



DISCLOSURE



How to disclose

2 LIVING WITH HIV: GETTING SUPPORT



zenzele
The Future Is Ours



Who to tell

Why tell them

SUPPORT



VIRAL SUPPRESSION

WHAT DISCLOSURE OF HIV STATUS MEANS

WHAT IS THE EXPECTED RESPONSE



DECISION





HIV: BASIC FACTS

HIV stands for the Human Immunodeficiency Virus. The main way HIV is spread is through unprotected sex. Babies can also get HIV from their HIV-positive mothers during pregnancy, birth and breastfeeding.

UNPROTECTED SEX



HIV IN THE BODY

HIV weakens the immune system - the body's defence force that protects the body against infection and disease. It hijacks the immune system's CD4 cells and turns them into factories to make more copies of HIV. In the process of making more HIV, the CD4 cells are destroyed. When the immune system is weakened, the body can't fight infections and diseases, such as TB.

IMMUNE SYSTEM IS WEAKENED



PREVENTING HIV INFECTION

HIV can be prevented by practising safe sex - using a condom correctly every time. HIV-positive mothers can enrol in the Prevention of Mother-to-Child Transmission (PMTCT) programme, which involves taking ART, practising safer sex and exclusive breastfeeding. Adhering to the PMTCT programme reduces the chance of passing HIV on to the baby.

SAFE SEX

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I said, 'dad I'm HIV-positive,' and he pulled me towards himself with my mom and they both hugged me. The next thing they were pushing me into the family circle in the kitchen and they were laying hands on me and praying for me, we were hugging each other and crying. And the feeling in my stomach was like an explosion, like something was released, I knew that I will be okay."

FAMILY

HOPE



Shane Petzer



Disclosure means telling a person something that has been a secret. It may feel hard to disclose that you are living with HIV, but having support is key to treatment adherence and reaching viral suppression. Getting encouragement and support adhering to treatment and going to follow-up visits at the clinic will mean that treatment will be effective. Adhering, which means taking ARVs exactly as prescribed by a healthcare worker, reduces the amount of HIV in the blood and body. This is called viral suppression. It allows you to lead a full, healthy life.



What disclosure of HIV status means

When you find out that you are HIV-positive it can be a very shocking experience. You may feel too ashamed, guilty or upset to tell anybody. You may be afraid of being rejected. You may not want people in your inner circle or community to know because you fear discrimination. To hide your HIV status, you could stop going to the clinic to get your treatment. While disclosure can be scary, disclosing to a trusted person, as early as possible, can be rewarding because of the benefits of love, acceptance and support.



I always say to people, the more you speak about it, the more you are free from it. The more open you are, the more I think you accept your status. It doesn't have to be disclosed to the whole world, but to the people who are close to you. It's better to speak up, so you can get help and support."

HELP, SUPPORT



SPEAK UP

Gugu Xaba



important step acceptance treatment buddy viral suppression

The benefits of disclosing

It is your right and choice to decide whether you want to disclose your HIV status or not. It is not something that has to be rushed into but there are many benefits to disclosure. Having somebody to support you will make it easier to cope with living with HIV.

- * *If you have disclosed and you have support it is easier to adhere to treatment and achieve viral suppression.*
- * *You will be able to take your ARVs freely. This will make it easier to adhere to treatment and achieve viral suppression.*
- * *You can have a treatment buddy to support you and remind you to take ARVs and go to clinic appointments.*
- * *If you feel accepted, supported and loved you stand a better chance to live a long and healthy life. Disclosing also reduces the burden and stress of keeping your status to yourself, this means you will have less chance of developing stress-related illnesses like high blood pressure, trouble sleeping and tiredness.*



Today when you check my viral load, it's suppressed because of the support that I get. Adherence, it's one of the biggest challenges because there will be a moment when you feel like saying: 'Remove this treatment. I don't need anything to do with pills.' But my partner will be there for me and gives me that word of encouragement : 'Remember where you came from. You can't give up today.'

