



Positive living with HIV and TB



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How to use this book

Positive living with HIV and TB has been written for people who are HIV positive. This book is for adults who are getting ready to start anti-retroviral treatment (ART) in the future or who are already on ART.

If you are starting ART, you need to prepare yourself and make changes to your life to make it easier. This book will help you to do this. This book will also be useful for family members, friends and caregivers of people who are going to take anti-retroviral medicines. Anyone who wants to learn more about ART will also find it useful.

There is a separate Soul Buddyz book for children called *Parents, children and anti-retroviral treatment*.

In this book the difficult words are underlined. They are translated into Zulu, Xhosa, Sotho and Afrikaans at the bottom of each page.



In this book there are coloured blocks with important information that looks like this:



Remember!

Always check the expiry date on the packet – old condoms are not safe.



It is important to find out how serious the side-effect is, and to do something about it.

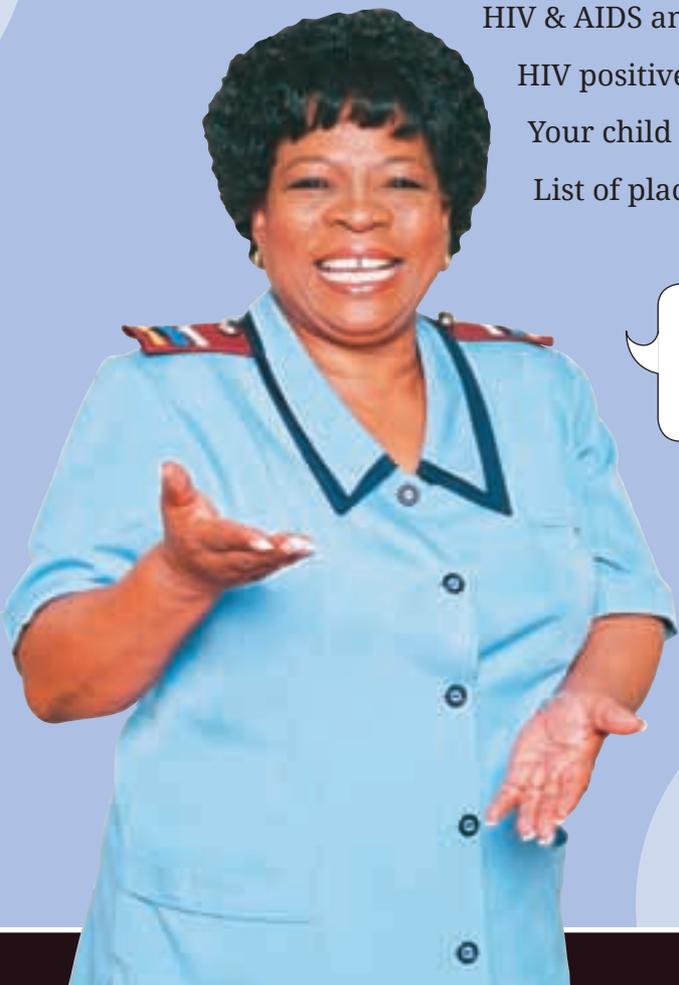


Community Information

It is your right to get **pre-test counselling**.
It is also your right to get **post-test counselling**, even if your test results are negative.

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This book will help you to prepare yourself for starting ART.

HIV and anti-retroviral treatment

HIV and AIDS affect us all. Anti-retroviral treatment (ART) will help people with HIV to live longer, healthier lives.

HIV and the immune system

- You have a very important system in your body called the immune system. This protects your body against germs and diseases.
- When the HIV virus gets into your body, it increases in number and slowly breaks down the immune system. This means that your body is less able to fight sicknesses. As time goes on, your immune system gets weaker and weaker. You start to get sick often. When you have many HIV sicknesses, we say that you have AIDS. This can take many years.
- We measure your CD4 count to tell us the strength of your immune system. Read page 4.



immune system

- namasoshaomzimba
- nomxokelelwano wamandla okuzilwelwa komzimba kwizifo
- masole a mmele
- immuunstelsel

virus

- igciwane
- intsholongwane
- kokwanahloko
- virus



What is ART?

- ART stands for anti-retroviral treatment. People can now be given anti-retroviral medicines (ARVs) at government clinics and hospitals. This is part of the South African Government's National Care and Treatment Plan for people living with HIV and AIDS.
- ARVs slow down or stop the HIV from making more viruses and from attacking the immune system.
- These medicines are not a cure for HIV. They help to stop any more damage to the immune system and allow it to recover. When the immune system has recovered, it can protect the body better from infections. This means that people living with HIV can live a longer, healthier life.
- Like any medicines it can be hard to remember to take them all the time. You need to prepare yourself and make changes to your life to make it easier. This book will help you to do this.
- When people are on ART, they usually take a number of anti-retroviral medicines. These medicines work together to control the HIV in the body. If you take ARVs in the right way, they can help you to live a longer, healthier life.

NB

It is important for everyone to be tested for HIV. If you are **HIV negative**, you can make sure you stay that way. If you are **HIV positive**, you can live a healthy life and go onto ARVs at the right time. Read about HIV testing on pages 6 to 7.



to prepare

- ukuzilungiselela
- ukulungiselela
- itokisetsa
- voor te berei

control

- izolawula
- lawula
- laola
- beheer

HIV and anti-retroviral treatment

What is a CD4 blood test?

- CD4 cells are an important part of your immune system. When your immune system is strong, your CD4 count is high (more than 350). You can tell how strong your immune system is by doing a CD4 blood test.
- HIV attacks the CD4 cells and breaks down the immune system. Then your CD4 count slowly goes down. As your CD4 count goes down, you will start to get sick often. Your health worker should now discuss ART with you. He or she will do a CD4 blood test to see if you need ART.
- When you take ART, your CD4 count will go up as your immune system gets stronger.

What is a viral load test?

- A blood test called a viral load test measures how much HIV virus there is in the blood.
- The goal of ART is to keep the amount of virus in your blood so low that it can't be measured. When this happens, the HIV in your body is under control. This doesn't mean that the HIV has gone. It is still hiding deep in the body's cells, but is not growing quickly.
- If you stop taking the ARV medicines, the virus will start to grow again and your immune system will get weaker.



Your CD4 count and ART

- If you are pregnant or if you have TB, you should start ART when your CD4 count is 350 or lower.
- If you are not pregnant and do not have TB, then you should start ART when your CD4 count is 200 or lower.
- If you have an AIDS sickness, you should start ART no matter what your CD4 count is.

goal

- inhloso
- injongo
- sepheo
- doel

support group

- iqembu elesekayo
- kwiqela lenkxaso
- sehlopheng sa tshehetso
- ondersteuningsgroep

VILENA'S STORY

1 I remember my life before ART. I had already found out that I had HIV. But when I got TB, I had to face the fact that I now had AIDS.



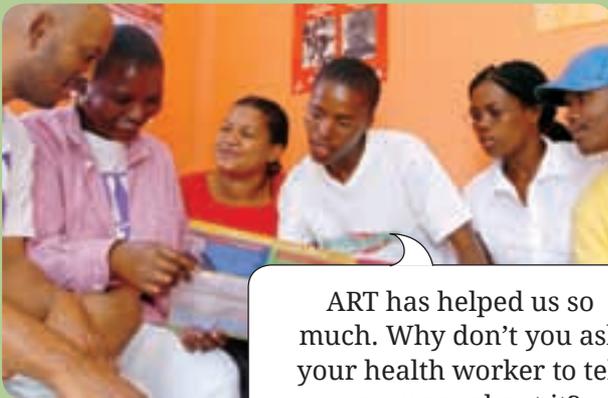
This cough is getting worse. I must go to the clinic.

2 At the clinic...

Your test shows you have TB. You need to take TB medicines for 6 months. I must do a CD4 test because you will have to start ART.



3 It was at the support group that I learnt more about ART.



ART has helped us so much. Why don't you ask your health worker to tell you more about it?

4 Later...



Your TB treatment is working well. Now you can start ART.

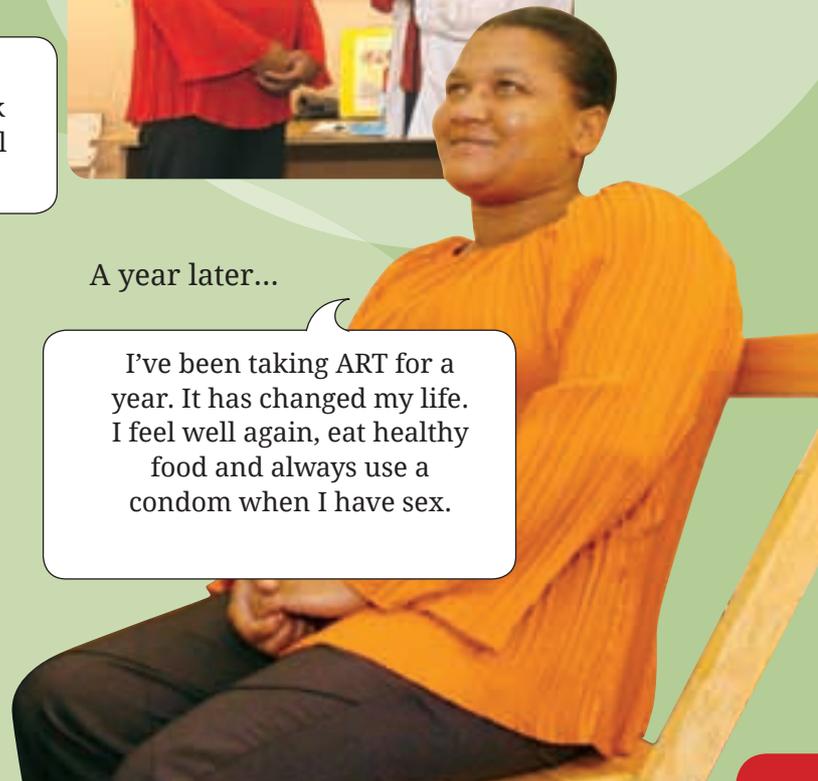
5 Vilena started ART a month after she started her TB treatment. If your CD4 count is 350 or lower, your health worker will start you on ART 2 to 8 weeks after starting TB treatment.

A year later...

I've been taking ART for a year. It has changed my life. I feel well again, eat healthy food and always use a condom when I have sex.



For more information on when to start ART, read pages 14 to 15.



How do you know if you are HIV positive?

Having an HIV test is not an easy decision to make. But the only way to know if you have the HIV virus is to have a blood test.

Why is it important to have the HIV test?

- Having the HIV test means you are taking responsibility for yourself.
- It is the only way to know if you are HIV positive or not.
- You need to know how to protect your health. Then you can stay healthy for longer.
- You also need to know how to protect other people from becoming HIV positive.



Community Information

It is your right to get **pre-test counselling**. It is also your right to get **post-test counselling**, even if your test results are negative.



Bettina, how can you tell who is HIV positive?

You cannot tell by looking at someone if they are HIV positive. Most people who have the HIV virus do not know they have it.

decision

- isinqumo
- isigqibo
- qeto
- besluit

responsibility

- umsebenzi
- osemahlombe
- uxanduva
- maikarabelo
- verantwoordelijkheid

counsellor

- umeluleki wezempilo
- ikhawunsela
- moeletsi
- berader

antibodies

- amasosha emzimbeni
- izilwabuhlungu
- dilwantshabolwetse
- teenliggaampies



Having the HIV test

It is important to speak to a counsellor or a health worker about having a test. They can help by answering any questions you may have about HIV, AIDS and the test. They know that you may be afraid and worried. They will give you support, and help you prepare for the results of the test. This is called pre-test counselling.

