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# **Counselling guidelines on disclosure of HIV status**

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# **Counselling guidelines on disclosure of HIV status**

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# Foreword

This publication is a first in a series of guidelines on counselling people who are infected with HIV, who are concerned about being infected with HIV, or who are living with or caring for people with AIDS. Each booklet in the series is designed to offer practical guidance on specific counselling issues. The publications are designed for use by volunteer counsellors, non-professional counsellors, and professional counsellors who do not have extensive experience in counselling in the context of HIV.

Each booklet is the result of a workshop organised under the SAT Programme "School Without Walls" initiative that brought together professional counsellors, people living with HIV, and staff of AIDS Service Organisations from Southern Africa. The booklets reflect their unique experience and take account of their specific expertise. Further publications on different counselling issues are in production, eventually making up a complete counselling kit to be used as reference material.

The SAT Programme is a project of the Canadian International Development Agency implemented by the Canadian Public Health Association. It has been on the forefront of supporting the community response to AIDS in Southern Africa since 1991. The School Without Walls is an initiative of the SAT Programme to validate, promote, and diffuse the unique Southern African experience and expertise in responding to HIV. The SAT Programme is profoundly grateful to the volunteers and professionals who have made this publication possible and who are supporting SAT in the preparation of further publications in this series.



Southern African AIDS Training Programme  
Programme d'Afrique australe de formation sur le sida

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*SAfAIDS*

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# Counselling guidelines on disclosure of HIV status

## Creating these guidelines

These guidelines are 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 guidelines were produced by the Southern African AIDS Training Programme (SAT) with funding from the Canadian International Development Agency. They were written and designed by Southern Africa AIDS Information Dissemination Service (SAfAIDS), on contract to the SAT Programme. Cartoons were drawn by Joel Chikware.



# Contents

Important terms -----	1
Decisions, decisions -----	2
Reasons to consider disclosure -----	2
<i>Testimony 1</i> -----	3
What is counselling -----	4
The need for effective counselling -----	4
General guidelines on effective counselling -----	4
<i>Testimony 2</i> -----	5
Steps towards disclosure -----	6
<i>Testimony 3</i> -----	7
Counselling process of disclosure -----	8
Possible consequences of disclosure -----	8
Possible consequences of non-disclosure -----	9
Coping mechanisms -----	10
Disclosure of HIV status for gay people -----	10
<i>Testimony 4</i> -----	10
The media and disclosure -----	11
Safeguards when disclosing HIV or AIDS to the media -----	11
The media and payment for stories -----	12
Non-disclosure form -----	14





# Important terms

**HIV status:** in these guidelines we use the term 'HIV status' to refer to HIV positive status.

**Voluntary disclosure** refers to when the client shares information about their HIV status with other people. This may be partial or full disclosure (see below). A counsellor should help the client to identify possible impacts on their decision.

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

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

**Non-disclosure** means that the client does not reveal their 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.

**"I disclosed my HIV status to prove to my community that there is a need to do something about HIV and AIDS"**

# Decisions, decisions— who, what, when and how

When someone discovers they are infected with HIV, they face a difficult decision about whether to tell anyone.

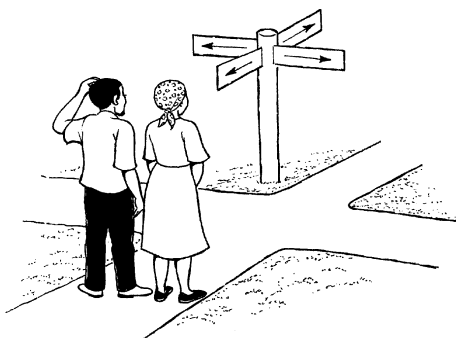
If they opt for disclosure, they may need your support. They will need to decide who to tell, how and when to tell them. Disclosure is to be encouraged, but it is important that people take time to think through the issues carefully. Their choices can have major implications.

These guidelines – developed from the direct experience of people living with HIV and AIDS – are to help those who may be called upon to counsel or advise people who are either thinking about disclosure or who are trying to cope with the consequences of involuntary disclosure.