VIRAL LOAD SUPPRESSION



Strike Tshabalala





How ARVs suppress HIV

The medicines that suppress or control HIV are called antiretrovirals, or ARVs for short. Three ARVs are taken together as Antiretroviral Treatment (ART). ARVs work by stopping HIV from hijacking the body's CD4 cells to make more HIV.

This is why when ARVs are taken properly, the amount of HIV in the body is reduced, which means there is less HIV in the blood and body. And, at the same time, the CD4 count goes up and the immune system recovers and becomes strong again.

Benefits of taking ARVs

Once you start taking ARVs it is important to always take them exactly as prescribed by a healthcare worker. This is called adherence. Adherence to ARVs leads to viral suppression. This is when the amount of HIV in the blood has dropped so much - to about less than 50 copies of HIV per millilitre of blood - that it cannot be detected by a viral load test. This does not mean that HIV is cured but that there is only a small amount of HIV in the blood. This has many benefits:

- * *HIV will not harm the body, which means you can live a healthy life.*
- * *There is less risk of developing drug resistance and having to switch to new second-line HIV treatment, which can have more side effects.*
- * *There are less chances of passing HIV on to a sexual partner.*
- * *You can have HIV-negative children without passing the virus on to your partner.*



For more information on Antiretroviral Treatment (ART) get a copy of the Zenzele 'Living with HIV: Making Treatment Work' brochure.



How to disclose

Disclosure is a personal choice and often a difficult decision to make. Speaking to a counsellor at the clinic may be helpful, or you can use the five "W" questions as a guide:

- 1 *Who to tell*
- 2 *What to tell them and what is the expected response*
- 3 *When to tell them*
- 4 *Where to tell them*
- 5 *Why tell them*

You should think about how disclosing might affect you and the person you are telling. How a person reacts will depend on what kind of relationship they have with you. You should be prepared to answer any questions or concerns the person you are telling might have.



For more information on adherence to ART get a copy of the Zenzele 'Living with HIV: Reaching Viral Load Suppression' brochure.





Disclosing to a partner

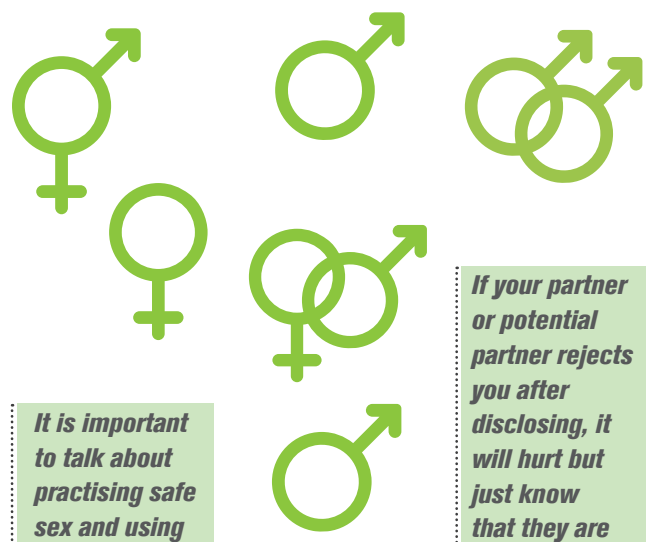
Telling current or past partners about an HIV-positive test result can be particularly difficult and emotional. However, your partner(s) needs to know that they could be at risk and should get tested. Disclosing to a current partner will also enable you and your partner to talk openly about having safe sex.

It is helpful to think about how your partner might

If you are in a loving relationship, it is likely that your partner will be worried but will support you.

It may take time for your partner to come to terms with the disclosure. They may react with anger, feel betrayed and be afraid that they might have HIV. The fact that you have been open and honest might bring you and your partner closer.

If there is a chance that your partner might get violent, consult your healthcare worker. They will know how to support you to deal with these challenges.



It is important to talk about practising safe sex and using condoms with your partner. Condoms will stop HIV and STIs (sexually transmitted infections) from being passed on during sexual intercourse. Even if your partner is also HIV-positive, using condoms will prevent re-infection with a different strain of the HIV.