Some people may choose to take a friend, their partner or someone they trust with them. This person can give them support and care before and after the test.

You will need to talk to a counsellor or health worker when you go and get your test results. They will discuss the results with you, and what this means. This is called post-test counselling.

➔ What if my test is negative?

This means you do not have antibodies to the HIV virus in your blood. You must still do these things:

- You must continue to have protected sex. Do this so that you do not get the virus later.
- If you had unprotected sex recently, the virus may not show up in the first test. Wait for three months and go for another test.
- Continue to learn more about HIV and AIDS.
- Support those in your community who are HIV positive.

➔ What if my test is positive?

- You may feel afraid and shocked. You may not believe what you hear. This is normal. Find someone who can help you deal with how you feel.
- Find out more about HIV and AIDS. This book has a lot of advice that can help you.
- Have a CD4 test to see when to start anti-retroviral treatment (ART). Read pages 14 to 15.
- You need to be tested for TB as well. Read page 44.



How to prevent the spread of HIV

The most important ways to stop the spread of HIV are:

- 1 Use a condom every time you have sex
- 2 Know your HIV status and the HIV status of your partner
- 3 Have only one sexual partner
- 4 Think about getting circumcised if you are a man
- 5 Abstain from sex



I have lost too many friends to AIDS. How can we stop it from spreading?

There are many ways, Mary. My partner and I have decided not to have sex in our relationship until we feel ready.

status

- ngemiso
- mo
- boemo
- status

circumcised

- ukusokwa
- ukwaluswa
- bolotswa
- besny

abstain

- ukuzithiba
- ukuzikhwebula
- ho nena thobalano
- wegby

stable

- obuqinile
- obuzinzileyo
- tsepameng
- stabiele

relationship

- ubudlelwano
- ubudlelwane
- kamano
- verhouding



1 Use a condom every time you have sex

Many South Africans use condoms, but they do not use them every time they have sex. That is why they are at risk of getting infected with HIV.

Usually, people stop using condoms every time when they are in a stable sexual relationship for a few months. This is dangerous unless you both know you are HIV negative and remain faithful to each other. So, even if you are in a relationship, it is important to know your HIV status and the HIV status of your partner (read the following page).

- Unless you are sure that you are both HIV negative, you need to use a condom every time you have sex.
- Unless you are sure that your partner does not have any other partners, you must always use condoms.
- If one of you is HIV negative and the other is HIV positive, you must always use a condom every time you have sex.
- If you are both HIV positive, you must still use a condom each time you have sex. This is so that you protect each other from getting new HIV infections. New infections can weaken your immune system.

2 Know your HIV status and know the HIV status of your partner

Some people think that if a person looks healthy, they cannot be infected with HIV.

- You cannot tell if a person is HIV positive or not just by looking at them.
- Having an HIV test is the **only** way to tell if a person is HIV positive or not.
- All people who are sexually active should have a regular HIV test, at least once a year. Couples can go to get tested together.

Other important times to get tested are:

- When you are starting a new relationship
- When you are thinking of having a baby
- When a relationship ends
- When you are worried because you had unprotected sex with a person whose HIV status you did not know for sure.



How to prevent the spread of HIV

3 Have only one sexual partner

Having more than one sexual partner at a time is very dangerous. A relationship where both partners are faithful to each other and practise safe sex together is the safest. Just one time outside the relationship can bring HIV into the relationship.

Being married does not protect you from getting HIV unless:

- You both tested negative before you got married
- AND**
- You both always have only each other as sexual partners



4 Think about getting circumcised if you are a man

Male circumcision is when the foreskin of the penis is cut off. Men who are circumcised are less likely to get infected with HIV. Circumcised men also have to use condoms because circumcision does not fully protect them.



5 Abstain from sex

HIV is spread mainly by having sex. The most effective way to stop getting HIV is to abstain from having sex.

- Having sex is a very serious decision, especially if you are a young person. Your body may feel like it is ready for sex, but you may not be able to deal with the responsibility of having sex at a young age.
- Anyone can choose to abstain from sex. You can have a relationship without sex. It is not always true that sex makes a relationship stronger. There are many ways you can show another person that you love them without having sex with them.

When you are ready to have sex, read pages 8 to 9 to find out how to have safer sex.



responsibility

- umsebenzi osemahlombe
- uxanduva
- maikarabelo
- verantwoordelikheid

tip

- isihloko
- incam
- ntlha
- punt

semen

- isidoda
- imbewu yesidoda
- lero la botona
- semen

expiry date

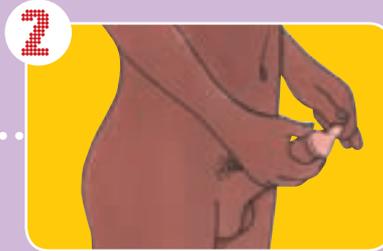
- ukuphelelwa yisikhathi
- imini yokuphelelwa
- letsatsi la ho fellwa ke nako
- vervaldatum

How to use a male condom

The illustrations below are here to make sure everybody understands the message clearly. It is important to use a condom correctly. You should use a condom this way:



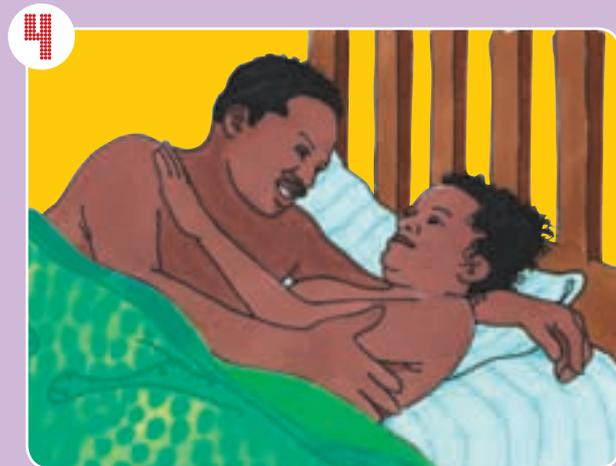
1 Use a new condom each time you have sex.



2 Just before you enter your partner put the condom onto your hard penis. If you are not circumcised, pull the foreskin back first. Press the tip of the condom when you put it on so that you push any air out.



3 Roll the condom down over your penis so that the whole penis is covered with the condom. Now you are ready to enter your partner.



4 Take your penis out after you have had sex. Hold the condom when you take the penis out so that the condom does not fall off. You must take your penis out before it gets soft.



5 Now carefully take the condom off your penis. Be careful not to let any semen spill or leak from the condom. Tie a knot in the condom.



6 Wrap the used condom in paper. Throw it in the dustbin or any place where children will not find it.



Remember!

- Always check the expiry date on the packet – old condoms are not safe.
- Some people want to use a cream with the condom to make sex easier. Do not use petroleum jelly or cream with oil for this because it damages the condom. Only use water-based creams or lubricants – find out which ones are water-based.
- Condoms do protect you from getting HIV infection, but they only protect you when you use them **every time** you have sex.

Why is HIV still spreading?



Why is HIV still spreading?

There are many reasons why HIV is still spreading. Read the opposite page to find out the main ones. There are also many wrong ideas and beliefs about HIV that help to cause the spread.



Community Information

We can all help stop the spread of HIV by having safe sex. We can also support people who are HIV positive – when we show them support, they can live a healthier life.



Tell me Sol, why is HIV still spreading?

The main reason is that many people still have unprotected sex with many partners. This means they have sex without using a condom.

at risk

- engozini
- usengozini
- kotsing
- loop 'n risiko

society

- umphakathi
- uluntu
- setjhaba
- gemeenskap

inequality

- ukungalingani
- ukungalingani
- ho se lekane
- ongelykheid

The main reasons why HIV is still spreading



Not using condoms every time

Many people do not use condoms every time they have sex. Because of this they can get infected with HIV. Lots of people stop using condoms when they have been together for a few weeks or months – they trust each other. But, if you do not know the HIV status of your partner, **you are at risk**.



Many sexual partners

In southern Africa, many people have more than one sexual partner at the same time – this is sometimes called “small houses” or *makwapheni* or *nyatsi*. If you have more than one sexual partner, you have more chance of getting HIV.



Unequal relationships

In many societies women do not have control of their sex lives. Society tells them they have to do what their husband or boyfriend tells them. They are afraid to ask their partner to use a condom, even if they know he has had unprotected sex with other women.



Inequality

Poor people living next to wealthier people means that poor people may use sex to get food and other things that make life easier. Wealthier people can use their money to have many sexual partners.



Not believing that we have control

Many people feel as if they are not able to control their own future, or have no hope that the future will be good. Because of this it can seem stupid to some people to try to practise safe sex or to behave safely.



Circumcision

Men who are not circumcised are more likely to get HIV. Although men who are circumcised are partly protected from HIV, they can still get infected with HIV if they have unprotected sex. That is why circumcised men must still use condoms **every time** they have sex.



Getting ready for treatment



When should I start ART?

HIV has different stages. It is important to know about them so you can go onto ART at the right time.



HIV positive and healthy

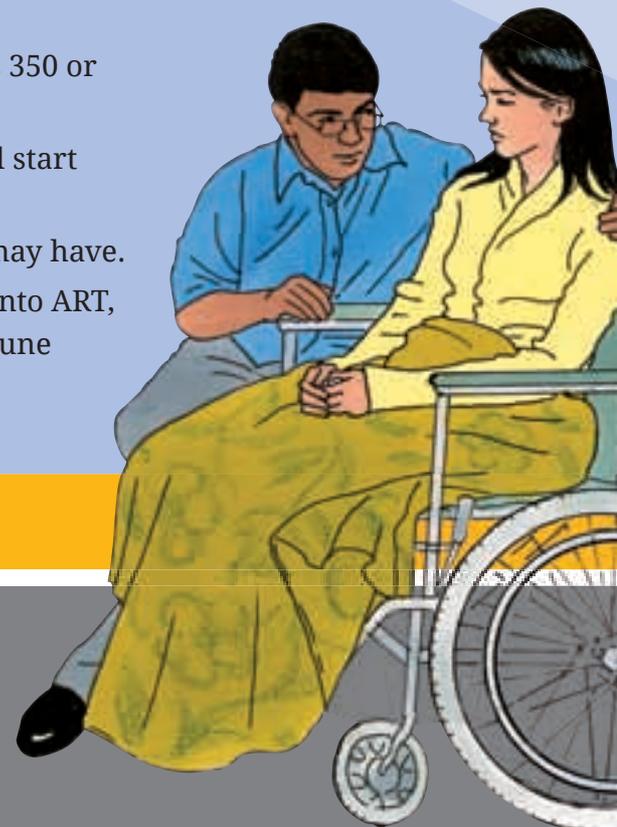


HIV positive with some sickness



HIV positive and sick

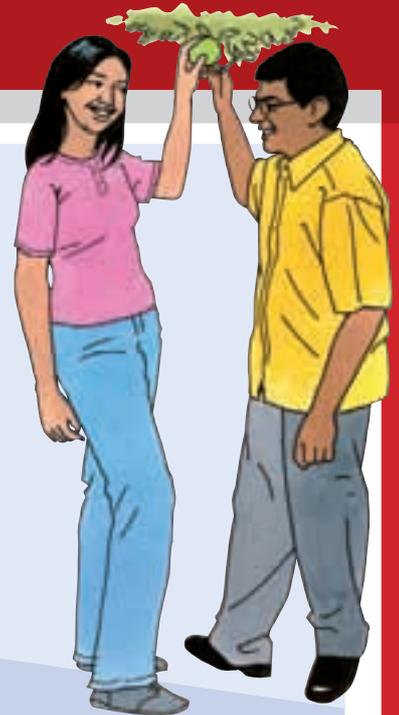
- 3** • You are HIV positive and your immune system is much weaker.
- You will start to get sick more often.
- If you are pregnant or if you have TB, and your CD4 count is 350 or lower, you should start ART as soon as possible.
- If you are not pregnant and do not have TB, then you should start ART when your CD4 count is 200 or lower.
- You will still need treatment for the different illnesses you may have.
- When a person with a very low CD4 count (below 50) goes onto ART, the treatment may not work. This is because his or her immune system is too damaged to get better.



damaged

- alimele
- yonakele
- senyehile
- beskadig

- 1**
- You are HIV positive and your CD4 count is high.
 - Your immune system is strong and you feel well.
 - You need to live positively and stay as healthy as possible.
 - You do not need ART.
 - Read pages 38 to 39 about keeping healthy on ART.



