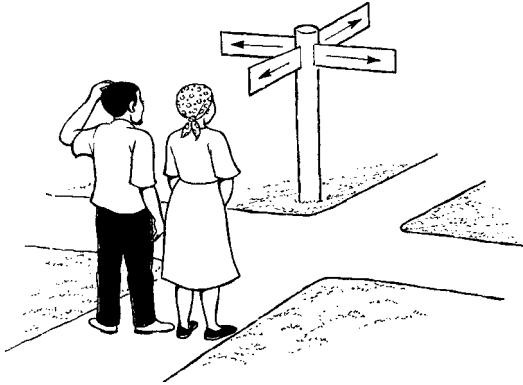


HIV status & disclosure:

choices & consequences



Disclosure decisions- who, what, when & how

If you discover you are infected with HIV, you will face a difficult decision about whether to tell anyone. If you opt for disclosure, you need to choose who to tell, and how and when to tell them. It is important to take your time and think through the issues carefully—your choices can have major implications for you and those around you.

This pamphlet is designed to help you think through the issues involved in disclosure, to help you make informed choices about disclosing your HIV status. They will raise issues that you can talk over with your counsellor, spouse or partner, or other person you can trust and feel comfortable with.



SAT

SAAIDS



Canadian International
Development Agency

Agence canadienne
de développement international

*This **publication** was supported through a partnership with the Canadian Public Health Association and the financial support of the Government of Canada through the Canadian International Development Agency*

Important terms

HIV status: in these guidelines we use the term ‘HIV status’ to refer to HIV positive status.

Voluntary disclosure refers to when you share information about your HIV status with other people. This may be partial or full disclosure (see below). A counsellor can help you to identify possible impacts of the decision.

Full disclosure is when you publicly reveals your HIV status to a person or organisation, for example, a family member, friend, support group or to the media. Before you disclose your HIV status, a counsellor can assist you to explore who to tell, how and when to tell. In this way, you can remain in control of what to say and how to say it.

Partial disclosure means that you will only tell certain people about your HIV status, for example, a spouse, a relative, a counsellor or a friend. You need to think carefully and prepare for the range of possible outcomes before disclosing your status. You may not be able to control what happens, once you have disclosed. Most cases of involuntary disclosure arise from situations where a person living with HIV or AIDS decides to partially disclose their status and without their knowledge the information is made public by an individual or organisation.

Non-disclosure means that you do not reveal your HIV status to anyone.

Involuntary disclosure happens when someone reveals someone’s HIV status without their approval or even without their knowledge.

Shared confidentiality. Disclosure is usually on the understanding that people will not tell others, unless they have been given permission.

Reasons to consider disclosure

You need to be clear about whether to choose partial or full disclosure of your HIV status. Counselling can help you make that decision. Disclosing your HIV status can have the following benefits.

Disclosure can help you accept your status and reduce the stress of coping on your own. “A problem shared can be a problem halved”.

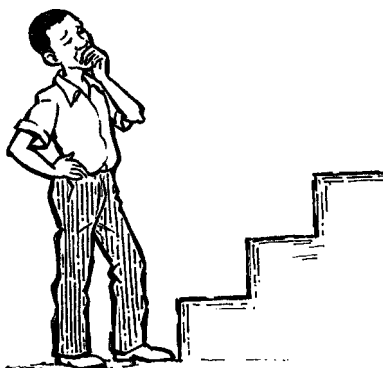


- ⌘ Disclosure can help you access the medical services, care and support that you need.
- ⌘ Disclosure can help you protect yourself and others. In particular, openness about your HIV status may help women negotiate for protected sex.
- ⌘ Once you have disclosed your status, you may be able to influence others to avoid infection.
- ⌘ As more people disclose their HIV status, it will help to reduce the stigma, discrimination and denial that still surrounds HIV and AIDS.
- ⌘ People may suspect your HIV status, particularly if you show symptoms of AIDS. Openness about your HIV status can stop rumours and suspicion.
- ⌘ Disclosure promotes responsibility—it can help your loved ones plan for the future.

