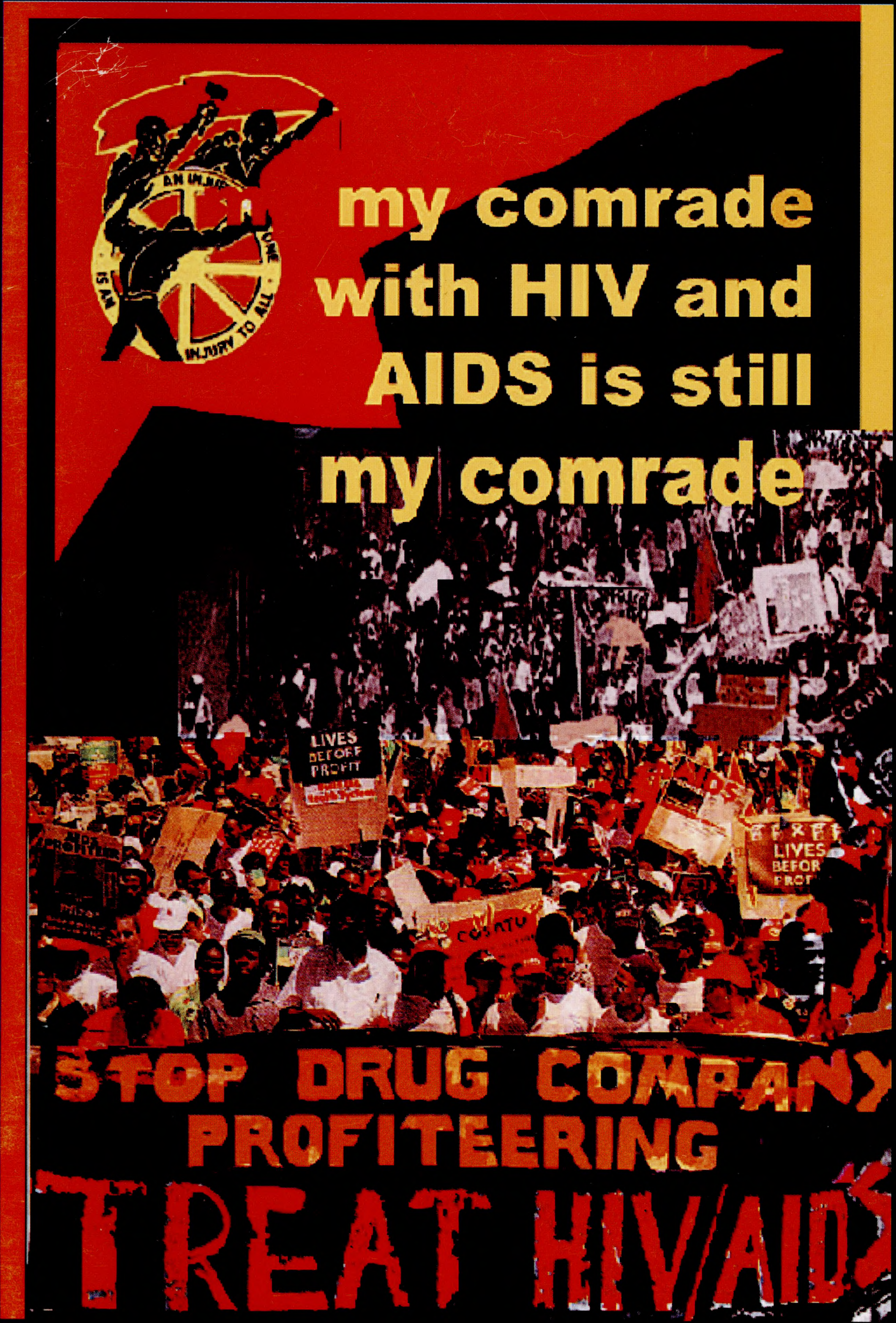
A WORKERS HANDBOOK ON HIV AND AIDS



my comrade with HIV and AIDS is still my comrade

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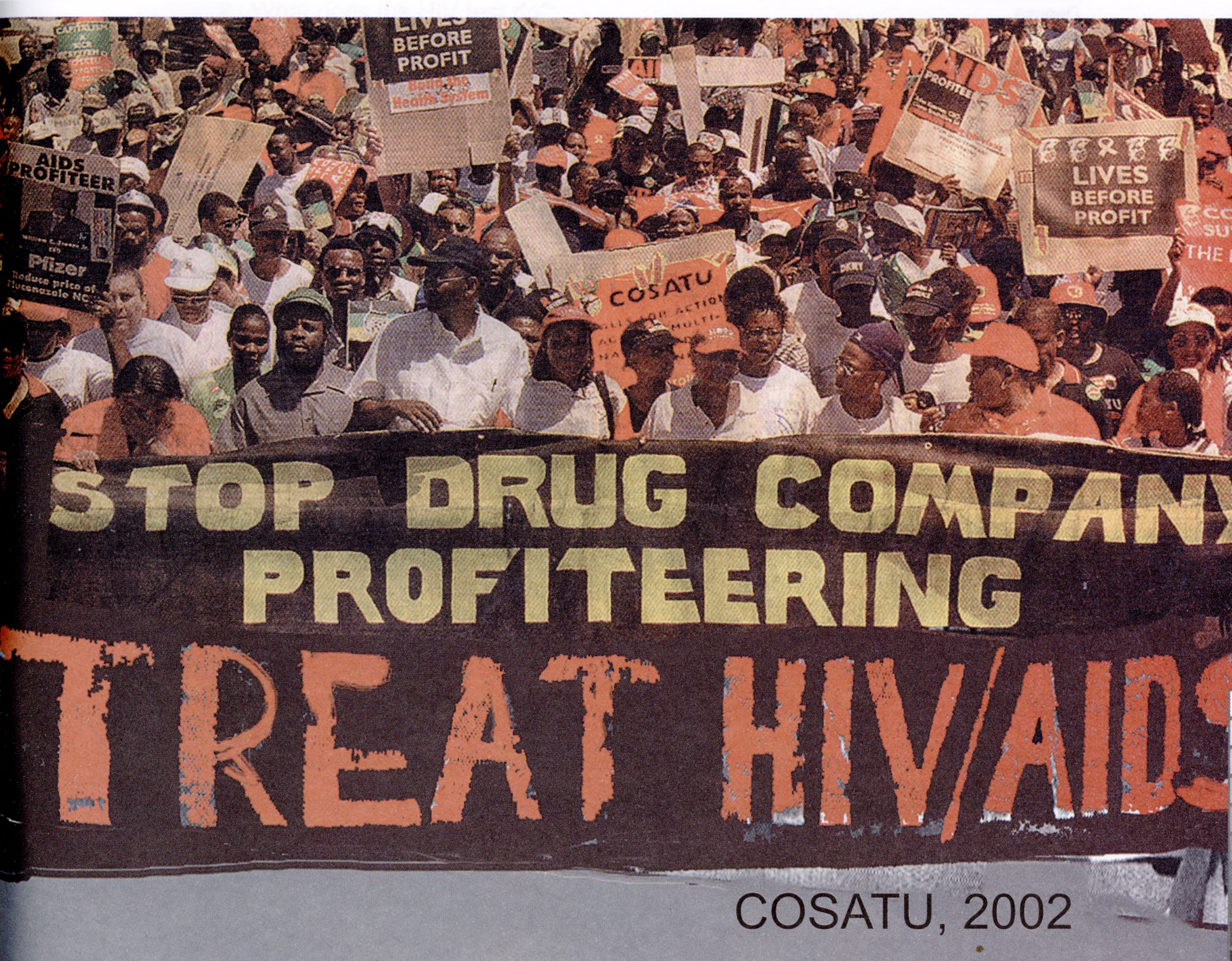
A Workers' Handbook to Fight HIV



COSATU, 2002

A Worker's Handbook to Fight HIV

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with contributions and assistance from basic conception to proofing from Dr. Neva Makgetla

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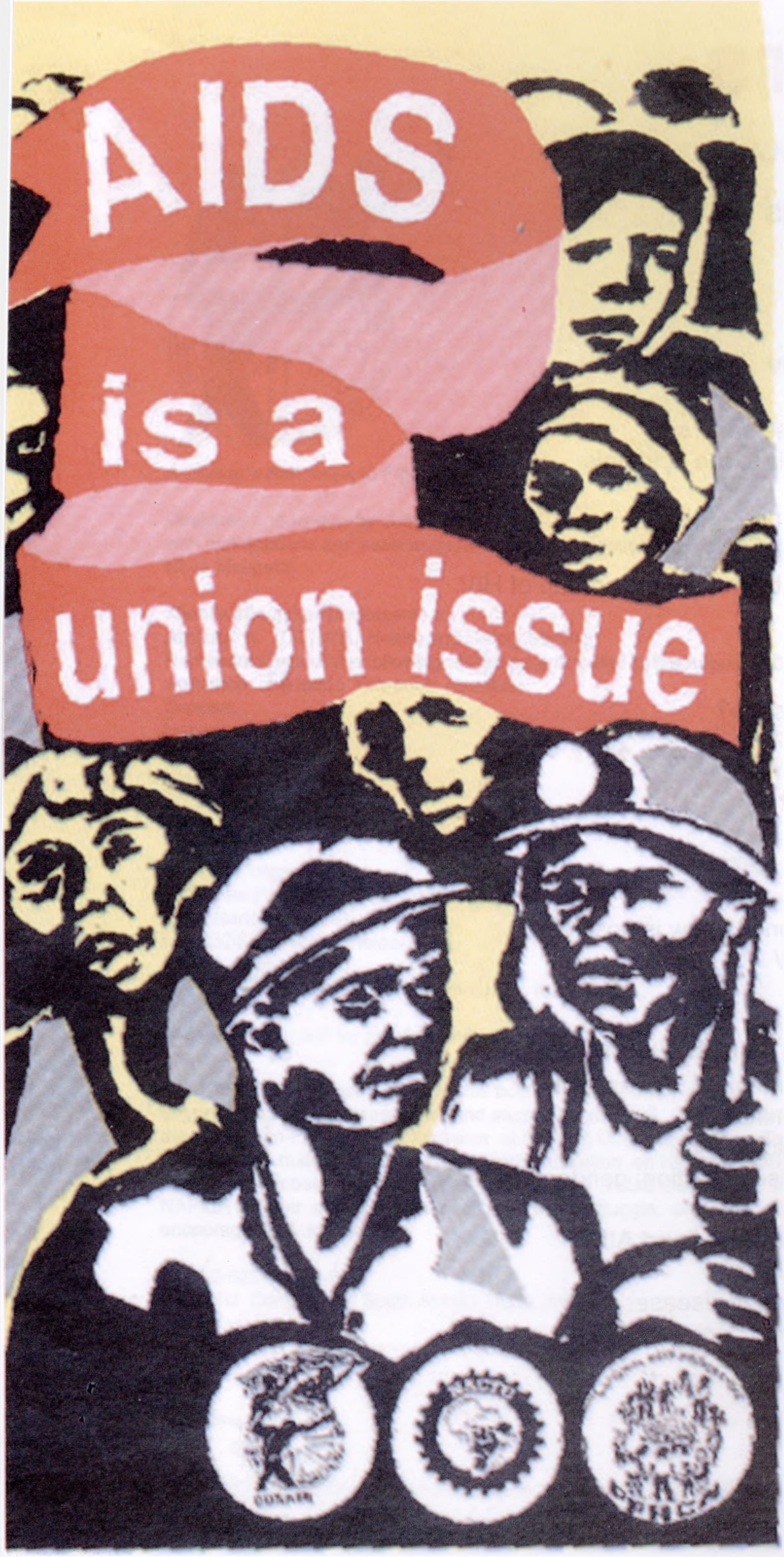


“ AIDS is a trade union issue

and must be discussed and placed on the agendas of all union meetings. We have committed ourselves to campaign for HIV prevention, care and treatment with the same determination and energy with which we fight many other working class struggles. COSATU has also committed to work in partnership with other trade unions, government, business and organs of civil society in the fight against the disease.”

Address by COSATU Second Vice-President Joyce Pekane to the Second National Conference for People Living with HIV / AIDS, 9 March 2000

1. Workers must unite against HIV and AIDS

This chapter talks about why we as workers must unite against HIV and AIDS, and about how you can use this book.

Today, no worker can ignore the realities of HIV and AIDS. Studies show that up to a quarter of our people carry the HIV virus in their blood. Most of us do not know for sure whether we have the virus or not. But nearly all of us have lost a family member, a friend or comrade, to AIDS.

We need to learn about the HIV and AIDS epidemic, how to stop it from spreading, how to live positively with HIV, and how to treat HIV and AIDS. We need to show solidarity with people who are infected and affected by AIDS.

We must unite to stop this epidemic!

We need to find ways to fight this battle:

- Together
- In solidarity
- To meet our people's needs.

Today, we are all infected with or affected by HIV and AIDS.

- Over 46 million people today have HIV and AIDS.
- An overwhelming 95% of people with HIV and AIDS live in developing countries.
- Africa accounts for only one tenth of the world's population, but nine out of ten new cases of HIV infection. 83% of all AIDS deaths are in Africa, where the disease has killed ten times more people than war.
- In nine countries in sub-Saharan Africa, including South Africa, more than 10% of the adult population is HIV-positive.
- In South Africa in 2002, 1600 people are infected with the HIV virus every day.

Source: UN AIDS, August 2002

As workers we CAN understand and deal with HIV and AIDS.

This book aims:

- ★ To educate workers about the realities of HIV and AIDS, getting rid of the myths
- ★ To empower people with HIV and AIDS to live positive lives
- ★ To build solidarity with people with HIV and AIDS
- ★ To help workers and unions develop and carry out strategies to stop the AIDS epidemic in workplaces and communities
- ★ To empower shopstewards to assist members with HIV, including with grievances and disciplinary action.

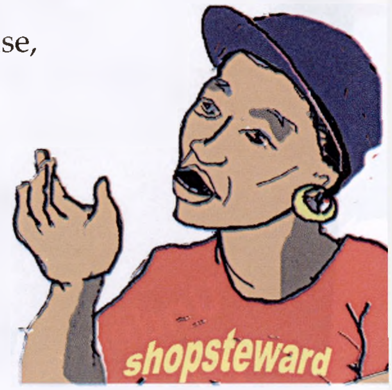
How to use this book

This book helps unions and workers deal with the HIV epidemic. It helps build solidarity with people living with HIV and AIDS. You can use it:

- By yourself, to find out the facts about HIV and AIDS and what you can do about them.
- With a group, to discuss what you can do with your comrades.
- For union educational work.
- To look up specific facts that you need to know about the disease, like how to prevent infection and how medicines can help.

If you need information on a particular aspect of HIV and AIDS you can find where this book discusses that by looking in the Index at the back of the book.

You can set up a study group to read the book. Then you can discuss each section together and learn from each other. Group members can bring in other material, too, so that you learn more – and you can work together to plan educational programmes and negotiations around HIV.



Discuss/Think about it!

Today, this epidemic has spread to the level where every person in South Africa has had some personal experience that involves HIV and AIDS. Some of us are ourselves infected. Others have lost friends and relatives. Still others do not have HIV, but have changed how they live to remain safe. What are your own experiences?

Many of the issues raised in this book are about how HIV and AIDS affect people in the workplace, as well as how the epidemic affects people in our community as a whole. We see the impact of HIV and AIDS on trade union issues – including sick leave, retrenchment, discrimination, and building a safe and healthy working environment. How should your union approach these issues where HIV and AIDS are involved?

HIV and AIDS are part of all of our lives . . .

The different sections in this book look at how we can answer these questions.

What is my status - and do I want to know it?

What should I do?
What about confidentiality?
What is workplace testing?
Why do I need counselling?

Chapter 4

Preventing HIV and AIDS in our society.

We need to protect our families and loved ones, our friends and comrades!

Chapter 3

Understanding HIV and AIDS: What is HIV? What is AIDS? What are opportunistic diseases?

Chapter 2

Workers must unite against HIV and AIDS

Chapter I

Living with HIV needs SKILLS:

- What to do when you test positive
- Healthy living
- Building good relationships

Chapter 5

Fighting DISCRIMINATION

How can we fight fear and oppression around HIV?

Chapter 6

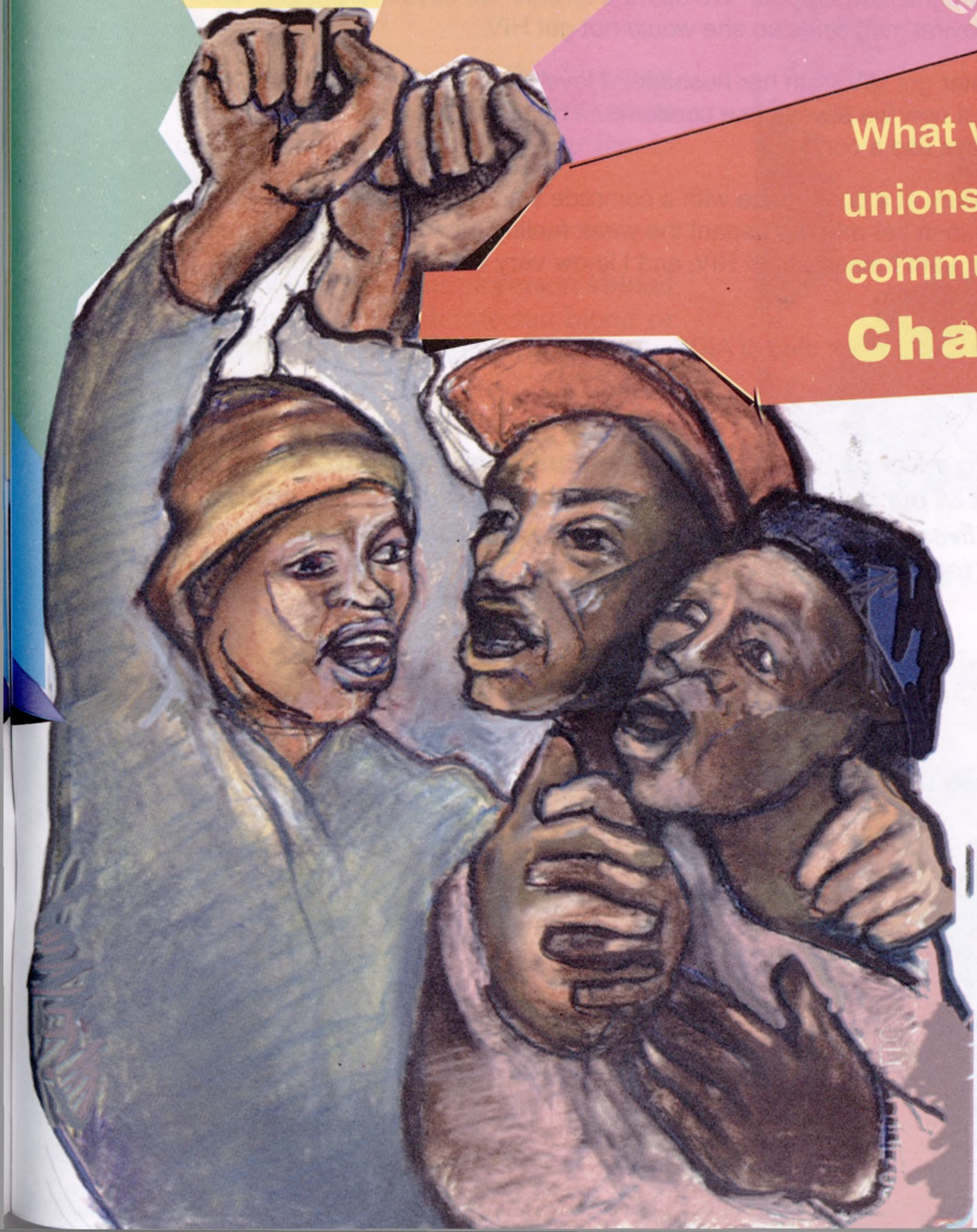
Treatment:

- What treatments work
- Fighting for affordable treatment for all

Chapter 7

What we must do as unions and in our communities

Chapter 8



Our stories: We are all affected and infected.

At a COSATU workshop on HIV and AIDS in August, 2002, every one of us had a story about how HIV has touched our lives. These stories include:

- **My sister died of AIDS. Her husband had left her. I take care of her three children, now 14, ten and four. We are still trying to get orphan grants for them, as they were born in exile and do not have birth certificates.**
- I have HIV. My partner died of AIDS many years ago. I take anti-retroviral medicine. I'm surviving.
- As a shopsteward, I work with many comrades on the shopfloor who live with HIV and AIDS. I have to know that I can help them, and how I can help them. Sometimes people look too ill to last another week, but then they recover and come back to work.
- My young daughter was raped. We spent a terrible two days making sure she got anti-retroviral medicines so she would not get HIV.
- My older sister got HIV from her husband. I love and trust my husband and my marriage, but now we always use condoms. The principle of safer sex is simple: always use a condom.
- I shared a room at a conference with a comrade who told me she had HIV, and serious thrush in her mouth. I spent the week feeling for sores in my mouth – even though I am trained about HIV, and I know very well that you cannot get it from sharing a room.
- One brother and a sister died of AIDS. Another was very ill, but he is better now.

When we shared our stories, we learned that we are all affected and infected. We learned to put all our stories together into a broader picture of the realities that make up our lives. We learned that together we can confront these realities, and that together we can win.

2. Understanding HIV and AIDS

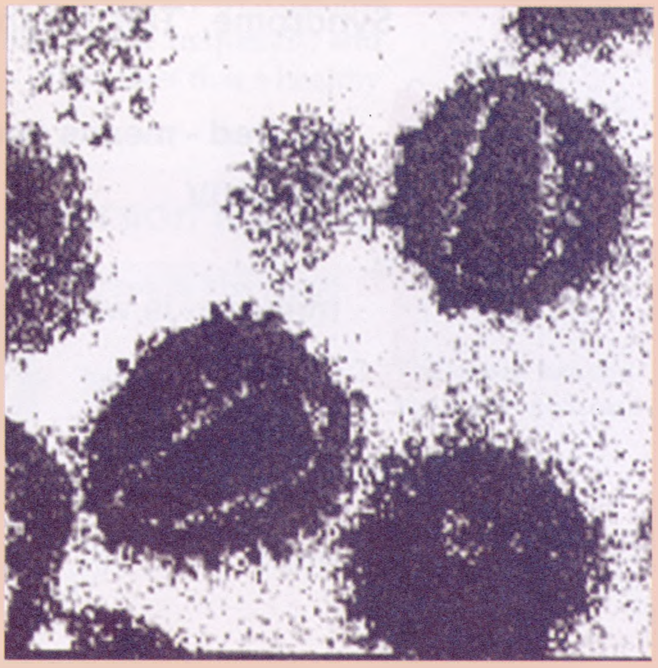
This chapter looks at:

1. What is HIV?
2. From HIV to AIDS
3. Illness with AIDS

1. What is HIV?

HIV is a virus, called the "human immune deficiency virus". It is made up of very small organisms that live in human blood, like germs.

The HIV virus gets into a person's blood through contact with infected blood or fluids from another person. This happens most often through sexual intercourse. It can also happen through blood transfers, injections, or even from one person bleeding into another person's cut. Babies can get HIV from contact with their mother's blood during childbirth or from breast feeding, if the mother is infected.



This is a photograph of an HIV virus. In this picture, the virus was viewed through a microscope, and photographed with a camera. A virus is much too small for a human eye to see without laboratory equipment.

HIV can stay quietly in a person's blood for many years before the person becomes ill. Often, the person does not even know that she or he is infected. This condition is called **"HIV-positive and healthy"**, or **"HIV well"**.

I do not understand. If a person can be healthy with HIV in their blood, then what is this thing called AIDS? Why are we so worried about it?

After a person has HIV in their blood for some time, it can affect how their body deals with illness. Then a person can get very ill indeed, very quickly. We say that person has AIDS.

The word AIDS comes from Acquired Immune Deficiency Syndrome. This means:

Acquired - means you are not born with it, but you get it from HIV

Immune - is what we call your body's ability to fight illness

Deficiency - says that the immune system is not working right

Syndrome - a syndrome is not one thing, such as one illness, but all the different kinds of illnesses that your body gets when it cannot fight disease.

Almost all scientists agree that AIDS is caused by the HIV virus. Some people claim that the HIV virus does not exist or does not cause AIDS. But medical and scientific studies give very clear proof that the HIV virus causes AIDS when it gets into someone's blood. We even know how it does this.

To understand how AIDS develops from HIV, we need to look at what the HIV virus does in a person's blood.

2. From HIV to AIDS

Human bodies have something medical doctors call the "immune system". This is a group of cells in the blood that works to defend the body from harmful germs, bacteria and viruses. These cause infections and disease. Scientists call these cells **CD4-cells** or **T-cells**. Sometimes they are called "fighter cells" because they help your body fight diseases.

A healthy person has a lot of CD4-cells in their blood. In a very small drop of blood – a measurement called a millilitre – a normal person has as many as 500 thousand to over a million (1000 thousand) CD4-cells.

Over a long period of time - often many years - the HIV in a person's blood will attack and destroy these fighter cells. Without its fighter cells, the person's immune system cannot defend the body well against other infections or disease. So the person falls ill more frequently, and more seriously. She or he gets different kinds of illnesses that a healthy immune system would have stopped.

In a laboratory, researchers can count the number of CD4-cells in a person's blood. Doctors say a person who has 500 thousand CD4-cells in each millilitre of blood has a CD4-cell count of 500.