By raising key issues and sharing practical hints, the guidelines are designed to promote informed choices about disclosing HIV status and improved coping strategies following disclosure.

## Reasons to consider disclosure

People thinking about revealing their HIV status need to be clear about whether to choose partial or full disclosure. If they are able to disclose their HIV status, it can have the following benefits.



- ⌘ Disclosure can help a person accept their status and reduce the stress of coping on their own. “A problem shared can be a problem halved”.
- ⌘ Disclosure can help a person access the medical services, care and support that they need.
- ⌘ Disclosure can help people protect themselves and others. In particular, openness about HIV status may help women negotiate for protected sex.
- ⌘ Disclosure means that people may be better equipped 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 the person's HIV status, particularly if they show symptoms of AIDS. Openness about their HIV status can stop rumours and suspicion. It can also reduce the stress caused by "keeping a secret".
- ⌘ Disclosure promotes responsibility – it can help the person's loved ones plan for the future.

**"I would make my disclosure to the closest persons to me, and only when I am prepared"**



## **Testimony 1: fear, love and support**

"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".

**"What made me disclose?  
I believe it was fear.  
Fear of illness ... of the  
unknown. I felt so alone  
and needed to talk to  
someone"**

# What is counselling?

Counselling is a structured conversation between two or more people that assists one of the participants to work through particular problems he or she faces, for example, disclosure of HIV status. Counsellors encourage people to recognise and develop their own coping capacity, so they can deal more effectively with problems.

## The need for effective counselling

Despite their need for support, many people feel unable to tell relatives or friends about their HIV status for fear of stigma and rejection. Even if they do reveal their HIV status they may not receive the emotional support and information they require. They may be overwhelmed by thoughts and fears about the future, the possible consequences to them and others, feelings of guilt, anger, shock and despair. People may need support to tell family members about their HIV status, and the family may need support to cope with their feelings about the information. Although disclosure of HIV status is usually advocated as a way to reduce stigma and to protect uninfected partners, this is a complex situation and there are many factors to consider before disclosure takes place. This is why counselling is essential.

## General guidelines on effective counselling

These are some basic, practical guidelines for those without formal counselling training who find themselves in a situation where counselling is required.

- ✘ Listen attentively to the client; give them time to say what they need and be patient. Help them express their feelings and emotions and show warmth and caring for the person.
- ✘ Treat clients and their families with respect and be reliable and consistent. Accept people as they are and avoid moralistic judgements.
- ✘ Try to avoid giving advice; rather let clients work through issues and make their own decisions with your help.
- ✘ Help the person focus on issues where they can achieve some positive change, rather than being overwhelmed by the problems of HIV and AIDS. Help them identify others they can rely on and receive help from.
- ✘ Do not pretend to have skills, knowledge or resources you do not have – know when (and where) to refer clients for more specialised help.

## Testimony 2: disclosure & a new lease of life

“I was tested unknowingly in 1988 and the result was disclosed in the ward where everybody heard. I was shocked and felt humiliated. When I got home, I only told my husband. I hoped he would support me but he accused me and after a short while he abandoned me.

I suffered alone for the next five years without telling anybody. I wasted away because there was nobody to advise me on what to do. I did not tell my parents and sisters about my HIV status because they were very negative on the issue of HIV.

**“The miraculous change came when I got my first counselling ... It was like I started living again. I stopped mourning”**

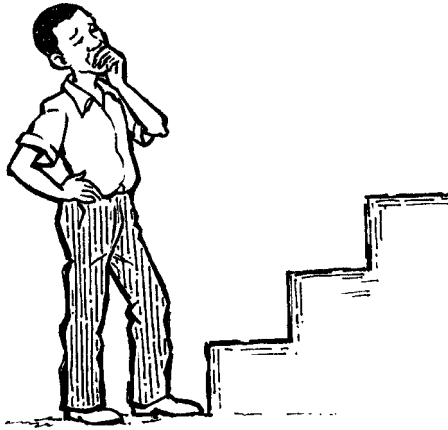
The miraculous change came in 1993 when I got my first counselling at The Centre in Harare. It was like I started living again. I stopped mourning for myself and started getting confident. I now knew the right foods to eat and how to avoid stress. I became a happy person and started gaining back my weight.