- 2**
- Your immune system has started to get weak.
 - You may get a few sicknesses, like chest infections and skin problems.
 - You need to get treatment for these sicknesses and live a healthy life.
 - You need to get your CD4 count and viral load checked. If the CD4 count is low, you will need to start treatment.

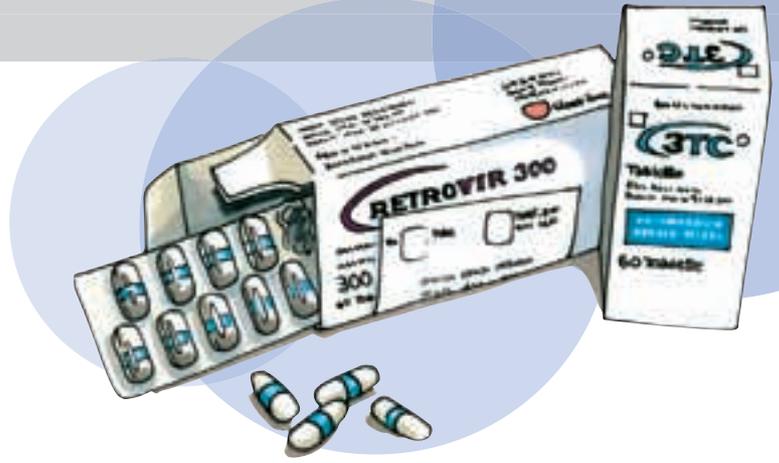


- live positively**
- ukuphila
 - ngokuzethemba
 - uphill unethemba
 - phela hantle
 - positief lewe

Getting ready for treatment

Steps leading to:

Anti
Retroviral
Treatment



By now:

- You will have made the choice to be tested for HIV.
- You will have found out that you are HIV positive.
- You may have had a CD4 count test that is low and shows that you should start ART as soon as possible.
- You may also have started getting sick with AIDS.
- You may have talked to your health worker about when to start ART.

Even if your health worker says that you are ready for ART, you need to be sure that you **are** ready for it.

How can I prepare myself for ART?

Taking ART is not easy. But there are things you can do to prepare yourself for treatment. Try to change the way you think about your illness. You need to accept that:

- There is no cure for HIV.
- HIV is part of your life.
- ARVs can make you feel much better.

If you can accept these things, then you will be able to get the most out of your life. You will cope better with ART. When you start treatment, your medicines will have to become a part of your daily life. You will need to take them in the right way, at the same time **every day**.

Try to tell someone that you are HIV positive before you start ART. This will help you cope better with the treatment.



cope

- bhekana
- kumelana
- kgema
- hanteer

The team of health workers

When you start ART, there will be a team of people who will look after you. We call the people in this team **health workers**. Health worker is a name used for the following people:



A **nurse** will examine you, treat you for any problems and prescribe your ARV medicines. He or she will refer you to a doctor if necessary.



A **pharmacist** will give you your ARV medicines and explain how to take them.



A **counsellor** will prepare you for ART, give support, offer advice about side-effects and help you to take your ARVs in the right way.



A **dietician** will give you advice about healthy eating while on ART.



The size of this team may be different in different places. Some big hospitals may have all these health workers, other smaller clinics may not.

The important thing you should know is that this team will help you to get ready for ART. You must also carry on taking your medicines in the right way. Read pages 36 to 37 for more information about health workers.

examine

- uzokuxilonga
- xilonga
- o hlahloba
- ondersoek

prescribe

- uzokubhalela
- kumisela
- kgetha
- voorskryf

side-effects

- nemiphumela eseoeleni
- kulawula
- mahloko a mabe a
- newe-effekte

Getting ready for treatment



What can I expect when I start ART?

You will not be given ART straight away. This is because your team of health workers need to be sure that you are well prepared for the medicines.

Before you start ART you will need to:

- Take part in a treatment readiness programme. Your health worker will tell you more about this.
- Be checked by the nurse or doctor to make sure you are ready for ART.
- Be treated for any illnesses that you have. Your nurse or doctor may not give you ART until you have finished these medicines.
- Take antibiotic medicines for a month, to prevent new infections.
- Go back to the clinic on the date you are given.

Questions about your treatment

These things might change, depending on:

- where you go to get your ART
- the health worker you see
- when you see him or her
- how often you see him or her

Here are some questions and answers to help you get an idea of the different roles health workers will play in your treatment.

Who will I see when I'm ready to start ART?

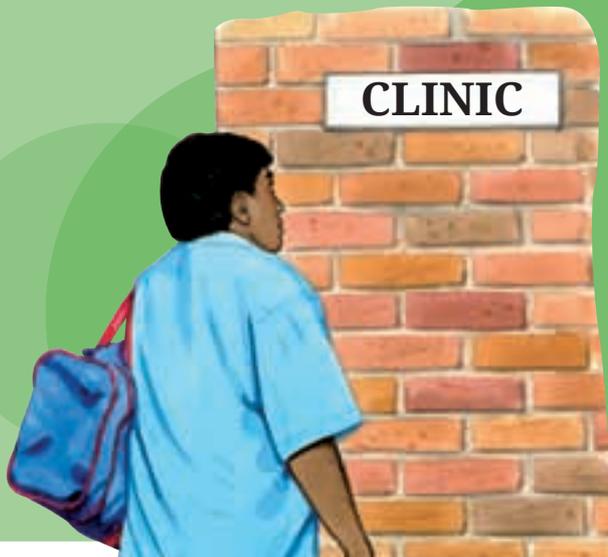
- For the first few visits, you will probably see a nurse and a counsellor. They will explain about HIV and ART, and will check your health. They may call a doctor if they are not sure if you should start ART.
- Some hospitals or clinics will ask you to go to group talks or workshops before you start ART. This will help them to see if you are ready to take ART.
- When you are ready to start, the nurse or doctor will give you the ARV medicines.



How often will I have to go to the clinic or hospital for my ART?

In the beginning, you will probably visit the clinic or hospital every 2 to 4 weeks. You will see a nurse or a doctor.

- After a while visits will probably be every 6 to 8 weeks.
- When you have been on ART for some time, you may only have to go back every 3 months.
- If at any time you are very sick or having bad side-effects, you should go to the clinic as soon as possible.
- Remember you will still have to collect your medicines every month.



What does the counsellor do?

- The counsellor will help you prepare for ART.
- He or she will also be at the clinic to listen to your worries and to help you to sort them out.
- You may see a counsellor on your own, or you may see him or her in your support group.



Remember!

It is very important to give your correct names, surname, address, date of birth and contact phone numbers for your patient records. Always tell the clinic if these change.

roles

- kweqhaza
- ngeendima
- diabo
- rolle

workshops

- imihlangano yokubonisana
- iindibano zokufundisana
- dithupelo
- werkswinkels

side-effects

- nemiphumela eseoeleni
- kulawula
- mahloko a mabe a
- newe-effekte

Anti-retroviral medicines



What anti-retroviral medicines (ARVs) will I need to take?

- There are many different ARVs, but none work well on their own.
- They work best when you take three ARVs together. This is called a combination.
- The combination you are given will control the amount of HIV in your body by stopping it from increasing in number.
- We are learning more about ARVs all the time. This is a good thing. New information will help scientists to develop new medicines, and new and better combinations.



I have been told that I need to take ARV medicines. What does this mean, Sol?

It means that you will take medicines at the same time every day for the rest of your life, Zandi. Then you will live a healthier, longer life.

combination

- inhlanganisela
- amayeza adityanisiweyo
- metswako
- kombinasi

control

- izolawula
- lawula
- laola
- beheer

scientists

- ososayensi
- izazinzulu
- ditsebi tsa saense
- wetenskaplikes

abbreviation

- isifinyezo
- izishungulelo
- kgutsufatso
- afkorting

ARVs can have different names

Here are some examples of names you may hear:

- ARV medicines or ARVs
- HAART or Highly Active Anti-Retroviral Treatment
- Cocktail
- Triple therapy
- Combination therapy



Why do ARVs have different names?

- Sometimes ARVs are called by their generic name (this starts with a small letter).
- Sometimes they are called by the label name on the box (this starts with a big letter).
- At other times they are called by a short name or abbreviation.

Think of an example like washing powder. The name may be **Omo**, **Surf** or **Skip** on the outside (**label name**).

But on the inside, it is the same thing – **washing powder** (**generic name**).

| Generic name | Label name | Short name |
|---------------------------|------------|------------|
| tenofovir | Viread | TDF |
| lamivudine | Epivir | 3TC |
| efavirenz | Stocrin | EFV |
| nevirapine | Viramune | NVP |
| emtricitabine + tenofovir | Truvada | FTC + TDF |
| zidovudine | Retrovir | AZT |
| didanosine | Videx | ddI |
| lopinavir + ritonavir | Aluvia | LPV/r |

Anti-retroviral medicines

Combination medicines (combination therapy)

At the moment there are two possible combinations available in South African hospitals and clinics. A doctor will decide which combination will be best for you.



1st-line treatment

- The first combination of medicines you take is called 1st-line treatment. For example:

tenofovir (TDF)
+
lamivudine (3TC) or
emtricitabine (FTC)
+
efavirenz (EFV) or
nevirapine (NVP)

- Most people start with this combination.
- If this combination gives you bad side-effects, or if it stops working well, your doctor may decide to change your medicines.

2nd-line treatment

- If the 1st-line treatment is not working, your doctor may try a different combination.
- This is called 2nd-line treatment. For example:

zidovudine (AZT)
+
lamivudine (3TC)
+
Alluvia (LPV/r)

How often will I have to take ARVs?

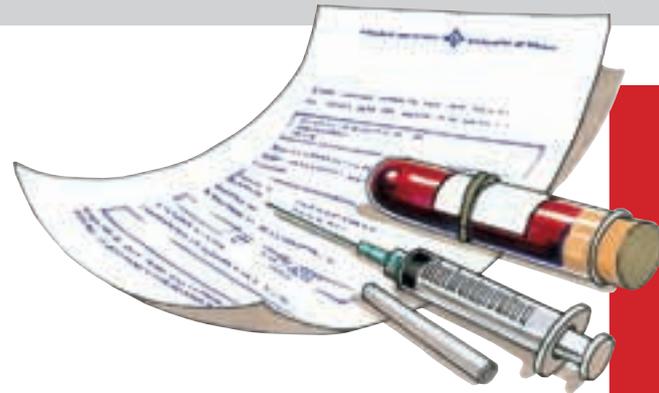
You will have to take these medicines once or twice a day, every day, for the rest of your life. If you take every pill at the right time, it should stop the virus from multiplying or growing.

See pages 32 to 35 for more information about how to take your ARV medicines in the right way at the right time.



How will I know if the ARVs are working for me?