How HIV destroys CD4-cells in a person's blood:

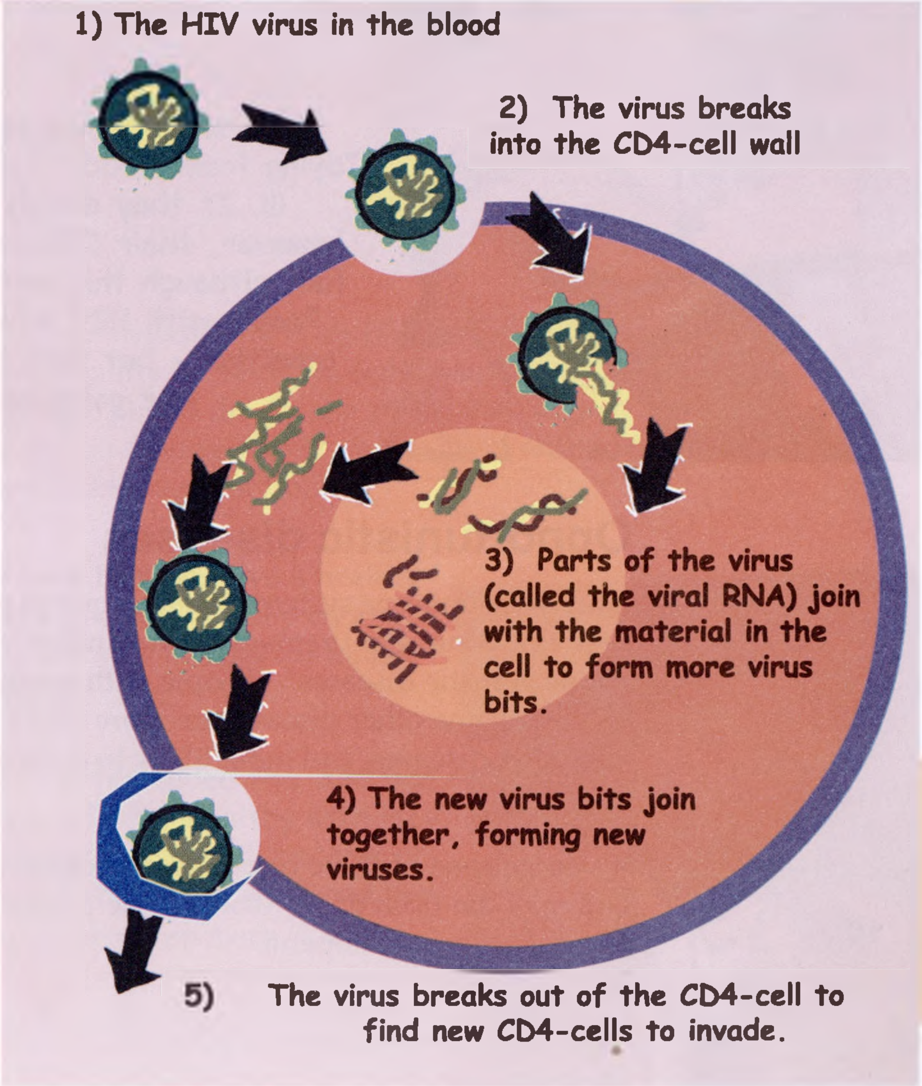
1) When the HIV gets into a person's blood, it finds the CD4-cells (or fighter cells).

2) It breaks into the CD4-cells through the CD4-cell wall. Once inside the cell, the virus lets out bits of itself, called viral RNA.

3) The viral RNA joins with the parts of the CD4-cell that would make new CD4-cells, making these parts into more viral RNA instead. Then the CD4-cell cannot reproduce itself to make more CD4-cells. Instead, it makes parts that become HIV.

4) These HIV parts come together inside the CD4-cell to form new HIV viruses.

5) The new HIV viruses go back into the blood, looking for new CD4-cells to invade.



3. Illness with AIDS

When a person's CD4-cell count drops to 250 or less, she or he is likely to get serious diseases. That is when we say that he or she has **AIDS.**

When the CD-4 cell count gets very low, the amount of HIV virus in the person's blood can grow very quickly. Doctors can measure the amount of virus in a person's blood in the laboratory. This measurement is called the person's "viral load". When the viral load suddenly gets much higher, the person is likely to become very ill.

But it often takes a long time for the virus to break down the body's defences. That is why people stay healthy with HIV for so long. People with HIV may have it in their blood for years, and remain well; they may not even know that they have it.

A person who has HIV is NOT always "dying from AIDS" - they may not even be ill. If they do not get treatment, however, their CD4-cell count is likely to fall, although this could take many years. People with HIV have a serious health condition - but that does not mean they are going to die soon.

Opportunistic diseases

Once your immune system is weak, you can get any kind of illness quite easily, and the illnesses themselves are more severe. We call these illnesses "opportunistic diseases". People with weak immune systems, whether from AIDS or some other disease, are more likely to get TB, pneumonia, diarrhoea and other diseases, and more likely to die from them.

If you get one of these opportunistic diseases and you do not get treatment, you may die from it. It's worse if the people around you do not support you and help you stay hopeful.

An "opportunistic disease" is an illness that becomes more serious - and sometimes very dangerous - when your immune system is already weak from HIV.

How long can you live with HIV?

No one really knows how long you can stay healthy with HIV. It depends on your lifestyle, on whether you look after your health, and on whether you can get treatment for the HIV and other illnesses that grow because your immune system is weaker.

The good news

Most people now have many years of healthy life with HIV. In the 1980s, doctors thought you would remain healthy for seven to eight years from the time you got HIV. Then you would get ill and die. By the 1990s, they argued that you would remain healthy for an average of 12 years, even without treatment – much longer than they had thought at first.

If you find out early on that you have HIV and live a healthy life – stop smoking, get exercise and good food, sleep enough, don't drink too much liquor – you will stay healthy for longer. (We discuss these issues in Chapter 5.)

SEVEN TO 12 YEARS is still often called the **average length of time** that a person will stay healthy with HIV. This means that some infected people will become ill after two or three years; and others will work and live happily for 15 to 20 years or more.

Today, we have medicines to treat and cure many opportunistic diseases. People can live much longer with HIV and with AIDS.

MORE good news…

In the past 20 years, doctors have found ways to treat the opportunistic diseases that attack people with HIV and AIDS. Someone with AIDS can be cured of diseases like TB, pneumonia and thrush, even if they are very ill indeed.

When a person with AIDS recovers from an opportunistic illness, they still have HIV in their blood. But they can go back to work, and live normal lives. If the HIV is still very active, they may get ill again. (This is discussed in Chapter 7.)

My own story:

The first time I found out that my husband had HIV was when he went into the hospital. He had TB, as well as HIV. The doctors told me when he went into the hospital he would only live for two weeks, at most. But they treated the TB, and he got better. He came out of hospital, and lived with us and worked at his job for three more years before he got another AIDS illness. That time, they said he was too ill to treat; so he died. That was in 1993. **But the first GOOD NEWS is: We CAN treat many opportunistic diseases today.**

… and EVEN MORE good news.

In the last ten years, doctors have discovered new medicines to treat the HIV and AIDS virus itself. We call these new medicines ***anti-retroviral drugs***. We discuss them in Chapter 7.

Today, no one knows how long you can live with HIV if you take anti-retroviral drugs. Some people have lived with HIV for over 20 years, since the disease was discovered. Some people have been seriously ill with AIDS, but responded to anti-retroviral treatment and recovered from their illness. They are alive and working today.

My own story continues:

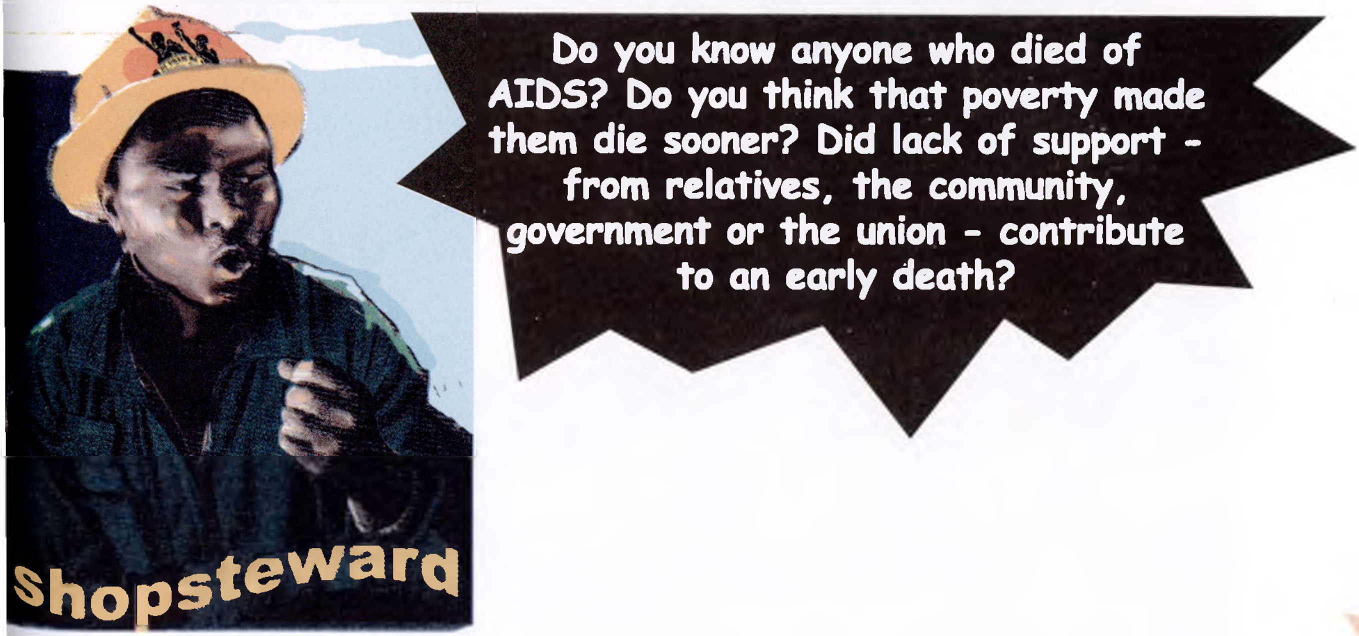
I was also diagnosed positive when my husband became ill with TB in 1990. The doctors said I might remain healthy for five more years. In 1997 I started to take anti-retroviral drugs, and the doctors say my immune system has become much stronger. I'm beginning to plan to die of old age - say, when I hit ninety. Not very soon.

Today we have medicine which CAN treat the HIV virus itself, so that AIDS does NOT have to kill!*(See Chapter 7)*.

Discuss/Think about it!

In your group, discuss:

- Do you understand how HIV works, and the differences between HIV and AIDS?
- A person with HIV will die sooner if they do not get treatment for an opportunistic illness, or if relatives and comrades do not support them. How should this affect how you act if you have HIV yourself, or a friend does? How does it affect what your union does about AIDS?
- How does what you have learned about HIV and AIDS affect the way you act if you yourself have HIV, or a friend has it?



“There is life after HIV and AIDS”

Nelson Mandela’s story:

“I arranged for a scholarship for a young lady of 20 to go to university. Her results on the tests were excellent. She attracted a lot of praise from her lecturers. Then, suddenly, she found that she had AIDS and went to hospital. She could not pay the hospital charges.

“I was out of the country. I came back and I immediately contacted her. She could hardly walk. I could hardly hear her talk. And for food, she just took one spoon. And very sadly, she had to go from there straight to hospital. . . The doctor in charge phoned me to say that there is very little that we can do. I was devastated. And within a week, because they couldn’t do anything, they discharged her.

“My wife and I went to see her. Then we arranged for her to have drugs, and to have good food. Then I phoned about two weeks later, and a very sharp, strong voice replied. I said, ‘Who is speaking?’ She gave me the name - same girl. I said, I can’t believe that.

“I send her some money every month so that she can eat properly, she can get all the drugs that she needs. One of the members of my staff took this money to her. She said, ‘I came across a new person, I can’t believe that it’s the same girl who was written off by the doctors. She is now recovered.’

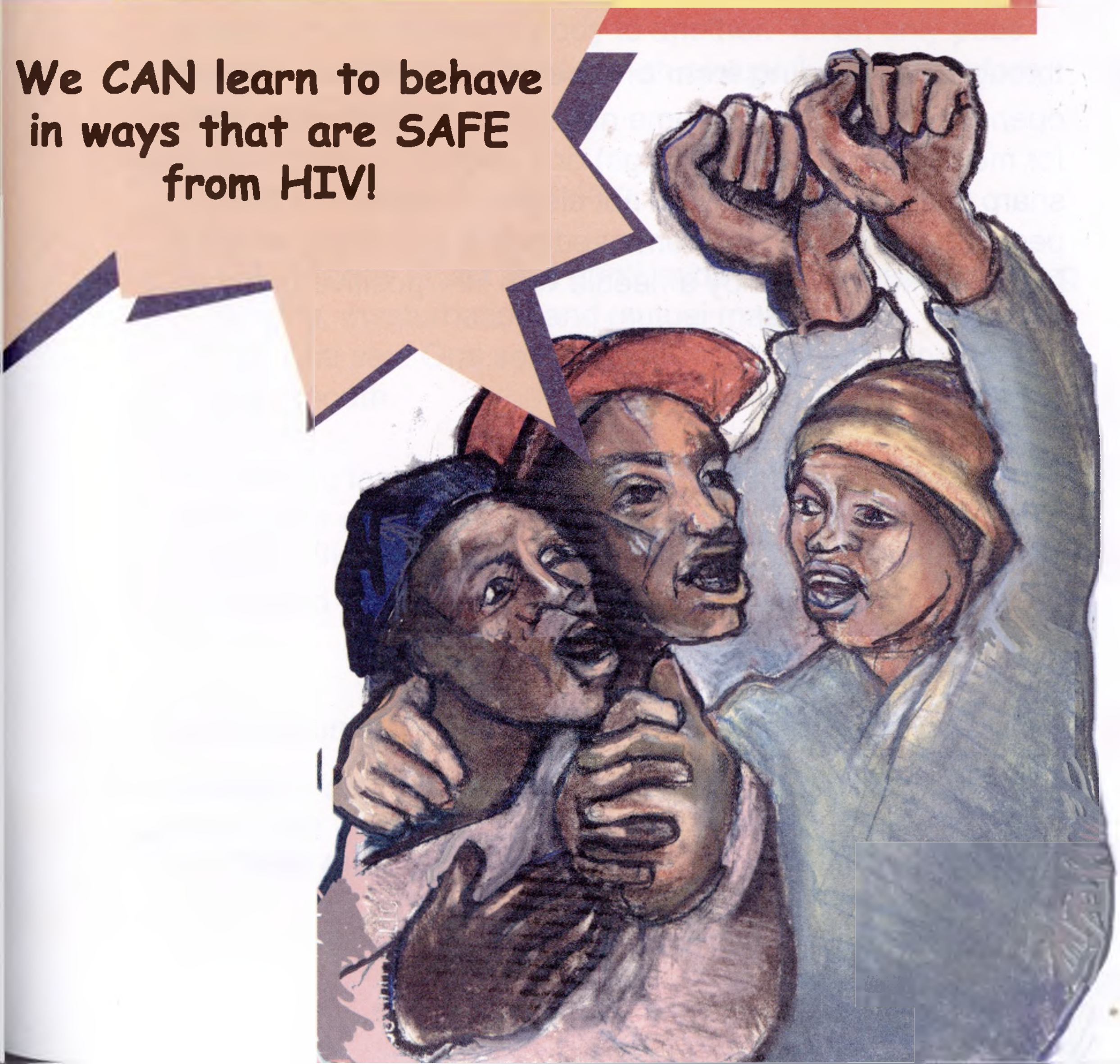
“ There is life after HIV / AIDS.”

-from the speech by Nelson Mandela to the closing session of the Barcelona Conference on HIV and AIDS, July 2002.

3. Prevent the spread of HIV

Our first responsibility is to keep this epidemic from spreading further. This chapter covers:

1. How HIV spreads
2. Safer sex
3. Gender inequality adds to the epidemic
4. Teach your children
5. Stop Mother-to-Child Transmission
6. Stop other ways of spreading HIV
7. Workplace measures to prevent the spread of HIV



1. How HIV spreads

HIV is not like TB or flu - it is not easy to catch. You CANNOT get it from touching a person, or if they breathe on you.

DANGER ZONES

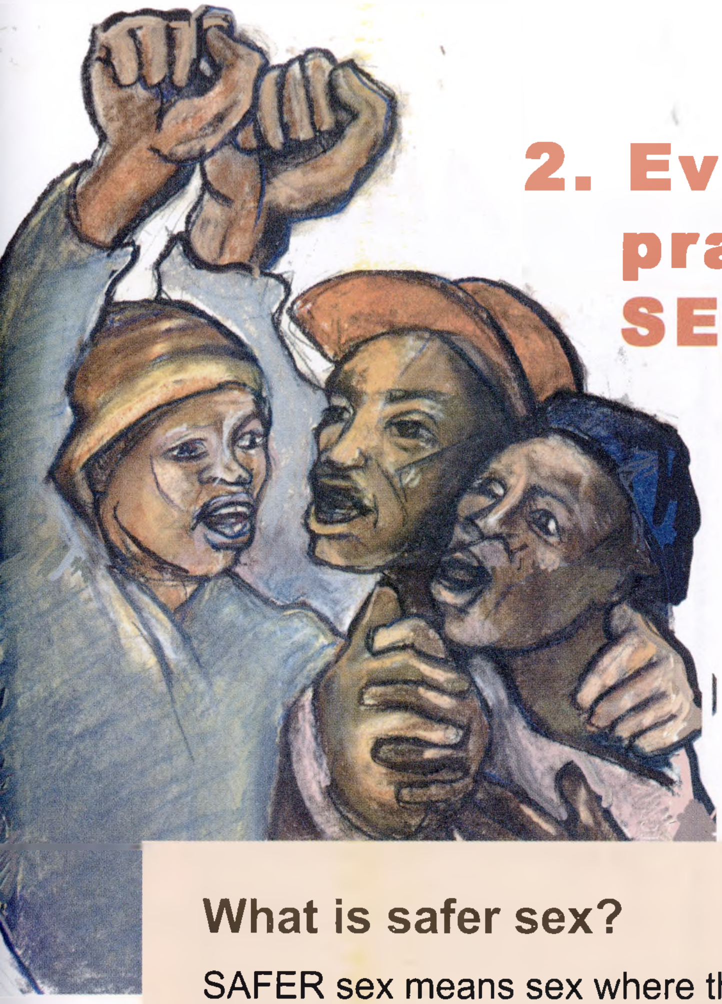
HIV spreads ONLY through some body fluids and blood:

- through **sexual contact when blood or sexual fluids go from one partner to another** - what we call "unprotected sex" (sex without a condom).
- without preventative medicine, about 60% of **pregnant mothers with HIV pass it on to their children** either before birth, in the birth process, or through breast feeding.
- through **blood going from one person to another** through open cuts, by using the same needles for injections (whether for medicine or for illegal drugs) or if doctors or sangomas use sharp instruments that were not cleaned properly. A few people have gotten HIV from needlestick accidents, where a healthworker is stuck by a needle with HIV-positive blood on it.

SAFETY ZONES

You CANNOT get HIV or AIDS from:

- eating, sleeping, or living with a person who has HIV (where you do not have unsafe sex, share needles or mix blood in other ways).
- working with a person who has HIV (unless, like nurses, your job involves working with other people's blood).
- touching anything used by someone with HIV, from toilets, to cups, to water in swimming pools or baths.



2. Everyone must practise SAFER SEX!

Most people around the world get HIV from sex. Everyone agrees that we need to have "safer sex" to stop the spread of HIV, and to end this epidemic.

What is safer sex?

SAFER sex means sex where there is no way for the HIV to pass from one person's body to another. It can only pass through contact with blood or with sexual fluids. Therefore, "safer sex" means:

- Intercourse using a condom, or
- Other forms of sex that don't involve intercourse, including kissing, masturbation and mutual masturbation, thigh sex and oral sex. Oral sex is safer unless a person has cuts in their mouth.

In all these forms of sex, a person can have an orgasm without an exchange of body fluids.

In contrast, any form of sex that can cause pain or cuts – including rape, anal sex and dry sex – is very UNSAFE.

How well do you know your ABCs?

"Know your ABCs" is a campaign that aims to prevent HIV by getting people to:

A bstain - do not have sex at all

B e Faithful - only have sex with one person to whom you are committed

C ondoms - use condoms when you have sex.

Government is promoting this ABC campaign in South Africa. But the ABC campaign has not stopped the spread of HIV. We need to ask: Why is the ABC campaign not working? What can we do to help people learn about safer sex?

What do you think about the ABCs?

When should a person decide to abstain?

Most people agree that very young people should not have sex, and that no one should have many partners. But very few adults will abstain from sex forever.

- Under what circumstances should we tell people to just abstain from sex?

Young people face difficult choices around sex. There is a risk with only telling them to abstain: if they DO decide to have sex, they may not know about or use a condom. So think about:

- When you had sex the first time, could you have insisted on using a condom? How could your parents or friends have helped?

Remember, too, that women are often forced to have sex – because they are raped, because they are married and their husband insists, or because they have to sell sex or starve. It does not help to tell women to abstain if they do not have the power to decide whether they will have sex.

It takes two to "Be Faithful"

Even if you are faithful, you should use a condom with your partner unless you plan to have a child.

Faithfulness ONLY prevents HIV when both partners remain free from HIV and are 100% always faithful to one another. But you or your partner might have had HIV before you met each other, and did not know that you had it. (Have you both been tested?)

Many people also feel they are very much in love and the relationship is permanent - but then find out, sometimes very quickly, that it is not. Short-term "faithfulness" carries the same risks as sleeping around.

How often have you heard this?

> *I love Dave wildly - at least so far this month. I loved Jim to distraction last month, of course - but that was a mistake, as I should have known. Safer Sex? I don't need it.... I'm always faithful, and always in love with the guy when we do it!*

Even with long-term, established couples, one of you may stray once or twice – often not for long or seriously, but it only takes once to get HIV. And this is not something that a loving partner can admit easily. So it is better for both of you to use a condom.

CONDOMS

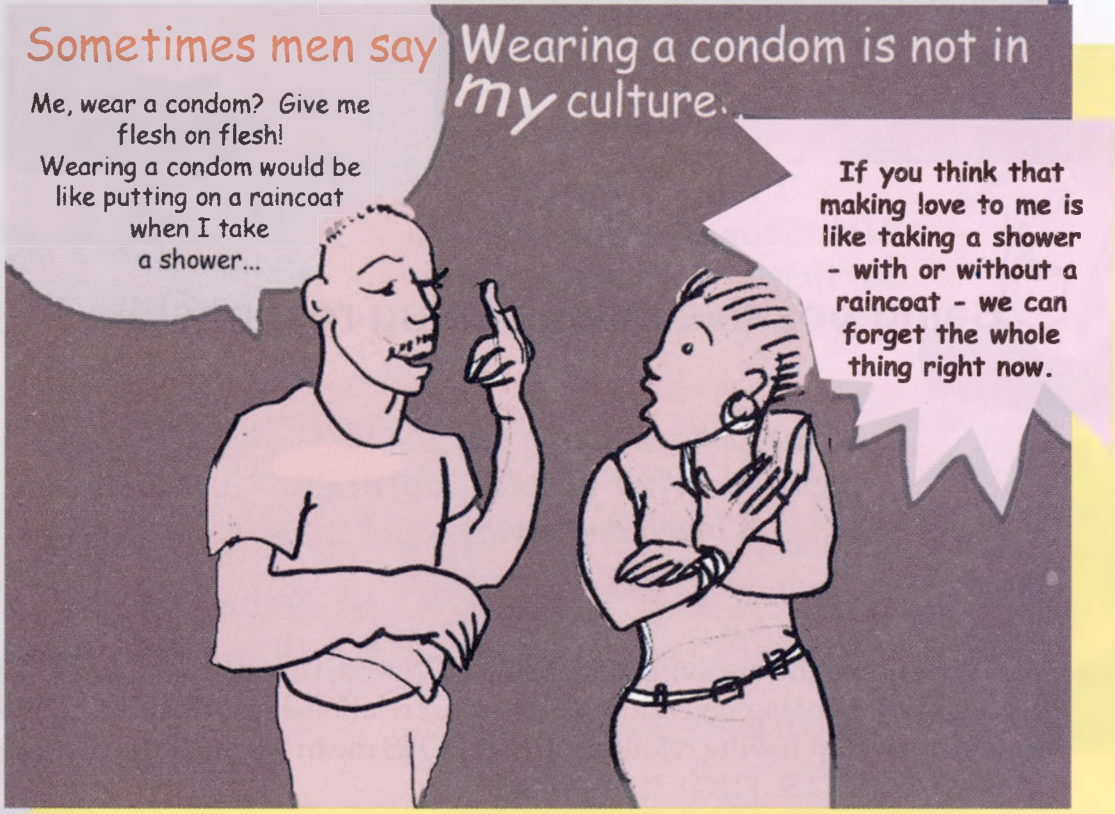
Condoms DO prevent HIV from passing from one person to another during sex. They prevent the sexual fluids of the partners from touching. But:

- Make sure you and your partner know how to use a condom – how to put them on and when. If they are not used correctly and rip, they won't protect you.

- You have to use a condom EVERY TIME you have sex. If you don't use one even just once, it won't work that once – and you might get HIV.

- That means you have to make sure you have condoms around. Make sure they're available for your children too, if you want them to be safe – even if you'd rather they didn't have sex yet. Condoms are expensive, but government offices and clinics should have them free. You should negotiate with your employer to distribute them at work, too.

Sometimes men refuse to use condoms. That is not clever, since it means they can get HIV. Women must be able to say they won't have sex if the man won't use a condom.