This big change was noticed by many people. I started talking much more about HIV issues, but not referring to myself. When I saw that they were now understanding I revealed my status to them. They were not shocked.

I was introduced to other people living with HIV and AIDS and started feeling comfortable talking about the illness. I started participating in a radio programme. At home my sisters made sure that whenever I went for the programme they would change the radio station so that my son would not hear my voice.

Unfortunately, one day he heard me and identified my voice. I had to give him a lot of counselling because he was so depressed. I am happy to know from his response that he would never shun me and up to now he is very supportive.

As for myself I talk freely about it at work, at home, or at conferences and workshops”.



## Steps towards disclosure

Disclosure is a process and not an event. It is a major decision that can have consequences for the person living with HIV and those around him or her. It is important that people do not rush into disclosure, but think it through carefully and plan ahead. Planning allows for possible prediction and control of the process of disclosure.

The ideas and advice below can be shared with a client.

- ✂ Help the client to take time to think things through. Make sure it is what they want to do and assist them to plan how they are going to go about it.
- ✂ Identify sources of support, such as groups for people living with HIV and AIDS, church members and counselling organisations.
- ✂ Role plays and “empty chair” enactment techniques could be used to help the client prepare for disclosure.
- ✂ Provide support and reassurance to the client and help them to accept themselves positively.
- ✂ Discuss about sexual partners who need protection from infection.
- ✂ Prepare the client for a shocked and even hostile reaction. This often happens, but you can reassure the client that with time people close to them should learn to accept their HIV status.
- ✂ Help the client to realise that once a decision to disclose has been reached, it may be easier to start with those nearest to them: relatives, family, friends, or someone they are very close to and trust.

- ✘ When a client has decided to disclose their HIV status to someone, assist them to think about the likely response. They will need to assess how much the person they plan to disclose to knows and understands about HIV and AIDS. This will help the client decide what they need to tell the person and how to tell them so it is less traumatic for both of them.
- ✘ It is important for a client to be strong enough to allow others to express their feelings and concerns after their disclosure. A counsellor can assist the client to work on these issues over time.
- ✘ Provide the client with information and support 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”**

### Testimony 3: life needs courage

“I decided to come out publicly because a lot of Swazis are dying and they think HIV is a problem in other countries but not ours.

I have had problems with my wife's family. They accuse me of being unfeeling and insensitive – to them it was humiliating that everyone knows my status. But my wife stood by me and we are still together.

**“In the long run I have always felt good about the choice I made by disclosing my status”**

In the long run I have always felt good about the choice I made by disclosing my status. It feels good not to have kept it to myself. Just talking about my situation has helped a lot of HIV positive people and their relatives. My advice is to remember that life needs courage”

## **Counselling process of disclosure**

- ✘ Allow the person to develop trust in you and feel at ease.
- ✘ Get to know them, in particular about what HIV and AIDS means to them.
- ✘ Assess the person's ability to cope and establish their sources of support.
- ✘ Discuss the implications of disclosure fully, to help the person consider in advance the reactions of family, friends, work colleagues and others.
- ✘ Help the person develop a plan on disclosure. This should cover any preparations they need to make before disclosure, who they will inform first, how and where they will disclose and the level of disclosure.
- ✘ The counsellor needs to work with the client on the implications of disclosing to inappropriate persons or groups.
- ✘ Arrange to see the person again – at a date and time agreed by both of you – to review this process.
- ✘ Counsellors have to protect their clients against undue pressure to disclose.



## **Possible consequences of disclosure**

The stigma attached to HIV and AIDS means that disclosure can sometimes lead to negative consequences, especially in the short term. Possible consequences include:



- ⌘ Problems in relationships, whether with sexual partners, family and friends, community members, employer or work colleagues.
- ⌘ The experience of rejection. People who have disclosed their HIV status may feel that people are constantly judging them. They need to be prepared for this and be ready to make full use of the support that is available.
- ⌘ Disclosure can result in pressure being placed on people living with HIV or AIDS to assist in AIDS work and become role models.