A health worker will check whether the ARV medicines are working well for you by doing:



1 A CD4 count. This test checks the number of your CD4 cells. If the ARV medicines are working well, you will have more CD4 cells to fight infection in your body. This is a sign that your immune system is getting stronger. If your CD4 count was less than 50, it may not go up very much in the beginning, but you will still feel better.

2 A viral load test. This test checks if your viral load is going down until there is so little HIV in the blood that the test can't find any virus. If the ARV medicines are working well, this can happen in about 12 weeks. Remember, ARVs cannot cure or remove HIV from the body completely even if the viral load test shows that there is no virus in the blood. If you stop taking ARVs, the virus will start to increase again in the blood.

3 An examination. A health worker will examine you to check your weight and to see if there are any changes in your body and your health.



NB

It is important to know the names of your medicines. This will help you to talk to your health worker about your treatment.

multiplying

- phindaphindeka
- kuziphindaphinda
- ikatiso
- vermeerder

immune system

- namasoshaomzimba
- nomxokelelwano wamandla okuzilwelwa komzimba kwizifo
- masole a mmele
- immuunstelsel

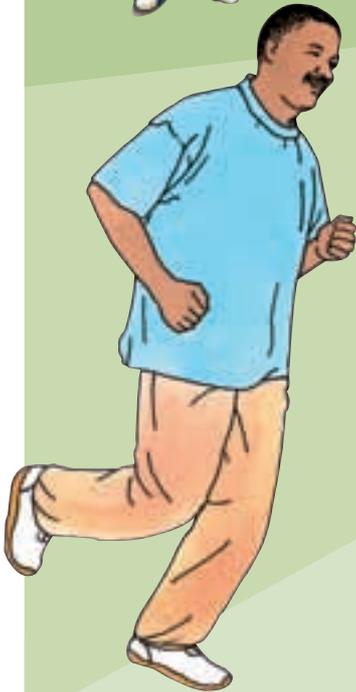
examination

- ukuhlolwa
- uxilongo
- tlhahlobo
- ondersoek

Anti-retroviral medicines



If the ARV medicines are working well, you will see it in the following ways:



- You feel better and will live a healthier and longer life.
- You will be stronger and have more energy.

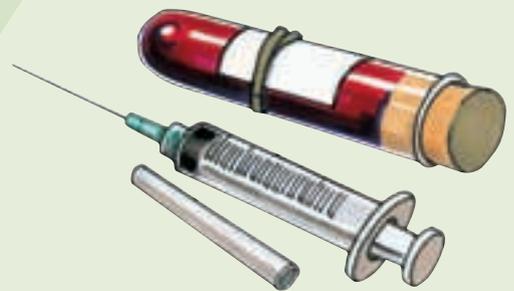
1

2

- Your immune system will be stronger.
- The HIV in your body will stop multiplying and growing.

3

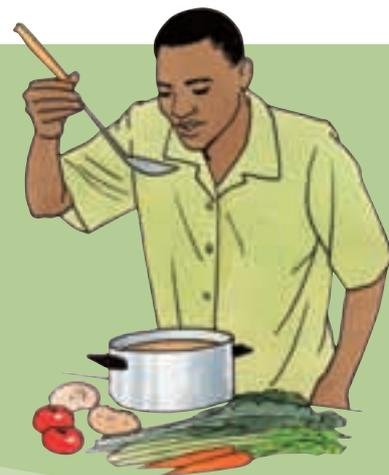
- Your viral load will drop.
- Your CD4 count will go up.



multiplying

- phindaphindeka
- kuziphindaphinda
- ikatiso
- vermeerder





7

- If your appetite was poor, it will improve, and you will want to eat more.

6

- If you lost weight, you will put some weight back on.



5

- You will recover from any problems you have. These may be a cough, thrush, a rash or diarrhoea.

4

- You won't get sick as often as you did before you went onto ARVs.



diarrhoea

- uhudo
- urudo
- letsholla
- diarree

appetite

- inhliziyo
- cacelanga ukutya
- takatso ya hao ya dijo
- aptyt

Side-effects of ART



Will I have side-effects from ARVs?

Most people have side-effects.

- Many side-effects begin quite soon after starting ART.
- Many will go away on their own after 2 or 3 months.
- Most of the ones you may get early on will be mild. They will settle after a while or can be easily controlled.
- Some may get worse and then the doctor may have to change your ARV medicines.

NB

Do not stop taking your medicines. Talk to your health worker if you find it hard to cope with side-effects.

Bettina, will I have side-effects from ARVs?

Many people get side-effects from ARVs, Connie, but we can find ways to manage these.



Learn about side-effects

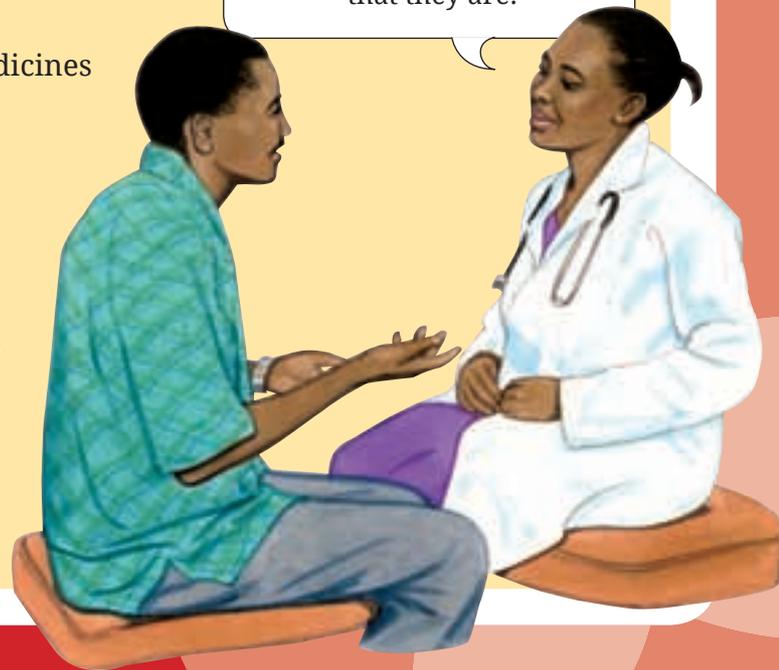
- If you do have side-effects, they can be very difficult to get used to and to cope with. You may worry about what is happening to your body.
- People will have side-effects in different ways. If you have a low CD4 count and a weak immune system, you will probably have more side-effects than someone who is healthy.
- One way to prepare yourself to cope with side-effects is to learn more about them.
- Join or form a support group with other people on ART and discuss ways to deal with your side-effects.



Questions to ask health workers

- What are the possible side-effects of the medicines I am taking?
- When will the side-effects start?
- How long will they last?
- Will they go away by themselves?
- What should I do if I have a side-effect?
- How will I know if the side-effect is serious?
- What can I do to reduce the impact of the side-effects?
- Will I feel sick?

Side-effects do not mean that the medicines are not working. A CD4 blood test will show that they are.



controlled

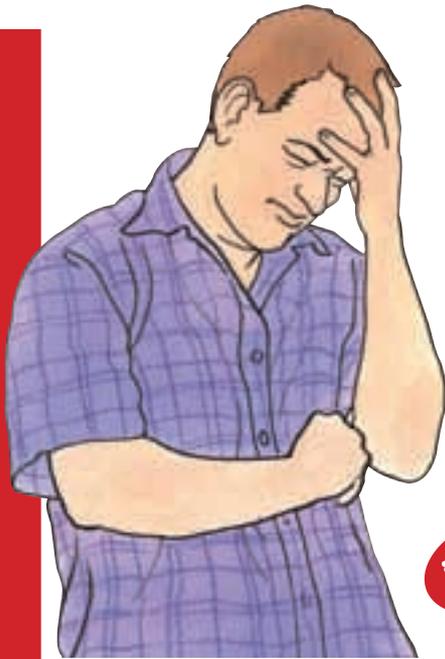
- ukuyilawulwa
- lawuleka
- a laolehe
- beheer

manage

- zokuyilawula
- lawula
- lapla
- beheer

to deal with

- zokubhekana
- melana
- ho sebitsana
- te hanteer



What are some of the most common side-effects?

- Dizziness
- Rash
- Headache
- Vomiting
- Nausea
- Not sleeping properly
- Bad dreams
- Feeling tired all the time
- Sleepiness
- Confusion

If you experience side-effects like these, make sure you tell the health worker.

NB

It is important to find out how serious the side-effect is, and to do something about it.

What **SERIOUS** side-effects should I watch out for?

Some side-effects may be serious. There may be a sign that the ARV medicines are not working or are causing serious damage to the body. The health worker should tell you what to watch out for and what to do.

Examples of these side-effects:

- A reddish skin-rash all over the body (arms, legs, hands, feet)
- Bad pain in the middle of the stomach
- Vomiting that doesn't stop
- No appetite and loss of weight
- Pain, burning or numbness in the hands and feet

NB

If you have any of these side-effects, speak to a health worker straight away.

dizziness

- inzululwane
- ukuba nesiyezi
- ho tsekela
- lighoofdigheid

nausea

- isicanucanu
- ukucatshu zelelwa
- ho nyeka pelo
- naarheid

confusion

- ukudideka
- ukubhuda
- ho ferekana
- deurmekaar voel

FLORENCE'S STORY



Let me tell you how I coped with side-effects in the early days of my ART.

Soon after I started taking ARVs, I felt as if I was going to vomit. It felt like the morning sickness that women get when they are pregnant. Every time I ate something, I wanted to be sick. I couldn't even stand the smell of food.

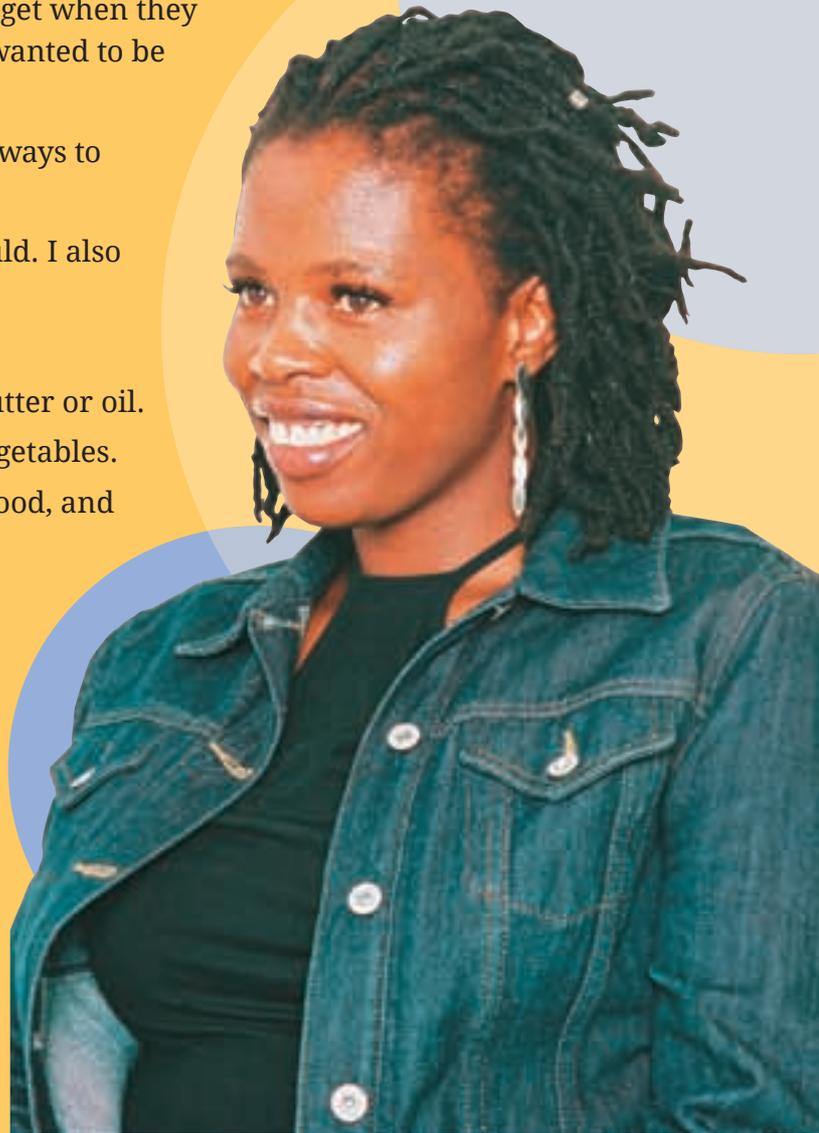
I knew I had to eat well, and so I had to find ways to cope with this sickness.