You should let your partner know that taking ARVs means you can become virally suppressed and that there will be less chance of HIV being passed on. Even though you may be virally suppressed, it is still important to continue using condoms.

If your partner or potential partner rejects you after disclosing, it will hurt but just know that they are rejecting HIV and not you as a person. Rejection comes from fear, lack of knowledge about HIV and the stigma and discrimination around HIV. You have done the right thing by disclosing. You will be able to have a loving relationship with someone else.



Disclosing to family and friends

How family and friends react will depend on how much they know about HIV. If they do not know much, they may think that their loved one is going to die soon, or even that they may get HIV by living in the same house as you.

It is important for you to know about HIV so that you can help your friends and family understand the basic facts. You can also give your family and friends information on HIV to read. You can find pamphlets at the clinic.

You should:

- ✱ *Keep it simple but not be afraid of showing how important it is to you.*
- ✱ *Let them know that HIV is not a death sentence.*
- ✱ *Tell them about ARV treatment and explain that viral suppression means that you will be able to live a full, healthy life and have HIV-negative children without passing the virus on to an HIV-negative partner.*
- ✱ *Explain that HIV cannot be passed on by sharing plates or cups, or by hugging and kissing.*
- ✱ *Especially with friends, remind them that your HIV status is private and ask them not to tell others.*
- ✱ *Let them know how much you need their love and support, and how you need them to support you.*



My girlfriend went for tests. The result came back negative, thank God, but it was the end of the road for our relationship. She said, 'These results show that you have never been faithful to me. That's why you are so ill.' But the lady that I'm involved with now since 2010 understands HIV/AIDS issues. She supports me and will always be there for me."

PARTNER



Strike Tshabalala

UNDERSTANDING



Telling HIV-positive children about their HIV status

Telling children that they are living with HIV can be very hard. It is the responsibility of parents or primary caregivers to tell them that they are living with HIV. Getting help from a healthcare worker who has the tools and experience working with children can be very helpful.

Children under 10: Until a child is 10 years old, the focus should be on making sure that they understand that they have to take their treatment every day to stay healthy. They should be encouraged to talk about what it means to them to be living with an illness. Children can be taught about the different types of germs, the soldiers that protect the body and treatment to fight the special germs. There is no need to name HIV until they are 10.

Children and adolescents older than 10: Once a child is ten or older, it becomes very important then that they know that they are living with HIV. They need to understand how it is passed on and how it can be managed. Adolescents go through body changes and may be experimenting with sex, so it is vital that they know how to practise safe sex, especially the importance of using condoms, which will prevent them from passing the virus on as well as getting STIs, or falling pregnant. Adolescents often have trouble adhering to ARVs. It must be clearly communicated that they must take their medication correctly if they want to live a long and healthy life. They need to know that they can talk openly to their parents or caregivers and that they are there to support them.



A positive parent or caregiver disclosing to a child

There are many reasons why as a parent, you may not want to disclose your HIV status to your child or children. It may be because you feel shame or guilt, fear that your children will be angry, want to protect them from worrying about you, or are still struggling to accept your status yourself.

Specialists who work with children believe it is best to be honest with your children because they have probably already sensed that something is wrong. They might worry less if they know more about the condition and that it can be managed.

As a parent, you do not have to disclose everything to your child/children all at once. It is a slow process and may involve many conversations. If you do not know how to begin the process, speaking to a healthcare worker or counsellor or other parents who have disclosed to their children can help. There is no right way but these are some questions you should ask when you prepare yourself:

Am I ready to tell my child?

You have to first accept your own status before you can tell your child or children.

How much am I going to tell my child?

The age of the child will affect how much to tell them and what to tell them. For example, it is best to tell a young child that you are living with an illness but not say that you are living with HIV.

How am I going to tell my child?

You should use language that is age-appropriate. You should explain that ARVs will keep you healthy. Unless you are very sick, you should let the child know that you are not going to die soon.

