



ADHERENCE



Adhere to ARVs

3 LIVING WITH HIV: REACHING VIRAL LOAD SUPPRESSION



zenzele
The Future Is Ours



Know your ARVs

Visit your clinic

MANAGE
SIDE EFFECTS

SUPPORT



BENEFITS OF
ADHERENCE

VIRAL LOAD
SUPPRESSION



DISCLOSURE





HIV: BASIC FACTS

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

UNPROTECTED SEX



HIV IN THE BODY

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

IMMUNE SYSTEM IS WEAKENED



PREVENTING HIV INFECTION

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

SAFE SEX



I drink my pills whether I am at home or not. I also keep my treatment in the car in case I am not home at 7. People must stick to the treatment. It is the one thing that can make you live longer."

LIVE LONG



Bheki Mazibuko

This pamphlet was supported by Cooperative Agreement Number GH001932-04 from the Centres for Disease Control and Prevention. Its content are solely the responsibility of the authors and do not necessarily represent the official views of the Centres for Disease Control and Prevention, the Department of Health and Human services, or the U/S government.



Adherence to Antiretroviral treatment (ART), or taking ARVs exactly as the healthcare worker advises, leads to viral load suppression. Viral load suppression is when ARVs have reduced the amount of HIV in the body so much that it is suppressed and the immune system gets a chance to recover. At this stage, there is so little HIV in the blood that there is little chance of passing it on. You will also be able to have HIV-negative children by following family planning advice from the healthcare worker. Although taking ARVs may feel like a burden, stick to the treatment. If HIV is suppressed you will be able to live a healthy and productive life.

Adherence to Treatment

For ARVs to be effective they need 100% adherence. This means:

- Not taking breaks from taking ARVs.
- Never skipping a dose.
- Taking ARVs at the same time every day. Not doing so is as bad as skipping a dose.
- Going for follow-up clinic visits and medical tests as advised by your healthcare worker.
- Avoid taking other medication that might interfere with ARVs. It is best to discuss other medicines that you are taking with the healthcare worker at the clinic, even simple pain killers. This includes telling the healthcare worker about any traditional medicine, immune boosters, drugs taken socially to get high, or alcohol.



There was a time that I said, 'Enough is enough with my treatment' - for almost a month because of lack of support. I started to develop a problem with swallowing. I started to develop complications and symptoms of HIV/AIDS- swelling of legs and so forth. And the TB was coming back again. I was weighing 22 kilograms! Then I realised the only choice that I have if I want to live, is to adhere to my treatment."

ADHERENCE

SUPPORT



Strike Tshabalala



importance of ARVs

Why adherence to ARVs is important

HIV and the immune system

The immune system protects the body against infection and disease. HIV is a virus that attacks and weakens the immune system. As a result, you cannot fight off different diseases, like TB.

HIV weakens the immune system by hijacking the immune system's infection-fighting CD4 cells and turning them into factories to make more copies of HIV. In the process of making more HIV, these CD4 cells are destroyed. This means that as more and more HIV is made, more and more CD4 cells are destroyed. This is why when someone has HIV – and they are not taking ARVs – the amount of HIV in their blood and body goes up (their Viral Load) as their CD4 Count drops.



Fagmedah Miller



How ARVs suppress HIV

Antiretrovirals, or ARVs, are medication that suppresses or controls HIV. ARVs are the only effective way to control HIV infection. There is no cure for HIV. Even spiritual healers cannot cure HIV. ARVs work by stopping HIV from hijacking the immune system's CD4 cells to make more HIV. This means that ARVs do two things:

- 1. They stop HIV from making more copies of itself.*
- 2. They stop HIV from destroying CD4 cells (the immune system).*

This is why when HIV treatment is taken properly: Viral Load goes down – the amount of HIV in the blood and body decreases – and CD4 Count goes up and the immune system recovers and becomes strong again.

To suppress HIV properly, three different ARVs must be taken together as Antiretroviral Treatment (ART). The treatment puts up roadblocks that stop HIV to make sure that it cannot hijack CD4 cells.

The ARVs stop HIV when:

- 1. It is entering the CD4 Cell;*
- 2. It is inside the CD4 cell;*
- 3. It is ready to release the new copies of HIV from the CD4 cell.*



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

terms, what does this mean?

More about the medical terms used at the clinic

CD4 cells are the immune system cells that fight infection and are the target of HIV. The higher the CD4 count the stronger the immune system is. You can only increase your CD4 count by adhering to ARVs.

