LIVING WITH HIV: ALL YOU NEED TO KNOW

Safe Sex

zenzele
The Future Is Ours

Age and HIV

Know your ARVs

HEALTH

SUPPORT

HAVING HIV NEGATIVE BABIES

WHAT DISCLOSURE OF HIV STATUS MEANS

Benefits of adherence

Viral Suppression

DECISION

PEPFAR

FPD

ACKNOWLEDGMENTS

This publication has been produced by the Centre for Communication Impact (CCI) with financial support from the United States President's Emergency Plan for AIDS Relief (PEPFAR) through the Centers for Disease Control and Prevention (CDC) with direction and technical support from the Foundation for Professional Development (FPD).

Acknowledgement is due the partners and individuals who made an input to the development of this publication, particularly people living with HIV (PLHIV) and the Department of Health who gave their time, effort and expertise to the process.

This publication is informed by a range of books, websites, manuals and other materials which are referenced at the end of the booklet.

ACRONYMS

The following abbreviations and acronyms are used in this book:

AIDS Acquired immune deficiency syndrome

ART Antiretroviral therapy

ARV Antiretroviral drugs

CD4 Cluster of Differentiation 4 T lymphocyte cells

CD8 Cluster of Differentiation 8 (glycoprotein) cells

FDC Fixed dose combination

HIV Human immunodeficiency virus

MMC Medical male circumcision

OI Opportunistic infection

PEP Post exposure prophylaxis

PMTCT Preventing mother-to-child transmission (of HIV)

PrEP Pre-exposure prophylaxis

STI Sexually transmitted infection

TAC Treatment action campaign

TB Tuberculosis

UTT Universal test and treat

CONTENTS

INTRODUCTION:

Five journeys living with HIV

Living with HIV is a life-long journey. For many, the journey follows the same path, although our personal experiences along this path are all different. We can all learn and get hope from other peoples' stories. In this book, we follow the journeys of five people who are living with HIV. The challenges that they have overcome and the positive lives they are living are inspiring. Their real-life stories can help us understand more about living with HIV.

Gugu Xaba

Gugulethu 'Gugu' Xaba is 24 years old and lives in Etwatwa. Gugu says that as a teenager she was careless and had unprotected sex with men, believing that this was a sign of her popularity. In 2012, she found out that she was HIV positive. She started ART immediately and changed her lifestyle. At the moment, she works at a car hire company. She has a support group on Facebook called HIV Survivor. She also writes for Shift an educational talk show on SABC1. She has a boyfriend who is also HIV positive and would like to have children one day.

Strike Tshabalala

Strike Fanyana Tshabala is 33 years old and lives in Shoshanguve. In 1999, he was hospitalised with a very bad skin rash that turned out to be TB. He found out he was HIV positive by accident when he looked at his medical file. It was only in 2006, after ARVs were made freely available at clinics, that he went onto ART. He is now a volunteer HIV counsellor at the Maria Rantho Clinic. He has been in a loving relationship since 2010 and has a 6 -year old daughter who is HIV negative.

Bheki Mazibuko

Bhekesisa 'Bheki' Mazibuko is 41 years old and lives in Winterveld. As a teenager, he had many girlfriends and knew nothing about HIV. In 1995, when he was in hospital, in hospital he overheard a nurse saying that he was HIV positive. This was confirmed in 1997 when he went to get tested. He joined the Treatment Action Campaign (TAC) which campaigned for the government roll-out of ARVs, in 2004. He started ART in 2009. Bheki is a volunteer HIV educator and has been interviewed on Ikwekwezi FM. He recently got divorced from his wife with whom he has two daughters.

Thomas Masego

Thomas Mashego is 41 years old and lives in Kabokweni. Thomas first found out he was HIV positive in 2013 but could not accept it. It was only when he got very thin and couldn't walk that he started on ART. He is strong now and counsels other people, particularly men, living with HIV in his community. He has a girlfriend but does not have any children with her.

Saidy Brown

Saidy Brown is 22 years old and lives in Itsoseng in North West. Both her parents had died by the time she was 10 but she never knew that they had been infected with HIV. She found out she was HIV positive at a school youth day when she was 14 but she wasn't counselled. She did not believe it was true until she got sick. In 2013, when she was 18, she tested positive again and went on ART. Both in her community and on Facebook she inspires youth living with HIV with her knowledge and her positive approach. She is in a relationship and would like to have children.

In this book, we have outlined the journey of living with HIV as a series of steps, each one of which is covered in a separate chapter:

Understanding HIV
Finding out your status
Disclosure and support
Making changes to your lifestyle
Starting treatment
Knowing your ARVs
Adherence to ART
Pregnancy and ARVs
Understanding co-infections
Age and HIV
Stigma, prejudice & the rights of people living with HIV
Believing in your future

1 Understanding HIV

Informing yourself about HIV is an important step towards being healthy.

> *“You see people die with HIV, because as young people growing, we are ignorant. We don’t think about the future of whatever the situation before you face it. The more you find more information, is the more you have knowledge.”* **Gugu Xaba**

HIV stands for the Human Immunodeficiency Virus. It is a virus that lives inside our bodies and cannot live outside our bodies on surfaces or in the air, and it cannot be spread through sneezing, touching, kissing, sharing dishes or toilet seats.

The only way we can get HIV is through contact with certain body fluids of an infected person. These fluids are blood, semen, vaginal fluids, rectal fluids (in the anus) and breast milk. The virus can only be passed on in three ways:

- Unprotected sex: having sex without a condom. This is the most common way that HIV is passed on in southern Africa.
- Blood contact: from one infected person to another person. This can be when drug users share injection needles, if a healthcare worker pricks themselves with a needle that was used on an HIV positive person; or through blood transfusions if the blood hasn’t been screened (which is very rare in South Africa).
- From a mother to a child: Mothers who have HIV can pass it on to their babies during pregnancy, labour and breastfeeding.

HIV does not spread as easily as some other viruses, like flu. There are also many ways to reduce the risk of HIV being passed on such as practising safe sex and people who are HIV positive taking treatment.

> *“I became sexually active when I was very young and I had my first child when I was 14 years old. I didn’t respect women at all. I was just sleeping around. After I tested positive I started changing and I developed respect for women. I made sure to protect every woman I met.”* **Bheki Mazibuko**

How HIV affects the body

The immune system is the body’s defence force. It is made up of an army of different kinds of white blood cells that protect the body against disease. HIV is a virus that attacks and weakens the immune system. It does this by hijacking the immune system’s CD4 cells. It clings to these ‘good cells’ and becomes part of them. It turns these cells into factories to make more copies of HIV which attack and destroy other CD4 cells. This means that as more and more HIV is made, more and more CD4 cells are destroyed. This is why if you are infected with HIV and are not being treated the amount of HIV in your blood (your viral load) goes up and your CD4 count drops. When your CD4 count is low and your immune system is weakened, your body can’t fight off other diseases, such as tuberculosis (TB).

What are CD4 cells?

CD4 cells are white blood cells in the immune system that fight off infection. They are sometimes called T4–cells or helper cells. Their job is to send a message to the CD8 ‘soldier’ cells in the immune system, to tell them to attack the virus. A CD4 count is a measure of how many CD4 cells there are in a small sample of blood. A normal CD4 count is between 800 and 1200. A low CD4 count means that you have a weak immune system.

What is viral load?

Viral load is the amount of HIV there is in the blood. The more HIV there is in your blood the higher your viral load will be. Viral load is measured as copies of the virus per millilitre of blood (copies/mL).

Antiretroviral therapy (ART) is a combination of different medicines, known as anti-retroviral drugs (ARVs) that are used to attack the HIV virus and reduce your viral load, and mean that you may never get AIDS.

Are HIV and AIDS the same thing?

People often talk about HIV and AIDS as if they are the same thing but they are not. HIV is a virus that causes infection. AIDS, which stands for acquired immunodeficiency syndrome, is a condition that develops when you have HIV and are not on antiretroviral therapy (ART). The HIV in your body multiplies and advances to AIDS in 10 to 12 years. If you have HIV and are not on treatment, your CD4 count drops to below 200 and your immune system is weakened so much that it is easy to get AIDS-related illnesses like thrush, TB, pneumonia and meningitis. AIDS is the last stage of HIV infection. On average you can live with AIDS for three years without treatment.

How HIV progresses

There are four recognised stages of HIV infection, which are:

These stages are a natural progression of the virus towards disease without treatment. If you are infected with the HIV virus and are not taking antiretroviral treatment (ART), you will progress from one stage of the disease to the next and to the final stage of AIDS. Treatment with ARVS can mean that you never progress to the later stages. Men and women go through the same stages but how each person reacts can be different.

> *"Many people don't know how to differentiate between HIV and AIDS. HIV is the virus, and AIDS is when you see the physical manifestation of what the virus is doing in your body. But HIV is the virus that attacks your immune system. AIDS happens when your immune system is down and then the virus takes over your system."*
>
> **Thomas Mashego**

2 Finding out your status

All sexually active people should know their HIV status. Knowing your HIV status helps you to make informed decisions on how to protect your health. If you are HIV positive you can get care and treatment, and avoid passing HIV on to others. If you are HIV negative you can protect yourself from getting infected.

> *"Between 2004 and 2008 when I was diagnosed with HIV, I had 2 stokes in 2005-2006 and I was admitted 2 weeks each time, then I had pneumonia, I was diagnosed with TB meningitis, then it was cancer which affected all my glands Angioimmunoblastic which is a rare form of cancer associate with HIV."*
> **Cindy Pivacic**

An HIV test is a blood test that shows if there is HIV in the body. The test shows if you have the antibodies that your immune system creates when it recognises that you have HIV in your blood. Having an HIV test is the only way to know your HIV status. A trained healthcare worker can do the test at any clinic, hospital or service centre. You can also test yourself by using an HIV self-test, but if you test yourself, you do not have a direct link to the services and care you might need. Testing for HIV is a personal choice and no one can force you to test for HIV.

If you go for an HIV test, you will need to give your consent, and you will be given counselling about HIV and what a positive or negative result means. The healthcare workers are committed to giving correct information and a correct diagnosis, through testing twice if necessary, and will ensure that you are connected to the services that you need after the test. They are also committed to confidentiality, and keeping your results private.

The most common HIV tests in South Africa is the rapid test: these tests are quick and give results within 30 minutes; and are the standard HIV tests offered by clinics and pharmacies. More sophisticated HIV tests are done at hospital-level, due to high costs.

Where should I go to get tested?

In South Africa, HIV testing is offered at government hospitals and clinics for free. Some pharmacies do HIV testing but you pay a small fee. They also sell home test kits that allow you to do the test at your home.

If my girlfriend is HIV NEGATIVE, do I need to get tested?

You cannot use your partner's status to find out your own status. HIV is not necessarily passed on every time you have sex. Therefore, it is quite common for one partner to be positive and the other to be negative but at some point, the virus will be passed on. It is important for each person to get tested for themselves and to know their status and act responsibly.

> *"There is this thing that men use their women as a testing kit. So, if a woman goes to the clinic to test and comes back negative, the man would take it that he is also negative. Men must stop having multiple partners, use condoms all the time, stop being abusive towards women and they must take care of their families. They must go to clinic. They'll find any help that they need thanks to government. Men must get tested and take care of themselves."* **Bheki Mazibuko**

The Window Period

Antibodies are produced by the immune system in response to an infection. For most people, it can take up to three months for these antibodies to develop after they have been infected with HIV. In rare cases, it can take up to six months for these antibodies to develop. This time is called the **window period**. During the window period, people infected with HIV have no antibodies that can be detected by an HIV test. However, the person may already have high levels of HIV in their body fluids such as blood, semen, vaginal fluids and breast milk. HIV can be passed on to another person during the window period even though an HIV test may not show that they are infected with HIV - a person is at their most infectious, but may not know that they are HIV positive.