Do I want my child to keep this a secret?

You may want to protect your child from discrimination but expecting a child to keep your HIV status a secret is too much of a burden. You should ask the child whether there is anybody they would like to talk to and share the information with.



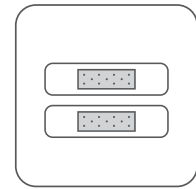
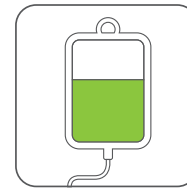
listen

be sensitive & kind non-judgemental emotional support

How to support somebody who discloses their HIV status

If someone is disclosing their HIV status to you, you should:

- * **Listen.**
- * **Be sensitive and kind.**
- * **Not be judgemental. Feeling judged will lead to the person feeling shame. They may stop talking.**
- * **Showing that you are not afraid of the other person's HIV status will make them relax.**
- * **Reassure them that HIV is manageable and not a death sentence.**
- * **If they are not on ARVs encourage them to get treatment so that they can live a healthy and full life.**
- * **Offer them practical and emotional support.**

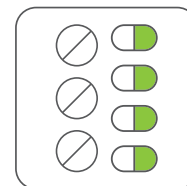


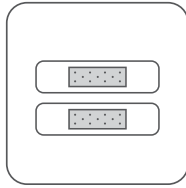
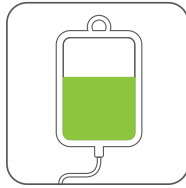
OTHER SITUATIONS WHERE A PERSON MAY BE ASKED TO DISCLOSE OR WANT TO DISCLOSE

There will be many situations where you will have to decide whether to disclose to people other than those close to you. It is helpful to ask the five 'W' questions as well as consider whether there could be legal consequences. These are some of the situations where you may be unsure about disclosing:

Medical insurance: You have the right to medical insurance but if you do not disclose your HIV status when you sign up, you may not be paid out when you make claims. It is advisable to check before signing up whether there are special policies for people living with HIV.

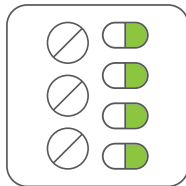
Life insurance: Before giving a life insurance policy, some companies will ask you to take health tests, including an HIV test. But having HIV does not mean you will not be allowed to have a life insurance policy. Since people living with HIV are living longer lives, more companies are offering them life insurance. Finding out which companies these are will take away the concern about disclosing.





Medical appointments or procedures: Disclosure of HIV status to healthcare practitioners is not a legal requirement. They are expected to take their own precautions. However, in order to get the best medical care, it is best to give a healthcare practitioner your full medical history.

Applying for a job: Current or future employers are not allowed to demand to know the HIV status of an employee or discriminate against you based on your HIV status. Even healthcare workers, such as nurses, do not have to disclose their status.



If you are unsure about whether you should disclose, you can call one of the helplines at the back of this brochure.



It was really tough to convince my people, the Muslim community, that regardless of your faith HIV can happen to anyone. I overcame this by being vocal about my own HIV status though a lot of people did not want me to speak about me being HIV-positive, especially our religious leaders, the imams."

ADVOCACY

STIGMA



Fagmedah Miller



STIGMA, PREJUDICE & THE RIGHTS of PEOPLE LIVING WITH HIV

Stigma is when something that a person has, or does, becomes marked as bad or negative.

Prejudice is a negative attitude or an opinion that is not based on reason or real experience.

Discrimination is the way someone, or a group of people, who are marked as different, are treated as less than others.

HIV-related stigma, prejudice and discrimination towards people living with HIV happen because of fear of HIV, which comes from a lack of information and knowledge about the virus.

Self-stigma is when people who are being stigmatised believe that they are bad or negative. This can happen to people who are living with HIV.