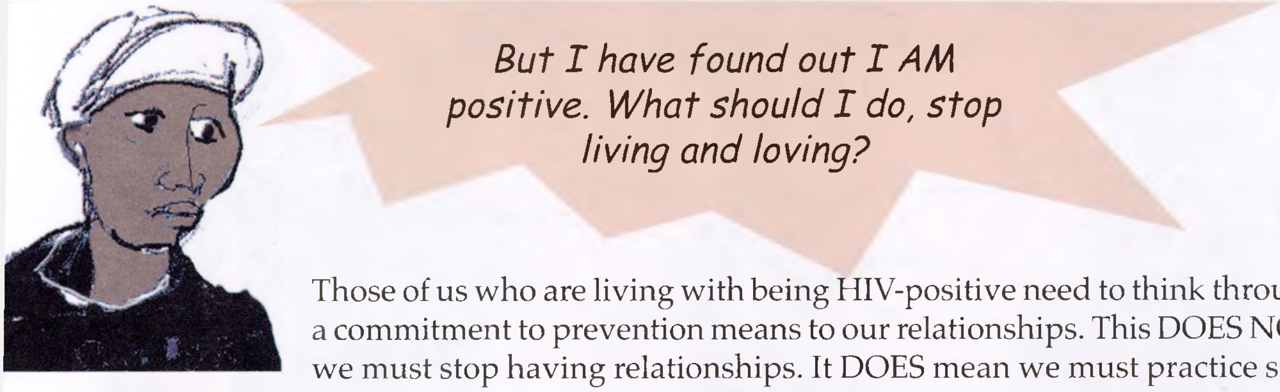


Using condoms is not about trusting a lover and partner. Even long-term and caring partners could have HIV from a previous relationship, long before they met each other. They could have had it for many years, and not know it.

Sometimes people think: if I ask him to use a condom, he will say I don't trust him - or even that I am playing around with other men!

We need to change this attitude! Using condoms every time should be a way of life - to protect ourselves and the people we most love. Using condoms does not challenge or threaten our love, but strengthens it.

Being positive means being responsible



Those of us who are living with being HIV-positive need to think through what a commitment to prevention means to our relationships. This DOES NOT mean we must stop having relationships. It DOES mean we must practice safer sex - always.

Safer sex when you are positive means WEAR A CONDOM EVERY TIME!

We all say: USE a condom

Sex is fun

I'm not abstaining!

You won't enjoy it if you're worrying about HIV, other Sexually Transmitted Diseases or pregnancy.

Because you respect and love your partner, you don't want to risk their health

You love and trust your partner, but either one of you may have got HIV long before you knew each other

Unlike other forms of birth control, condoms can't endanger a woman's health

Remember:

If you care about her and about yourself, you'll wear a condom.

Remember:

If you care about him and yourself, you'll make sure he is wearing a condom.

Unite and fight HIV and AIDS

If everyone wears condoms when they make love, it will become the normal thing to do – and the HIV epidemic will be stopped.

Gender inequality, rape, and domestic violence, make it harder for women to choose safer sex.

3. Gender inequality adds to the epidemic

Gender inequality promotes the spread of HIV and AIDS. Our demands for safer sex include the demand that a woman has the right to choose when and how to have sex.

This is most obvious in rape and sexual violence, where sex involves blood and cuts, which increases the chance of HIV spreading.

Gender inequality also feeds the epidemic in less dramatic ways. Society's structures and beliefs make it hard or even impossible for many women to say no to sex, or to say no to safer sex. Women are expected to marry and have children, by their families and friends - and for a wife to say "no", or "use a condom", is often not easy. Young women are sometimes expected to marry or have sex with older men, who have an established position in the community. Wives are often afraid to demand that their husbands use condoms. In some cases women take up sex work for food and survival.

Remember:
A woman in Africa most often gets HIV and AIDS from a person to whom she is faithful.

As workers, we must fight to end rape, domestic violence, and gender inequality throughout our communities.

Police and security forces must confront these issues as a matter of urgency. Unions representing police must demand education and resources to address violence against women.

4. Teach your children

Parents sometimes worry that if they give their children condoms or talk to them about sex , then their children will think it is O.K. to have sex. But where parents talk openly about sex, love, and gender equality, children are **less** likely to take sex lightly or have it when they are young.

If you start telling your children about love, sex, gender rights and condoms when they are young, then they grow up being aware of the importance of using condoms, and of gender rights. They will be able to think more rationally about sex, and be able to use safer sex.

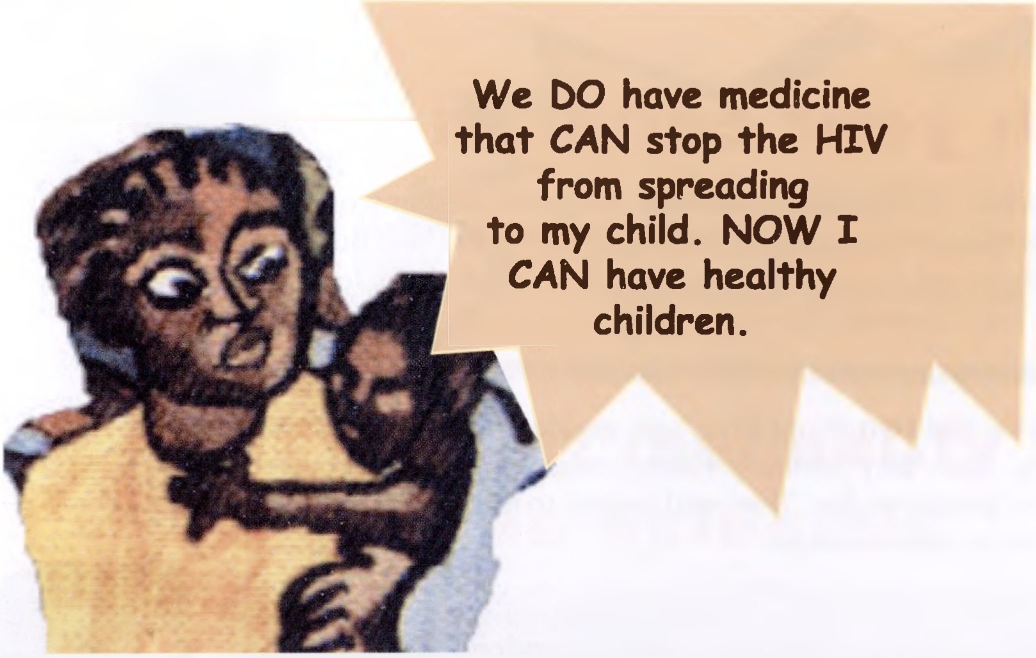
MY OWN STORY: I gave my daughter a box of condoms when she was 14. She is 20 now and in university – but she still hasn't opened the box. She says she wants to wait to have sex until she is in a serious relationship. And then, yes, she will use condoms (although the ones I gave her will be past their sell-by date by then!).

TALK ABOUT SEX AND PREVENTING HIV - in your groups and with this handbook, but also with your children and friends and partners and (if you dare) with your parents.

Discuss/Think about it!

Some of the issues that all of us need to think and talk about:

- What is safer sex - what works, what can we practice, how can we change our behaviour to make sure we and our loved ones are truly protected?
- How can we give women the power to demand safer sex every time?
- How does our culture and our society promote, or hinder, behaviour that encourages the spread of HIV? What can we do to change this?
- Talk about this statement: "It is not only people who misbehave who get HIV; morality around sex does NOT stop the epidemic from spreading. Using condoms does." Do you agree?



4. Stop mother-to-child transmission (MTCT)

Next to transmission through unsafe sex, the most common means of passing HIV to another person is from a positive mother to her new child. This is called Mother-to-Child Transmission (MTCT).

A pregnant mother can pass HIV on to her baby before birth; and sometimes through breast feeding after the child is born.

Around 40% of babies born to HIV-positive mothers (without treatment) are born positive. But most of these babies do not get HIV when they are still in the mother's womb. They get HIV in the birth process. A further 20% get HIV from their mother's breast milk. (Thus a total of 60% of babies are infected from their mother, if there is no treatment.)

One dose of the anti-retroviral medicine called Nevirapine, given to the mother at the time she gives birth, can help make sure her baby does not get the virus. A single dose of Nevirapine costs around R30.

Nevirapine is supposed to be supplied by hospitals and clinics in every province, to every mother who needs it. The Constitutional Court has ordered that as soon as possible, it must be available in ALL public health institutions for FREE to pregnant women.

To provide Nevirapine, hospitals and clinics must be able to test pregnant mothers for HIV, to find out if a mother should take Nevirapine when she gives birth. Mothers must be counselled both before and after they take this test. (Voluntary counselling and testing are discussed in the next chapter.)

Also, babies who did not become positive during the birth process can still get HIV from breast feeding. That means that positive mothers need to have access to powdered milk. But many mothers cannot afford to pay for powdered milk or get clean, boiled water to make up the milk. To make sure the baby stays free of HIV after the birth, health clinics must provide milk for positive mothers.

Discuss/Think about it!

- Does the hospital or clinic near you give tests for HIV and treatment with Nevirapine to positive mothers?
- What role should your union play in ensuring positive mothers can gain access to medicine to prevent MTCT?

5. Stop other ways of spreading HIV

It is possible to get HIV when treating people with AIDS, whether in a clinic or at home. But it is not easy. You can ONLY get HIV from "blood-to-blood" contact with an infected person's blood or other body fluids – for instance, if you help a person clean themselves when you have an open cut on your hand, or if you use a needle for an injection that was already used for a person who has HIV. You CANNOT get HIV from touching someone with HIV or AIDS.

Healthworkers and other people caring for people who are ill should learn to use UNIVERSAL PRECAUTIONS. These are steps a person should take EVERY TIME and ALL THE TIME when they are caring for someone who is ill with any disease - including HIV and AIDS. They should be used by people caring for sick people at home and in the hospital or clinic. COSATU's affiliates in the health sector demand education all healthworkers, including cleaners, about universal precautions.

Universal precautions are:

ALWAYS WASH YOUR HANDS with soap and hot water after touching an ill person, or after changing their sheets and clothing.

ALWAYS KEEP CUTS AND WOUNDS COVERED on BOTH the person giving health care and on the patient.

DO NOT ALLOW ANOTHER PERSON'S BLOOD OR BODY FLUIDS to come into contact with your skin. Wash off blood or body fluids under running water as soon as possible.

WEAR LATEX GLOVES to clean up blood, or if you are likely to touch the person's blood while you are caring for them (for instance when you are assisting someone who is giving birth). If you have cuts or broken skin on your hands, you should wear latex gloves while you are giving care.

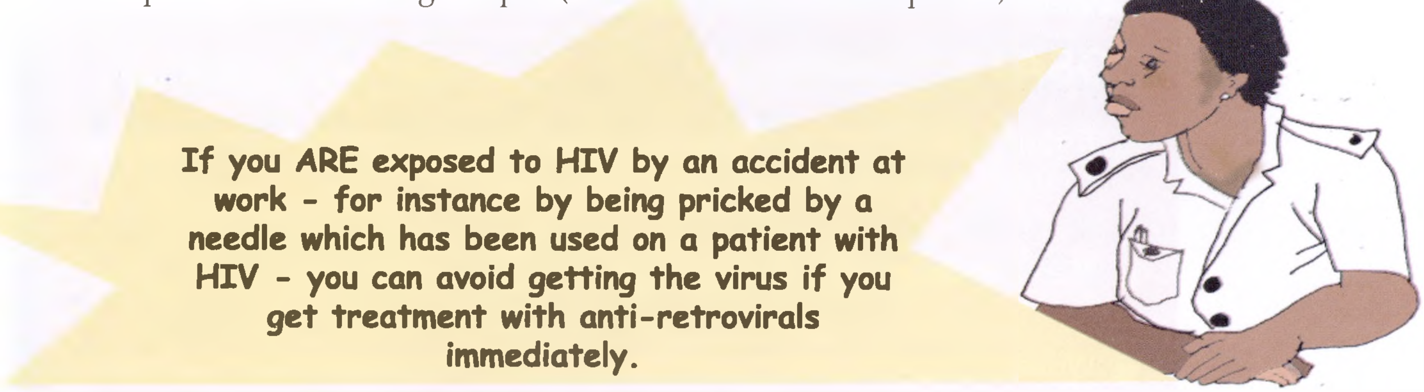
NEVER SHARE SHARP INSTRUMENTS which might have blood on them - such as razors, needles, or knives. ALWAYS sterilise instruments (boil them in water) before they are used on another person.

In Mozambique, traditional healers now demand that each patient bring his or her own new razor blade so the healer can make incisions which are safe from passing HIV.

COSATU's health affiliates call for the use of retractable needles – needles which cannot be used more than once – in clinics and hospitals.

Post-Exposure Prophylaxis (PEP)

PEP is treatment with medicine to prevent HIV from developing within your body. This requires taking anti-retrovirals for a short period immediately after the HIV came into your blood. PEP has been used very successfully to cut back the chances of getting the virus after needlestick injuries and after people have been exposed to HIV through rape. (This is discussed in Chapter 7.)



If you ARE exposed to HIV by an accident at work - for instance by being pricked by a needle which has been used on a patient with HIV - you can avoid getting the virus if you get treatment with anti-retrovirals immediately.

Discuss/Think about it!

- If you are employed as a healthworker, or in a hospital or clinic, does your job provide education, information and resources to use universal precautions? What is your union's position on this?
- If you are a teacher, a police person, or in another profession which may expect you to deal with ill people, are you taught and equipped to use universal precautions?

Preventing the spread of HIV in the workplace means EDUCATION about SAFER SEX, and PROVIDING CONDOMS TO EVERYONE.

6. Workplace measures to prevent the spread of HIV and AIDS

Employers and workers need to ensure that EVERY WORKPLACE provides training to workers about preventing HIV and AIDS, and that every workplace provides access to condoms. These should be a part of every workplace policy and programme on HIV and AIDS.

Some working conditions lead to a higher risk of HIV. Jobs which rely on migrant labour mean that workers often do not see their wives and families for long periods. Long-distance trucking and other jobs which require travelling often disrupt family life.

COSATU demands:

- Enough condoms must be available freely and easily to everyone, so that everyone can use one every time they have sex
- Men and women should both be able to get condoms
- Women must be able to refuse sex if the man won't wear a condom

Whatever your job, your beliefs, or your love life, safer sex helps defend ALL of us from HIV and AIDS.

A particular concern is that the Department of Correctional Services has been reluctant to make condoms easily available in jail. That behaviour ignores the realities of jail life – and can spread HIV, which affects us all.

poster from Combat AIDS, a book on HIV and AIDS in military forces throughout the world

SACTWU's story


Dr. Mansoor, head of SACTWU's AIDS project

The South African Clothing and Textile Workers Union (SACTWU) established its AIDS project in August, 1999. It was created to address the AIDS epidemic in the clothing industry, which by then was reaching crisis proportions. The programme now provides HIV and AIDS training to workers, shopstewards, and management throughout the country. The training programme covers comprehensive HIV and AIDS information, including:

- prevention, awareness and education
- clinical and wellness management
- policy and legal issues
- research, monitoring and evaluation.

The SACTWU AIDS project now employs ten people full-time, and provides education and support programmes in the clothing and textile industry throughout the country. The programme provides education and training, voluntary counselling and testing. It also supplies vitamins and medicines to prevent opportunistic pneumonia to workers with HIV.

Since 2000, the project has run a two-day shopstewards' training module. By the end of this year, it expects to have trained 800 shop-stewards in counselling and HIV support, and to reach 40 000 workers on the shopfloor.

In reviewing the experiences of the SACTWU AIDS project, its head, Dr Mansoor, highlights the need to negotiate time to provide workplace education. Her first experiences were of addressing several hundred workers at once during their 30-minute lunch-break. She emphasises the dangers of ignorance, of discrimination, of workplace rumours and the lack of confidentiality at all levels.

Discuss/Think about it!

- Are condoms readily available to everyone at your workplace, including women? Has this issue been addressed by your employer? By your union?
- Is education about correct condom use provided?
- Do you have a workplace programme on HIV and AIDS that includes education and resources to ensure workers have access to safer sex?

SHOULD I TAKE A TEST? Do I want to find out if I am infected with HIV? Maybe I am scared to find out!

4. Testing for HIV

This chapter looks at:

1. **Know your HIV status**
2. **What is an HIV test?**
3. **Getting counselling**
4. **Workplace testing for HIV**

1. Know your HIV status

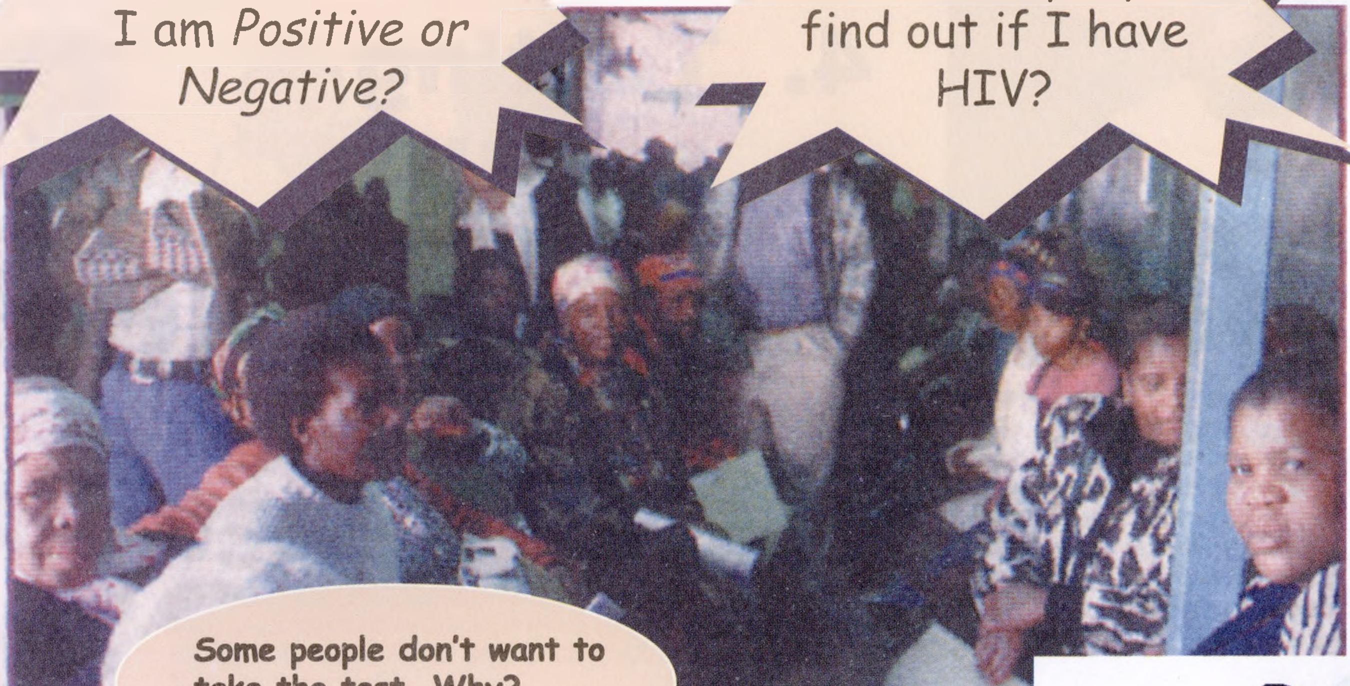
If you get an HIV test, you will find out if you are HIV-positive or not. This is important because you can:

- *Develop a better lifestyle*, with good exercise, food, rest and relaxation, so that you will live longer. (You should do this even if you don't have HIV!)
- *Avoid and treat opportunistic illnesses* that come with HIV before they become too serious for you to recover.
- *Make sure you do not give HIV to your loved ones.* Of course, you should ALWAYS practice safer sex in any case. But you will also know if you have to take Nevirapine if you are pregnant.
- *Find out about medicines and other measures you can take* to control the effects of the HIV in your body.

To protect our health, we need to KNOW whether we have HIV in our blood or not.

Do I want to know if I am *Positive or Negative?*

Will other people find out if I have HIV?



Some people don't want to take the test. Why?

Some people are scared of what they will find out. They can't deal with the idea that they may have HIV because they think it means they will die soon. **But knowing that you have HIV early on means you can live LONGER.**

Some people think that you can get HIV just from taking the test. **This is not true at all.** The test only shows if you have HIV already, even if you didn't know about it.

BUT some of our fears about taking the test come from very REAL problems.

- Many workers are afraid that if their employer finds out they have HIV, they will be fired or denied promotions.
- Many people are afraid that their family, friends and comrades will reject them if they have HIV.

YOU have a RIGHT to CONFIDENTIALITY about your HIV status.

- It is ILLEGAL for an employer to demand to know your HIV status - whether you are positive or negative.
- It is ILLEGAL for an employer to make someone take an HIV test or fire them if they are HIV-positive.
- It is ILLEGAL for a healthworker to tell your boss or anyone else what your HIV status is (unless YOU tell the healthworker to tell them).

It is a disciplinary offence for a health-worker to tell other people the results of your HIV test without your permission.

NO shopsteward should tell other people that a member has HIV, unless the member wants them to.

2. What does the HIV test do?

For the most common kind of HIV test (the ELISA test), a nurse takes a sample of your blood. The blood is sent to a laboratory. There, it is tested to see if it contains anti-bodies for HIV. Antibodies are cells your body creates in your blood to fight the HIV. If there are antibodies in your blood, then the HIV is also in your blood. You are "HIV-positive".

If a person takes a test soon after they were infected with HIV, however, the antibodies may not have developed yet. In that case, the test result could be negative. But the person would still have HIV in their blood. So you should ONLY take the HIV test several weeks after you think you were infected. The time between being infected and testing positive is called the "window period".

A few tests come back positive when the person does not have HIV. A person who gets a positive result the first time must take a second test to confirm it.

(There are other kinds of HIV tests. Some of these tests are faster. Some are more expensive. They are not often used in South Africa today.)

3. Get counselling

Speak to a counsellor BEFORE and AFTER you have an HIV test!

A person should ALWAYS get counselling before and after having an HIV test, whatever the results of the test are.

Taking the test may raise painful questions about yourself and the people you care for, even if you do not have HIV. And if you are not positive, a trained counsellor should still talk to you about how to prevent HIV in the future.

Whether you test negative or positive, there are issues you need to think about.

You and your counsellor should talk about:

- your lifestyle and how to make it healthier;
- ways to prevent spreading HIV and AIDS;
- ways to guarantee that the people you care for – partners, parents, children and comrades – share a healthy life;
- ways to make sure you and your dependents are economically secure;
- ways to deal with anger, guilt, blame and discrimination around HIV;
- ways to learn about how we can live with HIV, as a family, as a community, and as responsible and caring people.

Many people you usually turn to for advice - your minister, your doctor or nurse, friends and relatives - probably don't know much about HIV. They may even have wrong and discriminatory beliefs (see Chapter 6). So make sure you talk to a TRAINED counsellor when you have a test.

4. Workplace HIV Testing

COSATU says workers should be tested for HIV through a process called Voluntary Counselling and Testing.

Voluntary Counselling and Testing (VCT)

In VCT programmes, the company, the union, or an outside body provides testing facilities for the whole workplace. Every worker has a choice whether they will have the test. Workers are counselled before and after the test. The results are given ONLY to the worker, who can decide if they wish to tell others - including the company - what those results are.

If possible, unions should themselves provide counselling, by ensuring that some activists are trained to counsel people with HIV. It would be especially helpful if shopstewards can get some training in counselling.

VCT programmes are most effective when they are done as part of a broader campaign, with the provision of education and information on HIV and AIDS throughout the workplace, and when backed up by a programme of medical support for people who test positive.

take charge, get tested, stay well"

-slogan of the NUM and Gold Fields Wellness Management program, August 2002

Ian Cockerill, Chief Executive of Gold Fields, and Senzeni Zokwana, National President of NUM, publicly took the HIV test, as an example for workers.

Take charge, get tested, stay well

In August, 2002, the National Union of Minesworkers and Goldfields mine in Carletonville together launched a programme they call the "Informed, Consented, Voluntary Counselling and Testing Programme". Miners were counselled before and after the test.

Testing was done as a first step in Goldfields' "Wellness Management Programme" for all employees. The programme aims to provide education, support, and treatment for employees with HIV, as well as recognising and dealing with opportunistic illnesses such as TB.

Mineworker Joseph Mothibeli

A mineworker's story

(article by Mokgadi Pela, Business Report p. 5, Star, 16 August 2002)

Johannesburg– After months of denial and soul searching, Joseph Mothibeli has come to accept that he is among thousands of miners with HIV.

Most importantly, he has taken a conscious decision to look after himself and to boost his immune system.

A 51-year-old father of four and an AngloGold employee, Mothibeli wishes more workers could undergo HIV screening so that they can come to know their status and how to manage it or prevent it, depending on the outcome of the test.

"It does not help lying to yourself and burying your head in the sand; only an HIV test will put you in the clear. My simple advice is for those who have tested negative to abide by health warnings.

"To those who have tested positive, let's go for regular checkups at the Wellness Clinic so that, when the time is ripe, we can benefit from drugs that will soon be on offer."

As a member of the National Union of Mineworkers, he is also grateful for the landmark agreement the union signed with AngloGold on a strategy to fight HIV and AIDS.

Surveillance and prevalence testing: mass testing of the workforce

Sometimes employers ask their entire workforce to take HIV tests, usually to find out how many workers have HIV. In these cases, employers often promise that NO-ONE will know the results – not even the workers themselves. The reason given for mass testing is to help the employer decide how to deal with the epidemic in that workplace – for instance, how many workers might get ill in the next few years. Often there is no counselling or discussion with the workers of the reason for the tests, or education around the epidemic. Unlike VCT programmes, this kind of mass testing is often not linked to getting treatment or care for positive workers.

There are other ways for employers to find out how many of the workers are likely to have HIV. In most workplaces, the employer can assume the percentage of workers with HIV is the same as in the country as a whole – between 15% and 25%.

With this type of mass testing, there is always the worry that the results can not be kept as anonymous or confidential as they should be.

On the other hand, some workplaces may be more at risk, especially where they involve migrant labour or workers must travel away from home. In these cases, the unions may also want to know how many workers have HIV. But unions need to be very careful that workers' rights to voluntary and confidential testing are fully maintained.