Testing negative for HIV

If an HIV test result is negative, it means that you do not have HIV. However, you still need to do another HIV test after four to twelve weeks, to make sure that you are indeed HIV negative, as an HIV test will not pick up the virus if the test is done during the window period.

If you test negative for HIV, you may want to learn more about HIV and how you can stay negative, and practice safe sex to avoid getting infected at a later stage.

“In 2010, I tested negative. I told myself ‘Ok I’m clean’. At the time, I used to drink a lot. By the time I got home with someone the last thing I was thinking of is using a condom. I never used one to tell you the truth. The years passed. In 2012, I lost weight dramatically in one week. I wore size 28 trousers and I was size 40 before. My sister said: ‘Thomas, go and check for AIDS’. I flat out refused. Later I went with her to the clinic and I tested positive. I was very sick and bedridden. I said to myself if only I had acted back in 2010, I wouldn’t be in this situation.”

Thomas Mashego

Testing positive for HIV

For many people, getting an HIV positive diagnosis is a frightening and emotional experience. This is very normal reaction to the unknown. Some people will refuse to believe that the test is correct, and this denial is a way of trying to protect themselves by refusing to accept the truth. However, healthcare workers who do HIV tests always run a second test to confirm a positive result, and it is important to recognise that the positive diagnosis is accurate. It is important to visit your clinic or hospital as soon as possible after being diagnosed with HIV and to talk to your healthcare worker to start to understand your diagnosis. Your healthcare worker will talk to you about what it means to be HIV positive and will explain what will happen next.

“I started to get these sores around my breasts and arms. I blamed the sun, the heat and even brought an umbrella. I was living in my own bubble. I was still so much in denial that it never occurred to me that these sores were caused by the virus. I had to start treatment immediately.” **Saidy Brown**

There is no cure for HIV. However, with proper care and treatment you can live a healthy and productive life with HIV. It is better to start treatment as soon as possible and not wait until you get sick. If your CD4 count is low (200 or less), or you are already ill or have symptoms, it is important to start treatment as soon as possible. Your healthcare worker will talk to you about the treatment that is available to help you stay healthy.

“One of the older guys I was sleeping with passed away. People said it was AIDS. Eish! I tried to ignore it, but I couldn’t, because I knew I didn’t use protection. At the clinic, I did the test. I was very worried and scared. The result was positive. I thought it was the end of me and that I was going to die soon. But I met people at the TAC that were living with HIV for over 14 years. I started to say, ‘No, it’s fine, it’s not the end of me, but it’s the new beginning of me’.”

Gugu Xaba

3 Disclosure and support

Disclosure means telling a person something that has been a secret. It may feel hard to disclose that you are living with HIV, but it really helps you to cope with the diagnosis and get the support you need. Having support will make it easier to accept your status and adhere to your treatment so that you can enjoy a healthy and long life.

> *"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."* **Gugu Xaba**

Disclosing that you are HIV positive may be difficult

We all struggle with telling people things about ourselves if we feel that they will react negatively. After you have found out that you are HIV positive, you may feel too ashamed, guilty or upset to tell anybody. You may be afraid of being rejected or discriminated against by people in your community who do not understand HIV. But you may be surprised by the support and care loved ones will give you once you have shared this news with them.

Disclosing your status can be helpful

It is your right to decide whether you want to disclose your status. It is not something that has to be rushed into. You may want to get used to news of your HIV positive status and accept it before you share this news with other people.

When you are ready, disclosing to the right person can help you to get support and this can have many benefits.

- You will be able to take your ARVs freely. This will make it easier to adhere to treatment and reach viral suppression.
- Telling somebody will make it easier to cope with the illness.
- You can have a 'buddy' to support you and to remind you to take your treatment and go to your clinic appointments.
- If your feel accepted, supported and loved, you will have less stress, this means you will have a low 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. The unique warmness in terms of a reminder. Adherence, it's one of the biggest challenges because there will be a moment that 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 give me that word of encouragement: 'Remember where you came from. You can't give up today'."* **Strike Tshabalala**

How do I disclose my status?

If you want to tell other people about your status but don't know how to, you can speak to a counsellor at the clinic or use the five 'W' questions to guide you;

Who will you tell?

What will you tell them and what do you think the expected response will be?

When will be the best time to tell them?

Where will be a private, safe space to tell them?

Why do you think it is a good idea to tell them?

Before you tell somebody, you should think about how what you tell them will affect both you and them. Be prepared to give them information about what living with HIV means and answer any questions they might have.

Telling your family and friends

If you have loving family and friends, they will be understanding when you tell them about your diagnosis. If they do not know much about HIV, they may get very emotional because they think you are going to die soon or might even get worried that you will infect them by living in the same house. It will be up to you to help them understand to understand how HIV is transmitted and that HIV can be managed and with treatment you can live a healthy life and have a family. Explain how you are going to cope with having HIV and let them know how important their support is to you.

> *"So disclosure for me was extremely difficult. After a two-year period of being on ARVs silently got to a point where I couldn't anymore and I had my second mental breakdown and I landed in hospital."*
>
> ***Dorian Basson***

Telling your sexual partner

Telling a sexual partner that you have HIV might be the most important and urgent disclosure that you will have to make. Current and past partners who you have had sex with need to know that they could be at risk and should get tested. If you don't tell your partner, and you don't practice safe sex, you might pass the virus on.

> *"I told my girlfriend and she went for tests. The result came back negative, thank God, but it was 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 and AIDS issues. She supports me and will always be there for me."*
>
> **Strike Tshabalala**

When you are thinking about telling your partner, it is helpful to think about what you are going to say and how your partner might react. If you are nervous about telling your partner, you can speak to your healthcare worker who can help you to disclose and offer you couples counselling.

- If you are in a loving relationship, it is likely that your partner will be concerned but will support you. The fact that you have been open and honest might bring you closer.
- It may take time for your partner to come to terms with your status. Your partner may react with anger, feel betrayed or be afraid of having the virus. If you think your partner may get violent, it is advisable to have somebody else present.
- It is important to talk about safe sex practices, such as using condoms every time you have sex. Even if your partner is also HIV-positive, using condoms will prevent re-infection with a different strain of the HIV virus and protect you both from STIs.
- Let your partner know that with ART you can become virally suppressed and there will be very little chance of the virus being passed on.
- If your partner rejects you because you are HIV-positive, don't give up. You have done the right thing by disclosing. You will be able to have a loving relationship with somebody else.

> *"I told my boyfriend, but the following day he was acting funny. Sometimes he couldn't even reply to my messages, my WhatsApp's my call, then I could see that this guy was shocked or whatever, but I just told myself: 'at the end, I will find a partner who will accept me the way I am'."*
>
> **Gugu Xaba**

When do I tell somebody I have started dating that I am positive?

There is no right answer to this question. Some people feel that you should get to know each other better first. Find out how much they know about HIV and whether they are open to having a relationship with somebody living with HIV. This may make your disclosure easier. Other people feel that you should disclose your status before you get too involved so that you can protect yourself if the person rejects you. Being honest before you have sex is a good basis for open communication and trust.

Telling your child

There are many reasons why parents don't want to disclose their own HIV status to their children. They may feel ashamed, be afraid of their children's anger or want to protect the child from worrying that their parents are going to die soon. Children are often able to sense that something is wrong and they might worry less if they know what the problem is and that it can be managed.

> *"Looking back with the information I have now about HIV, I wish that my parents could have been more open to us as their children. I would have been so angry obviously, but it would have been easier for me to forgive them had I been told earlier. If they were open, they could have gotten the treatment that they deserved. Maybe they could still be alive to see me now because HIV did not kill me and it won't kill me."*
>
> **Saidy Brown**

Telling your child that you have HIV does not have to be a once off discussion. You will probably have many conversations about it. If you don't know how to begin the process, speak to a counsellor or other parents who have disclosed to their children.

There are some questions you can ask yourself before you disclose:

- **Am I ready to tell my child?** You need to accept your own status and have a plan for managing HIV before you can tell your child.
- **How much am I going to tell my child?** Your child's age should help you decide how much and what you want to tell them.

Reassure your child that you aren't going to die soon, unless you are very sick.

- **How am I going to tell my child?** Using language that is suitable for their age group will help your child understand more about HIV.
- You may want to protect your child from discrimination, but expecting a child to keep your status a secret may be too much of a burden for them. Children also need support and somebody to talk to about their concerns about your health. Ask your child whether there is anybody they trust and would like to share the secret with. Agree together on who they can tell, as they should know that she should not tell just anybody, as this might result in them and you being treated differently in the community.

Other situations where you may be asked to disclose or want to disclose your status

If you are living with HIV, there will be many situations where you are not sure whether to disclose your status. Often, this is when you think that NOT disclosing will result in legal action against you.

- **Medical insurance:** By law, medical aid companies cannot refuse you membership but they can ask you to disclose any medical conditions you already have when you sign up. If you aren't honest, then the medical aid can refuse to pay for HIV related treatment. Most medical aids have special benefits for people living with HIV, so it is advisable to disclose your status.
- **Life insurance:** Most life insurers require that you have a medical examination which includes an HIV test. They have the right to refuse your application if you have a condition which is life threatening. However, since people infected with HIV are living longer with ART, there are more companies that offer policies to people who are HIV positive.
- **Medical appointments or procedures:** Legally you do not have to disclose your status to health care practitioners, but it is advisable to tell them so that you can get the best medical care that you need. It is also important that they know if you are on ART as this can affect other medications that they give you.
- **Applying for a job:** Current or future employers cannot demand to know your status or discriminate against you if you are HIV positive. Even healthcare workers, such as nurses, do not have to disclose their status.

If you are unsure about whether to disclose your status, call one of the helplines listed at the back of this booklet.

> *"I found this job at an exclusive shop. They were impressed with my C.V and with me, but the contract mentioned HIV. I thought to myself: 'What if I lie? When I have to go and fetch my treatment, what will happen?' So, I emailed them saying 'I love the job, but I've seen on your contract that you don't want people living with HIV. I'm living openly with HIV. You will see me on TV talking about my HIV status, then it's going to be a problem with you'. They said: 'Thanks for being honest, but we don't need people who are HIV positive."*
>
> **Gugu Xaba**

Supporting others who tell you that they are HIV positive

If somebody has disclosed their status to you, they trust you. Let them know that you appreciate their confidence in you and that you do not think any less of them.