Steps in disclosing your HIV status

Don't rush into disclosure – it is an important decision for you and others. These ideas should help you in the process of disclosure.

- ⌘ Take your time to think things through. Make sure it is what you want to do and plan how you are going to go about it.
- ⌘ Identify sources of support, such as support groups for people living with HIV and AIDS, church members and counselling organisations.
- ⌘ A good counsellor can support and reassure you and help you to accept yourself positively.
- ⌘ Once you decide to disclose, it may be easier to start with those nearest to you: relatives, family, friends, or someone you are very close to and trust.
- ⌘ Think carefully about sexual partners who need protection from infection.
- ⌘ Be prepared for a shocked and even hostile reaction. This often happens, but with time people close to you should learn to accept your HIV status.



- ⌘ When you have decided to disclose your HIV status to someone, think about their emotions and their level of knowledge about HIV and AIDS. This will help you decide what they need to know and how to tell them so it is less traumatic for both of you.
- ⌘ It is important to be strong enough to allow others to express their feelings and concerns after your disclosure. You can work on these issues over time.
- ⌘ Look after yourself and try to 'live positively'.

"You have to decide for yourself if it is the right thing to disclose your status. It is helpful when you can be open, but you shouldn't judge others who may not be ready to divulge their status"



Coping mechanisms

Whether you choose disclosure or non-disclosure, or experience involuntary disclosure, it is important to try to adopt positive ways of coping with stress and anger. There are many options, for example, song, prayer, long walks, spending time with family and friends, or joining a support group. A counsellor can help you to explore what works best for you.

Possible consequences of disclosure

There is still a lot of stigma attached to HIV and AIDS. This means that disclosure can sometimes have negative consequences, especially in the short term. Disclosure can cause problems in your relationships, whether with sexual partners, your family and friends, community members, your employer or work colleagues. You may experience rejection or feel that people are constantly judging you. Be prepared for this and be ready to make full use of the support that is available.

Possible consequences of non-disclosure

Sometimes it seems as if there is too much to lose by disclosing your HIV status. But non-disclosure can also have major consequences for you and those around you. Possible consequences are:

- ⌘ Lack of support—your family and friends may not give you the support you need and you will have to deal with everything on your own.
- ⌘ Risk—placing others at risk of infection, particularly sexual partners and increasing the risk of re-infection for yourself.
- ⌘ Lack of care—you may be unable to access appropriate medical care, counselling or support groups if you are not open about your status.
- ⌘ Suspicion—people may become suspicious of your actions because they do not understand your HIV status.

Disclosure of HIV status for gay people

Disclosure can be particularly difficult for gay people. You may find it hard to discuss your sexuality with a support group of non-gays. In such settings you may have to counter discrimination and stigma attached to your sexuality.

Try and seek help and counselling from the gay community and join support groups that are sensitive to the needs of gay people.

“I tested HIV positive in July 1990. What made me disclose? I believe it was fear. Fear of illness. Fear of the unknown. I felt so alone and needed to talk to someone. I just could not handle it on my own.

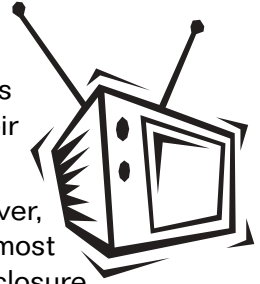
Love and support from everyone around me made it easier. Their acceptance gave me strength and courage to keep telling more people. I wouldn't have told so many if the first people had rejected me. If I had to do it again, I wouldn't do it differently. My friends have always given me support, so I guess I'd still tell them first”.

The media and disclosure

People living with HIV and AIDS have the same rights as anyone else to privacy, confidentiality and respect in their dealings with the media.

You may choose to go public about your status. However, you are not always in control of the situation. Since most people are still reluctant to reveal their HIV status, a disclosure story is a scoop in many countries and communities. The journalist may decide what questions to ask and what to emphasise, and may not always feel obliged to check back for accuracy. This can lead to misrepresentation of facts.