Viral load refers to the amount of HIV there is in the blood. It is measured as copies of HIV per millilitre of blood (copies/mL). Taking ARVs on time, every day makes the viral load drop very quickly. If someone is not on treatment, or is having difficulties taking ARVs properly, their viral load can increase daily to up to a million copies of HIV per drop of blood.

Viral Load Suppression is when the amount of HIV in the blood has dropped so much – to less than 50 copies of HIV per millilitre of blood – that it cannot be detected by a viral load test. This does not mean that HIV is cured but that there is only a small amount of HIV in the blood. If ARVs are skipped or stopped, HIV will take the chance to start up factories again, grow stronger and attack the immune system. Viral load suppression is the aim of taking treatment and can only be achieved if ARVs are taken at the same time every day.

Important blood tests done once a year, at the clinic, to keep track of your health:

A CD4 count

- *This blood test measures how many CD4 cells are in the blood.*
- *The higher the CD4 count is, the stronger the immune system is.*
- *Test results are given as cells per cubic millimetre (cells/mm³) of blood.*
- *A result of about 500 - 1,500 is considered normal.*
- *Every time the CD4 count drops by 100, the risk of AIDS-related illnesses doubles.*



A Viral Load (VL) test

- *Measures how much HIV there is in a drop of blood.*
- *Results are given as copies of the virus per millilitre of blood (copies/mL).*
- *If there are less than 50 copies of HIV in one millilitre of blood, this will not show up in the blood test. The test results will come back saying the virus is 'undetectable'. This is viral load suppression.*

- *The aim of treatment is viral load suppression. This can only happen with adherence to ARVs. It does not mean that you are cured. It only means that there is a small amount of the virus in your blood and body.*

You will have to have repeated blood tests while you are on treatment, but the Viral Load test is the most important test for knowing whether the ARVs are working.

- *Your CD4 count will measure how healthy your body is. It will tell the healthcare worker if you need to be tested for other diseases or illness.*
- *South Africa has a Test and Treat Policy, which means if you test positive for HIV you can start taking ARVs as soon as possible, no matter what your CD4 count is.*

Remember test results will be affected by:

- *Not adhering to ARVs.*
- *Infections, even a simple flu. Wait until the immune system gets stronger to have the blood tests. A doctor or nurse will decide when the tests can be done.*

Is it true that in the long run ARVs make you sicker?

Today's ARVs have a low risk of side effects. Some of the conditions that people experience happen because of HIV, or as a result of natural ageing, and not the ARVs.

Depending on which ARVs you are taking and what their possible long-term side effects are, there are other blood tests that might be included at the clinic, such as: a full blood count; tests that measure liver function; kidney function; blood sugar levels; cholesterol; and heart function. You may also be screened for TB, hepatitis and other illnesses associated with HIV. A healthcare worker at the clinic will decide if you need any of these other tests.



There is a problem that many people say that if you take treatment you are not a man.

I tell many people that I am a real man, because I take treatment.

I am more of a man than you are. You might be the bull but I am the ox. The bull and the ox are the same animal, but the ox has more strength."

STRENGTH



Thomas Mashego



Resistance to ARVs

When someone first starts taking ARVs they start on first-line treatment. If ARVs are skipped or stopped, HIV multiplies again. When HIV multiplies, it changes its form and makes different versions of itself. HIV can now trick the first-line treatment because the ARVs don't recognise the new HIV. This is how HIV becomes resistant to first-line treatment.

Because first-line treatment no longer works to control HIV, second-line treatment is needed. Skipping or stopping second-line treatment means HIV could become resistant to this treatment too. Third-line treatment is even more complicated, has more side effects and leaves you with almost no treatment options.

Treatment can only be switched upon instruction from a doctor or a nurse.

Why do I have to take my ARVs at exactly the same time every day?

If you do not take your ARVs at the same time every day you will not have the constant level of ARVs in your blood that is needed to control HIV. ARVs leave your body very quickly. This makes it even easier for HIV, which can make billions of copies of itself every day.

The benefits of adherence

Adherence leads to viral suppression, which means:

- * **Better health;**
- * **Better quality of life;**
- * **The ability to work without needing to take off too many sick days;**

- * **Less chance of passing HIV to a partner;**
- * **Being able to have HIV-negative children without passing HIV on to a HIV-negative partner;**
- * **Living a long life.**

What about alcohol and ARVs?

Drinking excessive alcohol is not good for anybody. Using alcohol and other substances has risks for people taking ARVs.