I read as many leaflets about nausea as I could. I also kept trying different things:

- I ate cold food.
- I didn't eat spicy food and food fried in butter or oil.
- I made sure I ate lots of fresh fruit and vegetables.
- I asked someone to help me prepare the food, and sit with me to encourage me to eat.
- I drank my medicines with cold water and ice.

The way I understand side-effects is that my body had to get used to the ARVs. While this was happening, I felt sick.

After a few months my body was used to the new ARV medicines and the nausea went away.



numbness

- inkwantshu
- ubundindisholo
- botsikinyane
- dooie gevoel

vomit

- angibuyise okusesiswini
- kugabha
- hlatsa
- opgooi

spicy

- okunezino ngo
- okuqholiweyo
- tse nang le dinoko
- vol speserye

The right way to take ARVs



What is resistance?

Resistance is when the ARV medicines stop having an effect on the amount of HIV in your body. Your CD4 count will then drop, and your viral load will get higher.

The HIV virus in your body can develop resistance because:

- You haven't taken your ARV medicines in the right way.
- You stopped taking your medicines.

Sometimes the HIV virus can develop resistance even if you have been taking the medicines the right way. This can happen after you have been on the same ARVs for many years. It can also happen if you were infected with a type of HIV virus that is resistant to the medicines.



Francis, why is it important to take my medicines in the right way?

Taking your medicines in the right way prevents resistance, Zandi.

resistance

- ukumelana nemishanguzo
- ukwaliwa kwamayeza
- monyetla wa ho hana ho amohela meriana
- weerstand

resistant

- ukumelana
- ewalayo
- e tla hano ho laolwa
- bestand

combination

- yinhlanganisela
- ngumdibaniso
- motswako
- kombinasië



Why is it important to try to prevent resistance?

If the HIV virus develops resistance to certain ARV medicines, you will have to try another combination. At the moment there are only two combinations available in the government's ART programme. It can get harder to find the right combination to keep the HIV under control if you develop resistance.



What happens if I share my medicines?

There may be other people in your household who need treatment. If you give them some of your medicines, the ART will not work for you or for them. If you don't take the right dose, it makes the HIV in your body stronger. So even if you take the treatment properly the next time, it will not work for you.



SIMON'S STORY



At the mine where I work, I am on the ARV programme. For the first few months, I took my ARV medicines properly and I felt so strong. Then my girlfriend started to get sick, so I shared my ARVs with her.

When I did this, my medicines finished two weeks before my next visit to the clinic. When I went back to the clinic, I didn't tell the nurse that I had stopped taking my ARVs. We just shared medicines for a while.

The nurse knew something was wrong when my viral load kept getting higher, and my CD4 count dropped. Then I told her what had happened. She explained how sharing medicines had made me stop taking my pills in the right way. So the HIV had developed resistance to the medicines.

Now I'm on new medicines. I understand why it is important to keep taking my ARVs in the right way, **every single day**. I have my own ARVs, and now my girlfriend also has her own.



How to make ART work for you



There are 4 important things that can help ART work well for you.

- 1 A treatment helper
- 2 A treatment plan
- 3 A treatment record
- 4 A good relationship with your health worker

1 A treatment helper

Tell someone you trust that you are starting ART. Ask this person to be your treatment helper. This person will do these important things for you:

- Remind you to take your medicines every day.
- Help you if you have side-effects.
- Come with you to see a health worker if you don't want to go alone.

Choose a family member you trust or a friend that lives close to you. Ask that person to find out more about ART and to be your treatment helper.

relationship

- ubudlelwano
- ubudlelwane
- kamano
- verhouding

trust

- omethembayo
- omthembayo
- mo tshepang
- vertrou



2 A treatment plan

Your health worker will work with you to develop a treatment plan. This will remind you:

- which pills to take
- how many to take
- when to take them
- whether to take them with food or on an empty stomach

Get a treatment plan from your clinic if they have one. You can also use the example below to write your own plan.



| My treatment plan | | | |
|---------------------------|-----------------|------------------|-------------------------------------|
| Name of ARV | Number of pills | When | Comments |
| Truvada (tenofovir + FTC) | 1 | 8am (once a day) | |
| efavirenz (EFV) | 3 | 8pm (once a day) | Do not take pills with a fatty meal |

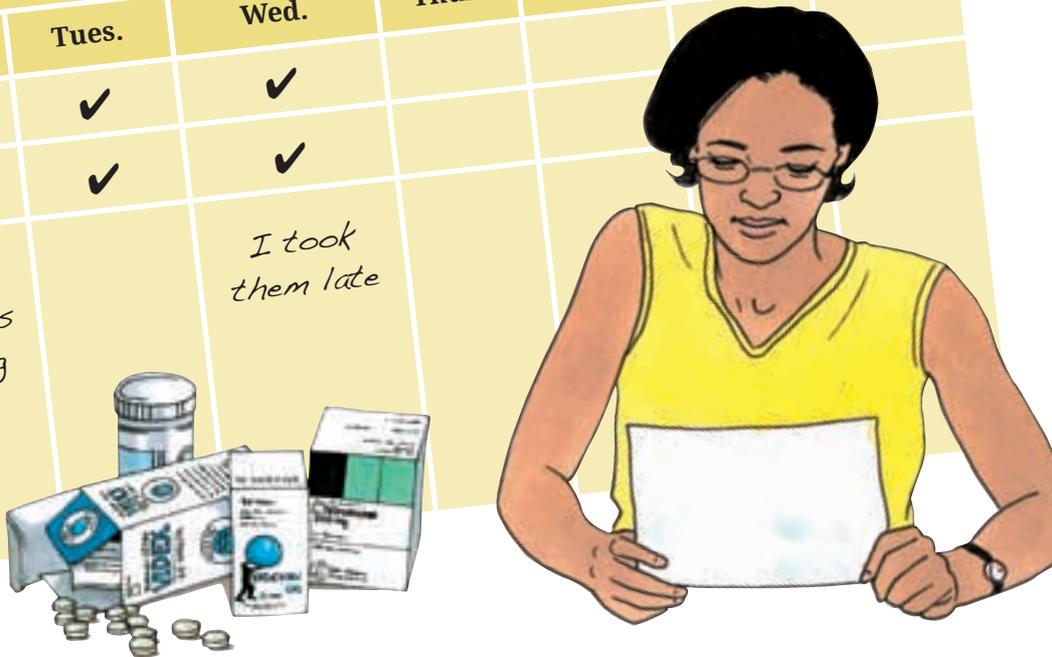
How to make ART work for you

3 A treatment record

You can use a treatment record to write down what pills you took and when you took them. It will help you to take your ARV medicines at the same time **each day and every day**. This is important because the medicines will keep the virus under control. But only if you take them exactly as the health worker has told you to.

My treatment record

| Did I take my ARV medicines? | | | | | | | | |
|--------------------------------------|---------------------------------|-------|-------------------------|-------|------|------|------|--|
| ✓ yes ✗ no | Mon. | Tues. | Wed. | Thur. | Fri. | Sat. | Sun. | |
| Morning | ✓ | ✓ | ✓ | | | | | |
| Evening | ✓ | ✓ | ✓ | | | | | |
| How ARV medicines made me feel today | <i>I felt sick this morning</i> | | <i>I took them late</i> | | | | | |



If you forget to take your pills, the virus will get stronger and you can develop resistance to the ARV medicines. If you develop resistance, the ARVs you are taking will not work properly anymore. Read pages 30 to 31 for more about resistance.

NB

- Get a treatment record from your clinic if they have one. You can also use the example above to write your own.
- Give a copy of your treatment record to your treatment helper. He or she can remind you to take your medicine.
- Your treatment record will be very important when you first start taking ARVs. It will help you get into a routine.

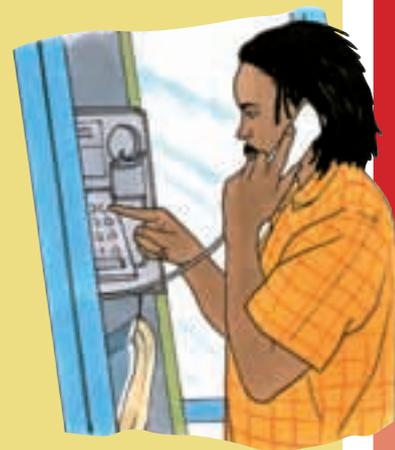
A good relationship with your health worker

The relationship between you and your health worker is very important. It is your **right** to get proper care. If there is trust between you and your health worker, it can make a big difference. Building trust may be hard if you don't see the same health worker each time.



Here are some simple things you can do:

- Try to see the health worker as an important part of your treatment. Then you will get the most out of your visits.
- Try to smile and be friendly.
- Try to go to the same clinic or hospital. Get to know the health workers there.
- Learn the name of the health worker you see at each visit.
- Be positive and show interest in your treatment.
- Write down any questions you have so that you can ask the health worker at your visit. Write down the answers.
- Try not to miss your clinic or hospital visits.
- Get the emergency number of the clinic in case you need it.



If you trust your health worker, you will be able to be honest about any personal issues like sex, alcohol and drug use.

- The health worker is there to help you and not to judge you.
- If you are honest, the health worker will know and understand all the problems you may have about staying on your treatment. Then you can get support and there is more chance that ART will work for you.

For more about you and your health worker, read pages 36 to 37.

routine

- ekuzejwayezeni
- kwimo yesiqhelo
- tlwaelo
- roetine

emergency

- yesimo esiphuthumayo
- yengxakeko
- ya tlokotsi
- noodnommer

personal issues

- kokuqondena nawe
- imibandela eyeyakho
- tse hlokolotsi
- persoonlike sake

to judge

- ukukwehlulela
- ukugweba
- ho o ahlola
- te veroordeel

ART and your health worker



What are my rights as a patient?

The Department of Health has drawn up a Patients' Rights Charter.

This is a list of rights that all patients have when they go to a hospital or clinic, or they use other health services.

The Patients' Rights Charter

As a patient you have the right to:

- Enjoy a healthy and safe environment.
- Go to a health care service that is nearby.
- Receive confidential care in private.
- Be referred to another person for a second opinion.
- Be able to choose your health service.
- Have ongoing care.
- Know the name of the health worker treating you.
- Make complaints about poor service.
- Join in decisions affecting your health.
- Receive information to assist your decisions about treatment.
- Refuse to have treatment.
- Know how your medical aid scheme or health insurance works.

What difficulties do health workers face?