Recently, a test which looks in saliva (spit) for HIV has been used to do mass testing on many people at one time. The test does not have to be done in the laboratory. However, this test has a higher number of wrong results.

You can also be tested privately at a clinic doctor's office

Individuals can go for HIV tests on their own. The clinic or doctor should always make sure the person gets counselling before and after the test. These tests are supposed to be completely confidential. But there have been cases where the employer has asked the doctor to do an HIV test, and the doctor sends written results in a letter to the employer. This is not ethical behaviour for the doctor.

Discuss/Think about it!

- Where can you get a test for HIV in your community or workplace? Are you worried that the results won't be confidential – and what can you do about it? Does the testing place provide counselling? Can your union help with counselling?

- Do you have a workplace policy that provides voluntary counselling and testing facilities for all workers?

- Should unions defend healthworkers who betray a patient's test results to an employer?

- Should a healthworker tell a family member that a person has HIV?

- Shopstewards must maintain every worker's confidentiality about their health status. But often the health status can become the basis for discrimination - and the shopsteward must be able to raise this issue. As a shopsteward, can you suggest processes and principles that could help you deal with these situations?

  For example: You may need to publicise the worker's health status in order to take up a case of workplace discrimination. Should you discuss the implications of this with the worker before taking up the case?

- Should COSATU support mass testing in the workplace as a way to assess the incidence of HIV?

5. Living with HIV

This chapter looks at living with HIV:

1. Learning that you have HIV
2. Tell someone: talk about it
3. What if someone I know is positive?
4. Healthy living with HIV
5. Can you afford it?

1. Learning that you have HIV

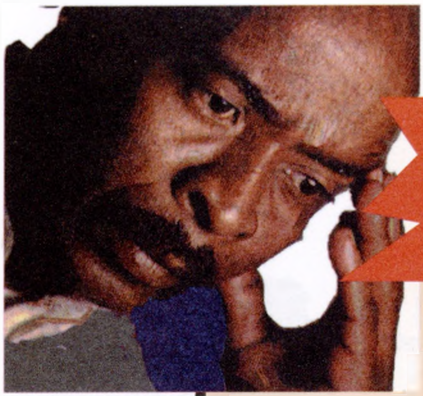
Learning you have HIV is NEVER easy. Nobody is going to "take it well". It puts most people on an emotional roller-coaster that can last for months. You are likely to feel shock, denial, grief, guilt, anger and depression. And nurses, comrades, and family members may react badly, which makes it even harder. For these reasons, it is important that you get counselling after your test.

If you can, get tested and know your status when you are healthy. It is much harder to deal with if you find out you have HIV only when you or your partner are already seriously ill.

I learned I had HIV when my partner collapsed with AIDS, six years after we began living together. I thought I would die then too. Certainly I would never see grandchildren, and no-one would even care when I became ill. I sat in my room and cried, and waited to die. A comrade made me go to see a counsellor. I had to learn that I still had a life worth living. . . . that was 12 years ago.

However you find out that you have HIV, remember:

You still have a life worth living. Your life CAN get better; YOU can make it better.



Checklist: What CAN I DO when my test comes back positive....

Here is a practical "to-do list" for your first few weeks of living with HIV.

✗ DON'T *do anything crazy.*

Testing positive for HIV is not a death sentence. Even without treatment, it takes, on average, more than ten years for HIV to progress to AIDS. The medicines available today are so effective that they may keep the virus under control indefinitely. And better drugs are being developed all the time.

So don't quit your job. Don't break off relations with your family and friends. Don't move to Antarctica. Don't do anything to destroy your life as it is! Having HIV is not good news – but it is not as bad as you may think. You're going to be around for a long, long time.

✓ *Practice safer sex.*

When you are HIV-positive, you HAVE to use a condom in order to protect your partners. You can still have a sex life - but you need to be completely responsible about it. *("Being faithful" will not protect your partner if you are already positive!)*

✓ *Take charge of your own health.*

People living with HIV – like people with diabetes, high blood pressure or any other chronic disease – must manage their own health. Your doctor and nurses will help. But you have to know what is going on so that you can make sure you get the treatment you need. (We talk more about this in Chapter 7.)

✓ *Talk to people - you are not alone.*

It helps if you can tell your partner, family, friends and comrades. They can't give you love and support for your condition if they don't know you're positive!

You can also join or form a support group for people with HIV. (See page 46.)

✓ *Get healthy.*

As your immune system gets weaker, you need to take better care of yourself. If you are abusing drugs or alcohol, now is the time to stop. If you're not eating right, start on a healthier diet. If you're a smoker, quit. If you're out of shape, start exercising. You have the rest of your life ahead of you - stick around and enjoy it.

With thanks to HIV Positive magazine, January 2002, New York, for the basic ideas

Our comrades and friends can only give us support when they know what the problem is.

2. Tell someone: talk about it

Most people with HIV are afraid to tell other people that they are HIV-positive. That adds to the burden of having HIV. It is often better if you can talk to your partner, family, friends and comrades about what is happening to you.

Some people are so prejudiced and angry that you may not be able to talk to them about it, even if you are very close to them. You have to decide for yourself what is possible. The reasons for this anger may include ignorance and prejudice; they may be the natural reactions to any disaster; or your loved ones and friends could be scared about their own health and economic security.

Think about this:

Blame and guilt follow every taxi smash. And HIV is no different.

When something bad happens, people look for a reason. That can help them feel that they themselves will be able to avoid the problem in future. And people who are NOT hurt may also feel guilty – that somehow they should have done something to prevent the bad thing happening.

Have you ever been in a taxi accident? Everyone looks for someone to blame. Maybe you blame the driver (who was reckless); or the owner (who did not repair the brakes); or the other driver (who was drunk or fell asleep at the wheel).

People who missed or survived the accident may feel guilty or responsible. They may think, “Why did I say my child should go to school that day, so that she was on the taxi?” Or even, “Why did they die and I live?”

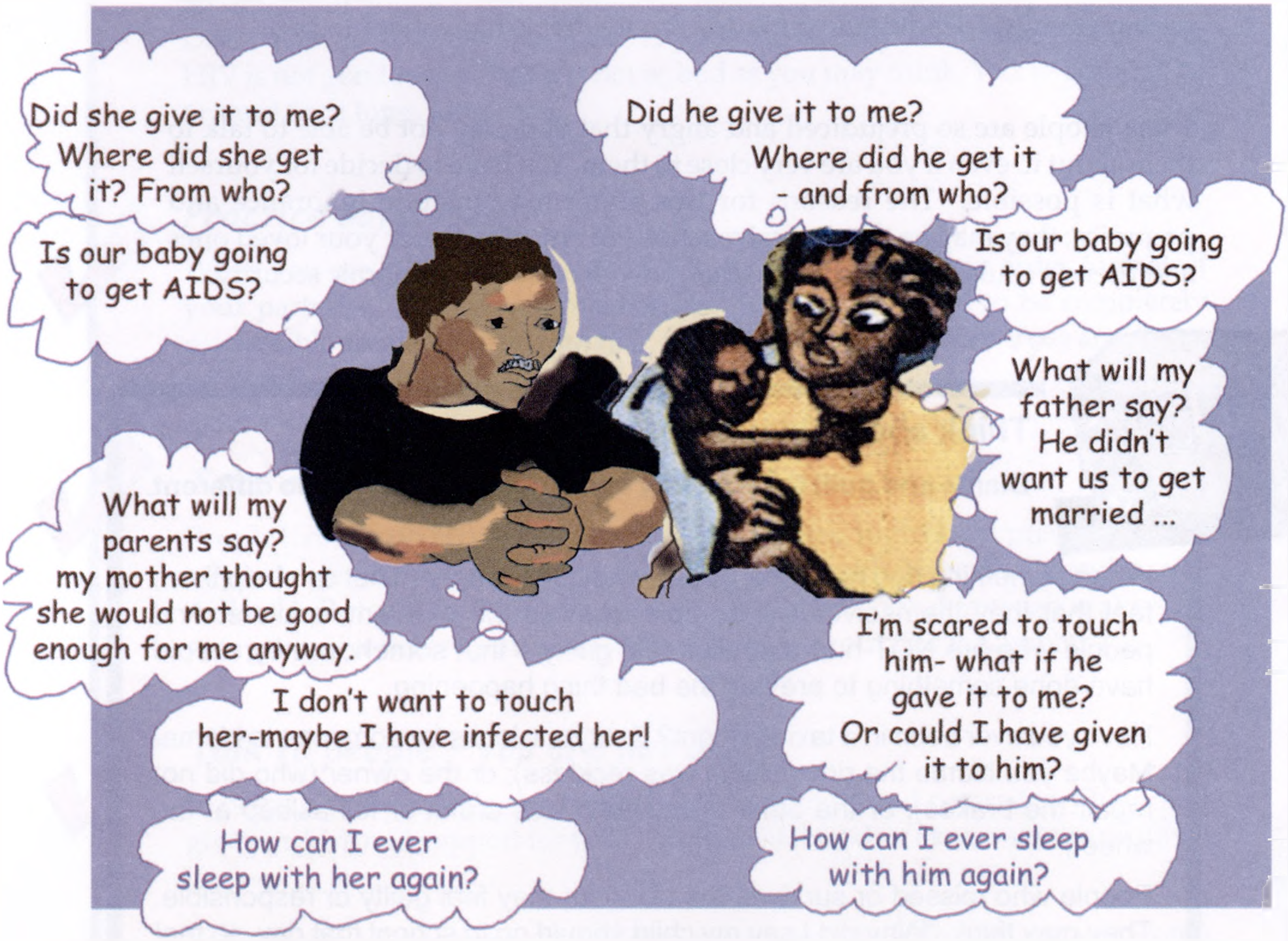
This blame and guilt can help us find out what went wrong and prevent it in the future. But blame and guilt can also become a burden, making people feel depressed and angry. And often the blame and guilt are not justified – some deaths are no one’s fault.

People have these reactions when a family member or comrade finds out they have HIV. But anger, blame and guilt do not help the situation. We need to make sure that people with HIV are not blamed for their condition. They need solidarity and support, not anger or reproaches.

YOU must inform your partner that you have HIV. No one else, including your doctor or nurse, should do this without your permission.

Telling your partner

It is very hard to tell your partner that you have HIV. It raises many questions for both of you. But your partner also needs to know about your health condition, so she or he can work out how it affects her or his own life. And it can be much harder on the partner to be the last to learn about it.



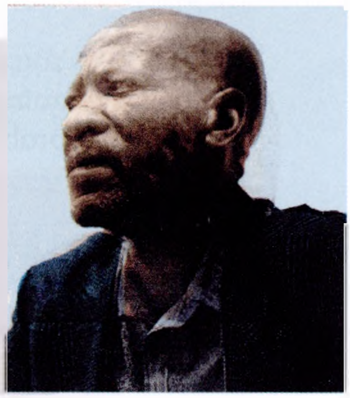
These are all difficult questions, and some of them have no answers. But in any case, both partners have to be strong and help each other.

- It doesn't help to blame each other or try to find out who was infected first – both of you need love and support
- Your baby will be much less likely to get HIV if the mother gets Nevirapine treatment
- You can still touch each other and have safer sex. USE CONDOMS!

Talk about it

to friends, fellow workers, and comrades; to your kids and parents; to your brothers and sisters.

> "I used to stay awake at night pondering how I'm going to disclose this to my family. Fortunately, I have done so, and I found a supportive, caring and loving family. Prior to disclosing my status, I was haunted by day and tormented by night. The situation has since improved, thanks to talking about the problem."
>
> \- M. Mothibeli, AngloGold mineworker and NUM member



You need to educate the people around you.

They may not know much about HIV. They have probably heard a lot of myths and scare stories about AIDS. You can tell them:

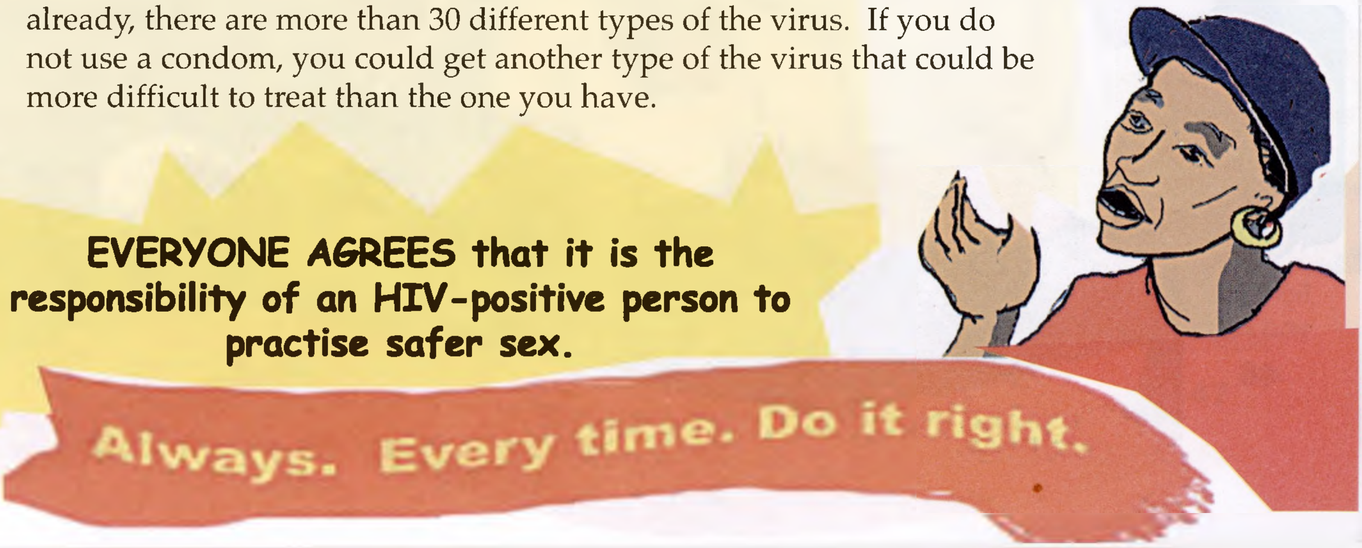
- If you are still healthy, you are likely to live for many more years.
- They can't get HIV from you during everyday work, or from touching you, or from any kind of normal contact that does not involve blood or other body fluids.

This book may help you tell them about living with HIV and AIDS.

Whatever you tell your partner or anyone else about your HIV status, you must ALWAYS use safer sex.

- If you know you are positive, the ONLY safer sex is by using a condom. Being faithful will NOT keep you from passing the virus to your partner. Only a condom will do that.
- **Wearing a condom protects you, too.** Even if you have the HIV virus already, there are more than 30 different types of the virus. If you do not use a condom, you could get another type of the virus that could be more difficult to treat than the one you have.

EVERYONE AGREES that it is the responsibility of an HIV-positive person to practise safer sex.



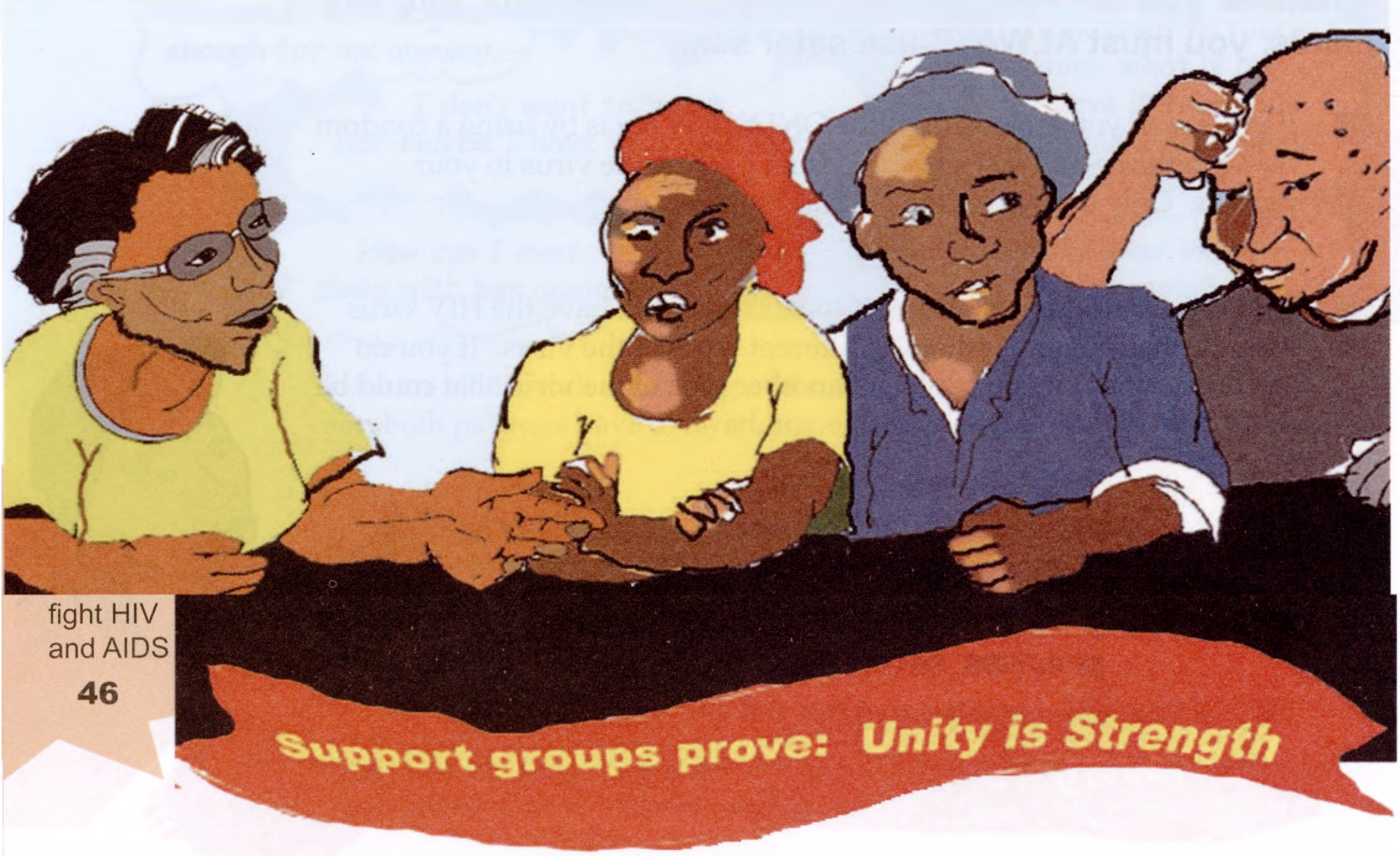
Find or set up a support group.

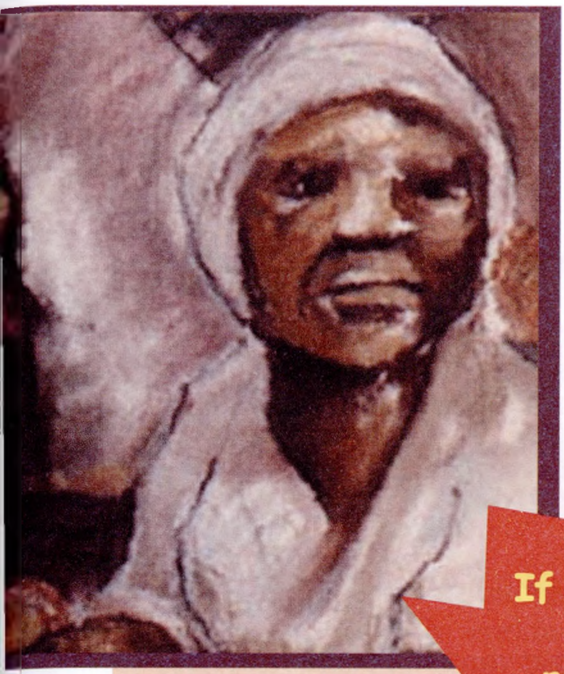
You are not alone. It helps to have people to talk to who understand what you're going through. It helps to approach problem areas knowing that these kinds of problems happen to other people too.

Support groups can empower you. You may be having problems about your HIV status with a clinic, with your employer, or with an unsympathetic teacher for your child. You may be worried about care for your family if you get ill or pass away. You may think you need medicine which your clinic can't or won't supply. If you talk these issues over with a support group, you will find that all of you have similar problems. You can work together for a solution.

Most organisations that offer HIV testing and counselling can put you in touch with an appropriate group. This could be a local branch of the National Association of People With AIDS (NAPWA).

Or ask your union or COSATU local to set up a support group! If you are were tested at your workplace as part of a broader survey, you may find that friends and comrades will join you. Then you can meet, say, once a week, and share your problems.





3. What do I do if someone I know is HIV-positive?

If your partner, child or comrade tells you they are positive, remember that they need your SOLIDARITY and SUPPORT.

- LISTEN! They need someone to talk to – give them a shoulder to cry on. Don't try to tell them how to feel, and don't make them listen to how you feel. They have their own problems. If they seem angry or hostile, be patient. Remember they are probably very scared.

- DON'T treat them oddly or act as if you are scared of them. You CANNOT get HIV from normal interactions or from safer sex. You can share food, drinks, dishes, bathwater and toilets with them without worrying about getting HIV yourself. If you are caring for a person who is very ill, you should learn about and use Universal Precautions (see page 28).

- See how YOU can HELP. People who find out they are HIV-positive may need to make some changes. They need to find information on HIV, healthcare, healthy living conditions, ways to talk to friends and parents. People who have AIDS may need help to get to clinics or hospitals, look after their children, and get home care.

- Make sure that your friends, comrades and employer DON'T DISCRIMINATE. Educate the people around you about the realities of HIV and AIDS. Make sure they know that most people with HIV won't die soon if they have healthy food, work and living conditions. And they should know that they CAN'T catch HIV from normal contacts or from safer sex.

- Make sure your conditions at work are O.K. for people with HIV. These questions are dealt with in Chapter 8.

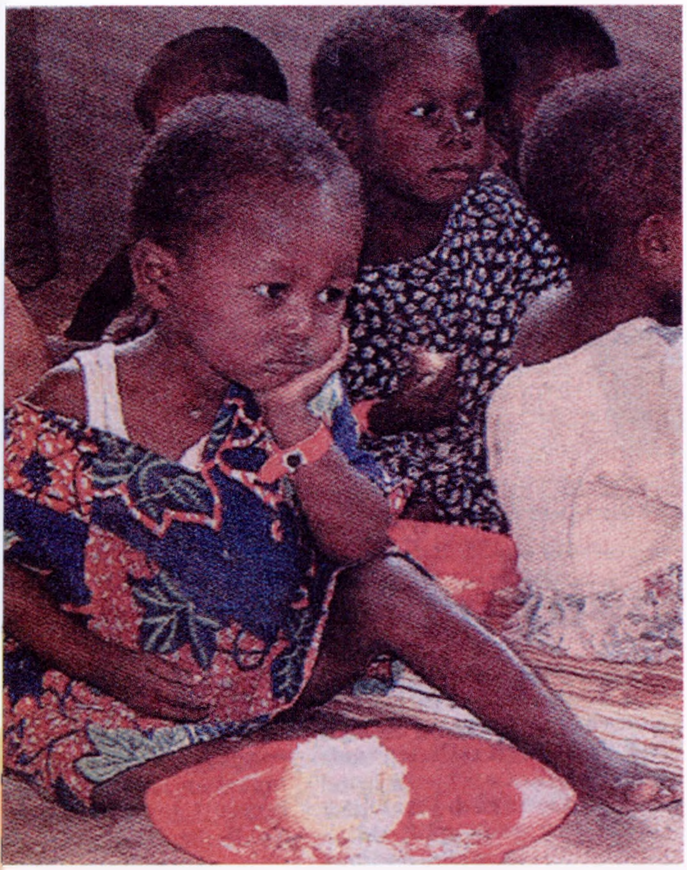
There are support groups and counsellors for partners and relatives of people with HIV; you may decide that you need help and advice too.

4. Healthy living with HIV

Eat Well and Eat More

An important part of healthy living with HIV is what you eat. People with HIV need to eat MORE and BETTER food to help their bodies fight against opportunistic illnesses. One sign that a person is losing the battle is if they lose a lot of weight very quickly when they become ill.

Some people have special health problems which mean they should not eat some kinds of foods. But for most healthy people with HIV, doctors say you should eat what you like, and eat a lot. Try to eat some foods from each of the groups below every day, to get the body building, protection and energy that your body needs.



Eat some of each of these food groups every day

- **Body-building foods** (called proteins): these are meat, chicken, fish, eggs, beans, nuts, milk and cheese
- **Protective foods** (fruit and vegetables): any greens, cabbage, morogo – especially with dark green leaves – pumpkin, tomatoes and carrots; also apples, bananas, oranges, guava and papaya (especially dark red and orange fruits).
- **Energy-giving foods**: bread, pap, rice, pasta and potatoes

COSATU says: Every worker must get a living wage - enough to get good food!

Selenium is a mineral found in some common foods. People with HIV take selenium to build their immune system, so that they remain healthy with HIV for a longer time.

Vitamins and immune boosters

People who are healthy with HIV can also take vitamins, minerals and immune-boosting medicines. These help a person's body stay strong, and fight off many forms of infection. They can help people who are not HIV-positive stay strong as well.

Some employers have offered immune-boosters, vitamins and minerals to members of their workforce. In several cases, they provided these WITHOUT asking which workers are positive. Early results from these programmes show that where immune-boosters and vitamins are given to workers, those who are living with HIV remain healthy for longer.

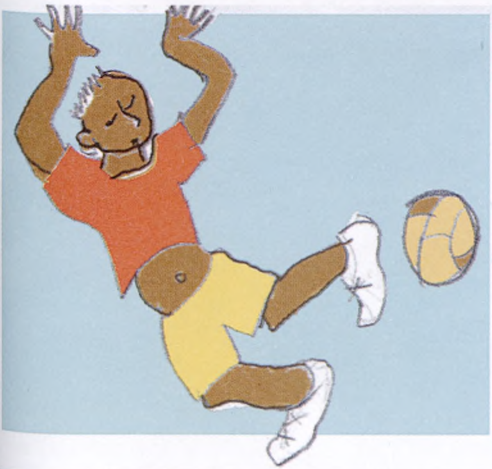
Drink a lot of CLEAN WATER

To be healthy, you should drink six to eight cups of water a day. But remember that UNCLEAN WATER can cause some of the worst illnesses for HIV. This is a common cause of diarrhoea.