- Be kind and sensitive;
- Talk openly, but take the lead from them about how much they want to share with you;
- Learn about HIV so that you can understand their concerns;
- Show them that you understand and are not afraid of their status;
- If they are not on ART, you should encourage them to start soon;
- Ask them how you can help them to adhere their treatment and stay healthy;
- Give them practical help when they are sick;
- Reassure them that with treatment HIV can be managed and is not a death sentence;

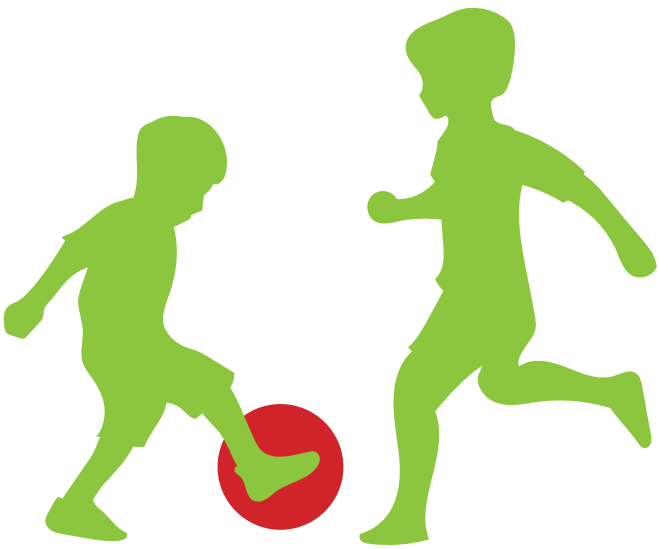
- Recognise the difficulties they face but don't define them by their illness;
- Let them know that you believe that being HIV positive does not mean that you are not still the same person you were before you tested;
- If you were friends before you heard about their status, do the things you did together before;
- Reassure them when they feel down and help them to empower themselves;
- Respect their trust and do not disclose their status unless they ask you to;
- If you are also HIV positive, you can share experiences and provide each other with support.

> *"My wife gave me support, she was always there. If I was ill in a hospital she would be there, she'll even remind me to take my treatment. She supported me emotionally, she was my pillar. She picked me up on my downfall. I am grateful I had such person in my life even though she is no longer with me, but I'll always remember her."* **Bheki Mazibuko**

Telling children that they are HIV positive

Telling children that they are living with HIV is emotionally very hard, but there will come a time when they will ask questions about their illness. Taking time to answer their questions honestly will help to create trust between you and create an ongoing conversation about living with HIV. Getting help from a healthcare worker who has experience working with children can be very helpful for a parent or caregiver.

The Department of Health (2015) gives the following advice about the information that should be given to children at different ages:



Telling children that they are HIV positive

3 Years

Focus on making sure children take their treatment so that it will make them to feel better. Don't talk about HIV

3- 9 Years

Talk about what it means to be ill, to have to go to the clinic and to take pills every day. Listen to how they feel without naming 'HIV'.

Explain that there are some things that they should only talk about to you, such as their illness. Tell them this is a secret that they share with you. This will protect children until they are older and more able to deal with what other people think.

10 + Years

It is very important to tell young adolescents that they are living with HIV. They may be angry and will want to know how they got the virus. But not telling them will make them even angrier. It may help to ask an HIV counsellor to be present when you tell an adolescent about their status.

These are some of the things you can discuss with them:

HIV infection and management: Explain how HIV is passed on and how it can be managed with treatment. Reassure them that they can still follow their dreams and have a future and a family.

Adherence: Explain that if they take their medication every day, they have a long life ahead of them. This is very important as adolescents often stop taking their medication when they find out what it is for.

Safe sex: They may be starting to experiment with their sexuality and need to understand how condoms can prevent the spread of HIV and STIs and prevent unwanted pregnancy.

If they express a need to talk to somebody else help them to find a counsellor or join a support group.

4 Making changes to your lifestyle

Living with HIV means that you are going to have to make some lifestyle changes. These changes will benefit all people who want to be healthy, whether they are HIV positive or negative.

> *"After I was tested positive that is where I stood up and I started to seek information because I wanted to know more about the infection that is in my body. HIV changed my life, it gave me a reason to live. Before I tested I was just too careless, but after I got tested I began to see how important life is."*
> **Bheki Mazibuko**

> *"No matter what your status might be, whether positive or negative, there is always hope. HIV is just a chronic disease just like other diseases the only thing is that you need to adhere to treatment. Yes, it was difficult, but the challenges we faced made us stronger."* **Strike Tshabalala**

Sex and HIV

There is no reason why people living with HIV should not enjoy a healthy sex life if you are feeling well, and communicate openly and act responsibly. Many people living with HIV are in loving relationships where one partner is negative and the other partner is positive or both partners are positive.

Many people in sexual relationship, may worry about passing HIV on to their partner. If you are taking ARVs and are virally suppressed there is a very small chance of passing HIV onto your partner. However, it is important that you use other HIV prevention methods.

- Use a condom every time you have sex. There are condoms that are used by males and others which are used by females. Condoms reduce the risk of an HIV negative partner being infected with HIV and are also a protection against sexually transmitted infections (STIs). Even if both partners are positive there is a risk that they will re-infect each other if they don't use a condom. This can result in a drug-resistant strain of HIV.
- Use a water-based or silicone-based lubricant or 'lube' with a condom to stop it from breaking. Using a lubricant can also stop skin from tearing and providing openings for HIV or STIs to enter the body. Never use an oil-based lubricant, Vaseline or other cream or oil as this can make the condom burst.
- Test for and treat sexually transmitted infections (STIs) quickly, because they increase the risk of HIV infection.
- Reduce the number of sexual partners you have.
- If you are a man, consider medical male circumcision (MMC) which removes the foreskin and reduces the risk of HIV infection and STIs. It does not totally remove the risk, so it is still advisable to use a condom.

> *"Even though I am undetectable I always use a condom. I'm very conscious of it because I don't know where you were last night, so no, sorry. I'm not getting a different strain here. I'm not getting STIs."*
> **Dorian Basson**

Can you get HIV from oral sex?

The risk is very low but if you have cuts in your mouth or on your genitals, you should avoid oral sex.

I am HIV positive and my condom broke while I was having sex. Is there a pill that my partner can take to prevent passing on HIV?

Any person you have had sex with can take PEP (Post-Exposure Prophylaxis) which is only used in emergency. It should be taken within 72 hours of being exposed to the virus. PEP is a 28-day course of antiretroviral drugs (ARVs) and must be prescribed by a doctor. If you are virally suppressed the chance that you have infected your partner is very low, even if the condom does break.

PrEP: Using ARVs to prevent HIV infection

PrEP which stands for Pre-Exposure Prophylaxis, is the use of ARVs to reduce the risk of HIV infection in people who are HIV negative.

This involves taking a daily dose of Truvada, a fixed dose combination of two ARVs, tenofovir and emtricitabine. When you start using PrEP you must take the medicine at least 21 days before you are exposed risky sex and very day for as long as you feel at risk of HIV infection. You must take PrEP every day and go to the clinic for follow-up checks every three months.

PrEP is NOT taken for life, but once you start taking it you must adhere to the treatment for the duration of the course. It is advisable to continue using PrEP for 28 days after your last exposure to risky sex to make sure that the treatment is effective. Thereafter, you can stop treatment.

How PrEP works

When you take PrEP, you will have high levels of ARVs in your blood and body. The ARVs in your body will stop HIV from attacking the immune system and making copies of itself. This will stop you from getting infected.

When taken correctly and every day, PrEP can reduce the risk of HIV infection by up to 92%, but it is advisable to still use a condom to prevent pregnancy and infection with STIs.

Where Can I get PrEP

In South Africa PrEP is available and can be prescribed by Doctors, but it is not yet free in public clinics and health facilities. At the moment, it is only offered in private clinics and can be bought at pharmacies.

Talk to your healthcare worker to find out more about PrEP and the steps to follow if you or your partner wants to start PrEP.

Adhering to ART

If you are living with HIV, one of the biggest lifestyle changes is starting ART and taking treatment for the rest of your life. If you want to stay strong and live a healthy life, you can never stop your treatment. Your body might take some time to adjust to the side-effects of the ARVs, and you will need to remember to always collect your pills in time, so you don't run out, and you have them with you when you need them so you can take your treatment at the same time every day.

> *"It's a life-time commitment, more than marriage. In marriage, you can wake up and say: 'I'm tired of this wife. I'm tired of this husband. Now I divorce'. With ARV's when you take the decision of divorcing, you must know that you are digging your own grave. I know it's not easy when you are in the battle, but just hang on there, and say: 'I will pass this stage'."*
>
> **Strike Tshabalala**

Living healthily

The healthy lifestyle that people on ARVs are encouraged to follow is the same lifestyle that we should all follow if we want good health. The combination of treatment and living a healthy lifestyle will build up your immune system and keep you strong.

- Maintain a healthy weight and make healthy food choices like eating a balanced meal- this could include more vegetable and high fibre food, and avoiding oily food. If possible create your own vegetable garden and cook your own fresh food. Take away food is mostly unhealthy and is more expensive;
- Drink lots of water;
- You may want to cut down or maybe even stop smoking and using alcohol and drugs. Too much drinking or drug use can affect your liver. It can also lead to poor adherence;
- Get enough sleep so that you get enough time to rest and relax. This is good for strengthening your immune system;
- Exercise regularly, this could be simply taking a walk every day.

> *"I don't take expensive supplements. Now I know what to eat and what not to eat. When I'm doing my groceries, I make sure I've got fruit, I've got healthy stuff on my list. Even my family, because we eat as a family, they even get used to my diet."*
>
> **Gugu Xaba**

Staying mentally strong

Living with HIV is challenging because ARVs can make you feel sick; visits to the clinic can be tiring and long; you may worry about your health and there is still a lot of stigma and discrimination against people living with HIV. If you feel stressed, you should reach out to your friends for help, join a support group or speak to a spiritual leader. Some people find that prayer gives them great emotional support and hope. Others find that setting goals for themselves and thinking about things to look forward to in their life make them feel stronger.

One way to develop resilience is to think about the things that you are good at and other successes you have had in your life. If you have overcome problems before, you have the strength to overcome this one too. Talking to a counsellor at your clinic about your fears and feelings can help you to find ways to deal with your emotions.

> *"I talk to a lot of young people through my social media platforms because I am very vocal about my status on social media. Usually I get approached by a lot of young people and I always let them know that it is not the end of the world. For many years HIV has been painted as this huge monster. You literally just live but you are walking dead. But it works with your mind. If you tell yourself: 'I am going to die'; then you're going to die. Rather focus on taking your treatment. Be mentally positive, be mentally a very strong person."*
>
> **Saidy Brown**

5 Starting treatment

The sooner you start treatment after testing positive, the better. South Africa has a Universal Test and Treat (UTT) Policy, which means that anyone who tests positive for HIV can start treatment straight away, no matter what their CD4 count is. This treatment is free for all who need it at government hospitals and clinics.