- In government clinics and hospitals, health workers have to see large numbers of patients. They often don't have enough equipment or good enough facilities. They get paid a lot less than health workers in private health care.
- Health workers are struggling because they have to see more and more people with HIV or AIDS. And they also have their other patients to see.
- Health workers are only human. They get tired, stressed, and sometimes feel they cannot work anymore. This can affect the kind of service they give.

drawn up

- uhlanganise
- lenze
- ngodile
- opgestel

environment

- indawo
- kwindawo
- ekungqongileyo
- tikotoho
- omgewing

confidential

- olunobumfihlo
- okuyimfihlo
- sephiring
- vertroulike

facilities

- izinsiwa
- ndawo zokusebenzela
- dibaka tsa tshebeletso
- fasiliteite

As a patient, I also have a right to the following:



1 Emergency care

If you have AIDS and you are very ill or dying, you have the right to emergency care at any clinic or hospital even if you can't afford to pay.

Government hospitals are not allowed to turn you away if you are seriously ill. Health workers follow the Department of Health policy that does not discriminate against people with AIDS.

2 Confidentiality

No health worker can tell anyone else about your HIV status. Information about your health and the treatment you are on can only be passed on to someone else if:

- You have agreed.
- You have given informed consent.
- There is a law case or court order.

However, health workers can talk to each other about your HIV status if they are involved in your treatment.

3 Attitude

You have the right to be treated with respect, dignity, patience, empathy and tolerance.

If you feel that a health worker has been unfair, rude or has embarrassed you, tell him or her how you feel. If the health worker doesn't explain or apologise, then you can complain to the management of the clinic or hospital.

discriminate

- bandlululi
- ongabacaluliyo
- kgetholleng
- diskrimineer

informed consent

- imvume ngokuqondo
- imvume esekwe kwinto oyiqondayo
- kananelo ho latela tsebiso
- ingeligte toestemming

empathy

- ngozwelo
- uvelwano
- kutlwelobohloko
- empatie / begrip

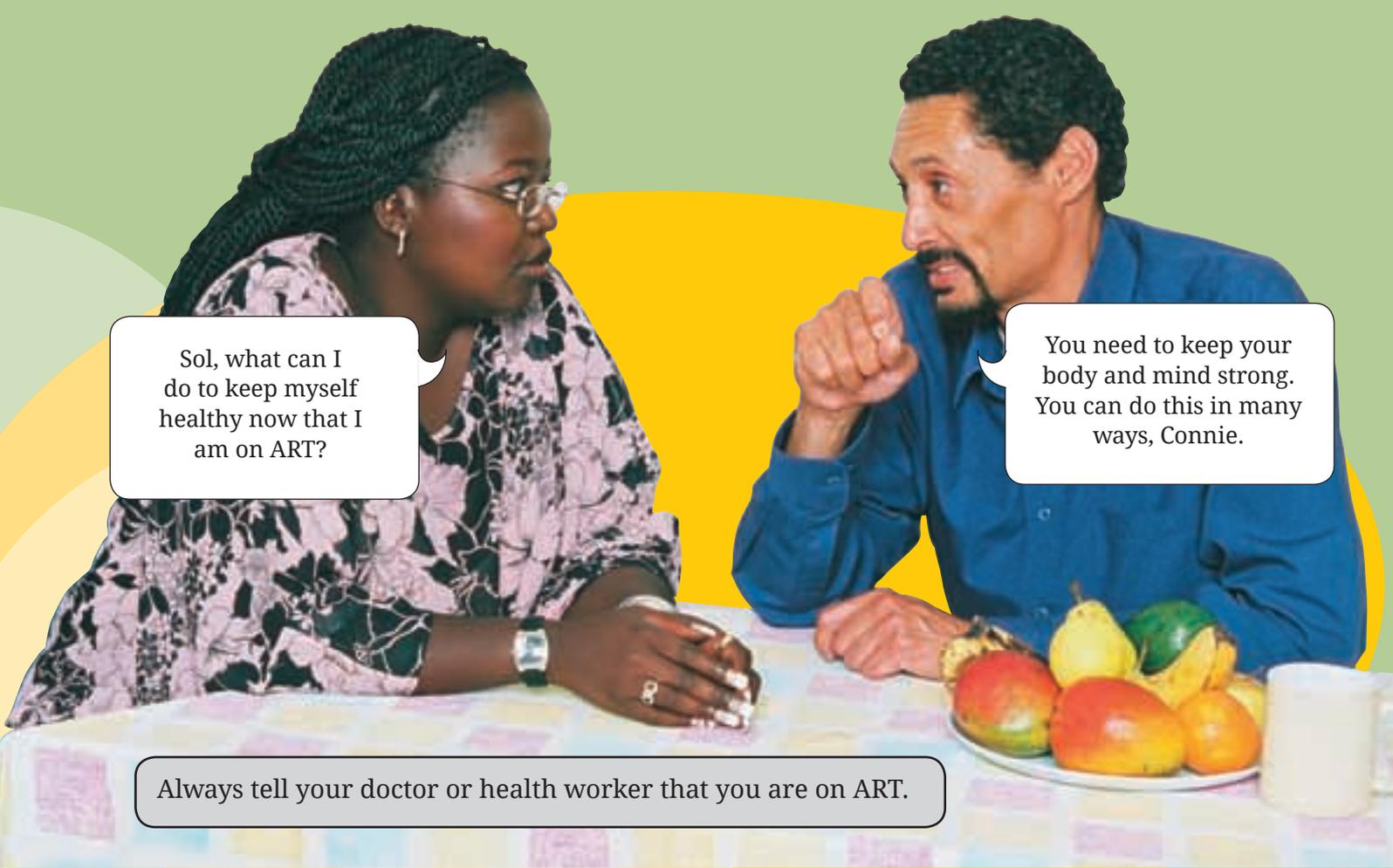
embarrassed

- ukuphoxile
- ukuphoxile
- swabisitse
- verleë gemaak / skaam laat voel

Keeping healthy on ART

When you are on ART, it is especially important to take care of your mind and your body. In this section, you will find ways to help you keep healthy:

- 1 **Practise safe sex while on ART**
- 2 **Eat the right foods**
- 3 **Cut down on alcohol and smoking**
- 4 **Exercise your body**
- 5 **Get support from people**
- 6 **Treat any new diseases or problems**
- 7 **Talk to your health worker first before taking other medicines**



Sol, what can I do to keep myself healthy now that I am on ART?

You need to keep your body and mind strong. You can do this in many ways, Connie.

Always tell your doctor or health worker that you are on ART.



† Practise safe sex while on ART

- Even if you are on ART, you can still infect your partner with HIV. This is why you still need to practise safe sex. When you have sex with someone who is HIV positive, you can get a new infection. New infections can weaken your immune system.
- You could also get a new HIV virus that is resistant to your ARV medicines. This will increase the viral load in your body. Always use a condom when you have sex. This will protect you and your partner from new infections.
- A condom will also protect you from sexually transmitted infections (STIs). STIs damage the skin and membranes of the penis and vagina. If your partner or you has an STI, it is easier for HIV to enter the blood and cause infection. STIs also increase the risk of you spreading your HIV to someone else. So get treatment **as soon as possible** for any STI.
- It is important to be in a relationship where both partners are faithful to each other. This will prevent either of you from getting re-infected with HIV.

You can use male or female condoms:

The male condom

The male condom is available free from most clinics. You can also buy them from many shops. Read page 11 about how to use the male condom.

The female condom

These are condoms that are used by women. Some women prefer to use them because they can put them in long before they have sex. Not all clinics have female condoms. Find out from your clinic where female condoms are available in your area. Women have the right to protect themselves against HIV and AIDS. We need to fight to make female condoms available for free in all areas.



resistant

- ukumelana
- ewalayo
- e tla hano ho laolwa
- bestand

membranes

- nolwebu
- nwebu
- lera
- membrane

faithful

- bethembekile
- thembeka
- tshepahalang
- getrou

Keeping healthy on ART

Eat the right foods on ART

People living with HIV should eat as many of these foods as they can every day:

- Fruit and vegetables. These foods help to fight sickness.



- Beans, lentils, meat, chicken, fish, milk and eggs. These foods build the body and keep us strong.



- Maas or yoghurt. These are sometimes easier to digest than milk.



- Brown bread, brown rice, pap and samp. These foods give us energy to grow, play, work and learn.



- Butter, oil, peanut butter and nuts. These give us energy. They can be added to our porridge or other foods.



Healthy eating does not have to be expensive

- Choose vegetables and fruit at the time of year when they are cheapest. If fruit is too expensive, eat more vegetables.
- Lentils, beans and soya mince are cheaper than meat and chicken.
- Drink water and rooibos tea rather than fizzy cooldrinks.
- Prepare your own fresh food rather than buying meals or takeaways.

3 Cut down on alcohol and smoking

- Alcohol can make you forget to take your ARV medicines. It can also make you eat less. Try to cut down your drinking or stop drinking altogether. Drink water or fruit juice instead.
- Smoking is not good for your health as it causes chest infections. It also makes people eat less because they will have a cigarette instead of a snack.



4 Exercise your body

- It is helpful to exercise your body. Then you will be more healthy.
- It is good to keep active and busy, so you will not worry so much about your HIV.
- Even if you are on ART, you still need to live a positive and healthy life.



5 Get support from people

- Join a support group.
- Speaking openly is important. It helps you to take your medicines properly.
- It also helps to reduce stress. Many people are afraid of being open about their HIV status because of discrimination and stigma.
- We need to provide more education and information about HIV. Get to know all about HIV. This can help to reduce the fear often felt by people with HIV and AIDS.



discrimination

- yokubandlululwa
- calucalulo
- kgethollo
- diskriminasi

stigma

- isigcwagcwa
nokubekwa amabala
- nesiphako
- tlwaelo e kelellong
- smet / stigma

Keeping healthy on ART

6 Treat any new diseases or problems

People with HIV can get sick, even if they are on ART.

- It is important to go to the clinic if you are sick. This is because every sickness makes the body weaker. Then it is less able to fight the HIV virus.
- If the health worker finds you have any new problems, they should be treated with medicines. If they are not treated quickly, they may get much worse.
- Go for regular check-ups.



7 Talk to your health worker first before taking other medicines

- Some people say that there are natural or traditional medicines that can help strengthen your immune system. At the moment we do not know enough about these medicines to know if they are helpful or harmful. They may have their own side-effects, and they may interfere with the ARVs.
- Talk to a health worker about other medicines you are using or thinking of using.
- It is also important not to share your medicines. They won't work for you or the other person. Read pages 30 to 31 to find out more about this.



NB

Only take the medicines that your doctor has given you.

traditional

- yendabuko
- wemveli
- ya tlhaho, ya setso
kapa ka botjhaba
- tradisionele

interfere

- ingaphazamisa
- angaphazamisana
- sitisana
- inmeng

ABDUL'S STORY

1

I recently found out that I am HIV positive after blood tests.

Abdul, your CD4 count is 580. You won't start ART until it drops to 200 – unless you get sick.

I still need to prepare for ART, and to change the way I live.

2

I was scared to tell you I have HIV. But I am so glad I did.

Remember your family and friends are here for you, Abdul.

Abdul has learnt that he needs:

- To have a CD4 count test every six months.
- To always use a condom when he has sex.
- To eat healthily and exercise 3 times a week.
- To stop smoking and drinking alcohol.

His family, friends, a traditional healer and a health worker help him to fight HIV. He has also joined a support group, and now feels less stressed.

3

I lead a healthier life now than I did before I found out I had HIV.

TB and HIV



People who are HIV positive can get TB more easily than people who are not HIV positive. This is because their immune systems are often not strong. TB can be treated and cured whether you are HIV positive or not. The same pills work to cure TB whether you have HIV or not.