- You can usually drink water from a tap, from the city water supply, straight.
- You MUST NOT drink water from rivers, boreholes or lakes without boiling it for several minutes first in order to kill any diseases it may carry.

COSATU SAYS: ALL OF OUR PEOPLE SHOULD HAVE CLEAN, PIPED WATER!

also....



Get some exercise

Football, aerobics, running, playing tennis, karate or ballroom dancing - exercise makes you feel better, cuts down on aches and pains, makes you know you really are healthy. It gets you hungry for good food and helps you rest and sleep better. So find time for any exercise you like!

Don't poison yourself

Don't smoke cigarettes. Cut down on drinking alchohol. It's your body, and now it needs all the help you can give it.

Rest and relaxation help too!

Take time out - take your children to the park, talk to someone you really like, visit your friends. Go to sleep early, get up late. Feel good about yourself. Women especially have to take real time off, and not feel they always have to be cleaning or cooking.

Cut down on stress: think about your life.

Think about the things you really like to do - and then do them! Think about the other things that make you angry and stressed - figure out how can you avoid doing them, or work out how you can change them so they cause you less grief and tension.

Look at how your work is organised. Can you negotiate changes so that you are not so tired at the end of the day?

Talk to someone you trust about your health!

People you care about, people you love, and people you like and respect can only give you support and help when they know what the problem is. It helps to know you are not alone, not cut off from your friends and comrades.

FIGHTING POVERTY AND UNEMPLOYMENT FIGHTS HIV

People who are poor or unemployed usually can't get the healthy conditions or food they need to stay healthy when they have HIV. We have to unite to fight poverty and unemployment to make sure ALL our people have

- Good food
- Good living conditions with clean water and sanitation
- Access to good healthcare and treatment for illnesses
- Places for recreation like parks, soccer fields and cultural centres

These questions are dealt with in more detail in Chapter 8.

One of the problems that grows with being HIV-positive is money. How can you afford medicine? How will you support your family if you are ill? What about the kids?

5. Can you afford it?

Medical aids, health insurance, and HIV

Medical aid schemes in South Africa have a long history of refusing to pay out for people with HIV and AIDS. Until recently, most refused to cover people with HIV or AIDS, because small print in many policies denied payout for "sexually transmitted diseases".

In 2000, new laws were passed to regulate the medical aids. They MUST now provide some cover for HIV, including for anti-retrovirals. Most medical aids now provide at least the legal minimum. Still, about 10% do not provide enough for on-going anti-retroviral treatment.

If you are choosing a medical aid, you should make sure it provides enough funds to cover care and treatment for HIV and AIDS.

Employer support for treatment

Many workers cannot afford to belong to a medical aid. Most workers earning under R3500 a month can't get medical aid.

We must demand that employers provide medical help for workers.

Some of the big mining companies now provide anti-retroviral treatment to workers with HIV. We must fight for this benefit in ALL our workplaces!

Disability pay

If workers with HIV get too ill to work, they should get disability pay either from their medical aid or from their pension or provident fund. They have the same right to disability pay as any other worker who is too ill to stay on the job. The payment will depend on the pension or provident fund rules. In the public service, for instance, the pension fund will pay a pension for disability if a doctor certifies that you are too ill to work any longer.

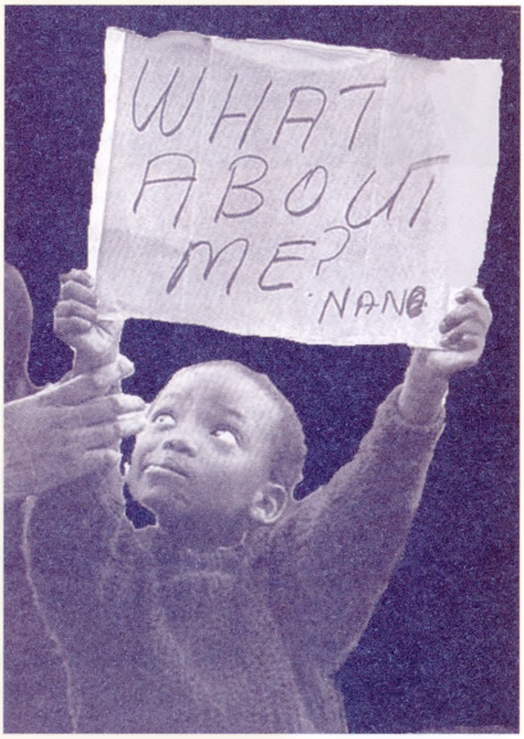
If you do not have a pension that covers disability, you have a right to a state disability pension when you are too ill to work. Even an unemployed person has the right to a disability pension when he or she is too ill. The pension is not much – the same as an old-age pension – but it is better than nothing.

Orphans payments

Most pension and provident funds provide some payment for your partner. But many provide nothing for orphans. We need to negotiate new rules to close this gap. Orphans should get the same payment as partners until they are at least 18 years old.

If orphaned children do not get a payment from their parents' pensions, they are eligible for a foster grant from the state. Again, the grant is not very much – about the same as an old-age pension – but it is something. Children can only get the grant, however, if they are formally fostered by their caregivers, even if they are close relatives. If they are not, they can still get the child support grant, which is over R100 a month.

Whatever kind of state grant an orphan gets, she or he will need proper ID papers. You can get them from Home Affairs, just like your own ID.



Housing allowances

Most housing allowances require that the worker has a bond. This is unfair in any case, since most Africans still live in townships and inner cities where they can't get a bond. It is particularly unfair for people with HIV, who often can't get bonds because of discrimination by the banks.

We should demand

- Housing allowances for people who rent or build their own homes, and
- Employer guarantees on housing bonds for people with HIV.

Life insurance and housing bonds

The financial institutions have a bad record of discriminating against people with HIV. Until recently, life insurance companies made people take a test to see if they had HIV – and made them pay more or would not give them insurance at all if the test came back positive. When a person could not get life insurance, the banks often would not give them a home loan. So even if the person could afford a house, they could not get a bond. At NEDLAC in August 2002, COSATU gained an agreement from the financial institutions to find a means of stopping this refusal to give housing bonds to people with HIV.

Your union should negotiate benefits that are suitable to people with HIV!

Lump-sum payments and disability leave

Sometimes when a worker gets HIV, the employer tries to get them to take a lump-sum payment or to retire on disability. Yet the person may live for many more years, especially if they can get anti-retroviral treatment.

Employers may try to pay out workers with HIV in this way because

- They are discriminating – they just don't want someone working for them with HIV
- They are worried they will end up helping to pay for treatment, either through the company medical aid or because the union demands it
- They believe that the worker will die soon (even if theworker is still healthy) and are trying to do the right thing
- Sometimes a worker with HIV will almost die from an opportunistic disease – then recover and live for many more years. Employers may not realise that they will get better.

If you have HIV and the employer offers you a lump-sum payment or disability, think about it very carefully. What are the costs and benefits of taking the payment?

- If you are going to live at least another ten years – which is probable – it may make more sense financially to stay at work. What would you do to earn an income if you leave? How risky would this be compared with your wage?
- If you have a medical aid or can negotiate to make the employer pay for treatment, it almost certainly makes more sense to stay at work.
- Remember: quitting work can make you depressed and lonely, no matter how much you think you hate your job. That is NOT good for anyone!

How will HIV affect my retirement fund?

Retirement funds usually pay a lump-sum benefit or survivor's benefits for members who die. In theory, the amount paid out should be more or less equal to what the person would have gotten if they retired early. But some funds pay more, and some pay less. In effect, the retirement fund is providing a form of life insurance for members.

If more people have HIV, AND they don't get treatment, then the cost of death benefits to the pension fund will rise. The impact on the fund will depend on whether the survivors' benefits are more or less than the member would have gotten on retirement.

As unions, we need to negotiate for death benefits at a level that will not undermine our pension funds, while providing decent benefits for our comrades' families. That means we need a correct assessment from pension-fund experts – the actuaries – about the effects of HIV and about the amount of death benefits that makes sense.

Actuaries are as much affected by the stories and discrimination about AIDS as everyone else. Sometimes they are using old information, which doesn't take into account the way better treatment lets people live longer.

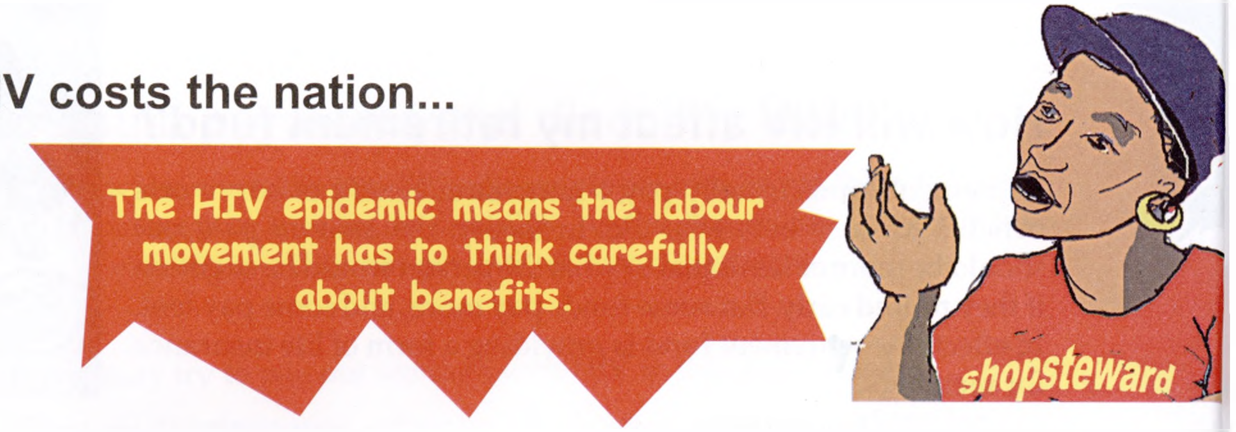
So always make sure the actuaries are using real facts about HIV, especially:

- What percentage of the workforce is HIV-positive – at all levels. Some actuaries assume that only lower-level workers will get HIV.
- How long people are likely to live with HIV. Remember that if we can get anti-retroviral treatment for all our members, there will likely be very little impact on the pension fund at all because people will live so long!

Every pension fund trustee should find out the facts about HIV, and make sure that their actuaries use them properly.

You can ask COSATU for the facts about HIV!

HIV costs the nation...



HIV imposes new costs on society – for medical care, disability pensions and benefits for survivors and orphans. COSATU has long argued that these costs must be borne by the state and financed through taxes on the rich. That means the government will have to pay more for public health care and welfare.

But right now, the government does not spend enough on public health and welfare. Unions have fought for private healthcare and retirement provision for their members. Now the cost of these benefits may rise in an effort to provide for members with HIV. This can reduce the benefits for ALL workers. In effect, it makes working people pay for a national problem – the HIV epidemic.

In the short run, we have to insist that our medical aids and retirement funds provide adequately for people with HIV. But ultimately, we must ensure that the government provides the basic social services and grants that are needed by all people with HIV. These services and grants must be paid for, not by contributions from ordinary working people, but by taxes on the rich. (We discuss this in chapter 8.)

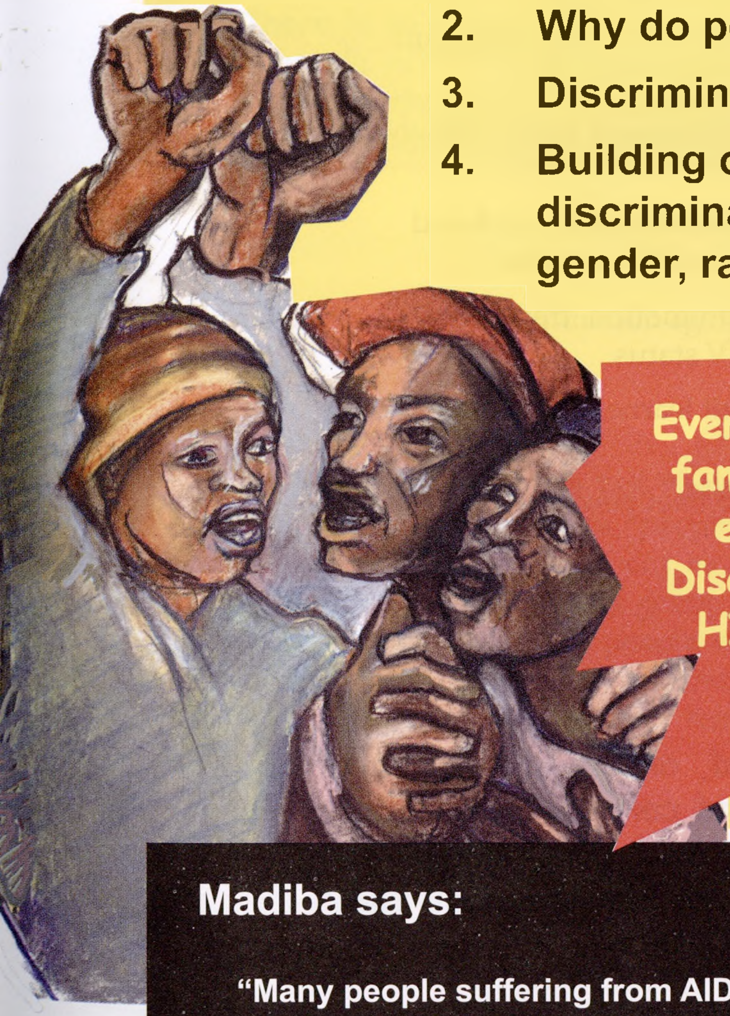
Discuss/Think about it!

- Do you eat enough of the right kinds of food? If not, why not? If you eat at work, is the food healthy?
- Can you discuss your HIV status with your family? with your shopsteward? Why or why not?
- What benefits do you get at work? Are these adequate for someone with HIV or AIDS?

6. AIDS grows on discrimination

This chapter looks at:

1. What is discrimination around HIV and AIDS?
2. Why do people discriminate?
3. Discrimination in employment
4. Building on existing discrimination: gender, race and class



Every person, every worker, every family member needs solidarity – even more when they are ill. Discrimination against people with HIV kills just as surely as the disease itself.

Madiba says:

> "Many people suffering from AIDS are not killed by the disease itself; they are killed by the stigma surrounding everybody who has HIV/AIDS. It is inexcusable to subject any person infected or affected by HIV/AIDS to such abuse and rejection. We must tackle the stigma and discrimination associated with HIV/AIDS with even greater urgency."

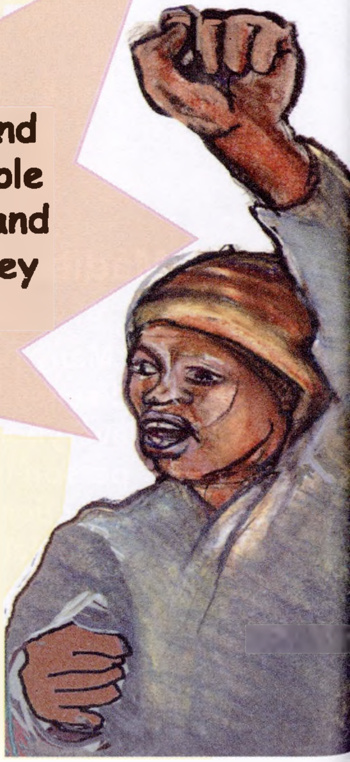
-Nelson Mandela, closing speech at the Barcelona Conference on HIV and AIDS, July 2002

1. What is discrimination around HIV and AIDS?

Discrimination over HIV and AIDS happens

- when people who have HIV or AIDS are isolated and rejected by co-workers and friends
- when people who are ill with AIDS are simply left to die, without help, support or treatment
- when women who are HIV-positive are beaten and thrown out of the house by their partners
- when families isolate and hide family members who are HIV-positive
- when workers are fired from their jobs, or refused employment, because they are HIV-positive
- when workers are refused promotion, training, or benefits because of their HIV status
- when schools refuse to admit learners who are HIV-positive
- when medical staff refuse to treat people because they have HIV or AIDS.

People with HIV have been killed, and beaten up, and thrown out of homes and jobs and communities. People have been denied their rights, denied jobs, income and support, even denied their right to life, because they have HIV and AIDS.

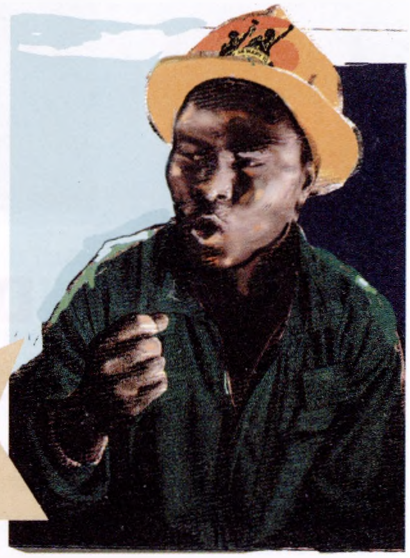


In one well-known case in 2000, a woman named Gugu Dlamini was stoned to death by people in her village in KwaZulu-Natal after she publicly said she was HIV-positive. She received death threats shortly before her murder, and asked the police for protection; but they did nothing.

2. Why do people discriminate?

A major cause of discrimination against people with HIV is FEAR. Everyone is scared that they might catch this disease. But as we have seen, it isn't easy to catch HIV. You certainly cannot catch it from working or living with a person, from sharing food, dishes, toilets, baths, towels, chairs… You won't even catch it from having sex if you use a condom.

There is no justification for discriminating against people with HIV because someone is afraid of catching the disease. You cannot catch it just by being around someone with HIV.



The second cause of discrimination against people with HIV is STIGMA.

Some people like to tell themselves that HIV only infects OTHER people, people who come from some other group, or who act or believe in some way different from MY group. Some people tell themselves that only people who "sleep around" get HIV – and they tell themselves they would never do such a thing.

COSATU says:

Stigma and fear lead to isolation and rejection of comrades and workers: these have no place in our workplaces or in our unions. EVERY shopsteward must be prepared to recognise and root out attitudes and behaviour that make it hard for a person with HIV and AIDS to get support when he or she needs it.

> **"The impact of discrimination on HIV-positive people is devastating. It is even more so when it occurs in the context of employment. It denies them the right to earn a living."**
>
> *Justice Ngcobo, speaking for the Constitutional Court on discrimination against people with HIV, City Press, 26 May, 2002*

3. Discrimination in employment

A healthy person with HIV can work as well as any other worker – and has the same rights and responsibilities.

It is ILLEGAL:

- To fire a worker just because they have HIV
- To make a worker take an HIV test
- To refuse to hire a worker just because they are HIV positive
- For your doctor to tell your employer your HIV status without your permission.

In Hoffman v South African Airways (2000), the Constitutional Court of South Africa decided that the employer, SAA, had violated Hoffman's constitutional right to equality, dignity and fair labour practices.

Hoffman applied for a job with SAA as a cabin attendant. He was asked to go for an HIV test, and was refused the job because he was HIV-positive.

The Court decided:

- SAA discriminated against Hoffman.
- The discrimination was unfair.
- Being HIV-negative was not an "inherent requirement" (essential to the job) for being a cabin attendant.

- from HIV /AIDS and the Law - A Resource Manual, p. 158

Like many other labour laws, employers don't always abide by the laws on HIV. Employers send workers who are unorganised, like domestic workers, to take HIV tests. Then they fire the workers if they are HIV-positive, even though it is an unfair labour practice.

The labour lawyer's story:

A worker asked my project for legal help, as her employer has discriminated against her after she had told him she had HIV. She had taken a week's leave for flu. She had given her employer a doctor's letter for the sick leave. When she returned to work, she discovered her employer had applied for her to leave her job with permanent disability for the HIV, even though she had been ill only for a week, provided the doctor's letter, had returned on time and had recovered fully from the flu.

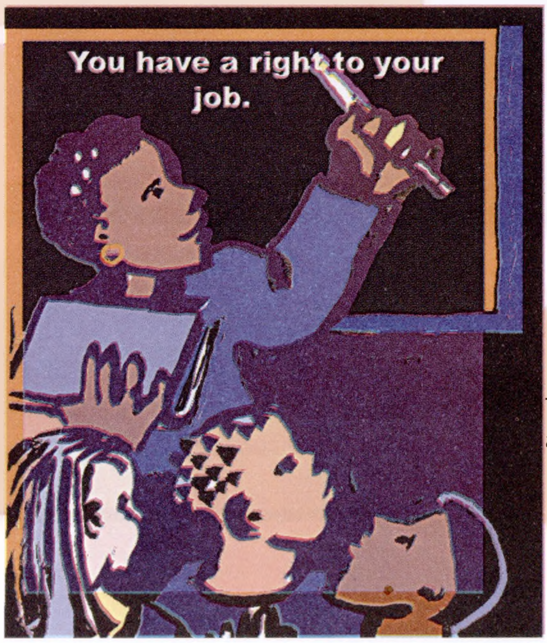
I suggested that she should ask her union to take up her case. But she said she did not want to go to the union (although her workplace has a union, and she is a union member). She was afraid that the shopsteward would not be willing to help her, and might tell the other workers that she had HIV. Then the other workers might also turn against her.

I contacted the employer and pointed out that this was illegal discrimination. The permanent disability request was dropped. But the management then changed her working conditions and assigned her to work in another place. When the staff were measured for new uniforms, they somehow "forgot" to supply her with one. Next, they proposed that she be retrenched with three other staff members during a restructuring – then decided she alone would be retrenched.

To me, this is a very clear case of discrimination by the employer because of HIV status.

SADTU's story

In 2002, a primary school teacher in KwaZulu Natal was fired from her job when she told her employer, the Provincial Department of Education, that she was HIV-positive. She was not ill or unable to work. The teachers' union SADTU objected to this as an unfair labour practice, and the teacher was reinstated in her job.



Conditions of work and HIV

When a person has AIDS, they may be too ill to work. In this case, they must be treated just like any other worker with a serious illness. The employer must ensure they work in the healthiest possible environment and that they get a normal number of sick days off for as long as they can.

The employer should provide the same kinds of "reasonable accomodation" that would be made for any employee with a disability. This could include developing flexible or part-time working schedules, leaves of absence for illness, and work restructuring or reassignment when working conditions interfere with the worker's health needs.

When a worker with AIDS can no longer work, they must get their pension paid out like any other person who resigns because of illness.

It is important to remember that a person with HIV who becomes ill may recover if they are treated for their illness. Many employers and even doctors and health workers wrongly believe that people with HIV will get more and more ill and die quite soon, and that they will never be able to do their job well. Some think this will be a burden for the company. The employer may then treat a person who is ill with HIV as if they are about to die. That is discriminatory and illegal.

Discuss/Think about it!

- How can we provide support for HIV-positive workers who still face discrimination at the workplace?
- What does your medical aid or retirement fund provide for people with disability?

4. Building on existing discrimination

Discrimination against people with HIV often builds on existing discrimination, which is most commonly based in race, gender, and class oppression. In the struggle against apartheid we fought this kind of prejudice. Now in the struggle against HIV and the AIDS epidemic, we still have to fight against myths, prejudices and inequalities that grow from those foundations.

GENDER

Blaming women for spreading AIDS

Many people in Southern Africa believe that HIV/AIDS is spread by women behaving immorally, rather than by men and women acting together.

This story has been told over and over again in South Africa.

A few of these cases made the press. But no one knows how many times it has happened, and the media does not report what happened to the victims.

A woman attends an antenatal clinic, where she is told - publicly, in the waiting room - that she has HIV. People at the clinic spread the rumour, and her husband has heard all about it by the time she gets home. He blames the woman for bringing the dread disease into HIS house, and kicks her out on the street. Often, the husband kicks out her children with her (even when they are also his children). Her own family refuses to take her back. What should she do? This is a short, fast road to death.

Women have fewer rights to property and less access to employment

Very often, the family's property legally belongs to the man of the house - the husband or the father. The house that a woman lives in (perhaps all her life) belongs to that man. So the man of the house can kick out the woman when she is HIV-positive. She has no "right" to claim material goods or support.

Ignoring the man's role is also a kind of denial.

There is at least a fair chance that if one partner is positive, the other is also. This is not a matter of guilt or fault, just a likely situation. But some men blame their wives and throw them out as "guilty" for bringing the disease into the house. The man often refuses to find out his own HIV status. Even knowing his partner tested positive, he may refuse to use condoms because he argues it was all the wife's fault.