- *Alcohol, drugs and ARVs all affect the liver. Using alcohol and drugs may increase the chance of having liver complications.*
- *You could get drunk and forget to take your ARVs, or vomit shortly after taking the ARVs.*
- *Using alcohol and other substances can increase the risk of having unprotected sex.*



Get Support

Getting support and encouragement to take your ARVs will help you to adhere and achieve viral load suppression. When you find out that you are HIV-positive it can be a very scary and shocking experience. You may hide your HIV-positive status and stop taking your ARVs because you feel ashamed, guilty and fear rejection and discrimination. Telling a trusted person like a close family member, a teacher, pastor or a healthcare worker about your HIV-positive status will help you feel loved, accepted and supported.

Disclosure is a personal choice and often a difficult decision to make. Speak to a counsellor at the clinic for help and guidance.



For more information on Disclosure get a copy of the Zenzele 'Living with HIV: Getting Support' brochure.

How to disclose

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

Who to tell

What to tell them and what is the expected response

When to tell them

Where to tell them

Why tell them

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

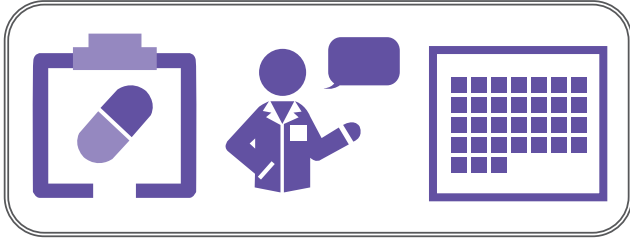
How to improve adherence

Here are some other steps that you can take to improve your adherence and achieve the goal of viral suppression:

- * *Finding out as much as possible about HIV by reading or talking to others.*
- * *Talking to your healthcare worker about your treatment if you are not sure of your ARVs or if you are struggling with taking treatment.*
- * *Joining or starting a support group for people living with HIV – these can be based at clinics, churches, schools or colleges. If you have been taking ARVs for over one year and you are virally suppressed, you can join an adherence club at your clinic or in your*

community or pick up your pre-packed ARVs at a pick-up point near your home, such as a pharmacy. Talk to your healthcare worker to learn more about adherence clubs and the different options to collect medication for stable patients.

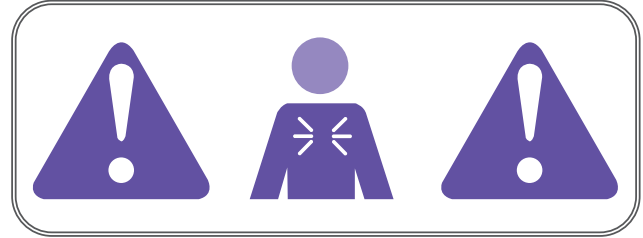
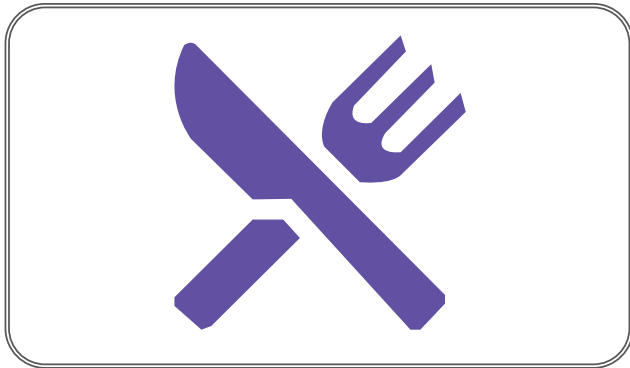
- * *Using a 7-day pill box to keep ARVs organised. Make time once a week to refill the box for the week ahead.*
- * *Setting an alarm, or a reminder, on a cell phone and taking the ARVs straight away when it goes off.*
- * *Setting a reminder on a cellphone or using a wall calendar as a reminder to return to the clinic for more ARVs a week before the medication runs out.*
- * *You should keep your ARVs in a place where you will remember to take them.*
- * *You can keep one or two doses of your ARVs with you at all times to ensure that no doses are missed if you cannot get home to take your ARVs.*
- * *Choosing a regular daily activity to help you remember to take your ARVs, like brushing your teeth, or when your favourite TV show starts.*
- * *Keeping a treatment diary to stay on track. Enter the name of each ARV and include the dose, number of pills to take, and when to take them. Record each ARV as it is taken. Reviewing the diary will help in identifying the times that you are most likely to forget to take your ARVs.*
- * *Planning ahead for changes that might be coming up, like weekends, going home or going on holiday. You should make sure you have enough ARVs to last the whole time you are away.*
- * *Getting a treatment buddy – someone who can remind you to take your ARVs.*



What do I do if I skip a dose? Take the dose you missed as soon as you can, unless it is almost time for the next dose. If it is almost time for the next dose, don't take the missed dose and just keep taking your ARVs as usual. Don't take a double dose to make up for the missed dose!