The sooner you find out that you have TB and start treatment, the easier it is to treat and cure the illness. If you think you have TB, **go to the clinic immediately.**



What are the signs of TB?

If you have TB, you will probably have some of the following signs and symptoms:

- Coughing for more than 2 weeks
- Tiredness or weakness of the whole body
- Not wanting to eat
- Getting a fever that comes and goes
- Sweating at night even when it is cold
- Losing weight
- Feeling pains in the chest
- Lumps or swellings
- Becoming short of breath easily



I have been coughing for more than 2 weeks now.

It is good that you came to the clinic so that we can give you a good check.

NB

For more information, read the Soul City book, *Take action to stop TB!*

symptoms

- izinkomba
- umqondiso
- matshwao
- simptome

fever

- imfiva
- ifiva
- feberu / motjheso
- koors

preventive

- evimbela
- athintelayo
- tshireletsang
- voorkomende



➔ If you are HIV positive and have TB

If you are already on ART and you get sick with TB, your health worker may need to change the ARV medicines you are taking.

If you are not yet on ART, you need to have your CD4 count checked when you start your TB treatment. This will help your health worker decide if you need to start ART.

- If your CD4 count is **350 or less**, you need to start taking ART. Your health worker will start you on ART 2 to 4 weeks after you start TB treatment. You will need to carry on taking TB treatment for the full 6 months.
- If your CD4 count is **more than 350**, you do **not** need to start ART yet. After you have completed 6 months of TB treatment and tests show that you are cured of TB, your health worker should repeat your CD4 count.

NB

TB treatment must be taken for 6 months. ART must be taken for life.

➔ If you are HIV positive and do NOT have TB

Make sure that you know the symptoms and signs of TB. Your health worker should check you for the symptoms and signs of TB at every visit.

If your health worker is sure that you do not have TB, he or she may give you preventive TB medicines for 6 months. This will help prevent you from getting TB.

➔ If you have TB and do not know your HIV status

If you have TB it does not mean you have HIV or AIDS.

- But TB is a common illness in people who are HIV positive.
- That is why it is important to have an HIV test when you get sick with TB.
- If you are also HIV positive, you can get the right treatment to help you live a longer, healthier life.

!

It is important to always complete your treatment for TB. This will make sure that you are cured before you stop the treatment. Only a health worker can tell that you are cured.

HIV & AIDS and pregnancy

What should I know about HIV and pregnancy?

A woman can pass on HIV to her baby during pregnancy, childbirth and while she breastfeeds. That is why every pregnant woman needs to know her HIV status early in the pregnancy.

A woman is more likely to pass on the HIV virus if:

- She gets infected with HIV while she is pregnant or breastfeeding.
- She gets a new HIV infection while she is pregnant or breastfeeding.
- She is sick with AIDS when she is pregnant or breastfeeding.

About one out of every four babies born to HIV-positive mothers will get HIV unless the mother and baby both take medicine to stop this happening

NB

Talk to your health worker about ways to protect your baby from becoming infected with HIV during pregnancy, childbirth and breastfeeding. Read pages 48 to 51.

Bettina, I'm HIV positive. Can I have a baby?

Yes, Dora, but if you want to have a baby, you need to plan it carefully.

contraception

- ngokuvala inzalo
- thintela ukukhulelwa
- thibelo ya pelehi
- geboortebeperving

dual

- okumbaxambili
- kabini
- ya bobedi
- dubbele

abortion

- lokuhushula isisu
- khupha isisu
- ho ntsha mpa
- aborsie



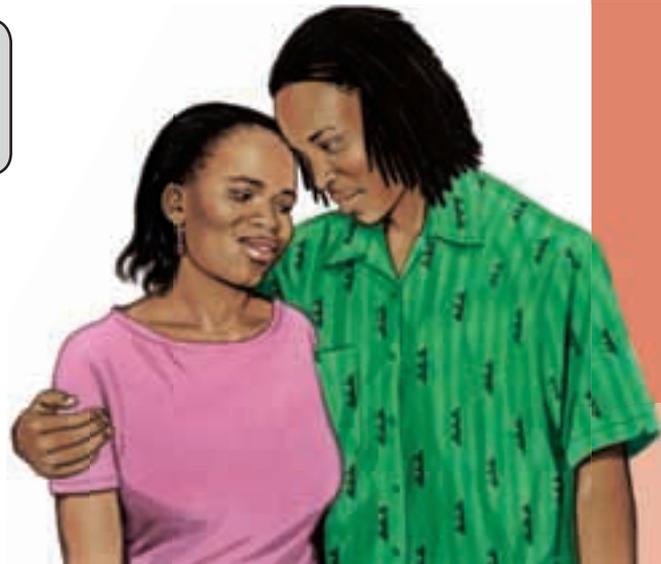
If you are HIV positive and do NOT want to have a baby

- If you do not want to have a baby, you need to use birth control (contraception) to prevent pregnancy. Using condoms every time you have sex will help prevent pregnancy. It will also protect you and your partner from new HIV infections and STIs.
- You can also use other methods of birth control, like the pill and the injection, and condoms at the same time. This is called dual protection. This is a more effective way to make sure that you do not fall pregnant. If you are on ART, you should use dual protection to prevent pregnancy.
- If you fall pregnant and you do not want to have a baby, you have the same right to an abortion as other women do. If you choose to have an abortion, it is better to have it early in the pregnancy. An abortion can be done until a woman is 20 weeks pregnant. Ask at your local hospital about where you can get an abortion.

Men often think that it is the woman's responsibility to prevent pregnancy. This is not true. Talk to your partner about birth control.

If you are HIV positive and are thinking about having a baby

- It is better to wait until you are well before you try to get pregnant. If you are already on ART, wait until your CD4 count has improved and the level of virus in your body is so low that it does not show up on a viral load blood test. This gives your body a chance to get stronger before you get pregnant.
- If your partner is HIV negative, there is a chance that he will get infected when you have unprotected sex to try to fall pregnant. If you are both HIV positive, there is a risk that you can get new HIV infections. There are ways to lower the chances of getting infected with HIV while you are trying to fall pregnant. Talk to your health worker about this.
- If you are already on ART, tell your health worker you are planning to get pregnant. He or she may change your ARVs so that they are safe for your unborn baby.



HIV and AIDS and pregnancy

I need to find out which ARVs can help protect my baby from HIV.



If you are on ART

Some women are already on ART when they get pregnant. Others start ART while they are pregnant. If you are seriously ill or your CD4 count is **below 350**, you should start **lifelong** ART for your own health. ART will help you to be healthy and live for a long time. ART also helps to protect your baby from getting infected with HIV during pregnancy, labour and while you breastfeed.

- Efavirenz (Stocrin) can harm your unborn baby in the first three months of pregnancy.
- If you get pregnant on efavirenz (and you are still in the first three months of pregnancy), your health worker will change it to an ARV that is safe for your unborn baby.

If you are not on ART

If you are well and your CD4 count is **above 350**, you should start the **PMTCT Regimen**.

- The ARVs that are part of the PMTCT Regimen will help protect your baby from getting infected with HIV.
- During pregnancy you will take an anti-retroviral medicine called AZT (zidovudine) twice a day, every day, until your baby is born. AZT should be started as early as possible from 14 weeks of pregnancy.
- You will also need to take anti-retroviral medicines during labour and soon after your baby is born. It is very important that the health workers in the labour ward know that you are HIV positive so that they can give you these medicines.

lifelong

- empilo yakho yonke
- yobomi bonke
- ya bophelo bohle
- lewenslange

NB

Make sure you go to the clinic as soon as you think you are pregnant. Then your baby will have a better chance of being born HIV negative.

Babies born to HIV-positive mothers should also get an ARV

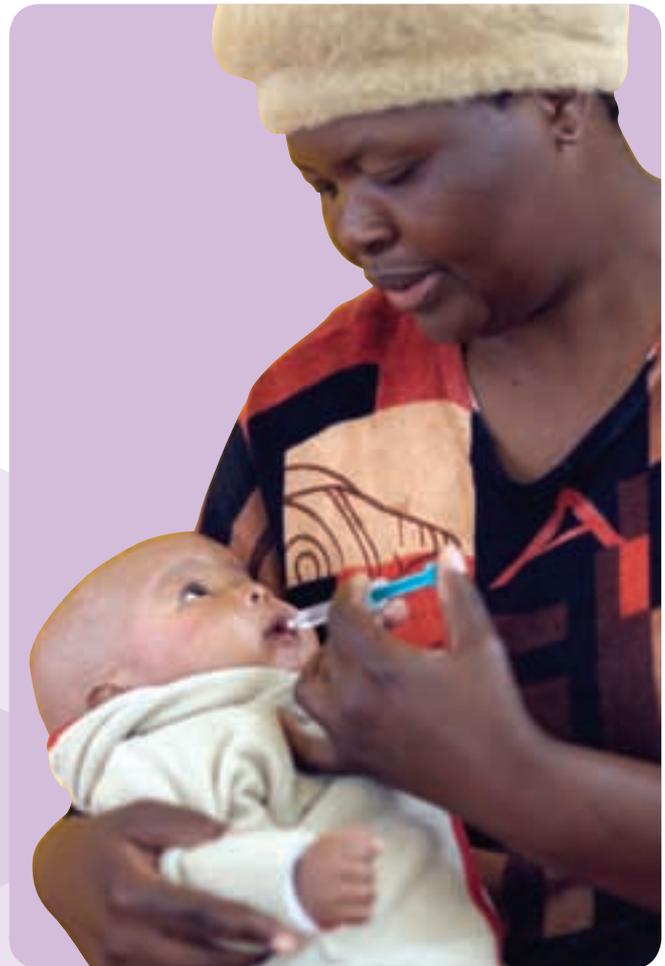
All babies born to mothers who are HIV positive should be given an anti-retroviral medicine called nevirapine every day for at least 6 weeks.

- Nevirapine should be started as soon as possible after birth and before the baby is three days old.
- Nevirapine should be continued every day for as long as the baby is drinking breast milk. If a breastfeeding mother is taking lifelong ART, her baby does not need to carry on taking nevirapine after the first 6 weeks.

Mothers can feed their babies in ways that can lessen the chance of the virus being passed on through breast milk. You can read about this on pages 50 to 51.

!

There is a bigger chance of passing on HIV to your baby if you get infected with HIV again while you are pregnant or breastfeeding. Always use a condom when you have sex.



HIV positive? How to feed your baby



How to feed my baby

This is a very important decision that only you, as the mother of your baby, can make. This can be difficult if you are HIV positive as there is no absolutely safe way to feed your baby. This is because:

- HIV is found in breast milk and so a mother can pass the virus on to her baby when she breastfeeds.
- Formula feeding can make a baby very sick if it is not made and given safely and correctly.

Start thinking about how you will feed your baby before the birth. Your health worker will give you information about the dangers and benefits of breastfeeding and formula feeding. Your informed choice will depend on your home situation, and your family and community support.

CHOICE 1

Breastfeed

Breast milk is the perfect food for a baby. Babies who are breastfed do not get sick as often as babies who are formula fed.

This is the best choice for most South Africans.



If you choose to breastfeed your baby, this is what you can do to help prevent HIV:

- Make sure that your baby gets nevirapine every day as long as he or she is having any breast milk. If you are taking lifelong ART, your baby can stop taking nevirapine when he or she is 6 weeks old.
- Breastfeed your baby, but do not give **any other food or drink** for the first 6 months of life. This will prevent tiny sores in your baby's stomach that make it easier for HIV to get into the baby's body.
- After 6 months, you can start to give soft foods. Carry on breastfeeding till your baby is 1 year old.
- When your baby is 1 year old, you can stop breastfeeding slowly over 1 month. At the same time, start feeding with milk formula or fresh cows milk. But make sure you can afford to give the milk.
- You should stop giving your baby daily nevirapine 1 week after the last drink of breast milk. Once you stop, do not give your baby any breast milk again.