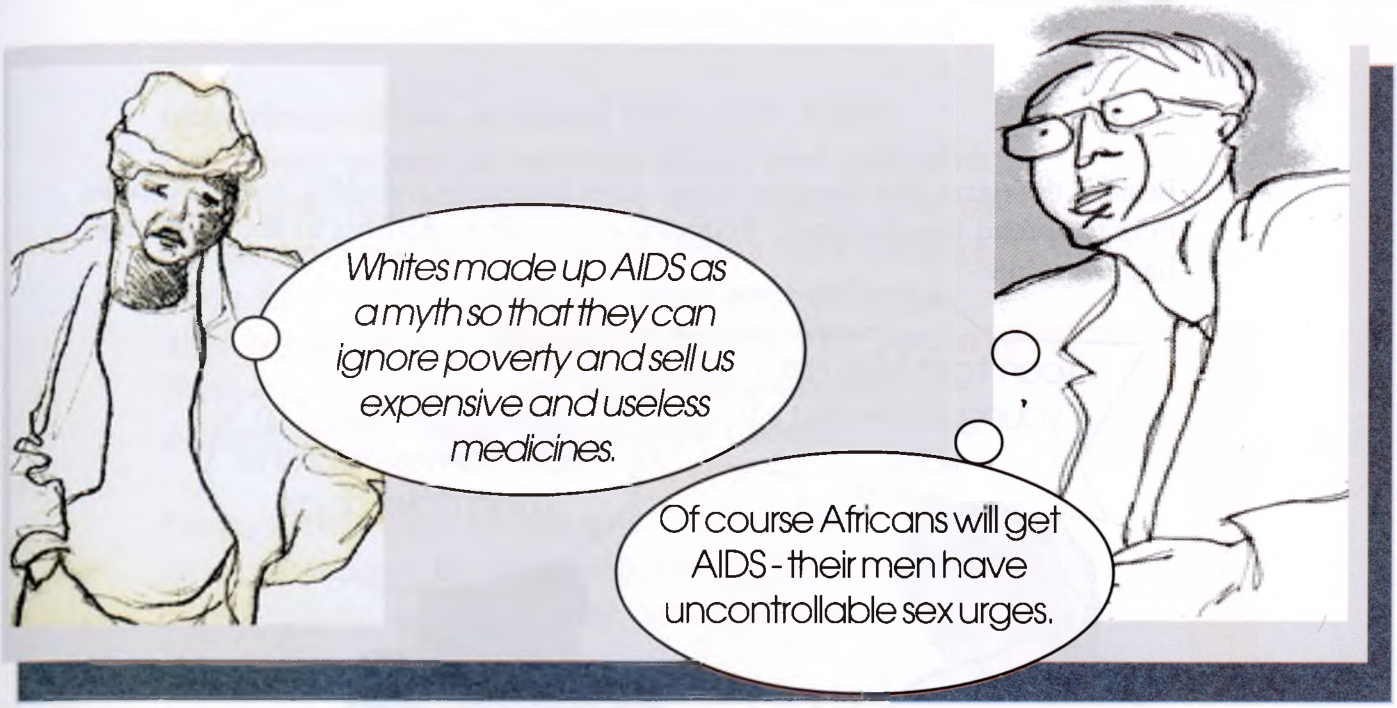
When we talk about "mother-to-child" transmission, we easily forget that BOTH parents are likely to be HIV-positive, not just the mother. Fathers also should be playing a role in prevention, and in caring for the child.

RACE & CLASS

Prejudices and stereotypes about race and class add to and reinforce the HIV and AIDS epidemic. These prejudices are inter-woven; often the myths and lies about race repeat and reinforce the myths and lies about poor people.

With our history of racial discrimination, it is not surprising that many people use racist prejudices to explain HIV and AIDS.

Some black people have argued that AIDS came from whites; that it was spread by whites to kill or harm blacks. Some have argued that AIDS is a myth invented by whites.



Some white people in Southern Africa believe that only black people are likely to get HIV and AIDS. Often they hold the racist view that blacks have no stable families or moral standards, or that "their culture" spreads HIV.

Rich people sometimes argue that poor people are more likely to "sleep around", and therefore more likely to get HIV. Educated people (both black and white) often say the same thing about people with less education. They tell themselves that they personally are not at risk. Besides, many rich people know that they personally CAN afford medicine to control HIV. So they say to themselves the epidemic is not their concern.

Class and race prejudices mean that many rich, educated and influential people are not willing to support prevention campaigns and safer sex. And they don't want to help make sure the poor get access to treatment. Some have even said that it would be no real problem if the very poor, the unskilled, and the unemployed die of AIDS.

Prejudices and stereotypes around class and race make it harder for poor people to access medicine and resources to live with HIV and AIDS.

Besides the harm that discrimination does to people with HIV, these attitudes help to spread the epidemic. People use all their prejudices to say: this won't happen to me!

- If you think only "bad" or "different" people get AIDS, you think it can't happen to you. You won't use a condom or get tested when you should. You might only find out you have it yourself when it is very late.

- If a person thinks only "bad people" get AIDS, they won't campaign to stop its spread or educate their children effectively in how to deal with the epidemic.

- If someone thinks only "different people - not *us*, not people in *my* group" will get AIDS, they will not fight for treatment for people with HIV.

Discrimination around HIV and AIDS happens when a person does not get the support, the benefits, or the rights she or he deserves, because of their HIV status. This is made worse by fear and stigma, and by on-going inequalities in our society that have grown out of discrimination based on gender, race, and class.

Discrimination is illegal. It is also destructive - to the people it happens to, but also to our society as a whole.

Workers must show solidarity with people with HIV and AIDS. We can stop this epidemic!

Discuss/Think about it!

- Think about the different ways you have been told that people can get or spread HIV - including all the myths and rumours and silly things people have said. If you are in a group, ask group members to list all the different things they have heard. How many of these start with a description of a person or a group that depends upon race, gender, or class?

  Some examples of these might be:

  "African men are unable to be faithful - polygamy and sleeping around are part of their culture."

  "Prostitutes spread AIDS by having sex with many different people."

  "AIDS is a myth spread by whites to keep us from having children."

- Do you know of any situation in your community or workplace where prejudice and discrimination around gender has made the living conditions of a person with HIV worse?

  One example is:

  A women is thrown out of the house by the husband because she is HIV-positive.

  How can members of the family and the community deal with these situations? What can your union, or other community organisations, do?

- Do you know of situations where race or class prejudice and discrimination has made the living conditions of a person with HIV worse?

  Do you think that prejudices or myths about race and class may prevent people from getting treatment for HIV and AIDS?

  How can members of the community or your union deal with these situations when they occur? What can your union, or other community organisations, do?

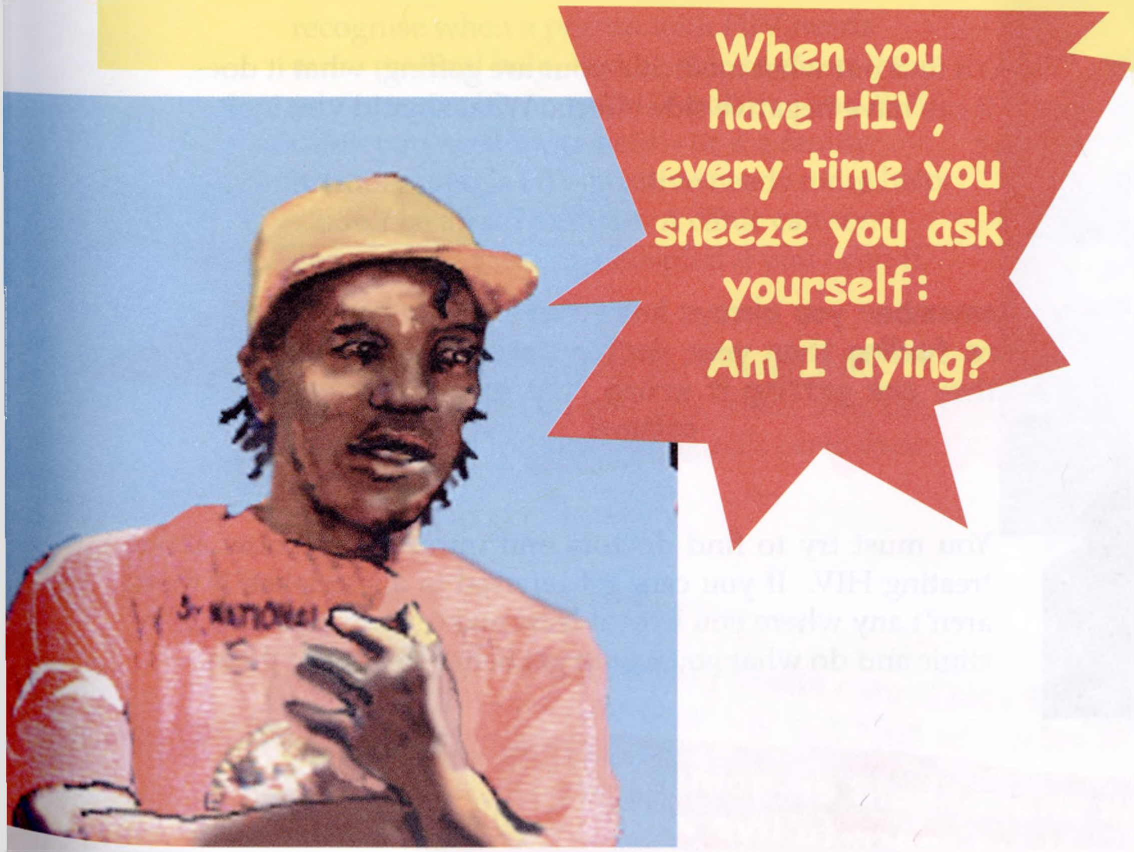
7. MEDICINE helps you live with HIV and AIDS

In the previous sections, we looked at how we can live healthier and longer lives when we have HIV.

In this section we look at the role that medicine has to play in fighting the AIDS epidemic, and how it helps us live longer.

This section looks at:

1. Health care and medicine
2. Treatment of opportunistic diseases
3. Anti-retroviral treatment (also called ARV, ART, HAART, and "combination therapy")
4. Using anti-retrovirals to stop infection
5. The problem of unaffordable medicine



1. Health care and medicine

Studies show that HIV-positive people who study the condition, find out about treatment options and know about their own care live much longer.

- Read about HIV and AIDS. Remember that the newspapers often get the information wrong, but they may still help you find out about new treatments and about living healthy. You can use this book. Ask nurses, doctors, counsellors and other people with HIV for more information. We can LEARN from each other!
- Think about how you talk to doctors and nurses. Sometimes they won't take the time to explain your health to you, what they have found out, what you have to do and what kind of medicine they are giving you. That may mean you have to be very strong and forceful with your doctor. It may help to bring a friend or comrade with you.
- ALWAYS find out exactly what your results are and what they mean. You should know your CD-4 count and viral load.
- ALWAYS find out what medicine your are getting, what it does, and if it can have negative side effects. What should you look out for?

You must try to find doctors and nurses who know about treating HIV. If you can, get referred to a specialist. If there aren't any where you live, at least make sure you find a good clinic and do what you can to get better treatment there.

Unions should hold on-going treatment literacy workshops to help workers learn to live with HIV and AIDS.

Primary health care for HIV

When you are HIV-positive and healthy, the first place you have to go is for primary health care. Primary health care means the kind of health care you get at a community clinic. It includes treatment for small illnesses like flu, health care that prevents diseases, like vaccinations for measles and polio, and advice on health conditions like high blood pressure, heart problems – and HIV.

A primary health care clinic should be a place where anyone can go when she or he is not feeling well. They should be able to go to a clinic and get help BEFORE they are so sick they have to go to a hospital.

For people with HIV, the local clinic or doctor is important because:

1. They can give you an HIV test. Make sure the information is CONFIDENTIAL. It must never be announced in the waiting room or told to employers! If necessary, COSATU comrades should visit the clinic and discuss procedures with the nurses there.

2. The care-givers at the clinic must be able to recognise when a person with HIV needs more medical help, and be able to direct them where to go. If you are HIV-positive and YOU think you need more help – or if a family member who is HIV-positive needs more help – don't be afraid to insist. A clinic can send you to a specialist at a hospital if you need it.

3. The clinic can give pregnant women with HIV information on how and where they can get treatment to stop passing HIV on to their babies.

All staff members at primary health care clinics need proper training and resources to treat HIV and AIDS ad related illnesses.

Traditional and alternative medicine and HIV care

Many workers go to traditional healers when they become ill. For people with HIV and AIDS, traditional medicines can sometimes help them feel better.

- Some traditional medicines contain immune boosters and vitamins.
- Some traditional medicines are used against opportunistic diseases.

Most of these medicines have not been researched by scientists. There is no agreement about how effective they are. But some traditional healers are working with medical doctors to find ways to treat illnesses that come with HIV and AIDS. In KwaZulu-Natal, some traditional healers are learning to treat oral thrush with fluconazole. Scientists in Europe have been testing a traditional herbal combination from West Africa, with early results showing success in cutting down the amount of HIV in a person's blood.

It is important that traditional healers, like all health workers, learn about HIV and AIDS and how to treat people with these health problems. Traditional healers' organisations need to support this training.

It is important to remember that people living with HIV and AIDS can become terribly ill and then recover "miraculously". When this happens after taking traditional medicines, some people may think that traditional medicine can cure HIV and AIDS.

WE DO NOT KNOW OF ANY MEDICINE, OF ANY KIND, THAT CURES HIV AND AIDS. A number of different medicines – both "Western" and "traditional" medicines – can make you feel better. But:

- Once you have HIV, you must ALWAYS use condoms.
- Be careful about spending a lot of money on a miracle "cure". There is NO known cure for HIV today. The most effective treatment for HIV and AIDS at this time is anti-retrovirals. These also cost a lot of money, but we do know how well they work (see pages 78 to 88).

Discuss/Think about it!

How can COSATU or your union make sure that the clinic in your community can deal with HIV? If you are a nurse, what kind of training do you need to help HIV-positive people, and where can you get this training?

2. Opportunistic Diseases:

treating illnesses that come with HIV and AIDS

People who are living healthy lives with HIV get other illnesses. Often, they get the same illnesses that other people in the community get. These include ordinary diseases like flu, coughs, pneumonia, TB, malaria, cancer and other sickness that are common around us. But if a person with HIV has a weakened immune system, any illness is likely to become much more serious very quickly.

When you are HIV-positive, and you get even an ordinary illness like a cold or flu, you may get sick much faster and much more seriously than you would have before you got the HIV.

Some common illnesses, such as TB, also interact with the HIV in a person's blood. This makes both the illness and the HIV more dangerous to the body. As well as TB, common illnesses that take advantage of an immune system weakened by HIV are:

- pneumonia and bronchitis
- thrush
- herpes
- diarrhoea
- hepatitis
- chicken pox in adults (called shingles).

We call illnesses that come on top of HIV "opportunistic illesses". Even without the HIV in his or her system, these diseases can be very serious. With HIV, they can be killers.

Many people get these illnesses, and get very ill, when they do NOT have HIV. And people without HIV can die from these diseases too, if they do not get treatment. It is wrong to just say - "oh, so-and-so has TB, he is always coughing, I'm sure he is dying of AIDS." Sometimes people with these illnesses do not go for treatment, because they are afraid they might have HIV. But people who are seriously ill need treatment, whether they have HIV or not.

Besides these well-known illnesses, a person with a weakened immune system can also get UNUSUAL illnesses. So his or her doctor should look for uncommon illnesses too!

People who have HIV can be cured of opportunistic illnesses, even when they are very ill – if they are treated, and particularly if they are treated in time. We have CURES for major opportunistic diseases, including TB, pneumonia, and thrush (in the throat and in the deadly version where it attacks a person's brain.)

A WARNING:

if you are HIV-positive, always check out new illnesses as soon as possible.

Getting this early warning for people with HIV is a major reason we need primary health care, and HIV tests, for all of our people!

Because there is really good news about opportunistic diseases. Whether you are HIV-positive or not, doctors today CAN and DO CURE many of these diseases.

Think about this!

In the United States, in the early 1980s, 60% of people who had AIDS died from a particular form of pneumonia, called PCP. In 1987 doctors found a cure for PCP pneumonia, and since then almost NOBODY in the USA has died from PCP pneumonia.

The fluconazole story:

- stopping fungal infections from thrush to cryptococcal meningitis

"Thrush" is a kind of illness – a fungal infection that can grow inside your body. Small babies – including babies who do not have HIV – often get thrush in their mouth. Women sometimes get thrush inside their bodies (in their vaginas). This is usually irritating but not dangerous.

When a person has HIV, however, thrush can become much more serious. It can make sores in the person's throat that are so painful the person cannot eat. It can cause serious diarrhoea. It can enter the brain, and cause brain fever (called cryptococcal meningitis).

In 1993 doctors discovered a pill which works against thrush - called *fluconazole*. (The brand name for flunconazole is Diflucan.) People who had thrush infections, whether in the mouth or the brain, could take the pills and get better very quickly. People who had bad thrush with HIV got better.

When fluconazole was first introduced in South Africa, it was very expensive. It cost nearly R100 for each pill in 1994. It had to be imported from the USA or Europe. But by the late 1990s, India, Thailand and Brazil were producing much cheaper versions of the same drug.

AIDS activists and COSATU fought to change the laws, to enable our people to get cheaper kinds of pills. Today, a pill that uses the same medicine, fluconazole, can cost as little as R4.

A GENERIC drug is a "no-name" medicine which is the same as a more expensive medicine made by a well-known company, using a well-known brand name. When you take a no-name drug with paracetamol for fever from the supermarket, you are using a generic drug, rather than buying Panado.

TB and HIV: a knock-out combination

In the past few years, the number of people dying from TB in South Africa has soared.

TB is even more widespread today than it was in the 1940s and 50s, when our grandparents fought for large mining companies to take responsibility for migrant workers ill with TB.

From the development of mining in the Witwatersrand, almost a hundred years ago, miners have known that one major threat they face is TB. In the apartheid era, TB grew in the terrible living conditions of mine hostels, and dust and pollution of mines. It was taken home to the rural areas by migrant labour. People who are very poor catch TB easily.

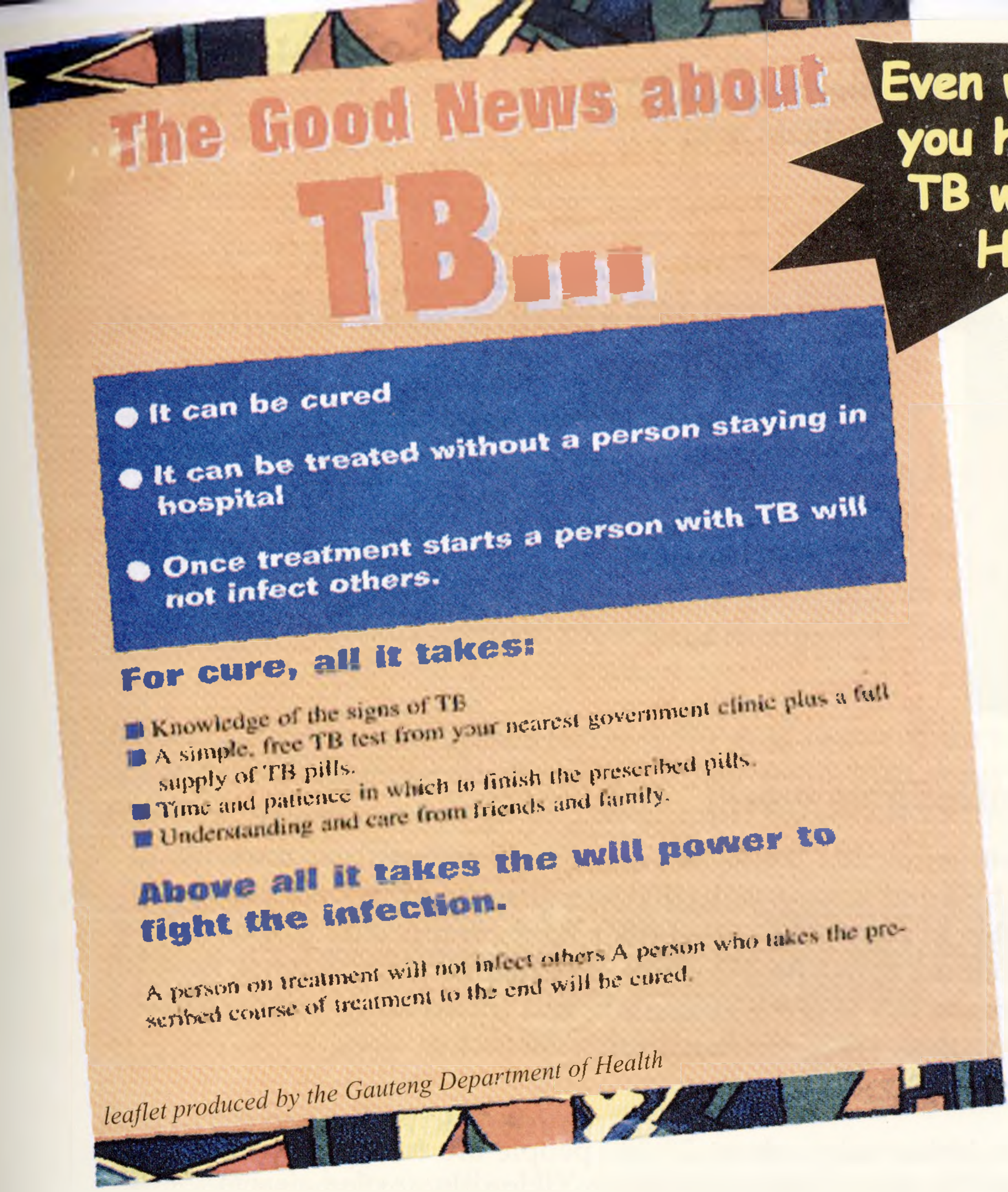
We say that TB "piggybacks" or "feeds on" on HIV. If your system is weak from HIV – even if you have been "HIV and healthy"so far – TB can attack you faster and harder than if you do not have HIV. About four-fifths of people in South African hospitals who have TB also have HIV.

In most cases in Southern Africa today, even when the person also has HIV, the standard TB drugs WILL cure the TB. But If you have HIV it may take longer for the drugs to work. and you may have to take more drugs.

TB on the South African Mines

4000 miners got TB on South African mines in 1999 and 2000. Of these 4000 miners who developed TB during these two years, 60% died within two years.

Many of those who died from TB also had HIV.



The Good News about TB...

- It can be cured
- It can be treated without a person staying in hospital
- Once treatment starts a person with TB will not infect others.

For cure, all it takes:

- Knowledge of the signs of TB
- A simple, free TB test from your nearest government clinic plus a full supply of TB pills.
- Time and patience in which to finish the prescribed pills.
- Understanding and care from friends and family.

Above all it takes the will power to fight the infection.

A person on treatment will not infect others A person who takes the prescribed course of treatment to the end will be cured.

leaflet produced by the Gauteng Department of Health

Even when you have TB with HIV!

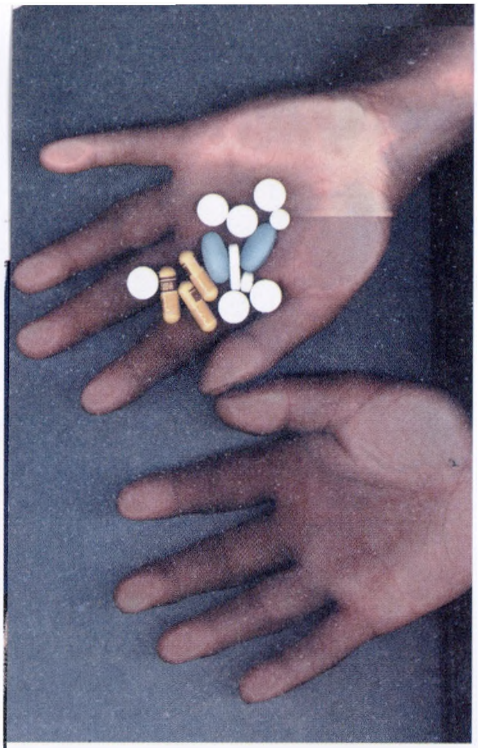
Today doctors have medicines to cure TB. They have used these medicines for years, including in South Africa. They are not expensive, and the public health service is committeed to making sure every person with TB has access to the pills that can cure their TB.

When a person has HIV with TB, the person becomes ill faster, or the illness can affect them in an unusual way. Sometimes in a person with HIV, the TB may take an unusual form – it may affect the liver or the brain, instead of the lungs. So the person's illness may not be easily diagnosed as TB. Also, a person with HIV is more likely to get TB a second time, after he or she stops taking the TB drugs.

People who have TB with HIV sometimes find it hard to get treatment. Nurses and doctors may say they will die in any case, even if the TB is cured. THIS IS WRONG. If someone is cured of TB, even if they have HIV, they can live for many years longer. And that is important not only for them, but also for their families, colleagues and society as a whole.

Government policy says that all people with TB should get the cure for TB. But some hospitals say that they do not have enough money to give TB medicine to people who have HIV and AIDS.

We must fight so that everyone with TB gets treated, whether or not they have HIV.



3. Medicines that fight HIV

The third major medical approach to HIV and AIDS is to attack the HIV virus directly. Medicines have been developed to do this. They have been used regularly and successfully, mostly in the United States and Europe, since the mid-1990s. These medicines have stopped many people dying from AIDS.

Anti-retrovirals work!

Where anti-retrovirals have been used, the effects have been dramatic. In both the USA and Europe, in the first year after the drugs were introduced **the number of people who died from AIDS dropped by 70% to 80%** – that is, four out of five people who were expected to die, did not. People who were too sick to move from AIDS, and whose doctors and relatives gave them up as dying, recovered and went back to work.

In South Africa today, about 20 000 people are taking anti-retroviral medicines. Studies on anti-retrovirals are taking place at Somerset Hospital in Cape Town, at Site B Clinic in Khayelitsha, and at Chris Hani Bharagwaneth Hospital in Johannesburg. The studies show the same kinds of results that anti-retrovirals have had in the USA and Europe: most people are getting better. Further, the study at Somerset Hospital has shown that people with HIV who take anti-retroviral medicines are much less likely to get TB than people who have HIV without anti-retroviral treatment.

Now AIDS does NOT always kill!

A UN report for 2002 says that "Anti-retrovirals are no longer an optional luxury for treating HIV". They are now seen as a key part of proper treatment for people living with AIDS.

When you have HIV and are NOT well....

Who should take anti-retrovirals?

Most doctors today agree that when you are HIV healthy, and the HIV has not damaged your immune system very much, you should maintain your health by natural means – good food, don't booze to excess, rest and exercise. You do not need expensive and strong medicines that you might have to take for the rest of your life. Many people live with HIV and remain healthy for a long time without taking these medicines.

But when your immune system becomes too weak to defend the body against disease, anti-retrovirals can help you get back to health. Doctors say you should take these medicines when your CD4-cell count falls below 250 (see page 72).