> *"Starting treatment changed my whole outlook on HIV as a virus. I used to be very skeptical, but seeing the results of how good and better the ARVs made me feel, it has changed the outlook of my life because now I can confidently say that living with HIV is not that bad."* **Saidy Brown**

> *"We have everything that we need in our clinics. We have the whole package now: dietitians, nutritionists and everything. The treatment is available everywhere, so people must take the treatment and adhere to it so that they can live longer."* **Bheki Mazibuko**

Antiretroviral drugs (ARVs)

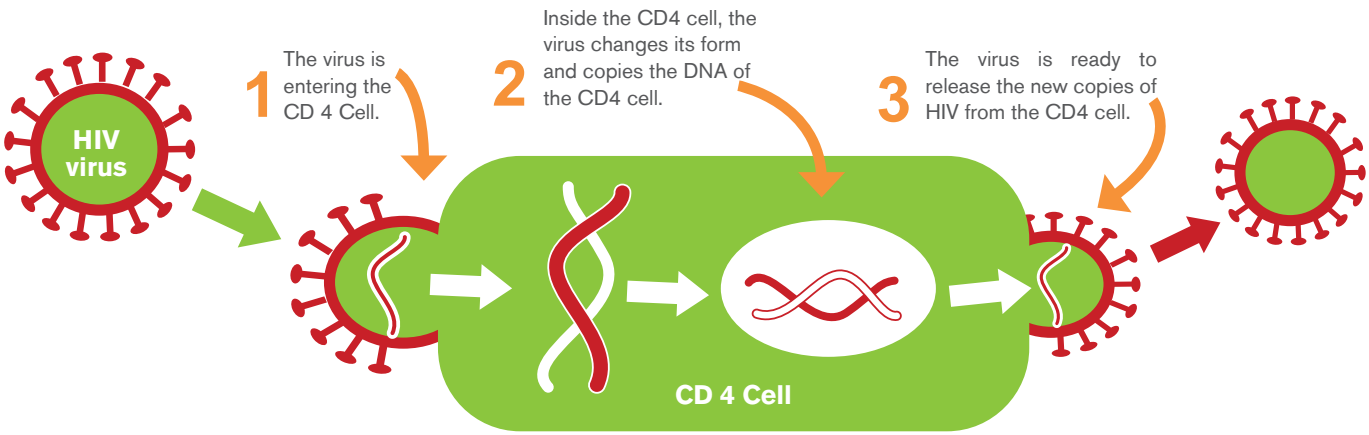
There is no cure for HIV. Antiretrovirals, or ARVs, are drugs that work to suppress or control HIV. They are the only effective way to control HIV infection. ARVs stop HIV from making more copies of itself and taking over the CD4 cells and destroying the immune system.

When HIV treatment is taken properly, the viral load decreases, which means that the amount of HIV in the blood and body goes down; and at the same time the CD4 Count goes up so that the immune system can recover and becomes strong again.

To suppress HIV effectively, three different ARVs must be taken together as antiretroviral therapy (ART). Often these drugs are combined into just one tablet. The different drugs work together to put up roadblocks that stop HIV, to make sure that it can't hijack CD4 cells. The different points that the drugs work at are when:

1. The virus is entering the CD4 Cell
2. The virus is inside the CD4 cell
3. The virus ready to release the new copies of HIV from the CD4 cell

The different Points that ARVs work and when



Can ART cure HIV?

There is no cure for HIV yet. Once you have the virus in your body, it will always be there, even if the levels are very low. ART is the best treatment option available if you take it correctly. Since the South African government introduced ARVs into its hospitals and clinics, the number of AIDS-related deaths has dropped and fewer people get sick with HIV-related illnesses.

The goal of ART is viral load suppression.

Anti-retroviral therapy (ART) reduces the amount of the HIV virus in the body. The goal of ART is for you to reach viral load suppression. Viral load suppression is when there are less than 50 copies of HIV per millilitre of blood and the virus does not show up in a blood test. You can only become virally suppressed if you take your ARVs correctly every day at the same time, as prescribed by your healthcare worker. In the first two to eight weeks of treatment, your viral load can drop by 90%. But ARVs can leave your body very quickly. If you skip doses or stop taking your ARVs, the HIV will take the chance to grow stronger and attack the immune system again. Without treatment, your viral load can increase daily to up to a million copies of virus per drop of blood. If you are virally suppressed you can enjoy a full and healthy life. You also have less chance of passing HIV on to your partner.

I am on ARVs but my viral load hasn't dropped. Why?

Sometimes ARVs do not work as they should to suppress your viral load. There are different reasons why this happens:

- Not every drug works for the same way for every person;
- After being on an ARV regimen for a period of time, it may stop working for you;
- If your viral load is very high when you start ART, you may need stronger ARVs or more than the standard combination of three ARVs;
- If you are taking other medication it may reduce the effect of the ARVs;
- If you stop taking your ARVs you may become resistant to one of the ARVs you are taking. This means it will no longer work for you.

There are many different kinds of ARVs that your doctor can prescribe for you if the first ones that you take are not working to suppress your viral load.

Getting started at the clinic

If you have not had an HIV test, you will be offered counselling before you are tested. This is to explain how the test works and what the results mean. This is a private conversation between you and the counsellor.

If you have tested HIV positive, you will be counselled before you start your treatment. ART is a lifelong commitment so the counsellor needs to be sure that you:

- Have a good understanding of HIV infection and the benefits of taking ART;
- Are fully aware that treatment must be taken correctly every day for it to work effectively;

Do not unmanaged alcohol or drug problems that might interfere with your treatment;

- Have a support system of people who you can share t h e news of your diagnosis with and who can help with taking your treatment. If you do not, the counsellor may encourage you to disclose to at least one person who will become your treatment supporter or 'buddy.'

If the counsellor feels that you have not yet accepted your HIV status or are not ready to commit to taking ARVs every day for the rest of your life, your treatment may be delayed until you are ready.

When you are diagnosed as HIV positive, you will have two blood tests to see how far the disease has progressed. This includes a CD4 count and a viral load test. These tests are carried out before you start treatment and you will have the same tests regularly when you are on ART.

The CD4 count

Before starting ART, the CD4 count is the best way of telling how healthy your immune system is and how urgently you need to start treatment. The higher your CD4 count, the stronger your immune system is. But starting treatment sooner, and not waiting to be sick or have symptoms is better. South Africa has a Test and Treat Policy, which means that if you test positive for HIV you can start taking ARVs immediately, no matter what your CD4 count is.

- The CD4 count test measures how many CD4 cells there are in your blood;
- Test results are given as cells per cubic millimetre (cells/mm3) of blood;
- A result of about 500-1,500 is considered healthy;
- If your CD4 count is low (200 or less) it is important to start treatment as soon as possible. But it is better to start treatment before your CD4 count drops.
  - The CD4 count test will be repeated every 12 months

> *"The medication is what saved my life. When I first started treatment my CD4 count was very, very low. I was bedridden. But last month, when I went to the clinic I found that my CD4 count was up and perfect. I feel like a young person again. It's not like I'm an old man that needs a walking stick to help him like before. I'm alive again. Nothing can stop me."*
> **Thomas Mashego**

The Viral Load (VL) test

After starting ART, the viral load (VL) test is the best measure of how well the body is responding to treatment and whether you are virally suppressed. When a person is virally suppressed, their CD4 count usually goes up, but this is not always the case. CD4 counts are affected by many factors such as the time of day or illnesses like herpes or flu. A viral load test will be repeated a few weeks after you have started treatment, and then again after 6 months; and once every year when you are virally suppressed.

- The viral load test measures how much of the HIV virus there is in your blood.
- Results are given as copies of the virus per millilitre of blood (copies/mL).
- If there are less than 50 copies of the virus in one millilitre of blood, the virus will not show up in the blood test, which means that the virus is suppressed by the ARVs you are taking.

Other tests

You will also be screened and tested for Tuberculosis (TB) before you start treatment. If you have TB, you will be started on TB treatment before you are given ARVs. You will also be screened for any sexually transmitted infections (STIs), hepatitis, and other illnesses associated with HIV. You may be given blood tests that measure liver function, kidney function, blood sugar levels, cholesterol levels and heart function. These tests allow your healthcare worker to understand your overall health better and they will know which is ARVs will work best for you.

Before you start treatment, your healthcare worker will ask you about:

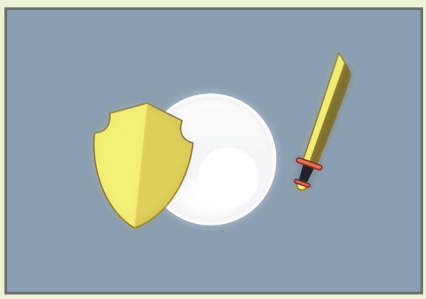
- Your medical history and any other medical conditions you have;
- Any other medications you are taking, in case they do not mix well with ARVs;
- Your daily routine, so that you can agree on a time for you to take your ARVs that fits in with your schedule;
- Any issues at home or at work that might make it hard for you to stick to your treatment.

Before you leave the clinic, you need to find out:

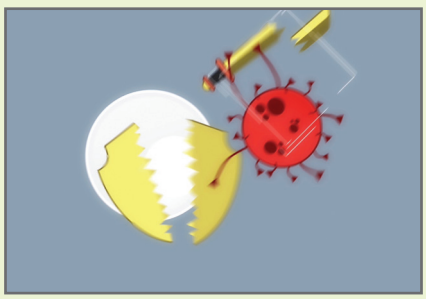
- What the different medicines are that you must take;
- What the side-effects might be, and how to deal with these;
- How much to take of each medicine;
- When to take each medicine;
- What to do if you forget to take your treatment;
- What to do if you vomit or have diarrhoea after taking the treatment;
- Whether the medicines must be taken with food or not;
- What to do if you are taking any other medicines;
- How the medicines must be stored;
- When you need to go back to the clinic.

It is important that you continue going to the clinic regularly once you start treatment, so that your progress can be monitored and any side-effects or other infections can be managed.

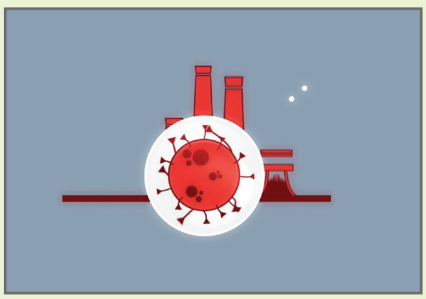
How ARVs Suppress HIV



1. We all have CD 4 cells in our blood, soldier cells that fight infections when they enter the body.



2. We do not have weapons to fight HIV.



3. So when HIV enters our blood, it turns our soldiers cells into HIV factories

Don't let side-effects stop you from starting treatment

Often people are scared to take ARVS because they have heard bad stories about their side-effects. Like all drugs, ARVs may have side-effects but it is important to remember:

- When you first start ART, you may have side-effects, but not everybody does;
- Two people taking the same drug may have different side-effects;
- Side-effects usually only last a week or two while your body is getting used to the ARVs. If the side-effects continue, go to the clinic to get help managing them.
- If you have serious or side-effects, your healthcare worker may change your ARVs.

> *"When I started to take treatment in 2006, it was Stavudine. That was the only accessible ARV at that time. My bum started to become big. My thighs started to become big. It was challenging because everybody was asking me, 'What's happening to you?' But you know it's a process that will last for a certain period. Then afterwards it actually goes away."*
> **Strike Tshabalala**

ARVs are the only effective way to control HIV infection.

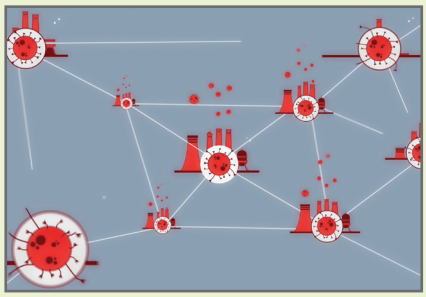
Even if you have problems when you start antiretroviral therapy (ART), it is important to continue with the treatment. If you adhere to your drug regimen it can be life-saving. Adherence means keeping to something. Taking treatment consistently and correctly is called adherence, this means taking all your drugs every day at the same time. Adherence to ART leads to viral suppression, which has many benefits.

- HIV is no longer harming the body, which means you can live a long and 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 is little to no chance of passing the virus onto a sexual partner.
- There is an opportunity for an HIV-positive person to have HIV-negative children without passing the virus onto their partner.