## Possible consequences of non-disclosure

Sometimes it seems that there is too much to lose by disclosing HIV status. But non-disclosure can also have major consequences. It is useful to discuss with the client the following potential consequences of non-disclosure.

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

# Coping mechanisms

Whether they opt for disclosure or non-disclosure, or experience involuntary disclosure, it is important for clients 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 the client to explore what works best for them.

## Disclosure of HIV status for gay people

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

Gay people should be advised to seek help and counselling from the gay community and to join support groups that are sensitive to their needs and to protect uninfected partners. This is a complex situation and there are many factors to consider before disclosure takes place. This is why counselling is needed.

### Testimony 4: 'coming out twice'

“Being gay and HIV positive in Zimbabwe has devastating stigmas attached. Disclosure of sexual orientation and HIV status for homosexual people often leads to discrimination at the work place, in the community and within the family.

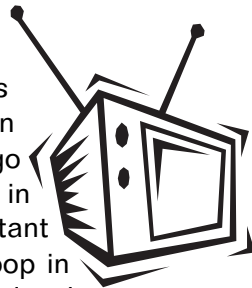
This makes it very difficult for gay people to find help and often leads to them living isolated lives and suffering the complications of HIV and AIDS alone.

**“Being gay and HIV positive has devastating stigmas attached”**

It is difficult and often impossible for a gay person to join a support group and disclose his or her sexual preference, because of homophobia and negative attitudes. That is why it was necessary for us to start the Gays and Lesbians Association of Zimbabwe (GALZ) HIV & AIDS Support Group in 1998”

## 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. They may choose to go public about their status. However, they 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 they do not always feel obliged to check back for accuracy. This can lead to misrepresentation of facts.



If you are called upon to counsel or advise someone who is thinking about disclosure in the media, what guidelines should you follow? These are some practical guidelines that a counsellor can offer to people thinking of talking to the media:

- ⌘ Assist the client to establish their motive for disclosing to the media. Advise them never to be pressurised to give an interview when they are not ready.
- ⌘ Assist the client to carefully select the journalist that they want to work with and help them prepare for the interview. They should have clear objectives for the meeting. It may help for them to write down everything they want to say in advance. This helps them to control the focus of the story.
- ⌘ The client should ask for the meeting to be recorded and insist on reading the story before it is printed. Sometimes this is not possible, but the client can request a discussion to clarify issues before the story is printed or broadcast.
- ⌘ Inform the client that if they do not like the way an interview develops, then they are at liberty to terminate it and explain why they have done so.
- ⌘ Advise the client to think carefully about having their picture taken. If in doubt, they are entitled to decline to be photographed.

## Safeguards when disclosing HIV or AIDS to the media

People living with HIV/AIDS strongly feel that safeguards are needed to protect them from exploitation from the media—newspapers, magazines, the radio or TV. Many journalists still fail to see anything positive to report

about HIV/AIDS – to them it is still a “gloom and doom” story and the issue of morality often is pushed to the forefront.

Counsellors can help clients thinking of disclosing their HIV status to the media to consider the following issues:

- ⌘ The client needs to be sure that they are prepared for the general public to know about their HIV status.
- ⌘ The client needs to try and ensure that what they have disclosed to the media is going to be reported correctly.
- ⌘ If the client seeks partial disclosure, it is advisable for them to use a non-disclosure form, such as the one provided in these guidelines. This sort of agreement can be binding in a court of law.
- ⌘ Counsellors and their clients can help improve reporting on HIV/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.

**“I am now full-time public about my status and I will continue until behavioural change is established among people, especially youths in Zambia”**

## The media and payment for stories

Some people living with HIV or 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/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. Establish if payment is involved at the outset.

**“My view is that going public is an important way to reduce stigma. The more we reveal our HIV status, the more difficult it is for society to stick to its attitudes towards people living with HIV or AIDS ”**

## **Non-disclosure form**

The form overleaf can be used as a safeguard against exploitation from the media and media personnel. Please photocopy the 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

# Notes

