Disclosure and HIV

Submitted on Aug 20, 2019

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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 and difficult.

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 health care setting so that support is readily available. The important thing is that you choose a place that is comfortable for you.

How Disclosure Affects You and Others

Disclosing your HIV status can be stressful [3]. While you may receive love and support from some of the people you tell, others may not be as accepting. Try to find someone that can support you through this difficult process. If you have not told any family or close friends yet, turn to your health care provider, social worker, counselor, or AIDS service organization (ASO). To find the ASO closest to you in the US, click here [4]. To find services worldwide, visit AIDSmap's e-atlas [5]. If you would like to connect with other women in The Well Project community, visit our page on Getting Connected [6].

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.

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 Violence Against Women and HIV [7].

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 may be important that you tell your current and past sexual partners and anyone with whom you have shared drug injection equipment [8]. 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 health care providers to ensure you receive appropriate care. Your health care provider may ask questions to determine if you are at risk for other diseases, such as hepatitis C [9] or other sexually transmitted infections (STIs or STDs) [10].

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. 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).

But 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, please also see our fact sheet on HIV Criminalization and Women [11].

**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 most likely have a sexual relationship, it is important to practice safer sex [12]. If you have already had sex without condoms [13], pre-exposure prophylaxis [14] or treatment-as-prevention [15] methods, it is important to let them know that they may have been exposed to HIV and should get tested [16]. Keep in mind, and feel free to share with your partner, that after many years of research and evidence we now know that a person living with HIV who is taking HIV drugs and is virally suppressed (has an undetectable viral load) is unable to transmit HIV to a sexual partner [17]. For much more information on this development, see our Undetectable Equals Untransmittable [17] 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. If you are worried that your partner may become violent, try the following to reduce the risk 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 health care 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 risk of violence [7] may be greater if a person feels you knowingly put them at risk or lied to them.

*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)]. You can also search for a safe space online at Domestic Shelters [18]. If you live outside the US, please go to the Hot Peach Pages [19] 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 safer sex [12] and how HIV is transmitted [20], fear and stigma [21] are still a reality. Your HIV status will prevent some from wanting to see you, while others will not be put off by the 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.

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 Understanding Your Rights and Responsibilities in the Workplace in the US [22].

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 health care 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." (from Why Even Share? [23] 12/5/12, msplusamerica2011)

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 moms considering telling their children, it is important to ask yourself why you want to tell them:
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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 Talking with Your Children about Your HIV Status or Your Children's Status [24].

Taking Care of Yourself

There are some good reasons to tell people that you have 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
- Reducing the risk of HIV transmission [20] to others
- Not having to live with the stress [3] of keeping HIV a secret
- Ensuring that you get the most appropriate care and treatment from your health care providers
- Feeling empowered from disclosing

However, telling other people that you have 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 health care 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.

Tags:

- Women and HIV Disclosure [25]
- Women and HIV and Disclosure [26]
- HIV disclosure [27]
- HIV and Disclosure [28]
- disclosing HIV status [29]
- when to disclose HIV status [30]
- when to tell HIV status [31]
- dating HIV [32]
- HIV+ women dating [33]
- HIV dating [34]
- HIV sex [35]
Additional Resources

Select the links below for additional material related to disclosure.

Disclosure (POZ) [36]
What It’s Like to Tell the Person You’re Seeing You Have HIV (Women’s Health) [37]
How to Make Sure Your HIV Status Doesn’t Define You in the Workplace (TheBody) [38]
HIV/AIDS and Discrimination (ACLU) [39]
Telling Others You Are HIV Positive (AIDS InfoNet) [40]
"Expressive Therapy" Intervention Assists Women Living with HIV (UCSF) [41]
Disclosing Your HIV Status (multiple articles; TheBody) [42]
Disclosure, Criminalization, and Stigma for Women Living with HIV (video; HIVE) [43]
Burden of HIV Disclosure Laws Falls on Women (Huffington Post) [44]
Talking About Your HIV Status (HIV.gov) [45]
Women and the Criminalization of HIV Non-Disclosure (Canadian HIV/AIDS Legal Network) [46]
Change Your Perception of What People Think About Your HIV (Be-Resilient.org) [47]
State Laws That Address High-Impact HIV Prevention Efforts (US Centers for Disease Control and Prevention) [48]

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Links
[8] https://www.thewellproject.org/hiv-information/cleaning-works
[10] https://www.thewellproject.org/hiv-information/sexually-transmitted-infections-or-diseases-stis-or-stds
[12] https://www.thewellproject.org/hiv-information/safer-sex
[14] https://www.thewellproject.org/hiv-information/prep-women
[16] https://www.thewellproject.org/hiv-information/hiv-testing
[18] https://www.domesticshelters.org/
[20] https://www.thewellproject.org/hiv-information/hiv-transmission
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[22] https://www.thewellproject.org/hiv-information/understanding-your-rights-and-responsibilities-workplace-us
[23] https://www.thewellproject.org/a-girl-like-me/aglm-blogs/why-even-share
[24] https://www.thewellproject.org/hiv-information/talking-your-children-about-your-hiv-status-or-your-childrens-status
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[38] https://www.thebody.com/article/how-to-make-sure-your-hiv-status-doesnt-define-you-in-the-workplace
[40] http://www.aidsinfonet.org/fact_sheets/view/204