Sharing your HIV-positive status

For many people living with HIV, particularly when they have just been diagnosed, whether and how to share their status with other people can be a big concern.

Sharing the news of your status (sometimes called disclosure) with your partner, a close friend or family member and talking about your feelings can be really helpful, and your friends and family may be a good source of support. However, it is up to you to decide who you tell and you should never feel pressured into doing this.

Unfortunately, in many communities, there is stigma attached to HIV, and it may be that some of the people you know do not really understand what it means to be living with HIV. They may not understand how it is passed on, be afraid, or judgmental. This means you may get some negative reactions.

Many people find it helpful to talk to a healthcare professional, or peer support group, before sharing their status with loved ones.
Who should I tell?

It’s up to you to decide who you tell. You may decide you want to be completely open about your HIV status, or you may decide to only tell a small number of people close to you – it’s your choice.

You might find it helpful to tell some people, especially those you trust, and you know care for you. You could start with a close friend or family member. Whether you’ve just been diagnosed or have been living with HIV for a while, talking about your status can help you get the emotional and practical support you need.

Sharing your HIV status should always be your decision. You should never feel pressured into it. Ultimately, your HIV status is your private information and it is down to you to choose whether to share your status and with who.

My parents have been nothing less than supportive and helpful through this entire time. They bought a ton of books about HIV and informed themselves as much as they possibly could about prevention and nutrition and how to help physically and emotionally. I am forever grateful to have their unwavering support and unconditional love.

- Jordan

Some people find it easy to tell others that they have HIV while others may find it very difficult and emotional. You may feel fearful, embarrassed, excited or relieved. Whatever you feel is OK. Remember that you don’t have anything to apologise for, simply because you are living with HIV.

Many people find that it gets easier once they begin to tell others, especially if the people they tell are able to offer support. However, you cannot be sure how each person will react to your news and what impact it might have on you. If you have only recently found out you are living with HIV, it might be a good idea to take time to understand your HIV status and to get used to how you feel before you tell many people.

Besides the doctor, my husband is the only one who knows my status. I'm afraid to tell anyone else because I fear them seeing me different.

- Mia
What reactions will I get?

It can be helpful to think about what kind of reaction you might expect from someone you are considering telling. Do you think they will be calm and supportive? Are they likely to get upset and worried for you? Is there a chance they could be angry, or even violent?

Talking to a healthcare professional, or a support group or organisation, can help you to think about the kind of reaction you are expecting and how you might handle it. In some situations, it might be possible for someone to be with you when you share your status.

While it is important to consider the negative reactions that some people sadly do experience, it’s also important to remember that many people have good experiences of sharing their HIV status.

Being able to be open and honest with someone about your HIV status and your feelings can be really powerful. It can make you feel closer to the person, and they may offer you emotional and practical support when you need it.

At first, I didn't want my parents and friends to know what was going on with me. I isolated myself from all my friends and family. I finally found the best opportunity for me to disclose my HIV status to my sister. I am thankful because my sister was able to understand me and I asked her to educate my mom about HIV. After disclosing my status I don't have any burden at all. I don't care if everyone around the world knows that I am living with HIV.

- Zion

How do I tell people?

How, when and where you tell someone about your HIV status is completely up to you. It can be helpful to think a few things through:

- What are you going to say?
- What questions might the person ask you? How would you answer these?
- Is there anything you are expecting from that person after you tell them?
- Do you feel able to cope with a bad reaction from this person?

It’s also worth planning the practicalities of where and when would be best to do it. Think about a time and place where you can both be relaxed and feel safe. You’ll want to have plenty of time together, so you can talk about it uninterrupted.
It can help to have some information on hand to share with them. They may not know about how HIV is passed on, or about HIV treatment. They may assume that you don’t have long to live, or that you won’t be able to have relationships or have a family. If you can help them to understand the facts about HIV, they are less likely to react negatively.

It’s important to remember that having HIV is nothing to be ashamed of. Hopefully whoever you decide to share your status with will see that and support you, though you may need to give some people time to process the information.

If you tell someone your HIV status there is a chance that they will share this information with others without your permission. If confidentiality is important to you it is a good idea to make this clear to them when you share your status. You should also think carefully about whether you can trust this person to respect your confidentiality.

**Sharing your HIV positive status with a partner**

Because HIV can be passed on during sex, telling someone who is a current or previous sexual partner can be particularly difficult and emotional. But the process of deciding how and when to tell a partner involves a lot of the same thinking as telling a friend.

Before you talk to your partner it can help to have some information on hand to share with them. If you can help them to understand the facts about HIV, and reassure them, they are less likely to react negatively.

Many people worry that sharing their HIV status will lead to rejection – that the person they tell may react badly and that this may damage their relationship.

While you can’t control how others react, remember, that negative reactions are normally based on poor knowledge of HIV. Giving someone the correct information on how HIV is passed on and how it can be prevented will help to reassure them and deal with some of the common fears and myths around HIV.

Communicating with your partner about your HIV status can be a very positive step in a relationship and means you can also discuss how to keep both of you healthy. Using PrEP, condoms and taking your HIV treatment correctly are all ways which will protect your sexual partner from HIV.

**How do I talk to my children about HIV?**

It can be difficult to decide how much information to give children about HIV. Every child is different, and every parent is different, so there isn’t necessarily a ‘right’ way to tell your child that they, and/or you have HIV.

Often, telling a child that they have HIV is done over time, giving them information at the level they can understand, depending on their age. Children will often have questions about why they are taking treatment, or why they have to see their doctor, and this can present an opportunity to give information and offer reassurance.

Talking to other parents and a healthcare professional at your child’s clinic can help you think about what you might like to do and when.
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Sources:

AIDSmap 'Do I have to tell anyone that I have HIV?' (Accessed April 2021)