What if I vomit after taking my dose? If you vomit less than an hour after taking your ARVs, you should take the dose again.

Should I take my ARVs with or without food? It is best to take your ARVs as advised by your healthcare worker.



Does everyone who takes ARVs have side effects?

ARVs can have side effects. They differ from person to person. Side effects usually stop after the first few weeks. If you have bad side effects that last for more than 7 days, do not stop your treatment. It is best to speak to your healthcare worker about steps that can be taken and medication that can manage the side effects. Sometimes the healthcare worker will swap an ARV in the treatment regimen for a different one that the body handles better.



These are the most common side effects of the ARVs that are available at our hospitals and clinics:

Chemical name	Brand name	Nausea (wanting to vomit)	Headache	Diarrhoea (Running stomach)	Skin rash	Extreme tiredness	Dizziness	Other symptoms
Abacavir	Ziagen	Feeling very tired	X	X	X	X		• Fever
Ritonavir	Norvir	X	X	X			X	• Tingling or numbness around the mouth
Efavirenz	Sustiva				X		X	• Feeling sleepy • 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			• Sore stomach • Tingling or numbness around the mouth • Tired feeling • 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: Changes in the shape or place where your body fat collects (especially in your arms, legs, face, neck, breasts, and waist)
FIXED DOSE COMBINATION (FDC) ARVs = 2 or more ARVs in 1 pill								
Emtricitabine + Tenofovir	Truvada	X	X	X	X (and itching)		X	• Feeling down or anxious • Sore stomach • Trouble sleeping • Strange dreams • Joint pain • Back pain • Lipodystrophy: Changes in the shape or place where your body fat collects (especially in your arms, legs, face, neck, breasts, and waist) • Changes in the colour of your skin on your palms or the soles of your feet
Lopinavir + Ritonavir	Aluvia or Kaletra	X	X				X	• Sore stomach • Weakness • Lipodystrophy: Changes in the shape or place where your body fat collects (especially in your arms, legs, face, neck, breasts, and waist)
Tenofovir + Lamivudine+ Dolutegravir	Kovatrax, Acriptega, Dovimil, TELADO, VOLUTRIP, Telatri, EMDOLTEN, Deltevir	X	X					• Slaapprobleme



Managing side effects

There are medications to manage some of the side effects common to ARVs, but there are also foods or steps that you can take that can help. If you experience severe side effects you must get medical care as soon as possible.

You should not take any herbal remedies without consulting a healthcare worker.

SYMPTOM	MEDICATION	STEPS TO TAKE
Nausea (feeling sick) or vomiting	Anti-nausea medication	<ul style="list-style-type: none"> • Avoid oily or spicy foods • Eat dry foods like toast • Sip on black tea • Drink water with lemon juice
Diarrhoea (running stomach)	Antidiarrheal medication	<ul style="list-style-type: none"> • Eat very ripe bananas, rice or toast • Avoid milk • Drink water that contains salt and sugar
Headache	Pain killers	<ul style="list-style-type: none"> • 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	<ul style="list-style-type: none"> • Use a natural soothing cream calamine lotion or castor oil
Loss of appetite		<ul style="list-style-type: none"> • Eat small meals regularly • Eat foods you like even if you aren't hungry • Avoid foods that have no nutritional value
Dizziness		<ul style="list-style-type: none"> • 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		<ul style="list-style-type: none"> • Go to sleep at the same time every night and get up at the same time every morning • Don't drink alcohol

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.**



Do it for yourself and accept your HIV-positive diagnosis
Know that you are not alone,
Know that you have support.
You have the choice to live.
Choose life because you can.

ARVs allow you to live a long and healthy life.
So, look beyond your diagnosis.
And commit to a solution for positive living.
Initiate and adhere to ARV treatment.
Live better. Do more. Inspire others.
Zenzele! This is your life.
Your dreams and goals matter.

Don't ever give up on them because of an HIV-positive diagnosis.
Your status does not determine your future.

Do not wait.
There is no time to lose.
Don't hide away any longer.
Stand tall and leave your mark.
Start treatment today.
Adhere to treatment and follow-up with clinic visits.

It is not a punishment, it is the key to your health and future.
A key that enables you to do everything you planned.
Zenzele! The Future is ours!

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



1 TREATMENT



2 DISCLOSURE



3 ADHERENCE



4 PMTCT



5 LOVE AND SEX



6 NUTRITION AND LIFESTYLE



7 ADOLESCENTS AND HIV



8 AGEING WITH HIV



9 UNDERSTANDING TB



10 WELCOME BACK

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

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

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

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

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

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