Living with HIV

Disclosure

Whether you’ve just found out you are HIV positive or you’ve known for a while, at some point you will likely have to decide whether to disclose your HIV status. Choosing who to tell is a personal decision, and you may often find yourself trying to balance honesty with protecting your right to privacy.

As with many issues surrounding HIV, no answers are right for everyone, but here are some general disclosure tips:

- Be selective. In most instances, choosing who to tell is your personal decision. It’s your choice and your right (Note: Some states have laws requiring you to disclose your status before sexual encounters, before sharing injection drugs or equipment or before receiving medical care.)

- Consider the 5 W’s. Who do you need to tell? What do you want to tell them about your HIV infection, and what are you expecting from the people you are disclosing your HIV status to? When should you tell them? Where is the best place to have this conversation? Why are you telling them?

- Easy does it. In most situations, you can take your time to consider who to tell and how to tell them. Consider whether there is a real purpose for disclosing or whether you are simply feeling anxious and want to share your feelings. Telling people indiscriminately may affect your life in ways you haven’t considered.

- No need to apologize. You have a virus. You don’t have anything to apologize for simply because you are HIV positive.

- Keep it simple. Just stick to the facts. You don’t have to tell the story of your life.

- Avoid isolating yourself. If you are unable to tell close friends, family members or other loved ones about your HIV status, allow yourself to draw upon the support and experience of others in the HIV community. Consider joining a support group or an online discussion, such as the POZ.
Forums.

- Go with your gut. There’s no perfect road map for how to disclose. Trust your instinct, not your fears.
- Relax. Millions of others have dealt with this experience and have found their way through it. You will get through it too.

Disclosing to Significant Others
Studies have shown that most people living with HIV disclose their HIV diagnosis to their significant other—their spouse or partner—within a few days of learning their status. It’s important to have someone to listen to your concerns and to offer support. At first, your partner may feel anxiety about his or her own HIV status and may also feel angry and upset if the HIV infection occurred sexually outside the relationship. Disclosing your HIV status can strain your relationship, so it’s important to give some thought as to when and how to disclose. Depending on the nature of your relationship, you might want to consider some professional couples counseling.

If you’ve had condomless sex with an HIV-negative partner, it’s important to alert him or her to the fact that he or she may be at risk and should get tested. Your partner’s test results may impact how you have sex together in the future. HIV-negative partners may consider pre-exposure prophylaxis (PrEP) to prevent acquiring HIV. Six months after you start antiretroviral treatment, if your viral load remains consistently undetectable, you will not transmit HIV.

It’s also important to be aware of the partner-notification laws in your state. Partner notification refers to information conveyed to spouses, sexual partners, needle-sharing partners and others who might be at risk for HIV. Check with your state’s department of health to find out the laws in your area.

Disclosing to Someone You’re Dating
Some people prefer to disclose their status to a potential date or sexual partner immediately, sometimes even before a first date. Others prefer to wait and see whether the relationship develops before disclosing. Despite the fact that most people know about safer sex and how the virus is transmitted, fear and stigma can stir up very strong emotions and your status may deter some people from proceeding further in a relationship with you.

While in most cases, sharing your HIV status is a personal choice, in some states, specific laws actually make it a crime not to disclose your status to a sexual partner. Check with your state’s department of health or get in touch with your local AIDS service organization if you have concerns about your state’s laws regarding HIV disclosure.

General dating and sexual partner disclosure issues to consider:
• Keep what you say as simple and direct as possible.
• Give yourself credit if you have been practicing safer sex with the sexual partner you’re disclosing your status to. You are already behaving responsibly with that person.
• If the person you’re disclosing to reacts negatively, remember that’s only one person. Not everyone is going to react the same way.
• Remember that you should give the person you’re disclosing your status to some time to process the information. Whatever their reaction may be at first, whether negative or positive, be aware that reactions can change in time.

Disclosing to Family and Friends
Your family and friends are likely to be concerned about your future, and disclosing your status to them may lead to even stronger relationships. You may find yourself having to educate them about HIV, but your family and friends can be a good source of support depending on the nature of your relationship with them.

While most people will respect that what you have shared was told in confidence, you need to be aware that your HIV status may end up becoming the subject of gossip among other family members, friends and acquaintances. If you have a tight-knit family or social group or you live in a small community or a rural area, confidentiality may be harder to maintain.