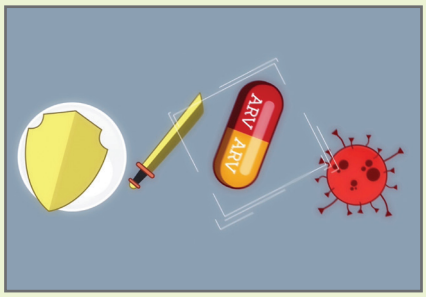
> *"Please take a chance on these antiretroviral (ARV) pills. Look at me. Four years of treatment and I am still here. I know now that I really need these pills. I have seen the difference it has made in my life and to my body. The pills have made living with HIV become so easy."* **Saidy Brown**

There are many traditional healers and religious leaders who claim that they can cure HIV. There is no proven cure for HIV, but ARVs have been proven to be effective in controlling the virus. It is important to get the support you need from your faith and from cultural practices, but to be aware that these cannot cure you.

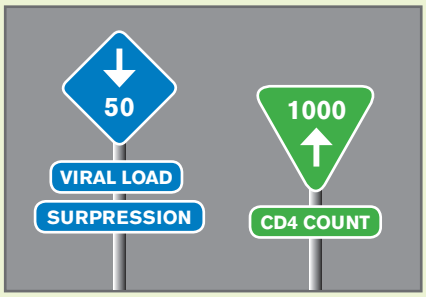
> *"I never consulted healers. There are people who will tell you: 'Drink this. If you eat healthily, if you go to this church, they heal HIV'. I even get messages on Facebook: 'Please e-mail me, I can heal HIV'. It is dangerous. Then I'll say: 'You know what, I'm fine with my ARV's. As soon as the government has got a cure, then I will have access to that, as I am having access to ARV's."* **Gugu Xaba**



4. These make more HIV infect cells, which then make more. There more HIV in our blood, the higher the viral load, the lower the CD4 count.



5. ARVs can stop the cycle. They strengthen the soldiers cells and shut down the HIV factories



6. The CD 4 count goes up and the viral load goes down.

6 Knowing your ARVs

If you are on ARVs, you should know as much as you can about them and about how they work.

> *"Treatment and adherence is something that needs understanding. Firstly, when you are adhering you must understand what exactly are you adhering to and why do you need to adhere to it. Adherence is when you comply according to the doctor's prescription."*
>
> **Strike Tshabalala**

If you are on ARVs, you should know as much as you can about them and about how they work.

ARVs have generic names and brand names and it is important to know the difference.

The generic name of the ARV medicine is the ingredient or recipe it is made of. The brand name is the name that the pharmaceutical company gives it and that it is sold under.

Two different pharmaceutical companies can make the same ARVs with the same ingredients. Each of them will give their ARVs different brand names. The pills might be different colours or shapes, and come in a different package, but they have exactly the same chemical ingredient in them. The most important thing to know is the generic name of the ARVs.

Chemical Name	Brand Name
Abacavir	Ziagen
Ritonavir	Norvir
Efavirenz	Sustiva
Emtricitabine	Emtriva
Lamivudine	Epivir
Lopinavir	Norvir
Nevirapine	Viramune
Tenofovir	Viread
FIXED DOSE COMBINATION (FDC) is one pill that combines 2 or more ARVs	
Chemical Name	**Brand Name**
Emtricitabine + Tenofovir	Truvada
Lopinavir + Ritonavir	Aluvia or Kaletra
Tenofovir + Emtricitabine + Efavirenz	Atripla, Atroiza, Odimune, Tribuss, Trutiva

There are many different kinds of ARVs and that means there are different treatment regimens. A regime in a particular prescribed course of treatment. When someone starts ART, the healthcare worker will discuss which regimen (which ARVs) will work best for that person.

First-line treatment is the course of drugs that is the simplest and generally the most effective treatment. Unless you have a complicated case, you will be given the first-line regimen of ART which involves a combination of three ARVs in one pill, known as a fixed-dose combination (FDC).

Treatment regimens for all people initiating ART, 15 years and older (Adapted from: Department of Health, 2015)	
Regimens for all people who test positive for HIV including: • Pregnant & breastfeeding women • People with Hepatitis B • People with TB	• Tenofovir (TDF) + Emtricitabine (FTC) + Efavirenz (EFV) (Usually given as 3 ARVs in 1 pill taken once a day and known as the fixed-dosed combination or FDC) **OR** • Tenofovir (TDF) + Lamivudine (3TC) + Efavirenz (EFV) **OR** • Tenofovir (TDF) + Emtricitabine (FTC) Dolutegravir (DTG)+ Available from 2018
If Efavirenz is not right for someone, it will be replaced with Nevirapine.	• Tenofovir (TDF) + Lamivudine (3TC) + Nevirapine (NVP)
If Efavirenz and Nevirapine are not right for someone, they will be replaced with Lopinavir/ Ritonavir.	• Tenofovir (TDF) + Emtricitabine (FTC) + Lopinavir/Ritonavir (LPV/r) **OR** • Tenofovir (TDF) + Lamivudine (3TC) + Lopinavir/Ritonavir (LPV/r)
If Tenofovir is not right for someone, it will be replaced with Abacavir	• Abacavir (ABC) + Lamivudine (3TC) + Efavirenz (EFV) **OR** • Abacavir (ABC) + Lamivudine (3TC) + Nevirapine (NVP)

ART side-effects

Many people will experience some side-effects when they first start taking their ARVS. This is normal, as your body adjusts to the treatment. Different ARVs may give you different side-effects.

Chemical Name	Brand Name	Nausea - wanting to vomit	Headache	Diarrhoea-Running stomach	Skin Rash	Extreme Tiredness	Dizziness	Other symptoms
Abacavir	Ziagen		X	X	X	X		• Fever
Ritonavir	Norvir	X	X	X			X	• Tingling or numbness around the mouth.
Efavirenz	Sustiva				X		X	• Trouble sleeping • Strange dreams and nightmares • Confusion or feeling mixed up • Not being able to concentrate • Feeling down and mood changes • Having visions • Loss of memory • Confusion • Feeling 'stoned' • Feeling unusually happy
Emtricitabine	Emtriva	X	X	X	X			• Skin discolouration
Lamivudine	Epivir	X	X		X	X		• No appetite • Sore stomach
Lopinavir	Norvir	X		X	X	X		• Sore stomach • Tingling or numbness around the mouth. • Lipodystrophy • Changes in the shape or place where your body fat collects (especially in your arms, legs, face, neck, breasts, and waist).
Nevirapine	Viramune	X	X	X	X(especially women)			• Sore stomach • Muscle pain
Tenofovir	Viread	X	X	X	X		X	• Sore stomach • Trouble sleeping • Feeling down and having mood changes • Lipodystrophy
FIXED DOSE COMBINATION (FDC) ARVs = 2 or more ARVs in 1 pill								
Emtricitabine + Tenofovir	Truvada	X	X	X	X		X	• Feeling down or anxious • Sore stomach • Trouble sleeping • Strange dreams • Joint pain • Back pain • Itching • Lipodystrophy • Changes in the colour of your skin on your palms or the soles of your feet

Managing the side-effects of ARVs

All side-effects can be managed, and many will go away once your body has got used to them. If you have side-effects, don't give up on your treatment. There are medications to manage some of the side-effects common to ARVs, but there are also other things you can do to feel better. It is best not to take any herbal remedies without consulting your doctor as they may not mix well with your ARVs.

Side-effect	Treatment	Other strategies to reduce side-effects
Nausea (wanting to vomit) or vomiting	Anti-nausea medication	• Avoid oily or spicy foods • Eat dry foods like toast • Sip on black tea • Drink water with lemon juice
Diarrhoea (running stomach)	Anti-diarrhoeal medication	• Eat very ripe bananas, rice or toast • Avoid milk • Drink water that contains salt and sugar
Headache	Pain killers	• Drink lots of water • Lie down and put a cold wash rag over your face • Massage the base of your skull with your thumbs
Skin rash	Anti-histamines	• Use a natural soothing cream calamine lotion or castor oil
Loss of appetite		• Eat small meals regularly • Eat foods you like even if you aren't hungry • Avoid foods that have no nutritional value
Dizziness		• Take your pills before you go to sleep and are lying down. Some people who have nightmares prefer to take their pills in the morning so their sleep isn't interrupted. Either way you need to talk to your doctor about this.
Tiredness		• Go to sleep at the same time every night and get up at the same time every morning • Don't drink alcohol

"I encourage people to take the pills, but I do not want to tell them the side effects because we are so scared and so focused in the side effects. I say to them: 'It is fine, you might not believe me, but please take a chance on these pills. I also took a chance and look at me now, four years later of treatment I am still here." **Saidy Brown**

Get medical care as soon as possible if you experience:

A severe running stomach that leaves you feeling weak and dizzy for over 24 hours.

Severe vomiting that leaves you feeling weak and dizzy for over 24 hours.

Extreme tiredness that makes you inactive.

Extreme dizziness that makes it difficult to stand or walk.

Serious rash with open sores.

"I was scared, because people say a lot of things: 'You will get sicker when you start treatment. There are side-effects'. I was very stressed, because at that time I was working at the restaurant. They say you see animals when you take your medication. In my mind, I said: 'What would happen if I see animals while I'm at work, what people will say?' The first week when I started treatment, I had bad dreams. But it happened for three days, and then I was okay. I didn't have any more side-effects." ***Gugu Xaba***

Side-effects of ARVs

Nausea
(wanting to vomit) or
vomiting

Diarrhoea
(running stomach)

Skin rash

Tiredness

Loss
of appetite

Headache

Dizziness

7 Adherence to ART

Adherence to ART means taking your medication exactly as your healthcare worker has explained it, and leads to viral load suppression. This is when ART has reduced the amount of HIV virus in the body so that it does not show up in a blood test and the immune system gets a chance to repair itself. If you are virally suppressed, there is very little chance you will pass the virus on to others and you will be able to live a healthy and long life.

> *"The most important is you must stick to treatment. Adhere to treatment. The treatment is one thing that can help you to live longer and is the only thing that can stop the virus to multiply. If you take the treatment accordingly, you will also see the difference in your life; even other people won't believe that you are positive."*
>
> **Bheki Mazibuko**

What adherence to ART means

For ART to work it needs 100% adherence. This means:

- Never skipping a dose;
- Never taking a break for any length of time;
- Taking your medication at the same time every day;
- Taking our medication with a healthy meal or on an empty stomach, depending on what has been prescribed, as this affects how well the ARVs are taken into the system;
- Not taking any other medication, even over-the-counter medicines, that might interfere with the work of the ARVs, without discussing this with your healthcare worker.

What if I skip a dose?

Take the missed dose as soon as possible, unless it is almost time for the next dose In that case, the next dose must be taken and treatment continued as usual. Never take a double dose to make up for the missed dose.

What if I vomit after taking my ARVs?

If you vomit less than an hour after taking your ARVs, you should take the dose again.

Should ARVs be taken with or without food?

It is best to take ARVs after a meal but fatty foods should be avoided.

If you don't adhere to your treatment you will become drug resistant

Missing treatment, skipping doses, or stopping ART can lead to drug resistance. If ART is not taken properly, the level of the ARVs in the blood gets low and HIV takes the chance to make changes to itself that can cheat the ARVs. The new version of HIV may be resistant to the medication that you have been taking. The ARVs you have been taking will no longer be able to suppress the virus. HIV will continue multiplying and your viral load will increase.