Doctors today say probably only a third of the people who have HIV in their blood need to take anti-retroviral medicine. But the longer you live with HIV, the more likely it is that you will need to take anti-retrovirals.

Anti-retrovirals for prevention

Anti-retrovirals help stop the HIV virus from reproducing within a person's body. Taking anti-retrovirals can prevent HIV from getting a firm hold in a person's blood, if they can be taken just after the infection occurs. Anti-retrovirals are used to STOP HIV infection in these three situations:

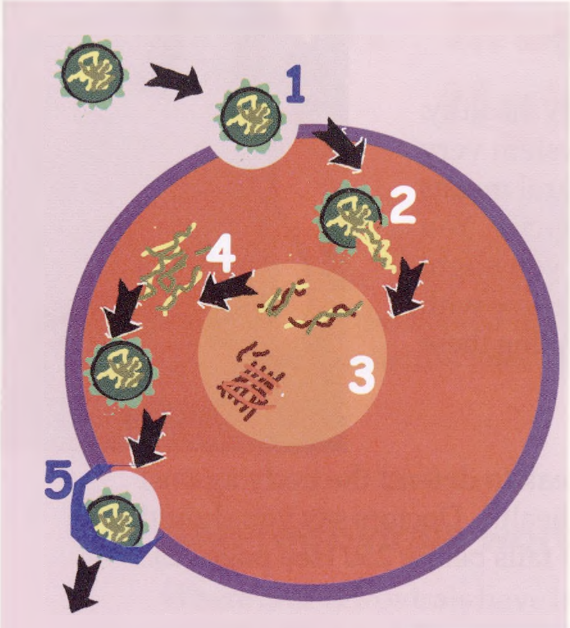
1. When a pregnant mother who is HIV-positive takes anti-retrovirals during childbirth, the pills can stop HIV from developing in her unborn child.

2. When a person has had a needlestick accident that exposes them to HIV (or any other blood-to-blood accident, usually at the workplace), taking anti-retrovirals can often prevent HIV infection from developing.

3. When a person is exposed to HIV through rape, immediate treatment with anti-retrovirals can cut down the chances of developing HIV.

(Pages 26 to 29 look at these treatments in preventing HIV spread; and pages 85 to 86 look at them in terms of anti-retroviral medication.)

How do anti- retroviral medicines fight HIV?



1. When the HIV gets into your blood, it breaks into the CD4-cells in your blood. (Remember how HIV spreads, see pages 8 and 9).

2. The bits of the virus prepare themselves to join with CD4-cell proteins; these bits are called "reverse transcriptase".

3. Then the viral bits join with parts of the CD4-cell to make new pieces of virus.

4. These new virus pieces join together with something called protease to form new viruses.

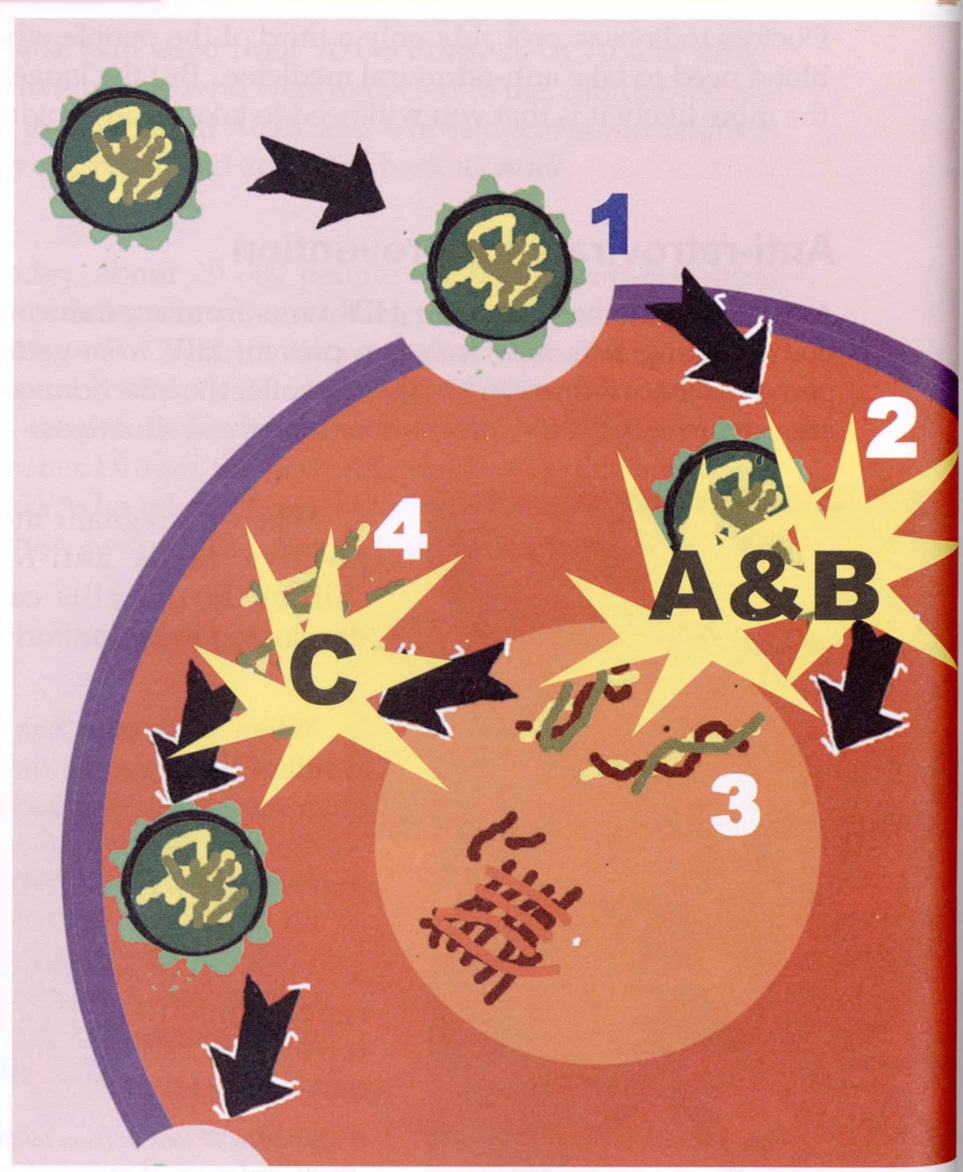
5.These viruses break out of the CD4-cell to go back into the blood. They attack new CD4-cells, and the cycle gets worse.

There are three main kinds of anti-retroviral medicines used today.

A. NTRIs (Nucleoside analogue reverse transcriptase inhibitors; called "nukes") stop the reverse transcriptase from forming (at point 2).

B. NNRTIs (non-nucleoside reverse transcriptase inhibitors, or "non-nukes") also stop reverse transcriptase.

C. PIs (protease inhibitors) stop the protease from joining the new pieces together (at point 4).



Most of these drugs have several different names. The drug companies like to call them by their brand names. This can make it very confusing if you want to find out what you are taking!

Anti-retroviral medicines we use today

There are sixteen different retroviral medicines used today. These are:

1. **NTRIs** (Nucleoside analogue reverse transcriptase inhibitors; sometimes called nukes):

AZT (brand names zidovudine, Retrovir)
ddI (brand name didanosine, Videx, VidexEC)
3TC (also called lamivudine, Epivir)
d4T (also called stavudine, Zerit)
abacavir (also called Ziagen).

2. **NNRTIs** (non-nucleoside reverse transcriptase inhibitors, or non-nukes):

nevirapine (also called Viramune)
efavirenz (also called Sustiva)
delavirudine

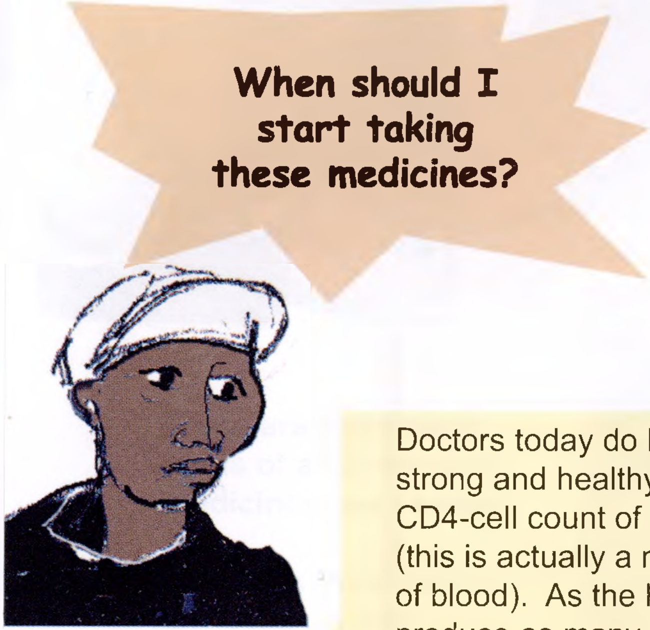
3. **PIs** (protease inhibitors):

indinavir, called Crixivan
saquinavir (also hard gel pill called Invirase, soft gel pill called Fortovase)
ritonavir (also called Norvir)
nelfinavir (also called Viracept)
amprenavir (also called Agenerase)
lopinavir/ritonavir (also called Kaletra)

More medicines are being tried out as experiments in the United States and Europe. They cannot be used for treatment in South Africa until these experiments show that they are effective and not harmful. This research process is likely to take several years.

Combination therapy: taking anti-retrovirals when HIV has weakened your immune system

For people who have HIV and a weakened immune system, doctors recommend taking three different kinds of anti-retroviral medicines. This allows the medicine to stop the virus in several different places. In this way, we can make sure that very little of the virus survives in the person's blood. This is called Combination Therapy.

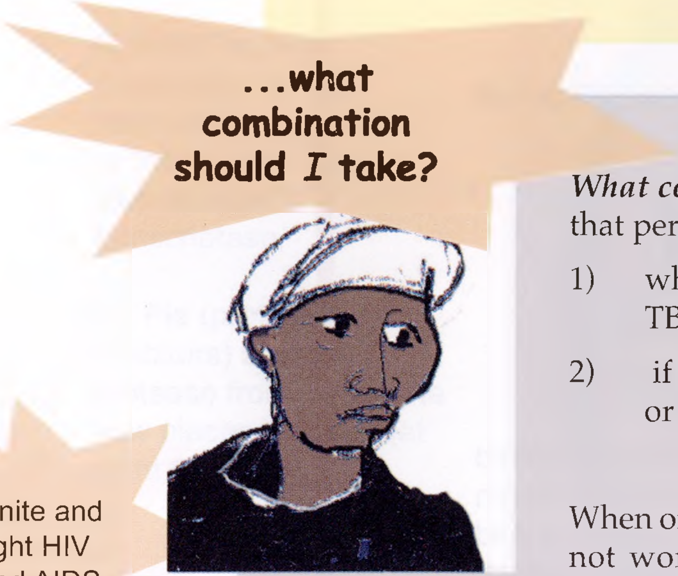


Today, doctors say you should take anti-retrovirals for HIV when:

1. You are seriously ill with an opportunistic disease
2. Your immune system is already damaged (you have a "CD4-cell count" of under 250.)

Doctors today do blood tests to measure if your immune system is still strong and healthy. A person with a normal immune system has a CD4-cell count of between 600 to 1000 in a small amount of blood (this is actually a measurement of thousands of CD4-cells in a milliliter of blood). As the HIV attacks the immune system, the body cannot produce as many CD4-cells, and the number of CD4-cells falls.

Doctors today say a person with HIV who has a CD4 count of under 250, or who is getting opportunistic illnesses, should take anti-retroviral medicines.



What combination a person should take depends upon that person's own condition. It depends upon:

1) whether he or she is taking other medicine, for TB, hepatitis, or other illness;

2) if the patient is a pregnant woman, a small child or baby.

When one combination of anti-retroviral medicines does not work well with a particular person, doctors can usually find another combination that works better.

It is important to take these drugs ONLY while supervised by a doctor who knows them, because they CAN be dangerous if used wrongly.

Bad reactions and drug resistance

Anti-retroviral drugs are very strong, and they are sometimes not easy to take. With any drug, even common drugs like aspirin or penicillin, some people react badly. Some people have problems taking anti-retroviral drugs. These reactions can include nausea, dizziness, headaches, and anemia. Some people feel bad for a few weeks when they start to take the drugs, but then they get better. A few people have reactions that are so bad that they stop taking the drugs.

Sometimes the particular medicine a person is taking stops working against the HIV. This is called **drug resistance**. Drug resistance is more likely to develop if a person does not take the medicine regularly, every day at the same time.

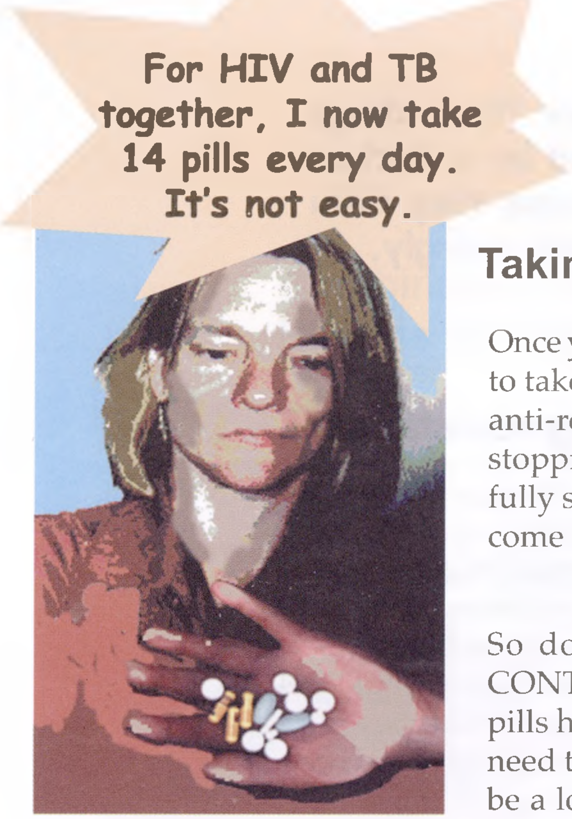
People who take anti-retrovirals must be checked regularly to make sure they do not have bad reactions or resistance. A doctor must decide if a person's bad reactions are so serious that they should stop or change their medicines.

Because anti-retroviral medicines have only been used widely for the last five years, we do not yet know how well they will work over a person's life. We do not know if they will keep working well for forty or fifty years.

But the medicines ARE getting better. If anti-retrovirals can keep you alive and healthy for ten years, maybe at the end of that time a better treatment will be available.

REMEMBER: Even when anti-retrovirals CUT DOWN the HIV in a person's blood, we still can not claim the person has been CURED of HIV! Even when only a few HIV cells still exist in your body, if you stop taking the pills the HIV will grow strong again....

And of course, it is NOT safe to have unprotected sex, when there is ANY chance you might still carry the virus!



Taking your pills can be a struggle

Once you start taking anti-retroviral medicines, you must continue to take them. Doctors say that it is wrong and dangerous to take anti-retroviral pills only sometimes, or to keep starting and stopping taking the pills. When that happens, the virus is not fully suppressed by the medicine, and it can come back. It might come back even stronger than before the medicine was used.

So doctors say that when you take these pills, you must CONTINUE taking them - probably all of your life. And these pills have to be taken at certain times every day. Because people need to take a combination of different anti-retrovirals, there can be a lot of pills, too. And a person may also need to take other medicines for opportunistic diseases.

Some pills have to be taken at certain times every day. It is important that you do not miss taking the pills when you should, even if it is annoying and difficult to take them so often.

Patients taking anti-retroviral medicines have worked with their doctors to find ways to make sure the pills are taken RIGHT. One of these ways is to form MEDICINE SUPPORT GROUPS.

IN KHAYELITSHA: WORKING TOGETHER helps us get the treatment we need!

In Khayelitsha, in Cape Town, people taking anti-retroviral medicines (through an experimental medical programme run by a group of doctors called "Medicins sans Frontieres") attend medical support groups once a week. They come to a meeting with other people who are also taking the drugs. There, they talk to each other and to doctors who know about the treatment. They talk about how they are feeling, and whether the drugs are helping, and whether they are having any problems getting or taking the drugs. The doctors can help make sure that the medicine is taken the way it is supposed to be taken, and that it is doing the job it is supposed to do!

4. Using anti-retrovirals to stop infection

Anti-retroviral medicines can help stop HIV infection from developing. It is used worldwide in three situations: stopping HIV transmission during pregnancy, from occupational injuries (particularly needlestick injuries), and from rape. This is called PEP – for "Post Exposure Prophylaxis".

...unlike the situation where HIV has already taken a strong hold in the person's blood, with PEP a person has to take the anti-retrovirals for only a fairly SHORT period.

Occupational injuries and HIV

Health workers sometimes get stuck by a needle in an accident at work (called a "needlestick injury"). If the needle was used earlier on a person who has HIV, it could still have HIV-positive blood on it. Then the health worker might get HIV.

This does not happen very often (some studies say it occurs in less than one out of a hundred needlestick injuries). But studies have shown that taking anti-retroviral drugs after a needlestick injury stops the chances of getting HIV from the injury almost completely.

Health workers and their unions have demanded and reached agreement that anti-retroviral medicine for needlestick injuries will be provided by health employers in South Africa.

PEP works best if taken immediately; the medicine must be taken within 48 hours of exposure.

Rape

A person who is raped is more likely to get HIV than from normal sex (because there is violence and blood). Very often the person who was raped cannot know if the rapist was HIV-positive. Fear of getting HIV makes the rape even more traumatic.

However, giving anti-retrovirals as PEP to people who have been raped does lower the chances of developing HIV. In a study in Johannesburg, over 1000 people who had been raped were given AZT within 72 hours of the rape. Not one person developed HIV.

Some public hospitals provide anti-retroviral treatment for free after rape. You should find out where people can get the treatment, in case you or your family or friends need it.

Stopping Mother-to-Child Transmission

The third common use of anti-retroviral medicines for PEP is to stop the infection of new-born babies, who are exposed to their mother's infected blood in the birth process. (This is discussed as a preventative measure, on page 26.)

Discuss/Think about it!

- What can your union do to ensure anti-retrovirals are available to people who need them?
- How can we make sure that all health workers are fully trained in treating HIV and AIDS and opportunistic illnesses? If you work in the health sector, have your employer and your union addressed this issue?
- Is the clinic or hospital you use equipped and are staff trained to provide PEP for pregnancies, rape, and occupational injuries?

5. The problem of unaffordable medicine

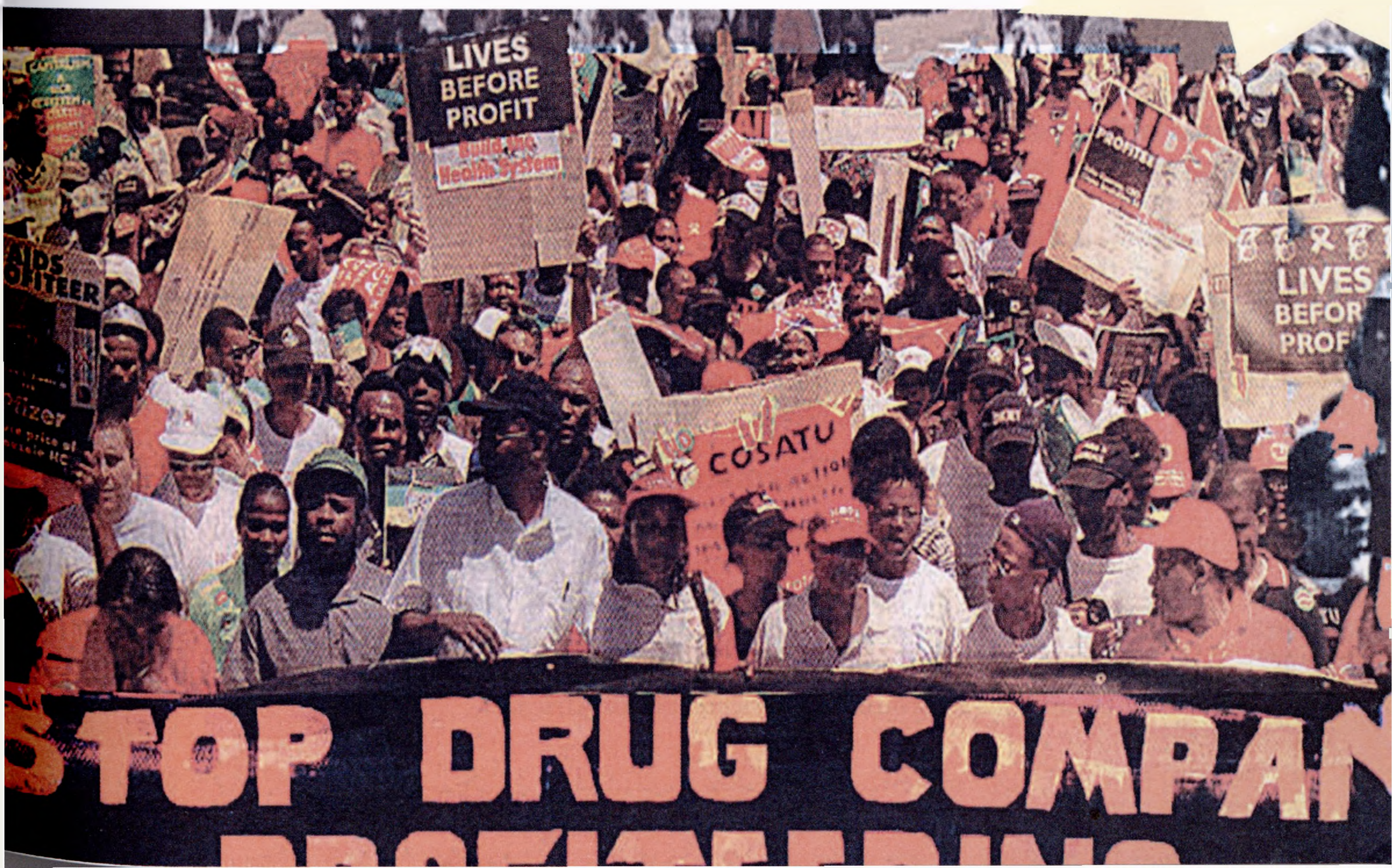
Anti-retrovirals and medicines for opportunistic diseases can now keep people with HIV alive for decades. But they are very expensive. As of 2002, the South African public health system does not provide anti-retrovirals (except for PEP for rape, pregnant mothers with HIV, and needlestick injuries). If you get anti-retrovirals from a private doctor, you have to pay at least R500 a month for the cheapest treatment, and R4000 a month or more for the strongest treatments. And as we have seen, once you start taking these medicines, you will probably have to keep taking them for the rest of your life.

Why are HIV medicines so expensive?

It does not cost so much to produce HIV medicines. They are expensive because the big pharmaceutical companies from Europe and the US continue to make huge profits from selling them to people who need them to survive.

To keep making these profits, pharmaceutical companies got patents for these medicines. For many years, they claimed these patents gave them the legal right to stop anyone else throughout the world from making these medicines.

A patent is a law which says that a new idea, object, process or medicine is the property of the person who first invented it. No other person, company or even country is then supposed to make it, use it or sell it without the patent owner's permission.



COSATU demands affordable medicines for HIV!

Together with activists around the world and in South Africa, COSATU has campaigned for the production of medicines in South Africa and other developing countries, in spite of the patent laws. These are called "generic medicines". They are the same as the medicines made by big pharmaceutical companies, but they have different names and are much, much cheaper.

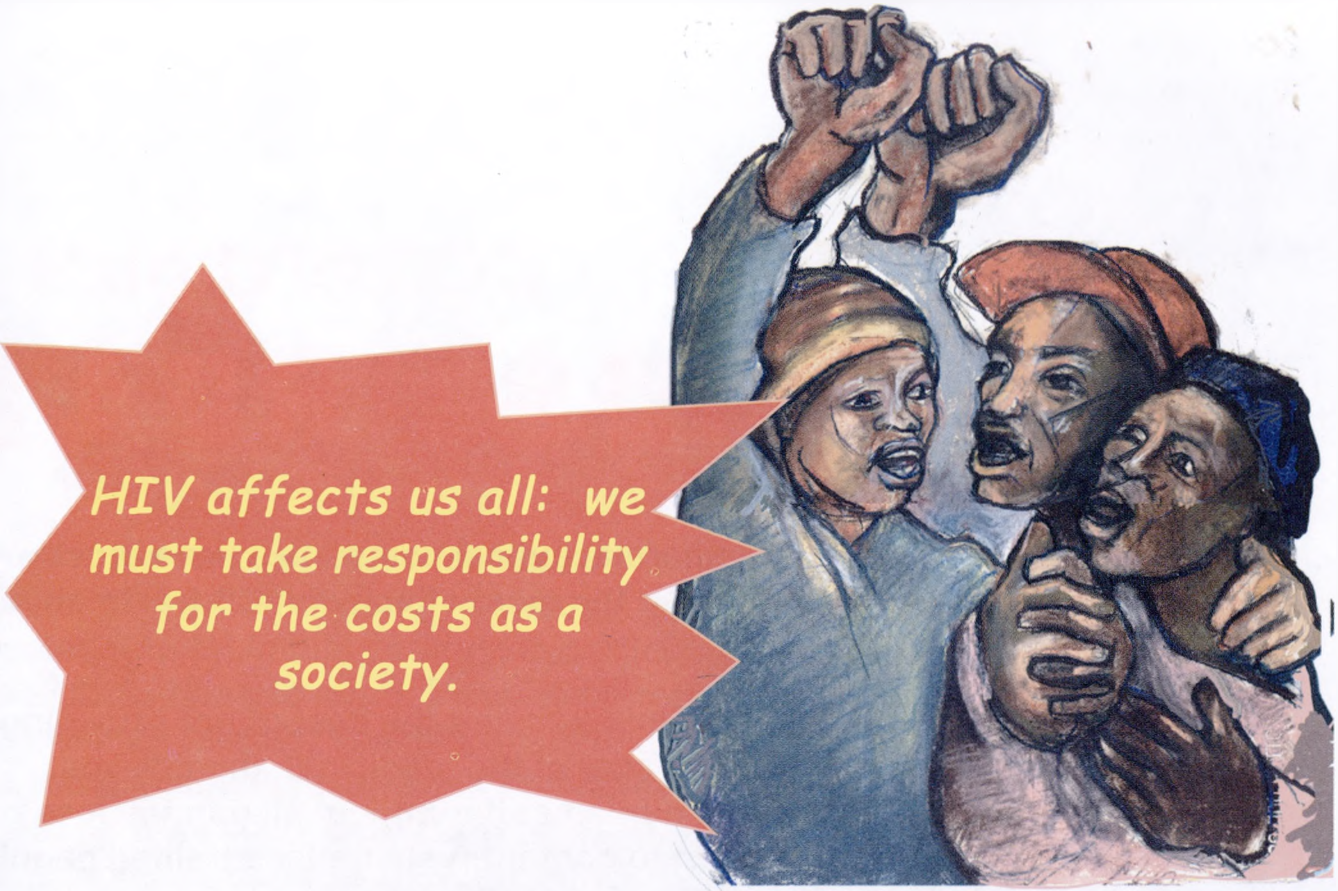
We have won three major victories in this fight.

