

FACTSHEET: DISCLOSING OUR HIV STATUS TO OTHERS

Talking about our HIV and disclosing our status to others is one of the most challenging things about living with HIV. Deciding who to tell can feel very daunting, especially when we are first diagnosed. There are lots of different people we might want to disclose to: a partner, family, friends, work colleagues and healthcare providers. This factsheet gives some general tips on how to go about this and some things to consider with particular audiences.

General disclosure tips

- You don't have to tell everyone. The choice is yours about whom to tell. Be selective
- Easy does it. In most situations, you can take your time to consider who to tell and how to tell them
- Consider the **five "W's"** when thinking about disclosure: who, what, when, where and why.
 - Who do you need to tell?
 - **What** do you want to tell them about your HIV infection and what are you expecting from the person you are disclosing your HIV status to? What might happen?
 - When should you tell them?
 - Where is the best place to have this conversation?
 - Why are you telling them? What are the benefits to YOU and to THEM
- Consider whether there is a real purpose for you to tell this person or if you are simply feeling anxious and want to "dump" your feelings
- Telling people indiscriminately may affect your life in ways you haven't considered
- You have a virus. That doesn't mean you've done anything wrong. You don't have anything to apologize for simply because you are HIV positive
- Keep it simple. You don't have to tell the story of your life
- Avoid isolating yourself about your status. If you are still not able to tell close friends, family members or other loved ones about your HIV status, allow yourself to draw upon the support and experience available to you, through organized groups in the HIV community
- There's no perfect roadmap for how to disclose. Trust your instinct, not your fears
- Whatever the response you receive in a specific situation, and even if it doesn't go the way you'd hoped, you're going to survive it and your life will go on
- Millions of others have dealt with this experience and have found their way through it. You will get through it too
- Choosing whom to tell or not tell is your personal decision. It's your choice and your right

Disclosing to sexual partners and dating

If you choose to tell an **existing partner**, a number of questions may arise for them. Are they likely to have been exposed to a risk of catching HIV themselves? Why you didn't tell them earlier? How will it affect the sex you are both having? You may need to explain that it was important for you to

become comfortable with your status and be fully informed before talking to them and being able to help them answer these questions. You may also need to discuss your partner taking an HIV test themselves.

When you start seeing a **new partner**, your HIV status will inevitably be at the back of your mind. Do you tell them your status soon after you have met? Do you tell them once it seems things are becoming serious and moving to a sexual level? Or do you wait until the relationship is blossoming and you feel that a serious commitment may be on the horizon? Should you not tell them at all? Only you can decide the best time to tell when in a relationship, but it certainly helps if your new partner has got to know you and understands you as an individual with your own qualities. This should mean that when you tell them your status, they will see you as someone more than living with HIV. It also helps that you are comfortable with your own status. Your attitude when you tell them could influence their reaction.

Some additional tips:

- Keep what you say as simple and as 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 sometime process the information. Whatever their reaction may be at first, whether negative or positive, be aware that reactions can change in time

For information on HIV and the law in relation to transmitting HIV to another person go to: <u>http://www.lifewithhiv.org.uk/criminal-prosecutions</u>

Disclosing to family

Family members can be one of the greatest sources of support. However when it comes to telling your family you need to make sure that you are ready for their reaction. Some might find it very difficult to hear and you may even suffer rejection. On the other hand, they might react positively and give you the support you need. Sometimes it is better to first come to terms with your diagnosis and gather information about HIV so that when you disclose to your parents, siblings or children you will be able to support them and assure them that you will be alright. Again your attitude when you tell them could also influence their reaction.

Some additional tips:

- Tell them you have something important to tell them
- Request that what you're going to discuss be kept in confidence
- Tell them why you want them to know
- Offer to answer any questions they may have
- Let them know they don't have to worry about your health
- Ask them to be there for you
- Tell them how much they mean to you and how much you love them

- Consider how you would feel if someone in your family was in your situation, or something similar, and chose not to tell you about it
- Don't be afraid to show your feelings and to express how important this issue is for you

Disclosing to friends

Because someone you regard as a valued friend is in many ways like a family member, but one of your own choosing, many of the tips for disclosing to your family will also apply when disclosing to friends. However, there may be some additional things to bear in mind.

- Request that what you're going to discuss be kept in confidence
- If you have particular HIV-related issues or concerns that you're trying to sort out, let them know that because your friend may have some helpful suggestions. Often just being able to talk about what's on your mind is a great relief and that is enough in itself

Disclosing to your employer and work colleagues

Under UK legislation through the **Equality Act 2010**, all people diagnosed with HIV are considered to be 'disabled' regardless of their health status. Being considered disabled gives people with HIV protection against discrimination in many aspects of employment, including the recruitment process. Except in very restricted circumstances, employers are prohibited from asking job applicants questions about your HIV status until you have been offered a job. Even when you have been offered a job, it is not good practice for employers to ask your HIV status and if they do, you are generally under **no legal obligation** to tell them.

It is important to remember that most people living with HIV have a good experience at work and most employers have a positive approach to disability. However, under the legislation, employers are required to make **reasonable adjustments** for employees and protect them from any **harassment**.

For people living with HIV, the most commonly requested adjustment tends to be time off for clinic appointments or for feeling unwell as a result of treatment side effects. If you suffer any harassment from your employer or a work colleague, such as written or spoken abuse, your employer must protect you from this. If you need to request an adjustment or report harassment, you will need to disclose your status. However, only your immediate manager or HR manager need to know and the information should be treated as confidential.

The most important thing to remember is that you are in charge of the disclosure process! If you do decide to tell people at work, including work colleagues, the following tips might also help:

- Consider very carefully what the 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 with them
- Request that what you're going to discuss be kept in strict confidence and be mindful that a request for confidentially is not an absolute guarantee that it will be respected
- Tell them why you want them to know

- Tell them you are receiving appropriate health care and that your health is well maintained by HIV treatment
- Ask if you need a particular adjustment such as occasional time off for a medical appointment
- Let them know you are sorting out issues related to your HIV status and their support is important to you
- 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

Hopefully you will not need legal help to protect your rights. But remember, if that happens there are laws to protect you. Further information on employment rights and HIV can be found here:

http://www.tht.org.uk/myhiv/Your-rights/Equality-Act-2010

http://www.nat.org.uk/Publications/New-publications.aspx#thelawhumanrightsanddiscrimintaion

Disclosing to your medical and healthcare providers

All healthcare providers are bound by confidentiality laws.

By telling a doctor, a nurse or other healthcare providers, you do give up a degree of privacy, but that does not release them from adhering to laws regarding confidentiality.

Sometimes treating your status as privileged information is not as scrupulously observed as it should be. 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 healthcare providers may share HIV information with each other but should request your permission before doing so.

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.

Useful online information:

http://www.lifewithhiv.org.uk/telling-other-people

http://www.tht.org.uk/myhiv/Telling-people/Who-to-tell

http://www.aidsmap.com/resources/living-with-hiv/Telling-people-you-have-HIV/page/1254853/