CHOICE 2

Use milk formula

If you want to formula feed, think carefully about these questions. They will help you decide if it is safe:



- Will you be able to cope if your family, friends and community think that giving formula milk only is the wrong way to feed your baby?
- Have you disclosed your status to someone at home who will be able to support you in your choice not to breastfeed your baby?
- Will you always be able to buy formula milk if you cannot get it free from the clinic?
- Will you be able to prepare formula feeds safely and correctly? This means you must have:
 - clean tap water close to your home
 - a way to boil water (electricity or gas) many times during the day
 - feeding bottles or feeding cups
 - soap for washing hands and cleaning cups or bottles
- Do you have a fridge in your home to store prepared feeds?

If you answered NO to any of these questions, then it is NOT safe to formula feed. You should breastfeed your baby ONLY for the first 6 months.

I am choosing to formula feed – what should I do?



- Use only milk formula to feed your baby. Do not breastfeed at all.
- Your baby can stop taking nevirapine every day when he or she is 6 weeks old.
- Always use clean, boiled water to mix the formula with.
- Feed your baby with a cup and spoon or a bottle (it is easier to clean a cup and spoon). If you do bottlefeed, make sure you know how to clean the bottles properly.

What should I do if my baby has already tested HIV positive?

Breast milk is the best food for your baby. It will help him or her to grow well and be protected from other illnesses. Continue breastfeeding till your baby is 2 years old.

If less than 1 year old, he or she will need to start ART as soon as possible. Read pages 52 to 55 and the Soul Buddyz book *Parents, children and anti-retroviral treatment*.



Your child and HIV

Finding out your child's HIV status

If you are HIV positive, there is a chance that your child will be HIV positive too.

Most babies who are HIV positive are healthy in the first few months. The only way to find out if your baby is HIV positive is for him or her to have a blood test for HIV. It is important to find out your baby's status so that he or she can get the correct treatment as soon as possible.

Babies should be tested for HIV from 6 weeks old. If a baby is ill or has signs of HIV, then it is important for him or her to be tested before 6 weeks. The HIV test used to test babies is called a PCR test. Most clinics and hospitals have this test.

Your baby can get tested for HIV from 6 weeks.

- Most babies will test HIV negative.
- If your baby is HIV positive, finding out early on will improve the chances of staying healthy.



Will my baby also be HIV positive like me?

Yes, there is a chance, Sophie. But finding out early will help your baby to stay healthy.



My child is HIV positive

What will happen if my child tests HIV positive?

- If you find out that your child is HIV positive, he or she must be given antibiotic syrup called co-trimoxazole (Bactrim, Doctrim, Medtrim) to take **every day**. Co-trimoxazole helps to stop babies and children from getting serious illnesses, such as pneumonia.
- Your health worker will decide whether your child should start ART.
- You should only stop the co-trimoxazole when the health worker tells you to. Co-trimoxazole is **not** an ARV.

How quickly will my child start to get sick with AIDS?

Most children who are HIV positive are healthy in the beginning. But some children get sick with AIDS very quickly. They will get lots of sicknesses such as:

- diarrhoea that won't go away
- pneumonia
- bad thrush (white sores in the mouth)
- skin problems
- TB
- not growing well



NB

Children with AIDS will often die before they are 2 years old unless they are given ART.

diarrhoea

- uhudo
- urudo
- letsholla
- diarree

pneumonia

- inyumoniya
- inyumoniya
- nyomoniam
- longontsteking

Your child and HIV

I wonder if my child will need to start ART.



Babies under one year old

- If your baby is younger than one year old, he or she must start lifelong anti-retroviral medicines **as soon as possible** after testing positive for HIV. Your baby must start even if he or she is healthy and the CD4 count is high.
- Because the immune system of very young babies is not yet fully developed, they can get sick with AIDS very quickly and die. Starting ART early on, in the first few months of your baby's life, improves the chance that he or she will survive and be healthy.



Children older than 1 year old

If your child is older than one year, he or she will be ready to start ART when the immune system has become weak. To find out if your child is ready for ART, the health worker will examine him or her and do a CD4 test. This test will tell the health worker how strong your child's immune system is.

- Take your child to be checked by the health worker every 6 months, even if he or she is well. Your child should have a CD4 test every 6 months. Regular clinic visits are important to make sure that your child is started on ART at the right time.
- Every child is different. Each child will start ART at a different time.

lifelong

- empilo yakho yonke
- yobomi bonke
- ya bophelo bohle
- lewenslange

developed

- khulile
- khuli
- hole
- ontwikkel

The CD4 test and ART

The CD4 test measures how many CD4 cells there are in your child's body. Your health worker may talk to you about your child's CD4 percentage if he or she is **younger than 5 years**.

- If your child is **younger than 1 year**, he or she must start ART as soon as possible, no matter what the CD4 percentage is.
- If your child is **between 1 year and 5 years**, then he or she will be ready to start ART when the CD4 percentage is 25 or less.
- If your child is **older than 5 years**, he or she will be ready to start ART when the CD4 count is 350 or less.

If children are very sick or they get sick a lot, they may need to start ART even if their CD4 percentage or CD4 count is high.

NB

It is safe for children to take ARVs. In fact, children do very, very well on ART. Children who were sick before they began ART, can now grow up healthy and have an active life.



percentage
• amaphesenti
• ipesenti
• phesente
• persentasi

List of places to help you

Provincial Organisations

EASTERN CAPE

Port Elizabeth AIDS Training, Information and Counselling Centre (ATICC)

Ground Floor, Brister House
191 Govan Mbeki Street
Port Elizabeth, 6001
Tel: 041 506 1415

Umtata AIDS Training, Information and Counselling Centre (ATICC)

Room 41, 8th Floor,
Botha Sigcau Building
Cnr Leeds and Owen Streets,
Umtata, 5100
Tel: 047 531 2763

NORTH WEST

Boitumelong Clinic

927 Phuduhudu Street
Boitumelong Loc., Bloemhof
Tel: 053 433 1736

Lifeline

Mafikeng; Tel: 018 462 1234
17 Connaught Street, Golf View
Tel: 018 381 4263

Naledi Lifeskills Training and AIDS Information Centre

Stand 3770, Danville Ext.
(Opp. Mafikeng Provincial
Hospital), Mmabatho
Tel: 018 383 3978

North West Region – Hospice

13 Hendrik Potgieter Street
Oudorp, Klerksdorp
Tel: 018 462 3916

LIMPOPO

Polokwane AIDS Training, Information and Counselling Centre (ATICC)

Cnr Potgieter and Diaz Streets
Polokwane, 0966
Tel: 015 290 2363

MPUMALANGA

White Rose Hospice

27 Jellicoe Street, Witbank, 1035
Tel: 013 656 6218

Witbank AIDS Training, Information and Counselling Centre (ATICC)

City Health Services,
Witbank City Council
Cnr Swartbos & Louise Roads,
Witbank, 1035
Tel: 013 690 6204

NORTHERN CAPE

Hospice Association of Kimberley

156 Du Toitspa Road, Kimberley
Tel: 053 832 2591

WESTERN CAPE

AIDS Action Group – Northern Areas

7 Meath Street, Bellville
Tel: 021 948 7699

Medicins SANS Frontiers

Town One Properties
Sulani Drive, Khayelitsha
Tel: 021 364 5490

The Pletade Foundation HIV/AIDS Forum

Simunya Centre
Cnr. Khathula Street,
Plettenberg Bay
Tel: 044 533 5616

Western Cape AIDS Training, Information and Counselling Centre (ATICC)

Lady Michaelis Day Hospital
Centre, Timour Hall Road,
Plumstead, Cape Town, 7801
Tel: 021 797 3327/763 5320

GAUTENG

AIDS Training, Information and Counselling Centre (ATICC)

Esselen Clinic
17 Esselen Street,
Hillbrow, Johannesburg, 2001
Tel: 011 725 6711/2/0

Pretoria AIDS Training, Information and Counselling Centre (ATICC)

Higher Ground Level H0001,
City Core, Cnr Vermeulen and
Prinsloo Streets, Pretoria, 0002
Tel: 012 358 8743/4

Medico Post-exposure Prophylaxis Sites

Nthabiseng Clinic
Baragwanath Hospital, Soweto
Tel: 011 933 1206

Sinakekelwe Clinic
Natal Spruit Hospital, East Rand
Tel: 011 389 0500/0675

Skinner Street Clinic, Pretoria
Tel: 012 354 1654

Sebokeng Hospital, Vaal
Tel: 016 930 3000

KWAZULU-NATAL

Durban AIDS Training, Information and Counselling Centre (ATICC)

Tel: 031 311 3604/3632

Pietermaritzburg AIDS Training, Information and Counselling Centre (ATICC)

Tel: 033 345 0781/9

Other Organisations

AIDS Consortium

Tel: 011 403 0265

Treatment Action Campaign (TAC)

Tel: 021 422 1700

AIDS Law Project

Tel: 011 356 4100

AIDS Action Plan

Tel: 012 312 0151

Black Sash

Tel: 021 461 7804

Nelson Mandela Foundation (46664)

107 Central Street
Houghton,
Johannesburg
Tel: 011 853 2621

Society for Family Health

8 Hillside Road
Metropolitan Park
Block B, 2nd Floor
Parktown, Johannesburg
Tel: 011 484 5320

Moral Regeneration Movement

Zandile Mdhlahla
Tel: 011 403 3559

Reproductive Health & HIV Research Unit (RHRU)

Hillbrow Health Precinct
Hugh Solomon Building
Esselen Street, cnr Klein
Street, Hillbrow, 2001
Johannesburg
Tel: 011 358 5300

Johns Hopkins Health and Education South Africa (JHUCCP)

Block D, Equity Park
257 Brooklyn, Pretoria
Tel: 012 366 9300

LoveLife

48 Wierda Rd West
Wierda Valley, Sandton
Johannesburg
Tel: 011 523 1000

Community AIDS Response (CARE)

26 Grant Avenue
Norwood
Johannesburg
Tel: 011 728 0218

Treatment Action Campaign (TAC)

Westminster House
122 Longmarket Street
Cape Town 8001
Tel: 021 422 1700

GreaterGood South Africa Trust

Postnet Suite 293
Private Bag X16
Constantia 7848
Cape Town
Tel: 021 794 0580

Humana People to People

Zimondi Kilford
45 Barry Hertzog Drive
Florida Park, Johannesburg
Tel: 011 472 7474

Government Departments

Department of Social Development National HIV/AIDS Co-ordinator

Tel: 012 312 7500/7546

Department of Health

Directorate: HIV/AIDS and STIs
Tel: 012 312 0121

Children's Organisations

CINDI (Children in Distress)

Tel: 033 345 7994

Child and Family Unit

Tel: 021 685 4103

Cotlands Baby Sanctuary

Tel: 011 683 7200

Child Welfare

Tel: 011 492 2888

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It is not possible, in a small booklet like this, to give you all the answers you may need. The purpose of this booklet is just to give you some ideas. You should not rely on everything that is written in this book for each and every situation. If you need more information, speak to one of the organisations on this page. Soul City and Jacana cannot be held responsible for any medical problems.

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Beyond Education there
is Empowerment

The empowerment of women, and respect for wives, mothers and daughters is one of the cornerstones of a happy, secure family life and a harmonious society. Through our partnership with Soul City, we strive to educate communities and families, to bring an end to violence against women.



beyond petroleum™

bp.com