If you have been on a regimen of three ARVS in one pill, known as first-line treatment, this will mean that you will need stronger ARV drugs, which may have more side-effects. These stronger ARVs are called second-line ART. If you do not adhere to this again, you may need to be hospitalised and put on the third-line treatment which consists of four ARV drugs. There are only a limited number of ARVs that can be used to treat HIV, and after this there may not be any treatment options for you. This is why adherence to the prescribed treatment is so important.

> *"There was a time that I said: 'Enough is enough' with my treatment, for almost a month because of a lack of support. I started to develop a problem with swallowing and I started to develop complications and symptoms of HIV and AIDS, with swelling of my legs and so forth. And the TB was coming back again. I weighed just 22 kilograms! Then I realised that if I want to live, I must adhere to my treatment."*
>
> **Strike Tshabalala**

The benefits of adherence

Adherence leads to viral suppression which means that you will be:

- Much healthier;
- Able to work without needing to take off too many sick days;
- Less likely to pass on the virus to a partner;
- Able to have children without passing the virus onto them;
- Live a longer life.

Tips for taking ART

Taking ART is a lifelong commitment and that might feel overwhelming sometimes. But there are practical steps you can take that to help you to adhere and become virally suppressed:

- Practice sticking to a routine by using sweets and eating them every day before starting ART.
- Get a 7-day pillbox and fill it at the start of the week as a way to make sure you take your ARVs and any other medication;
- Send yourself a reminder on your cell phone or set an alarm clock to ring when you need to take your dose of ARVs;
- Have a reliable 'buddy' who reminds you that it is time for you to take your treatment;
- Use cell phone messaging or a wall calendar to remind you to go to the clinic a week before your medication runs out;
- Keep your ARVs in the same place, where you have breakfast or carry out other daily activities like brushing your teeth or watching your favourite TV show;
- Keep two sets of pills, with one at home and one with you, so that you don't miss a dose if you are away from home;
- If you are going away make sure that you take enough ARVs to last the time that you are away.

> *"One thing you must realise, taking ARVs is a journey that you need to uphold for the rest of your life and what people do not realise is that you cannot just decide that tomorrow I'm not going to take ARVs."*
> **Fagmedah Miller**

Make sure you have support

Adhering to ART is easier when you have support. To find this support you can:

- Disclose your status to somebody you trust who will encourage you to adhere to your treatment;
- Talk to other people who are on ART so that you feel less alone;
- Join a support group at the clinic or in the community;
- If you have been on ART for two years and are stable, you can join an adherence club which meets every two months. You will be able to get a two-month supply of ART. Over the Christmas holidays you will be given a four-month supply of ARVs. A healthcare worker will do basic check-ups and provide group counselling. If you are doing well on your treatment, you will only have to go to the clinic once a year

> *"I don't ever forget my medication. Even when I go out with my friends, they know when it's 8 o'clock, I leave everything and I take my medication. Even if I'm far, maybe going to a workshop, my mom is very supportive. She will always check on me: 'Gugu, did you take your medication?' Having support helped me a lot and other people sharing their stories helped me big time."* **Gugu Xaba**

Adherence might be more challenging if you are an adolescent, a pregnant woman or the parent of a child taking ARVs; and you may benefit from a support group of people who are in the same position as you.

Pregnant women may find it helpful to get together with other pregnant women to discuss all of the changes they are going through and any fears they might have about the health of their babies. This support will be important after childbirth, as mothers may be overwhelmed with additional responsibility and default on taking their ART.

Adolescents who are already dealing with many physical and emotional changes often stop taking their ARVs. Being in a support group under the guidance of an older mentor may help them adhere to their treatment.

Parents or caregivers may find it lonely being the only person responsible for giving a child ART. Talking to other parents in the same position might make it less stressful and they can share strategies on how they talk to their children and how they cope with the situation.

If I drink alcohol will my ARVs still work?

Drinking excessive alcohol is not good for anybody. The biggest risk if you are on ART is that you will get drunk and forget to take your ARVs. Or you may forget about practising safe sex or engage in other risky behaviour.

8 Pregnancy, HIV and ARVs

It is possible to get pregnant if you have HIV, and to have a healthy baby. If you do not wish to get pregnant, you should use a condom when you have sex. If you do wish to get pregnant, you should speak to your healthcare worker about how to do so safely.

> *"When you are negative and your partner is positive, it is important to follow the doctor's orders. A doctor will give you options on how can you protect your child from being positive. After my wife got pregnant she received the medication to prevent the mother to child infection. She is negative but she took the ARVs during the pregnancy. After birth, she stopped taking them and the child continued with the treatment for 28 days. My child is fine. My kids are the example that you can have HIV and still have beautiful kids."*
>
> **Bheki Mazibuko**

Falling pregnant when you have HIV

Many people living with HIV have children who are HIV negative. There are different ways that you can greatly reduce the risk of the virus being passed on to a child depending on your condition. This may vary from couple to couple. Before you try to fall pregnant discuss your options with a doctor.

If the father is HIV positive and is virally suppressed:

The risk of a baby being born HIV positive is related to the HIV status of the mother, not the father. If a man is positive, is on ART and is virally suppressed; then there is very little risk that he will pass the virus onto the mother. However, to be safe if they are having unprotected sex the man must have been be virally suppressed for at least 6 months.

If the father is HIV positive and not virally suppressed:

If the man is not virally suppressed, the woman can take pre-exposure prophylaxis (PrEP) for the period that they are trying to conceive. This is a preventative medication which prevents HIV from reproducing in your body. It is sold under the name of Truvada and has to be prescribed by a doctor. You have to take it daily for it to be effective. It can lower the risk of infection via sexual intercourse by 90%.

> **I am HIV positive. Will this affect my sperm count?**
>
> Men living with HIV may have a low sperm count and be infertile. Women with HIV might find it difficult to conceive. However, there are many treatment options available. People living with HIV should get professional advice.

If the mother is HIV positive:

There is a risk of mother-to-child transmission where a woman can pass the virus onto the baby during the pregnancy, during childbirth or when breast-feeding. However, if she starts treatment within the first three months of her pregnancy, she will be virally suppressed by the time she gives birth. This will mean that the chances of her baby being born with HIV are less than two in 100. The baby can also be given treatment for the first four weeks of their life.

> **Will being pregnant make my HIV worse?**
>
> Being pregnant does not make HIV worse. A pregnant woman's CD4 count may drop a little, but will pick up again once the baby is born. A CD4 count is less important than the viral load test for checking whether treatment is working. Taking ARVs can help to boost your immune system during pregnancy.

If both parents are HIV positive:

If both partners are on ART and are virally suppressed they can have a baby that is HIV negative if the mother is on treatment. ART is given to all pregnant women who test HIV positive, regardless of their CD4 count. ART reduces the risk of a baby being infected with the virus. Mothers are encouraged to continue with lifelong ART so that they remain healthy and are able to parent their child.

What to do if you think you are pregnant

Whether you know your HIV status or not, it is best to go to the clinic for antinatal care (ANC) clinic as soon as you think you are pregnant. If you do not know your status you will be offered an HIV test. Going to the clinic will also it give the healthcare worker a chance to treat and manage any other medical conditions you have, such as high blood pressure, and other pregnancy-related complications.

If you test negative:

- You will be counselled about how to stay negative;
- You need to continue attending ANC.

If you test positive:

- You will be given counselling about ARV treatment and how you can prevent your baby from getting HIV before and after childbirth;
- You will have a CD4 count and viral load test. These will be repeated throughout your pregnancy to make sure that the treatment is working and you are virally suppressed;

- Unless you have TB, which needs to be treated first, ART can be started immediately. This will reduce the risk of mother-to-child transmission to less than 2%.

Follow up visits at the clinic

It is important for all pregnant women, regardless of their HIV status, to make at least eight visits to an ante-natal clinic (ANC) before labour and delivery. This will allow your healthcare worker to monitor yours and your baby's health, and attend to any complications that may arise during your term of pregnancy.

Antiretroviral therapy (ART) during pregnancy

ART is recommended for all HIV positive pregnant women, no matter what their viral load is. A once-daily fixed-dose combination of TDF + 3TC (or FTC) + EFV will be given as first-line ART for pregnant and breastfeeding women, and Nevirapine (NVP) will also be given from the start of pregnancy.

I am HIV positive and pregnant. Is it safe for me to take ARVs?

It is safe. A high viral load is the biggest risk for mother-to-child-transmission so it is very important that you take ARVs as soon as possible if you are pregnant. You must adhere to your ARVs during pregnancy, labour and breastfeeding. Adhering to your treatment will lead to viral load suppression. This means;

- You will stay strong and health;
- There will be very little to no chance of passing HIV on to your baby;
- It will be safe to breast feed your baby.

Will I have more side-effects from ARVs when I am pregnant?

Some of the side-effects that you might have from ARVs are similar to the changes that happen during pregnancy. For example, ARVs can make you want to vomit, but so does morning sickness when you are pregnant. Get advice from your healthcare worker about how to manage your pregnancy and any side-effects from the treatment.

Antiretroviral therapy (ART) during labour

- If a pregnant woman is already on ART, this must be continued as usual during labour;
- If a woman is only diagnosed HIV positive when she is in labour, she will be given a dose of Nevirapine, Truvada and AZT every three hours during labour, and then be put on the fixed dose combination pill (FDC) immediately after giving birth as the start to lifelong ART;
- Women who have an emergency caesarean section will be offered the same treatment.

How will I know if my baby has been infected with HIV?

All babies born to HIV positive mothers are tested for HIV at different times for the next 18 months after birth. This includes;

- At birth;
- Six weeks after birth;
- Six weeks after you have stopped breastfeeding your baby;
- 18 months.

This will help the healthcare worker to know, as soon as possible, if your baby has been infected with HIV and your baby will be able to start treatment as soon as possible.

Antiretroviral therapy (ART) for new-borns

- Babies of mothers who are on ART and are breastfeeding will be given nevirapine every day for the first six weeks of their life;
- If the mother is not on ART, and is breast-feeding, the baby will be given nevirapine daily for up to three months;
- If the mother is not breastfeeding, and the baby did not receive nevirapine, the baby will be started on ART.
- Babies who are exposed to HIV will be tested regularly to check their HIV status.

I am an HIV positive mother. Is it safe to breastfeed my baby?

HIV can be passed on through breast milk, but if the mother is virally suppressed there is very little risk of this happening. The benefits of breastfeeding outweigh the risks because:

- Breast milk is more nourishing than formula;
- Antibodies from breast milk protect babies against infections like pneumonia which can be life threatening;
- Breastfeeding is free and formula is expensive;
- Feeding babies only breast milk for the first 6 months if the mother is on ART reduces the risk of passing HIV on to the baby;
- Breastfeeding can be combined with other feeding after 6 months and continued until 12 months.

9 Understanding co-infections

Co-infection is the word used to describe when you have HIV as well as other infections or diseases. There are some infections that many people living with HIV get, and these are called opportunistic infections (OIs) as they are diseases that take the opportunity to attack your body when your immune system has been weakened by HIV.

OIs are caused by different bacteria, viruses or funguses. Common infections include tuberculosis (TB), pneumonia, meningitis, thrush, hepatitis and herpes. It is easy to get sexually transmitted infections (STIs) when you have HIV, and certain cancers are also common. All of these infections can be tested for and treated, which it why it is important to visit the clinic regularly, especially if you have any unusual symptoms.

Tuberculosis

TB is a very serious infection which usually affects your lungs but can spread to other parts of the body. It is spread through the air when an infected person coughs or sneezes or laughs or speaks or spits or sings. Anyone who breathes in this air can get TB. It is a serious disease but it can be cured.