It is important to ensure that your story will be handled correctly and (with the print media) that the facts are checked prior to publication. Accuracy and sensitivity in the use of language is also very important.



Guidelines for contact with the media

These are some practical guidelines if you wish to talk to the media.

- ⌘ Consult a counsellor or someone who is aware of your HIV status to assist you consider your decision.
- ⌘ Never be pressurised to give an interview when you are not ready.
- ⌘ Try to carefully select the journalist that you want to work with.
- ⌘ Prepare for the interview by writing down everything you want to say in advance. This helps you to control the focus of the story.
- ⌘ Ask for the meeting to be recorded and insist on reading the story before it is printed. Sometimes this is not allowed, but you can request a discussion to clarify issues before the story is printed or broadcast.
- ⌘ If you seek partial disclosure, then it is advisable to use a non-disclosure form, such as the one provided at the back of this leaflet. This sort of agreement can be binding in a court of law.
- ⌘ If you don't like the way an interview develops, then terminate it and explain why you have done so.
- ⌘ Think carefully about having your picture taken. If in doubt, you are entitled to decline to be photographed.

Safeguards when working with the media

People living with HIV and AIDS strongly feel that safeguards are needed to protect them from exploitation from the media. Many journalists still fail to see anything positive to report about HIV and AIDS—it is still a “gloom and doom” story. The issue of morality often is pushed to the forefront.

If you disclose your status to the media be prepared for the general public to know about you. Try and ensure that your story is reported correctly, and prepare your family—keep them informed so that your public disclosure is not a shock to them.

You can help improve reporting on HIV and AIDS by cultivating a good relationship with the media. Establishing such a relationship can help the media to be more sensitive and avoid use of words and phrases that are negative.

The media and payment for stories

Some people living with HIV and AIDS feel that since the media is making money out of their stories, they should be paid for giving interviews. However, this can create ethical problems for journalists. It is important to realise that when a person living with HIV or AIDS and a journalist agree to do a story, each is trying to achieve something different although sometimes their objectives can merge. Payment can complicate the motive for telling the story and can lead to allegations of selfishness and money-making on the part of the person living with HIV or AIDS. Check if your story will be paid right at the outset.



Creating this pamphlet

This pamphlet is based on the experiences and advice of people from across Southern Africa who are either living with HIV or who have extensive experience of counselling people living with HIV. The pamphlet was produced by the Southern African AIDS Training Programme (SAT). Funding was provided by the Canadian International Development Agency. It was written and designed by Southern Africa AIDS Information Dissemination Service (SAfAIDS), on contract to the SAT Programme, a programme of the Canadian Public Health Association. Cartoons were drawn by Joel Chikware.

Please photocopy this non-disclosure form if you wish to use it

Non-disclosure form

I,,
do hereby state that I:

- Am a Person Living with HIV or AIDS (delete as appropriate).
- Have agreed to speak to or be interviewed by _____
of _____ with regard to my HIV status.
- Have been offered remuneration for my story in the sum of _____, **or** that I have not been offered remuneration for my story (delete as appropriate).
- Participate in the interview on the following grounds:
 - That I shall not be identified either by name or by any description that is likely to identify me.
 - That the said _____ or his/her employer _____ or his/her friends, relatives or associates shall not be permitted to sell, cede or in any other manner give or assign the rights to my story to any other person or organisation without my specific written consent.
 - That any story written about me and concerning my status as a Person Living with HIV or AIDS shall not be published until I have had sight of the draft and agreed to the same.
 - That any departure or deviation from the above conditions shall entitle me to full redress including but not restricted to damages for loss of privacy and dignity and any consequential damages arising therefrom.

Signed by:

Date:

PERSON LIVING WITH HIV or AIDS

UNDERTAKING BY INTERVIEWER

I do hereby state that I have read and understood the above declaration and hereby state that I agree to the conditions attaching thereto.

Signed by:

Date:

INTERVIEWER