

Disclosure and HIV ^[1]

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Preparing for Disclosure

Disclosure means telling someone that you are living with HIV (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](#) [2]. 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](#) [3]. To find services worldwide, visit [AIDSmap's e-atlas](#) [4]. If you would like to connect with other women in The Well Project community, visit our page on [Getting Connected](#) [5].

Disclosing your HIV status will also have an effect on the people you tell. People will react differently to the news. Your friends and family 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 been infected, 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 and check The Well Project's article about [Violence Against Women and HIV](#) [6].

Just like you, people you tell will 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 (a good government site is at <http://aids.gov/hiv-aids-basics/> [7]). Also let them know who else is aware of your status, so that they can go to each other for support.

Who Needs to Know

You do not have to tell everyone that you are HIV+. However, it is important that you tell your current and past sexual partners and anyone with whom you have shared drug injection equipment. This way they can be tested and seek medical attention if required. 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 how you were infected to determine if are at risk for other diseases, such as [hepatitis C](#) [8] or other [sexually transmitted diseases \(STDs\)](#) [9].

Disclosure and Relationships

In most cases, sharing your HIV status is a personal choice. However, in the case of sexual relationships, it can be a legal requirement. It is best if you disclose your status prior to having sex with anyone.

Not disclosing your HIV status in a sexual relationship can lead to criminal charges whether or not your partner becomes infected with HIV. In most states in the US, the law requires that you disclose your HIV status before knowingly exposing or transmitting HIV to someone else. Penalties vary from state to state. In many states, you can be found guilty of a felony for not telling a sexual partner you are HIV+ before having intimate contact. To find information about disclosing in your state, look at [this list](#) [10] by Lambda Legal.

UNAIDS reports that over 60 countries have laws that that penalize HIV+ people who engage in sex without disclosing their status. Outside the US, click on [this link](#) [11] to AIDSmap's list to find information for your country's laws about disclosure.

Serious Relationship

If you are in a serious relationship, telling your partner is one of the first things you will probably think about. Many 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, you do need to let them know that they may have been exposed to HIV and should get tested [12]. Also, it is now even more important to practice safer sex [13].

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.
- Consider disclosing with a third person present, like a friend or a health care provider
- Meet only in public with that person until you feel safe
- Avoid exposing others to HIV without warning them ahead of time. The risk of violence [6] may be greater if a person feels you knowingly put them at risk or lied to them.

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 and how HIV is transmitted, fear and stigma 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, you should think carefully before disclosing your HIV status at work. You do not have to tell your employer that you are 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 regards an HIV+ person as a disabled person, your employer is required to reasonably accommodate your needs if you are otherwise qualified to perform the 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 article on Understanding Your Rights and Responsibilities in the Workplace in the US [14].

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 HIV+ people, 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." (from "Why Even Share?" [15] 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 became infected. 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:

- Will they be angry if you keep a secret?
- Do they suspect something?
- Are you sick?

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 consider appropriate for their age.

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. Several books are available that deal with the issue of disclosure to children. A good place to start is [Let's Talk...Children, Families and HIV](#) [16]. Also see [The Well Project's Talking with Your Children about Your HIV Status or Your Children's Status](#) [17].

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](#) [18] to others
- Not having to live with the [stress](#) [2] of keeping HIV a secret
- Ensuring that you get the most appropriate care and treatment from your health care providers
- Feeling empowered from disclosing

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.

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.

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Additional Resources

Select the links below for additional material related to disclosure.

[Telling Others You Are HIV Positive \(The AIDS InfoNet\)](#) [30]

[HIV and the Criminal Law: Individual Country Data, Organised by Region \(AIDSmap\)](#) [11]

[To Tell or Not To Tell: Disclosing Your HIV Status \(AIDSMEDES\)](#) [31]

[What It's Like to Tell the Person You're Seeing You Have HIV \(Women's Health\)](#) [32]

[HIV & Your Civil Rights: Know Your Rights in the Workplace \(ACLU\)](#) [33]

[HIV Disclosure to Sex Partners \(Positive Women's Network\)](#) [34]

[Challenges Associated with Disclosure \(aidsmap\)](#) [35]

[HIV Disclosure Acknowledgment Statement \(Sero Positive\)](#) [36]

[Burden of HIV Disclosure Laws Falls on Women \(Huffington Post\)](#) [37]

[Do You Have to Tell? \(AIDS.gov\)](#) [38]

[HIV Criminalization: State Laws Criminalizing Conduct Based on HIV Status \(Lambda Legal\)](#) [10]

[Women and the Criminalization of HIV Non-Disclosure \(Canadian HIV/AIDS Legal Network\)](#) [39]

[What HIV Criminalization Means to Women in the U.S. \(HIV Positive Justice Project\)](#) [40]

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- [HIV Information](#)
- [A Girl Like Me](#)
- [Partners](#)
- [Who We Are](#)
- [Terms](#)
- [Privacy](#)
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Links:

[1] <http://www.thewellproject.org/hiv-information/disclosure-and-hiv>

[2] <http://www.thewellproject.org/hiv-information/stress-management>

[3] <http://directory.poz.com/>

[4] <http://www.aidsmap.com/e-atlas>

[5] <http://www.thewellproject.org/node/178>

[6] <http://www.thewellproject.org/hiv-information/violence-against-women-and-hiv>

[7] <http://aids.gov/hiv-aids-basics/>

[8] <http://www.thewellproject.org/hiv-information/hepatitis-c-hcv>

[9] <http://www.thewellproject.org/hiv-information/sexually-transmitted-diseases-stds>

[10] http://www.lambdalegal.org/sites/default/files/publications/downloads/fs_hiv-criminalization_1.pdf

[11] <http://www.aidsmap.com/law-country>

[12] <http://www.thewellproject.org/hiv-information/hiv-testing>

[13] <http://www.thewellproject.org/hiv-information/safer-sex>

[14] <http://www.thewellproject.org/hiv-information/understanding-your-rights-and-responsibilities-workplace-us>

[15] <http://www.thewellproject.org/a-girl-like-me/aglm-blogs/why-even-share>

[16] <http://www.kidstalkaids.org/program/index.html>

[17] <http://www.thewellproject.org/hiv-information/talking-your-children-about-your-hiv-status-or-your-childrens-status>

- [18] <http://www.thewellproject.org/hiv-information/hiv-transmission>
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- [30] http://www.aidsinonet.org/fact_sheets/view/204
- [31] http://www.aidsmeds.com/articles/Disclosure_7568.shtml
- [32] <http://www.womenshealthmag.com/health/dating-with-hiv>
- [33] https://www.aclu.org/lgbt-rights_hiv-aids/hiv-civil-rights-brknow-your-rights-workplace
- [34] <http://pwn.bc.ca/hiv-community/disclosing-your-hiv-status/hiv-disclosure-to-sex-partners/>
- [35] <http://www.aidsmap.com/page/1442642/>
- [36] http://seroproject.com/wp-content/uploads/2012/10/sero_brochure_colorprint-1-1.pdf
- [37] http://www.huffingtonpost.com/craig-and-marc-kielburger/burden-of-hiv-disclosure_b_229676.html
- [38] <http://aids.gov/hiv-aids-basics/just-diagnosed-with-hiv-aids/talking-about-your-status/do-you-have-to-tell/>
- [39] <http://www.aidslaw.ca/publications/interfaces/downloadFile.php?ref=2009>
- [40] <http://www.heart-intl.net/HEART/040111/WhatHIVCriminalization.pdf>