TB is one of the most common diseases that affect people living with HIV. When your viral load is low and your immune system is weak, there is a very high chance of being infected with TB. But, if you start HIV treatment soon after testing HIV positive and adhere to your ARVs - your viral load will be suppressed and your immune system will be strong and health - your chances of being infected with TB can be reduced.

I have lost a lot of weight for no real reason. Is that a sign that I have TB?

Weight loss is one of the symptoms of TB, but could also be because of another illness. Some of the other symptoms of TB are:

- Coughing that lasts three or more weeks or coughing up blood;
- Chest pains;
- Sudden weight loss;
- Feeling very tired;
- Fever;
- Sweating at night;
- Cold chills;
- No appetite.

If you have these or any other unusual symptoms, you should report to the clinic.

Why it is necessary to have a TB test before going on ART

Not everybody who has been infected with TB has symptoms. To find out whether you have TB, you will need to have a test at the clinic. If you have HIV, TB can become very active because of your weak immune system, and can be life-threatening. As soon as you are diagnosed with HIV you will also be tested for TB, so that you can start on TB treatment if necessary.

How do you know you have TB?

To find out whether you have TB, you will need to have a test at the clinic. To test for TB, you will be asked to cough out a sputum/mucus which will be tested for TB bacteria in the laboratory. If TB bacteria is found in your sputum, you will start TB treatment. Sometimes an x-ray will be done to see if there is TB in the lungs.

Treatment for TB if you are HIV positive

Treatment for TB will begin before you start ARVs. Since TB drugs and ARVs do not always mix well together, treatment has to be carefully monitored and managed. Your Healthcare worker will tell you how to take your TB treatment with your ARVs.

Even if you are HIV positive, TB can be treated and cured by taking combination of antibiotics that kill the TB bacteria, and the treatment must be taken for six months. This involves an initial intensive treatment regime which is a two-month course of a combination of four drugs: isoniazid, rifampicin, pyrazinamide and ethambutol; and a continuation treatment regime which is a four-month maintenance course of isoniazid and ethambutol.

The TB treatment has some side-effects, but these usually go away in the first few weeks. Common side-effects of TB drugs are:

- Feeling like you want to vomit;
- Feeling dizzy;
- Skin rashes;
- Pins and needles or burning feeling in feet;
- Loss of appetite;
- Feeling like you have flu or a fever;
- If you are one of the few people who get yellow eyes or skin (jaundice) see a doctor right away.

Even if you feel better once you start on the TB treatment, you need to adhere to your treatment finish the full six-month course of antibiotics or the infection could return and treatment could take longer. You may also develop drug resistant TB which has more side-effects. There are two types of drug resistant TB, multiple drug resistant TB (MDR-TB) and Extensively drug resistant TB (XDR-TB). These are every dangerous types of TB and they can be passed on to other people. That is why more and more people are being infected with DR-TB.

It is very difficult to treat MDR-TB and XDR-TB, treatment can take nine to two years, or even longer and it has more severe side effects. Adherence is important for treatment to be effective.

> *“At first I was taking TB medication and the HIV medication. I would get skin rashes. It would be as if my skin was coming off. My feet were very itchy at the sole. I wasn’t even able to wear shoes. When the pavement was burning hot, I wouldn’t feel it at all and yet if I was to step on just a small stone, the pain would be unbearable. But I started to gain weight again. I started feeling like myself again. I had stopped the TB medication but I carried on with the ARVs.”*
>
> **Thomas Mashego**

Sexually transmitted infections

It is a good idea to use a condom to protect yourself from STIs if you have HIV, because they can make you sicker, and can also increase the risk of you passing on HIV to others. STIs can usually be treated with a course of treatment that you can take at the same time as your ARVs.

Human Papillomavirus (HPV)

The human papillomavirus (HPV) is a common sexually transmitted infection, and causes cervical cancer. Women with HIV have a higher risk of developing cervical cancer and should go for cervical screening (a pap smear) once a year to check for this.

Herpes

Herpes is caused by a common virus that can be transmitted by skin contact.

Oral herpes causes tingling or painful fluid-filled blisters on the edge of the lip where it meets the skin of the face (‘cold sores’). These can occasionally develop on the nostrils, on the gums or on the roof of the mouth. Genital herpes involves painful, fluid-filled blisters in the genital or anal areas, sometimes accompanied by fever, headache, and muscle ache.

People living with HIV and herpes are more able to pass on HIV as having herpes increases your HIV viral load; and the HIV virus is present in herpes blisters.

Pneumonia

Bacterial pneumonia and other infections that affect the lungs can be caused by one of several bacteria, and are common infections for people living with HIV.

Symptoms of bacterial pneumonia include chills, shivering, chest pain, fever, rapid breathing, rapid heart rate, and wheezing.

Pneumonia can be diagnosed by chest x-rays, blood tests, and examination of sputum (phlegm) samples; and can be treated with antibiotics.

Meningitis

Meningitis is the swelling of the lining of the brain and spinal cord, and can be caused by a virus or bacterial infection.

The symptoms of meningitis include a headache, neck stiffness, change in mental status, a fever, sensitivity to and loud sounds, irritability, confusion, vomiting, seizures, blindness and coma.

Meningitis is serious and often requires hospitalisation. It can be treated with antibiotics or other drugs.

Thrush

Thrush, also called candidiasis, is caused by a fungus that gets overgrown in the body, particularly if your immune system is weak, if you are stressed, or if you have been taking antibiotics for a long time.

- Vaginal thrush happens in a woman’s vagina, and can cause itching and pain.
- Oral thrush happens in the mouth, and can make it painful to eat and difficult to swallow.
- Oesophageal thrush happens in the oesophagus that runs from the throat to the stomach, and can cause chest pain as well as pain and difficulty when swallowing.

Thrush can be detected by your healthcare worker and can be cured with anti-fungal treatment.

Hepatitis

Hepatitis B and hepatitis C are common among people living with HIV, and are passed on through blood contact. Hepatitis affects the liver and can be very serious if untreated.

Symptoms of hepatitis include feeling sick or vomiting, aching muscles and joints, weight loss, tiredness and loss of appetite. A blood test can check if you have hepatitis. There is a vaccine against hepatitis B, and both hepatitis B and C can be treated at the same time that you are on ART.

10 Age and HIV

The age that you are when you are diagnosed with HIV, and the age that you are when you are living with HIV might affect your treatment plan as well as how you cope with the diagnosis.

Children and HIV

Most children living with HIV are born with the virus. They get the disease from their mothers during birth. Other children may get HIV through rape and sexual abuse.

Children living with HIV have special needs as they are not able to take care of themselves. They depend on their parents or other caregivers to take care of them and help them with their treatment and other psychosocial needs. It is important to give children living with HIV proper support, show them love, and show that HIV does not mean they are less important than other children.

Preventing illness

Like all children, HIV positive children should be vaccinated to keep them from getting sick. But because in children, HIV attacks an immune system that is still developing, children living with HIV, even those who are taking ARVs, have more chances of being infected with bacterial illnesses. Taking children for regular medical checkups will safeguard that infections are treated early and they can stay healthy. Teaching children to thoroughly wash their hands often will help keep germs away and help them to stay healthy.

ARV Treatment for Children

Because children with HIV are still growing, the dosing of HIV medicines is not always based on their age, but usually on their weight or stage of development. The doctor or nurse will prescribe ARVs according to the weight and stage of development of each child.

It is important to ask children who are taking ARVs if they are experiencing any pain. Staying aware of how your child is feeling will help you to know if they become ill or experience side effects. Parents and caregivers should talk to the child's healthcare provider if you notice any problems.

Children often have difficulty adhering to treatment because:

- They do not like the taste of ARVs
- They may struggle to swallow the pills,
- They may forget to take their ARVs
- They may hide their ARVs
- Fear of side-effects
- They do not understand why they need to take ARVs

Helping children adhere to ARVs

- Talking to your child about HIV and their HIV status will help them to understand their illness and take their ARVs. For tips on how to disclose to children go to page 10 of this booklet.
- Make taking ARVs a part of your child's daily routine- just like bathing, brushing of teeth or getting ready for bed - will help them accept their ARVs and get into used to taking them.
- If you are also HIV positive, taking your ARVs at the same time with you child can also help to make taking ARVs normal. This will help your child to accept the treatment.
- Talk to your child's healthcare provider about your concerns and if you know other families affected by HIV, ask other parents for tips.
- Take your child for clinic follow visits.
- Encourage your child to join a support group on HIV positive children.

With good care and support children living with HIV can live a normal life like other children, they can play and enjoy themselves, and grow into healthy adults and pursue their dreams.

Adolescents and HIV

Some adolescents may have been born with HIV, and some may have acquired it more recently when they became sexually active during their teen years. There may be strong feelings of fear and guilt for teenagers who are diagnosed with HIV, no matter how they were infected.

Adolescents go through a period of physical and mental change which often comes with strong emotions. Adolescents have a strong need for independence, and being a teenager often involves risk-taking behaviours, a preoccupation with self-image, and a desire to fit in with their peers. These normal teenage thought processes may make it difficult for them to think about their long-term health and about living with HIV. It is important that adolescents living with HIV receive the care and support they need and are encouraged to take responsibility for their health.

Teenagers living with HIV can still enjoy themselves and have meaningful relationships and a healthy sex life if they use condoms, and should know that they have the choice about whether or not to disclose their status to other people, and that they can get support when they need it.

Going to a support group with other young people living with HIV is a good way for adolescents to share their feelings and experiences.

ART is recommended for all HIV-infected individuals, including children and adolescents. Before starting on ART, the teenager's readiness and ability to adhere to treatment will be assessed and support will be provided.

> *"When I found out I never ever spoke about it until a week or two weeks later and I desperately needed a distraction because it was forever in my mind, this HIV thing. How do I speak about it? I am only fourteen and I'm just so scared, I mean its HIV and I don't even have a boyfriend."* **Saidy Brown**

What is the treatment for adolescents living with HIV?

The first-line regimen for adolescents aged 10-15 years who weigh less than 40 kilograms is the same as the paediatric regime for younger children, which is a combination of ABC + 3TC + EFV. Sometimes Nevirapine is used if EFV is contraindicated.

Adolescents with an undetectable viral load and no side-effects on the paediatric regime will stay on the same regimen until they are older and eligible for FDC.

If the adolescent is over the age of 15 and weighs more than 40 kilograms, they will start the same first-line regimen as adults, which is the fixed dose combination of TDF + 3TC/FTC + EFV.

Aging and HIV

Being on ART means that people living with HIV can remain healthy into old age. Growing older with HIV can impact on your health, but there are many things you can do to look after yourself.

Growing older with HIV can increase the chance of experiencing normal illnesses that are commonly associated with the later stages of life. These non-communicable diseases can include hypertension (high-blood pressure), diabetes, obesity, heart disease, lung problems and cancer. Other problems associated with getting older include hearing loss, receding gums, and the menopause for women. Some people also face greater stress and depression as they get older and start to worry more about their health, their families and their future.

It is important to visit your healthcare worker regularly to talk about any changes you are experiencing, and to get checked for these problems. If you are on ART and need to take medication for other age-related illnesses, the healthcare worker will make sure that it is safe to take these treatments at the same time.

Taking ART over a long period of time may also have an effect on your kidneys, liver, bones and heart as you get older. Routine check-ups are important so that any problems can be identified and treated early.

Taking treatment and making lifestyle changes early on can also mean that you live healthily into old age with HIV.