General tips to consider when disclosing to family and friends:
• Keep what you say as simple and as direct as possible.
• Tell them you have something important to tell them.
• Offer to answer any questions they may have.
• Let them know they don’t have to worry about your health.
• If you have particular HIV-related issues or concerns that you’re trying to sort out, let them know.
• Request that what you’re going to discuss be kept in confidence.
• Ask them to be there for you.
• Tell them how much they mean to you and how much you love them.
• Don’t be afraid to show your feelings and to express how important this issue is for you.
Disclosing to Employers

If you’re applying for a job, prospective employers do not have the right to inquire about your health or whether you have a disability prior to a conditional job offer per the Americans with Disabilities Act (ADA). However, they may legally inquire whether you are aware of any physical limitation that might interfere with your ability to perform the essential functions of the job.

If your HIV is interfering with your work to the extent that it might place your employment in jeopardy, you might consider disclosing to your supervisor. Or you could provide a letter from your doctor that states that you suffer from a “chronic condition” without specifically disclosing your HIV status. Your employer is required to reasonably accommodate your needs if you are otherwise qualified to perform the essential duties of your job. Knowing your company’s policies will help you to determine whether or not you need to disclose your HIV status. Hopefully, you will not need to turn to legal recourse to protect your rights. However, if that becomes necessary, there are laws to protect you.

General tips to consider with regard to employers:

- Unless your HIV status affects your current ability to perform your job, you are under no legal obligation to disclose your status to your employer.
- Consider very carefully what your purpose is for disclosing your status to your employer.
- If you do disclose, tell the person you want to speak with that you have something important to discuss.
- Stress that you’re requesting that what you’re going to discuss be kept in strict confidence.
- Be mindful that a request for confidentially is not an absolute guarantee that it will be respected.
- Some employers will rise to the occasion and be supportive. Others may be disappointing in their responses, and you will understandably feel hurt and angry.
- Keep what you say as simple and direct as possible.
- Let him or her know that you are receiving appropriate health care.
- If you may need a particular accommodation, such as occasional time off for a medical appointment, mention it.
- Tell your boss that you will make every effort to ensure that your work is properly covered and that you’re committed to doing your job reliably and well.
- Medical-related employer decisions about HIV (or any other disability) must be based on facts
about you, not simply an employer’s opinions about HIV.

Disclosing to Coworkers
Think carefully before disclosing your status to your coworkers—even those you consider to be good friends. What you’ve disclosed in confidence could end up becoming the subject of gossip in the workplace, with unforeseen and possibly serious consequences.

General tips to consider with regard to the workplace:

- Tell the person you have something important to tell him or her.
- Stress that you are requesting that what you’re going to discuss be kept in the strictest confidence.
- Keep what you say as simple and direct as possible.
- Tell the person why you want him or her to know.
- Let him or her know that you are sorting out issues related to your HIV status and his or her support is important to you.

Disclosing to Medical and Other Health Care Providers
All medical providers are supposed to use “universal precautions,” which means special procedures to protect themselves against any transmissible infection, not just HIV. Regardless, it’s helpful to inform your health care provider about your HIV status in order for him or her to give you the best possible care. Knowing that you are HIV positive can help your doctor identify certain health problems and ensure that he or she doesn’t prescribe any medications that could interact with your HIV meds. Also, some states have laws requiring disclosure prior to receiving medical care. Be sure to check with your state’s department of health or get in touch with your local AIDS service organization to find out about the laws where you live.

Your medical information (including your HIV status) is protected by the Health Insurance Portability and Accountability Act’s (HIPAA) Privacy Rule and cannot be released without your permission except in circumstances where not disclosing the information could result in harm to another person.

Health care providers cannot deny their services to someone simply because the person is HIV positive. If a doctor or other health care provider is uncomfortable treating someone with HIV and makes that known to you in any way, be aware that you have legal recourse in such situations.

General tips to consider with regard to medical and health care providers:
• All health care providers are bound by confidentiality laws.
• By telling a doctor, a nurse or other health care providers, you do give up a degree of privacy, but that does not release them from adhering to laws regarding confidentiality.
• Your status should be treated as privileged information. If, for instance, a doctor’s employee discusses details with you that another patient might overhear, politely request that such conversations be discussed in private.
• A hospital or other health care provider may share HIV information with a patient’s insurance company if the information is necessary to pay for medical care.
• If you’re in doubt about whether you have to reveal your status for either medical or insurance purposes or indeed legally for any other reason, call your local department of health or AIDS service organization. In some instances you may learn that it’s necessary to disclose in order to have access to medical resources and services.

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