure to children. A good place to start is our fact sheet on <u>Talking with Your Children about Your HIV Status or Your Children's Status</u>.

Taking Care of Yourself

There are some good reasons to tell people that you are living with HIV:

- Getting support from family and friends, at the time of diagnosis and in the future
- · Fostering a sense of closeness with friends and loved ones
- Not having to live with the stress of keeping HIV a secret
- Ensuring that you get the most appropriate care and treatment from your healthcare providers
- Feeling empowered from disclosing

However, telling other people that you are living with HIV can also have downsides. It is important to think carefully about whom you tell. Remember that once you disclose, you cannot take it back. ASOs and healthcare clinics can offer resources to guide you through the disclosure process.

In close relationships, studies show that living with a secret, such as HIV, can be more emotionally harmful than the rejection that could result from disclosure. Many women who have kept a secret for a long time feel a sense of relief after telling at least one other person.

Image



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Additional Resources

Select the links below for additional material related to disclosure.

- Disclosure (POZ)
- #PWNCares 3: Disclosure-It's Complicated (Positive Women's Network USA; inclu...
- What It's Like to Tell the Person You're Seeing You Have HIV (Women's Health)
- How to Make Sure Your HIV Status Doesn't Define You in the Workplace (TheBody.c...
- HIV/AIDS and Discrimination (ACLU)
- <u>"Expressive Therapy" Intervention Assists Women Living with HIV (University of ...</u>
- Disclosure, Criminalization, and Stigma for Women Living with HIV (HIVE; includ...
- Burden of HIV Disclosure Laws Falls on Women (Huffington Post)
- Talking About Your HIV Status (HIV.gov)
- Women and the Criminalization of HIV Non-Disclosure (Canadian HIV/AIDS Legal Ne...
- State Laws That Address High-Impact HIV Prevention Efforts (US Centers for Dise...
- <u>Confidentiality and Disclosure (The Center for HIV Law & Policy)</u>
- Privacy, Confidentiality and Disclosure (Lambda Legal)
- Telling Others (US Centers for Disease Control and Prevention)
- Pros and Cons of Disclosing Your HIV Status (aidsmap)
- Telling People You Have Sex with That You Have HIV (aidsmap)
- Disclosure (POZ)
- Telling Others You Have HIV (International Association of Providers of AIDS Car...



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