> *"You know, growing up I knew there is this HIV and people who are infected with HIV, and I thought they will die soon. I didn't have a clue that you can live long with HIV."* **Gugu Xaba**

> *"When I first started my CD4 count was very very low. But last month, when I went to the clinic I found that my CD4 count was up and perfect and clean. They asked me to continue with the lifestyle I am living."* **Thomas Mashego**

What can I do to stay healthy as I get older with HIV?

Looking after your general health becomes more important as you get older. You should stop smoking, try and maintain a healthy weight, eat healthily, manage your stress and take regular exercise. Have regular check-ups and report any new symptoms to your healthcare worker so that you can deal with any problems that you have.

11 Stigma, prejudice & the right of people living with HIV

Stigma is when people are marked as being different in a negative way. Self- stigma is when the person believes these bad things about themselves and feels shame because of what others think or say about them. This often happens to people who are living with HIV.

People who are stigmatised feel the prejudice of others towards them. This is a dislike without any real reason. They may also be discriminated against which means that they are actively treated badly. For people living with HIV, the fear of being stigmatised often means feeling too ashamed or afraid to disclose their status.

> *"My partner knew my status, but she needed me to confirm it. There was a rumour within the neighbourhood, that this guy is living with HIV and 'Be aware ladies, maybe he can infect you'. Even after I was graced with this relationship, the stigma attached to HIV is timeless. Her colleague would always say: 'Are you sure? You are in this relationship with this sick guy?' My surname was 'Sick guy'. But eventually we knew what we wanted. Even today we are still together since 2010."*
>
> **Strike Tshabalala**

Stigma is often born out of fear or lack of knowledge. You can try and change this and deal with discrimination in different ways:

On a personal level

- Join a support group to avoid feeling isolated;
- Speak to a counsellor who will help you to realise that this is the other person's problem and not yours;
- Tell people who are discriminating against you how this makes you feel.

> *"I have a niece who would behave like HIV just jumps from one person to another. I remember asking her to bring me water, while I was sitting here on the sofa, and she brought me water in a plastic cup. She didn't want to have much to do with me. But right now, you would be surprised. We eat our food together where in the past we would never eat together."*
>
> **Thomas Mashego**

At a community level

- Create more public awareness through education;
- If it is safe to, you can openly disclose your status in your community, on television or social media and show people that people living with HIV can lead full and productive lives.

We all need to speak out against the stigmatisation of people living with HIV. When brave, ordinary people speak out, they help others to speak out.

> *"When I found out that I am HIV-positive, I disclosed my status to everyone. At that time HIV was a big issue. The community didn't want me. Everyone was talking about me but I didn't care. I stood by my decision that I want to make a change in my community. I want people to know about HIV which is why I am involved in campaigns of HIV and AIDS."*
>
> **Bheki Mazibuko**

Know your rights

The Bill of Rights in the South African Constitution protects all people. This means that if you are living with HIV you have the same rights as anybody else.

- You have the right to privacy and no one can give out information about your HIV status unless you agree;
- You have the right to medical treatment and care but you also have the right to refuse treatment;
- You have the right to choose what kind of work you want to do and you cannot be fired, retrenched or refused a job simply because you are HIV positive, or be forced to test before taking a job.
- You have the right to make choices about your pregnancy if you are a woman, and you cannot be forced to have a child or to have an abortion;
- You have the right to attend any school if you are a child;
- You have the right to not to be discriminated against.

12 Believing in your future

HIV is not a death sentence. If you adhere to ART you can live a healthy and productive life with an active social life, work life, and sex life. You can work, you can marry, you can have children and you can follow your dreams.

It is a good idea to set goals for yourself if you are HIV positive. These can be treatment goals (how to adhere to your treatment), health goals (about adopting a healthier lifestyle) and life goals (the things that you want to do in your life). Setting goals is the first step in motivating yourself to achieving them.

Strike Tshabalala

"You still have your life that you need to live. You still have your dreams that you need to accomplish. Each and every time you wake up is a step forward. I've achieved a lot after being diagnosed. I have done a lot of courses. I'm determined to live a meaningful life despite being HIV positive. I always tell people 'I'm not going to die because of HIV. HIV is just a virus in my body and it doesn't have power over me, because I never invited it. Now I even forget that I'm HIV positive."

Bheki Mazibuko

"Even if you tested positive you can still live your life to the fullest because there is a treatment that can help you to sustain your life. Anything can happen even if you are living with HIV, you can even have kids. Having HIV doesn't mean your life is over. You can be something even if you are HIV positive."

Thomas Masego

"I feel like a young person again. I'm alive again. Nothing can stop me at this point. It's like I've gone back to the days when I was ok. I feel I am well. It's not like I'm an old man that needs a walking stick to help him. I feel like I've gone back to the days of my youth. And the medication is what saved my life."

Gugu Xaba

"I'm still a woman. HIV didn't take my "woman" away, so I'm still a woman and I hope one day I will have a child and I think I will be the best Mom, because now I know what relationship I must give my kids. I think they will learn a lot about life from me."

Saidy Brown

"I would like to study communication sciences and do a bachelor's degree so that I can have the experience of talking to young people who are affected by this virus. I don't want people to think that living with HIV is the end. I want them to know that there is more to life and we can be great, we can flourish."

FINDING HELP

To find a Facebook support group, write to **ask@brothersforlife.co.za** or send a message via their page **www.facebook.com/BrothersforlifeSA** and they 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 you can visit **www.healthsites.org.za** or dial ***120*662#** to find a support group in your area.

REFERENCES

Books

HIV & AIDS by Marina Coleman

Coleman, M (2009). HIV & AIDS; Your complete guide and resource book, Jacana Media. Johannesburg

Websites searched for a range of content areas

https://www.cdc.gov/

http://www.who.int/en/

http://www.webmd.com/

https://www.uptodate.com/home

https://medlineplus.gov/

http://www.mayoclinic.org/

http://www.thebody.com/

http://www.unaids.org/

http://www.aidsmap.com/

https://www.hiv.gov/

https://www.brothersforlife.org

HYPERLINK “http://www.ccisa.org.za/” www.ccisa.org.za/

Articles and documents

National Adherence Guidelines for HIV, TB and NDCs, National Department of Health(NDoH) South Africa, 2016

Centres for Disease Control and Prevention.About HIV/AIDS .

Accessed from https://www.cdc.gov/hiv/basics/whatishiv.html.

Centres for Disease Control and Prevention .Stages of HIV Infection. Accessed from

https://wwwn.cdc.gov/hivrisk/what_is/stages_hiv_infection.html.

AIDSinfo;The Stages of HIV infection. Accessed from https://aidsinfo.nih.gov/understanding-hiv-aids/fact-sheets/19/46/the-stages-of-hiv-infection.

AVERT. (14 February 2017) . Symptoms and Stages of HIV infection.

Accessed from https://www.avert.org/about-hiv-aids/symptoms-stages on 17/8/2017

AVERT.(14 February 2017) How HIV infects the body and the lifecycle of HIV. Accessed from **https://www.avert.org/about-hiv-aids/how-infects-body** on 17/8/2017

Nachega J.B, Stein D.M., Lehman D.A, Hlatshwayo D, Mothopeng R, Chaisson R.E, and Karstaedt A.S. AIDS Research and Human Retroviruses. October 2004, 20(10): 1053-1056

https://www.ncbi.nlm.nih.gov/pubmed/15585095

World Health Organization (Nov 2013).HIV and adolescents: Guidance for HIV testing and counselling and care for adolescents living with HIV. Accessed from **http://www.who.int/hiv/pub/guidelines/adolescents/en/**

Myers, L., Hajiyiannis, H., Makhubele, M.B., Matekane., Delate, R., Mahlasela, L., and Goldblatt, B. (2015). 'Confirmation of an unspoken truth': Community perspectives on men's HIV testing behaviour. Johannesburg and Cape Town: CADRE. Accessed from https://aidsfree.usaid.gov/sites/default/files/aidsfree.usaid.gov/sites/default/files/events/presentations/unspoken_truth_perspectives_south_africa.pdf

World Health Organization (2005). Basic counselling guidelines for anti-retroviral (ARV) therapy programmes. (Mental health and HIV/AIDS series. Accessed from http://apps.who.int/iris/bitstream/10665/43196/1/9241593067_eng.pdf

World Health Organization. (June 2016) Consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection: Recommendations for a public health approach- second edition. Accessed from http://www.who.int/hiv/pub/arv/arv-2016/en/

World Health Organization (2010).Antiretroviral therapy for HIV infection in adults and adolescents.Recommendations for a public health approach. Accessed from//www.who.int/hiv/pub/arv/adult2010/en/

Amy L Graziani. Patient education: Tips for taking HIV medications (Beyond the Basics). UpToDate. Inc. Accessed from https://www.uptodate.com/contents/tips-for-taking-hiv-medications-beyond-the-basics

RxList: the Internet drug index [Internet] (Feb 2015); Accessed from: http://www.rxlist.com/truvada-side-effects-drug-center.htm

Managing Side Effects of HIV Medications :New York State Department of Health AIDS Institute; November 2006 https://www.health.ny.gov/publications/9408.pdf

Stall R. Efforts to Prevent HIV Infection That Target People Living with HIV/AIDS: What Works?, Clinical Infectious Diseases, Volume 45, Issue Supplement_4, 15 December 2007, Pages S308–S312, https://academic.oup.com/cid/article/45/Supplement_4/S308/460302/Efforts-to-Prevent-HIV-Infection-That-Target

Trust, T. HYPERLINK "https://www.google.com/url?sa=t&rct=j&q=&esrc=s&source=web&cd=16&ved=0ahUKEwjMic3JsaXWAhXCJ8AKHQ44A44QFgh8MA8&url=http%3A%2F%2Fwww.tht.org.uk%2Fmyhiv%2FHIV-and-you%2FYour-treatment%2FDealing-with-side-effects&usg=AFQjCNGObH63Wnhg3zCswG2XkGJxwaZfLg" Dealing with side effects of HIV medication. Terrence Higgins Trust. Accessed from Terrence Higgins Trust

http://www.tht.org.uk/myhiv/HIV-and-you/Your-treatment/Dealing-with-side-effects

Post-exposure prophylaxis. Accessed from https://www.hiv.gov/hiv-basics/hiv-prevention/using-hiv-medication-to-reduce-risk/post-exposure-prophylaxis

South Africa Department of Health. National consolidated guidelines for the prevention of mother-to-child transmission of HIV (PMTCT) and the management of HIV in children, adolescent and adults. Pretoria: Government Printer; 2014.

World Health Organisation.(2010). New guidance on prevention of mother-to-child transmission of HIV and infant feeding in the context of HIV. Accessed from **http://www.who.int/hiv/pub/mtct/PMTCTfactsheet/en/**

Granich R, Akolo C, Gunneberg C, Getahun H, Williams P, Williams B; Prevention of Tuberculosis in People Living with HIV, Clinical Infectious Diseases, Volume 50, Issue Supplement_3, 15 May 2010, P

NOTES

J7175 0860 PAPRIKA / 0860 727 7452

This publication was compiled by Hot Dog Designs and edited by Act Two Training, with design and layout by Paprika, as part of the Zenzele Living with HIV publication range.

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 or dial*120*662 # to find a support group in your area.

#Zenzele

CCI CENTRE FOR COMMUNICATION IMPACT

Phila Inspired to live

BROTHERS FOR LIFE

ZAZI