Dealing with stigma, prejudice and discrimination

On a personal level

If you are being stigmatised you can:

- ✱ *Join a support group of people living with HIV to avoid feeling isolated.*
- ✱ *Speak to a counsellor to help realise that this is the other person's problem not yours.*
- ✱ *Tell people who are discriminating against you how this makes you feel.*

At a community level

Stigma is often born out of fear or lack of knowledge. For this reason, HIV activists believe that the way to challenge stigma is to:

- ✱ *Create more public awareness through education.*
- ✱ *Openly disclose your status and share your personal story to show that people living with HIV are just like everyone else.*



When I was 18 I wrote this piece, 'An Open Letter To HIV', about how my self-confidence was less, how I felt less pretty and I felt less of a human being because of the virus. I posted it on my Facebook page and the next year I also read it at a poetry session. It was the first time I stood in front of the community to disclose my status. Most people were so supportive and so amazing. They did not stigmatise me at all. I hope they don't stigmatise other people."

YOU ARE NOT ALONE

GET HELP



Sadie Brown



THE RIGHTS OF PEOPLE LIVING WITH HIV

The Bill of Rights in the South African Constitution protects all people. This means that People Living With HIV (PLWHIV) have the same rights as anybody else.

- * *PLWHIV have a right to privacy. No one can give out information about a person's HIV status unless they agree.*
- * *Routine testing of a person for HIV for the purpose of protecting a healthcare worker from possible HIV infection isn't allowed.*
- * *PLWHIV have a right to medical treatment and care, including reproductive healthcare.*
- * *Women living with HIV have a right to make choices about their pregnancy. A woman cannot be forced to terminate her pregnancy because she is HIV-positive.*
- * *PLWHIV have a right to make decisions that affect their marriage and having children. Information and counselling around these decisions should be provided.*
- * *PLWHIV have a right to choose what kind of work they want to do. They cannot be fired, retrenched or refused a job simply because they are HIV-positive. No employer can require that a job applicant have an HIV test before they are employed or demand to know their status.*
- * *Children living with HIV have a right to attend any school.*
- * *PLWHIV have the same rights to housing, food, social security, medical assistance and welfare as all other members of our society.*
- * *Any person living with HIV has the right to live their life with respect, dignity and freedom from discrimination and shame.*



Do it for yourself and accept your HIV-positive diagnosis

***Know that you are not alone,
Know that you have support.***

You have the choice to live.

Choose life because you can.

ARVs allow you to live a long and healthy life.

So, look beyond your diagnosis.

And commit to a solution for positive living.

Initiate and adhere to ARV treatment.

Live better. Do more. Inspire others.

Zenzele! This is your life.

Your dreams and goals matter.

Don't ever give up on them because of an HIV-positive diagnosis.

Your status does not determine your future.

Do not wait.

There is no time to lose.

Don't hide away any longer.

Stand tall and leave your mark.

Start treatment today.

Adhere to treatment and follow-up with clinic visits.

It is not a punishment, it is the key to your health and future.

A key that enables you to do everything you planned.

Zenzele! The Future is ours!

The 'Zenzele Living with HIV' publication range includes the following brochures :



1 TREATMENT



2 DISCLOSURE



3 ADHERENCE



4 PMTCT



5 LOVE AND SEX



6 NUTRITION AND LIFESTYLE



7 ADOLESCENTS AND HIV



8 AGEING WITH HIV



9 UNDERSTANDING TB



10 WELCOME BACK

*If you are living with HIV
You are not alone. You can get help and support.
To find a Facebook support group write to
ask@brothersforlife.co.za or send us a message via our
page www.facebook.com/BrothersforlifeSA and we can
introduce you to a group moderator. You can also visit
www.brothersforlife.mobi
www.thefutureisours.co.za*

*For youth and adolescent support visit
www.facebook.com/BWiseHealth*

*There are also many experienced counsellors that
can help you at the organisations listed below.
All calls are free and counsellors are available
24 hours a day.*

*AIDS Helpline 0800 012 322
LifeLine 0861 055 555
Childline 0800 055 555 for children
and teenagers under 17 years
Momconnect *134*550#*

*If you are looking for HIV support services in
any part of the country visit
www.healthsites.org.za
to find a support group in your area.*

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