- The government passed the Medicines Control Act, which lets it import generics and licence companies to produce generics in South Africa.
- The World Trade Organisation (WTO) has agreed that countries can produce generic medicines, even if a foreign company has the patent.
- Within the last year, the price of combination therapy, even when using patented and brand-name medicines, has dropped from as much as R4000 a month to R700 a month in South Africa. This is still too expensive – but it is a step in the right direction. We are now fighting to cut the cost to R250 a month.

How much cheaper are generic medicines? Flucanozol from the company that makes it used to cost R100 for each pill. The Treatment Action Committee imported flucanozole from a generic company in Thailand for R4 for each pill.

Producing affordable medicines

The next step is to start large-scale production of anti-retrovirals and other HIV medicines in South Africa. We are one of the few African countries with the expertise to make these medicines. Producing these drugs would save lives here and also create jobs. And we can export the medicines to all of Africa, saving lives across the continent. But the government still has not licensed companies to produce generics in South Africa.



The public health system does not provide anti-retrovirals except to stop mother-to-child transmission and, in some cases, for women who have been raped.

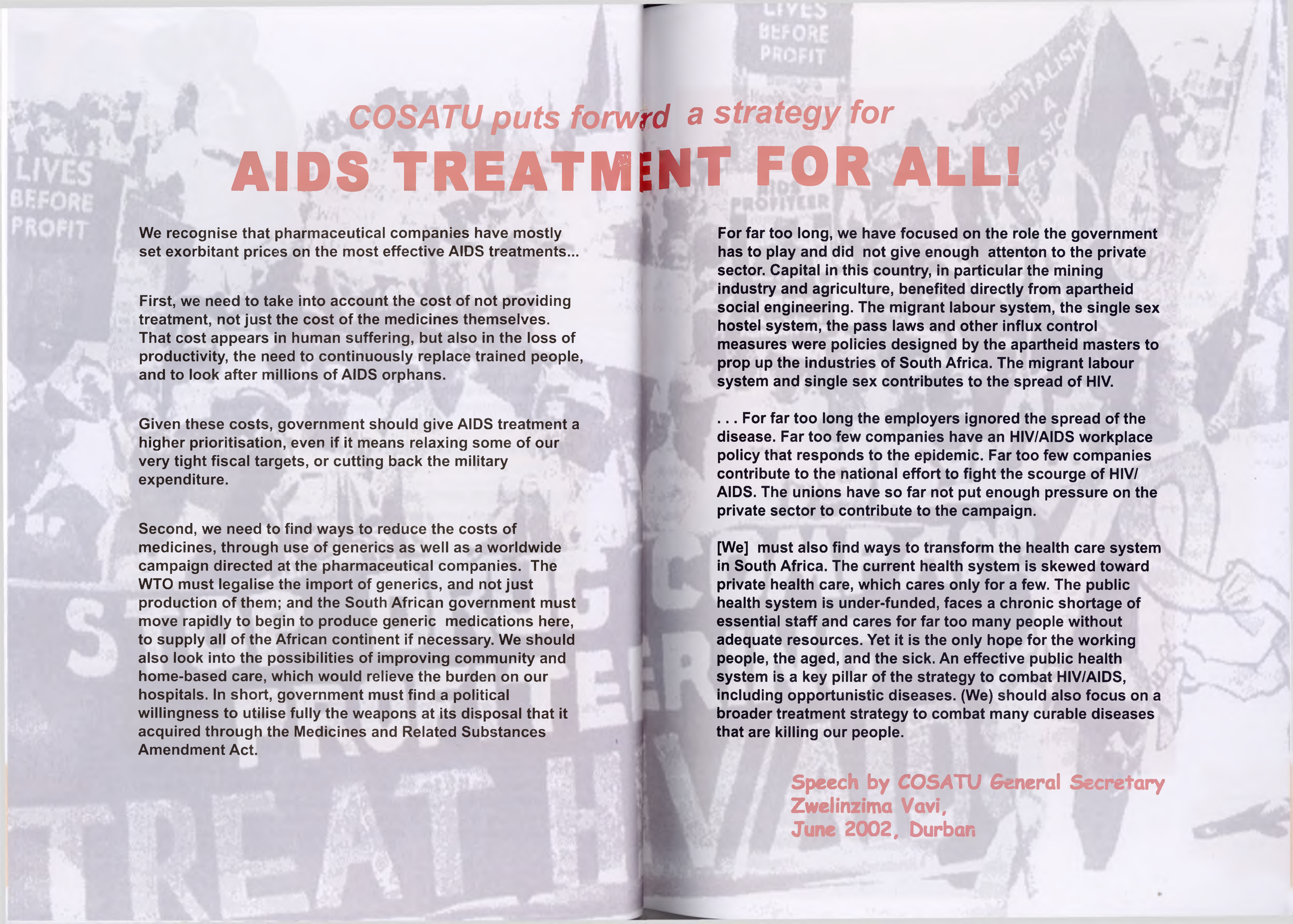
COSATU says the public health system must:

- Use cheaper generic drugs
- Provide anti-retrovirals to people who need them.

COSATU also demands that employers provide treatment directly to workers. Many workers cannot afford medical aid. It is especially important that employers help these workers get the treatment they need for HIV and AIDS.

We demand employers provide:

- Access for all workers, even those who cannot afford medical aid, to doctors who know how to treat HIV
- Assistance in buying medicines for HIV, including anti-retrovirals.



COSATU puts forward a strategy for

AIDS TREATMENT FOR ALL!

We recognise that pharmaceutical companies have mostly set exorbitant prices on the most effective AIDS treatments...

First, we need to take into account the cost of not providing treatment, not just the cost of the medicines themselves. That cost appears in human suffering, but also in the loss of productivity, the need to continuously replace trained people, and to look after millions of AIDS orphans.

Given these costs, government should give AIDS treatment a higher prioritisation, even if it means relaxing some of our very tight fiscal targets, or cutting back the military expenditure.

Second, we need to find ways to reduce the costs of medicines, through use of generics as well as a worldwide campaign directed at the pharmaceutical companies. The WTO must legalise the import of generics, and not just production of them; and the South African government must move rapidly to begin to produce generic medications here, to supply all of the African continent if necessary. We should also look into the possibilities of improving community and home-based care, which would relieve the burden on our hospitals. In short, government must find a political willingness to utilise fully the weapons at its disposal that it acquired through the Medicines and Related Substances Amendment Act.

For far too long, we have focused on the role the government has to play and did not give enough attenton to the private sector. Capital in this country, in particular the mining industry and agriculture, benefited directly from apartheid social engineering. The migrant labour system, the single sex hostel system, the pass laws and other influx control measures were policies designed by the apartheid masters to prop up the industries of South Africa. The migrant labour system and single sex contributes to the spread of HIV.

. . . For far too long the employers ignored the spread of the disease. Far too few companies have an HIV/AIDS workplace policy that responds to the epidemic. Far too few companies contribute to the national effort to fight the scourge of HIV/AIDS. The unions have so far not put enough pressure on the private sector to contribute to the campaign.

[We] must also find ways to transform the health care system in South Africa. The current health system is skewed toward private health care, which cares only for a few. The public health system is under-funded, faces a chronic shortage of essential staff and cares for far too many people without adequate resources. Yet it is the only hope for the working people, the aged, and the sick. An effective public health system is a key pillar of the strategy to combat HIV/AIDS, including opportunistic diseases. (We) should also focus on a broader treatment strategy to combat many curable diseases that are killing our people.

Speech by COSATU General Secretary
Zwelinzima Vavi,
June 2002, Durban

In the 2002 June Conference on HIV and AIDS Treatment Access in Durban, COSATU put forward the following strategies to address the problems of making effective AIDS treatment available:

A. Provide affordable HIV and AIDS medicine:

1. Demand lower prices for essential medicines to treat HIV and AIDS, targetting lower profits for drug companies, insurance and medical schemes;
2. Access and distribute life-saving generic HIV and AIDS drugs (available at fractions of the price of current drugs); and
3. Develop industrial capacity to produce generic HIV and AIDS drugs in South Africa. (This would also contribute to job creation and economic growth).

B. Target business and employer responsibility for workplace strategies to manage both the prevention and treatment of HIV and AIDS among workers.

C. Transform the public health care system and welfare to provide adequate and effective treatment for all sectors of the community.

VIII: Fighting AIDS Together

Our community and society must learn to fight HIV and AIDS!

This section looks at what we can do to end the AIDS epidemic. Above all, we must improve education, prevention and treatment, in the context of measures to create jobs and fight poverty.

1. In the workplace
2. In our society
3. Crush poverty and create quality jobs!

The main steps in the campaign to fight AIDS are:

- **Mobilise people to stop the spread of HIV**
- **Fight discrimination against people with HIV**
- **Improve healthcare for all our people**
- **End poverty and ensure healthy living conditions, especially by creating jobs and improving housing**

1. In the workplace

Every union and every sector needs to develop and implement workplace policies and programmes which provide:

1. Education and information about HIV and AIDS
2. Resources to ensure prevention
3. Voluntary counselling and testing
4. Treatment and support.

Every union must address the specific impact of HIV and AIDS in their workplaces and their sector, and develop programmes that empower workers to deal with the epidemic.

As unions, we CAN learn, and we CAN take control of this epidemic.

Critical demands for negotiations include:

- **Demand and develop workplace policies and programmes** on HIV and AIDS.
- **End discrimination** in hiring and employment against people with HIV
- **Make condoms freely available** to all workers.
- **Get the employer to provide counselling and voluntary testing**. It is critical that the testing is CONFIDENTIAL. Think about ways to ensure that no one is tested without counselling both before and after. You also need to think up ways to make sure the test results are given ONLY to the affected person, and not to the employer or even friends and relatives.
- **Get the employer to pay for time off** for training on HIV and for additional sick days.
- **Get the employer to pay for educational campaigns.** There should be posters giving the right information on preventing and treating HIV, and supporting people with HIV, where everyone can see them.
- **Ensure safe and healthy working conditions.** It is especially important for people with HIV, who may have weaker immune systems, to work in healthy conditions.
- **Ensure that medical aids cover AIDS**, including anti-retroviral treatment, as well as providing disability cover for workers with AIDS. Try to make medical schemes affordable for all workers.
- **Most workers earning under R3500 cannot afford medical aids, so we also need to negotiate alternatives**. For instance, you can demand that the employer provide anti-retrovirals directly to workers with AIDS, and ensure the pension fund covers disability due to AIDS.

Some unions and sectors have specific demands around HIV and AIDS

There are some workers who, because of the nature of their jobs, may be more likely to get HIV. These comrades work in occupations that make it hard to maintain a stable relationship. It is particularly important that they know the facts about HIV and AIDS, and about always using condoms. It is also important that these sectors, in particular, make the employer provide condoms, anti-retroviral medication, and medical and pension benefits that are suitable for people with HIV.

Some of the most seriously affected occupations are:

- Miners who work far from where their families live. As a result, they may end up in relationships where they work, get HIV – then go home and infect their wives.
- Transport workers, who must often travel away from their families. Again, they may have sex while they are travelling, then come home and infect their wives.
- There is some evidence that HIV is also very high amongst soldiers, who also often work far from home.

In addition, the spread of HIV and AIDS makes a difference for how public servants serve the people.

- Nurses, clerks, cleaners and other hospital workers must know how to advise, treat and support people with HIV. They need to know that it is safe to hold, feed and clean these patients. They must know when to refer these patients to specialists, counsellors and support groups.
- Police must be able to assist people with HIV in emergencies and accidents.
- Corrections officers must be able to help prisoners who have HIV. HIV is very widespread in our prisons, so this is particularly important. Corrections officers need to think about how to make condoms available to prisoners, when to get them medical care, and how to help them stay healthy.
- Teachers have to teach our children about HIV. They have to be able to talk about how HIV is spread through sex as well as in other ways. In addition, they have to teach children with HIV, which means they have to know how to help them get the care they need.
- Welfare workers also need to know how to help people with HIV and AIDS.

Shopstewards must support people with HIV!

As activists and leaders in our unions and communities, shopstewards have to play a leading role in dealing with HIV. That means:

- Every shopsteward must fight discrimination in the workplace, whether by employers or by other workers. We have to find out the facts about HIV – you can use this book! – and educate the people around us.
- If a member has HIV and doesn't want their workmates to know, a shopsteward must respect that and keep the information confidential.
- Every shopsteward must defend workers with HIV against discriminatory practices by the employer. They must ensure that workers with HIV are not fired, forced to work in unhealthy circumstances, or put on disability when they are still well. They must take grievances for these workers as seriously as every other grievance.
- Every shopsteward must support demands to improve health, pension and survivors' benefits to deal with the HIV epidemic. Shopstewards must consider whether the union should demand that the employer provide treatment for workers with HIV, as well as free condoms for all workers.
- Shopstewards should think about what the union can do to improve conditions for people with HIV in their communities. For instance, can you lobby the local government for training in HIV for health workers at the local clinic?

Discuss/Talk about it!

What are the challanges around HIV in your workplace? Which issues has your union raised? Which should you raise urgently?

2. In our society

HIV and AIDS spreads and causes devastation because of the way society functions. It continues to spread, and to destroy people's lives, because society as a whole is not taking the necessary steps to prevent it and treat it.

The student's story:

My class at university researched the impact of HIV and AIDS a rural town in the Cederberg region of the Western Cape in September 2002.

The town contains about 15,000 people. Not much has changed: the whites live by the river, the Coloureds live on the other side of the main road; the black township is farthest away, on top of the hill going out of town.

A lot of people come to town in search of work. Most are employed on farms in the area during the fruit-picking season, from April to August every year. Average wages are R120 a week for the season. Farmers drive into town and pick workers up each day. Many people are unemployed when the season is over. The dop system (paying farm workers' wages with alcohol not money) is now illegal, but still exists as "gifts" given to workers with their pay. Farmworkers say they work ten hours a day, seven days a week.

The farmworkers here do not have a union, they have no time off to go to see a union. They worry that they would be fired if they tried to organise.

The town's largest visible health problems are TB and alcoholism. But community leaders say HIV/AIDS is one of the biggest problems they are facing. At present two to three people are buried every week.

The local clinic is overworked: patients queue for 4 to 5 hours from early in the morning just to see a nurse. Each visit to the nurse costs R8; seeing a doctor costs R80. Medicines are subsidized but not often free.

There are no community awareness programs around HIV and AIDS issues. The local churches and schools do not have programmes to address safer sex, HIV prevention, support, treatment, and care. People say they do not know what to do about HIV or AIDS in their community. They know it is there, but without resources and help they cannot stop it or care for those affected.

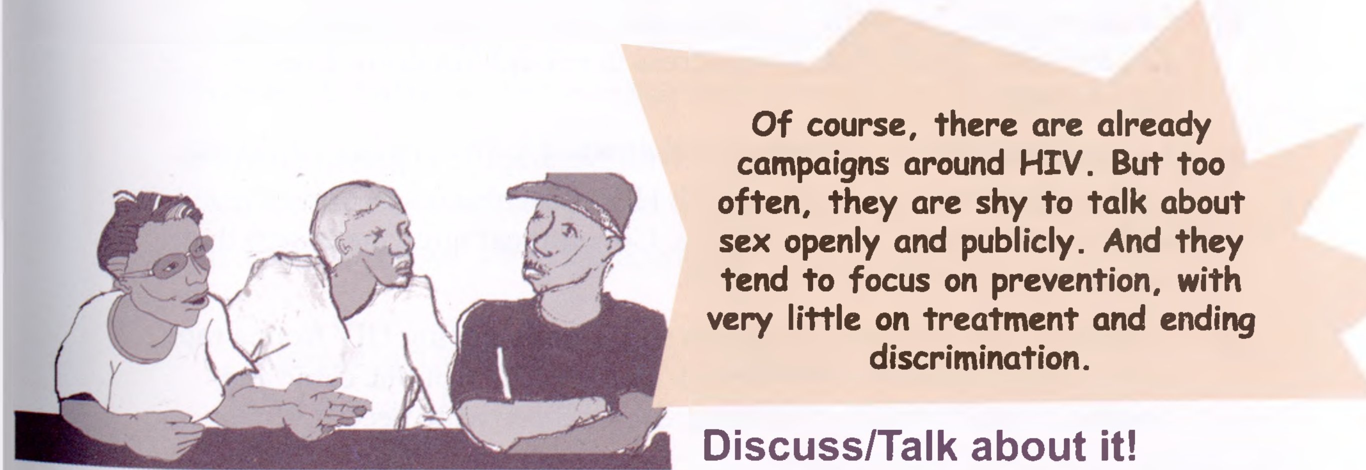
We need a massive campaign to educate around HIV

To end the AIDS epidemic we need a truly massive, national campaign, which reaches into every community, every school, every gathering, every workplace. The national campaign must ensure that EVERY South African knows how to prevent HIV, what to do if they are HIV-positive, and how to fight discrimination against people with HIV. The campaign must also strengthen respect for women's rights, since rape and unprotected sex are the main ways HIV is spread.

This type of campaign must be led and funded by government. But it requires support from all of civil society. We ALL need to talk about AIDS – in our union meetings, but also in schools, in churches, wherever we meet. Education on HIV must be included in lifeskills courses in schools and in every SETA course.

In addition, we need education on HIV for public servants who must care for people with HIV. That means health workers at all levels and in all areas, as well as teachers, welfare workers, corrections and police officers.

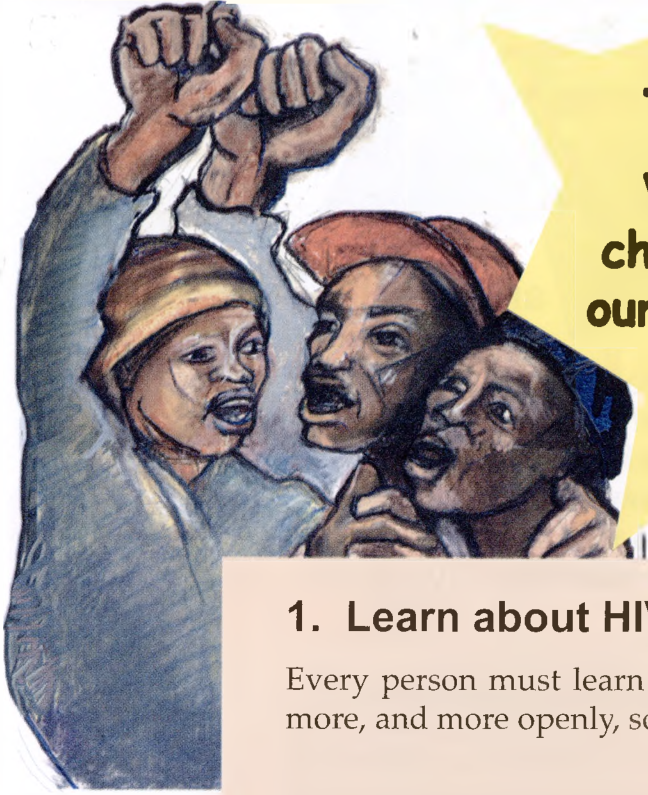
Finally, we need an end to sensationalised, inaccurate and discriminatory reporting in the mass media. That only makes the problem worse. Reporters also need training to understand and report on HIV.



Discuss/Talk about it!

The main public campaign right now is the LoveLife Campaign. Most of us have seen their billboards, advertisements and publications. Some people say the messages from Lovelife are vague and confusing. What do you think?

- What do LoveLife advertisements say about sex, love, and the spread of HIV in our society? Do you think they will help members of our community deal with the HIV and AIDS epidemic?
- Think about other education processes around HIV and AIDS in the community - for instance, in your church or your children's school. Are they helpful?



This is OUR struggle!

We need to face these same challenges, in our communities, in our organisations, in our churches and schools, in our nation.

1. Learn about HIV and AIDS - and control your life

Every person must learn about HIV and AIDS. We all need to talk about it more, and more openly, so that we can learn from each other.

We need to know our own health status. And we need to ensure that EVERYONE who needs it can get counselling and testing on HIV, throughout the society. At all levels, testing also must be linked to programs to maintain the health of people with HIV.

2. Prevent the spread

To prevent the spread of HIV requires, first and foremost, that all South Africans know about safe sex. But it also needs:

- Condoms must be easily available and free. We need to ensure that EVERY adult South African has access to enough condoms to enjoy their love life.
- Mothers with HIV need treatment with Nevirapine to prevent mother-to-child transmission. Mothers with HIV must also have counselling and powdered milk for their babies. Government must make sure that every hospital offers these services.
- Treatment with anti-retrovirals can stop people getting HIV from a rape or, for health workers, a needlestick injury. EVERY public clinic and hospital should provide this treatment for those who need it.

3. Treatment, care and support

Today, the type of treatment you get for HIV mostly depends on whether you can afford anti-retrovirals yourself or through your medical aid. The public health system does not provide any anti-retrovirals except for pregnant mothers and people who have been raped. Most health workers have not been trained in treating people with HIV and AIDS.

COSATU demands that the public health system provides anti-retrovirals for ALL those who need it, irrespective of their income.

3. Crush poverty – create quality jobs!

The epidemic feeds on unemployment and poverty. COSATU's Jobs and Poverty campaign is also important in fighting the AIDS epidemic.

"The rapid spread of the disease is related to poverty and the lack of access to socio- economic rights such as housing, clean water and health care. The COSATU campaign for jobs is necessary because poor living conditions is one of the factors that make it difficult for many people to change behaviour that puts them at risk of HIV infection. There is a link between poverty and unemployment as half of all the households in South Africa depend for their survival on money from a family member who works. On average one wage earner supports ten people. Because there is no social security system in South Africa, when one worker loses his/her job it affects whole families and communities. Currently about 37% of workers are unemployed, which is over 4,5 million people. Without addressing poverty the spread of HIV / AIDS will continue, which will affect the economy of our country."

Address by COSATU 2nd Vice President Joyce Pekane to the 2nd National Conference for People Living with HIV / AIDS, 9 March 2000

Fighting to end poverty

Poor people often have to live in unhealthy situations. In South Africa, one in seven people does not have access to clean water in their home, and one in four does not have electricity. Very poor people are not able to get enough food, or enough good food. Many people live in informal settlements, hostels, and inner city slums, where sanitation and refuse removal are poor.

Diseases like TB, pneumonia, and diarrhoea – to mention only a few – spread more rapidly when people live under these kinds of conditions. People living with HIV and AIDS who live in poverty are more likely to become ill sooner from opportunistic illnesses.

COSATU has called for government to ensure that all South Africans have decvent housing and basic services, like water, sanitation, and electricity. COSATU has also called for an end to privatisation, which makes these services too expensive for many people in poor communities.

HIV and AIDS should be on the agenda for EVERY sector job summit!

We need jobs!

The rise in unemployment – from 16% in 1995 to around 30% today – is the main factor behind continuing poverty. COSATU has long called on government to develop stronger strategies to create jobs.

We have demanded Sector Job Summits to restructure the economy to create jobs, as well as large public works and community service programmes. Education and skills development must also be improved so that graduates can get jobs more easily. This is critical for improving living conditions for all South Africans.

Build a welfare system that works

We need a welfare system that addresses the problems of the AIDS epidemic.

- All eligible children should get the **Child Support Grant.** This grant is available to every poor child under the age of seven, but many families don't know about it. To get it, you must apply at the local welfare office.
- People with AIDS who are too ill too work should get state **disability grants.** There is no clear policy on this in most provinces. We need to ensure ALL provinces make the disability grant available to people with AIDS.
- AIDS orphans should get **foster child grants**, which are much higher than the Child Support Grant. Right now, however, only children who are formally in foster care get this type of grant. The Department of Social Welfare must change the rules so that it also goes to orphans who are looked after by relatives or who don't have anyone to look after them.

Many people who have a right to these grants don't know about them or can't get them because they don't have IDs. But even if everyone who was eligible got a grant, many poor people are not eligible.

For this reason, COSATU has called for the introduction of a **Basic Income Grant** (BIG), which would give every South African over 18 around R100 a month. The Government Commission on the Comprehensive Social Security System has supported this demand – now we must make sure government implements it.

Build the health system

Government must do more to bring down the cost of medicines for HIV and opportunistic diseases. The two main ways to do this are through imports and local production of generic medicines. As we have said earlier, South Africa could produce anti-retrovirals locally to supply all of Africa.

In addition, every health worker should be trained to treat HIV. Primary health workers in clinics should know how to recognise and treat the major opportunistic diseases, and when to refer HIV-positive patients to hospitals. National treatment guidelines should be developed for HIV. These should include the provision of anti-retrovirals. And ALL health workers must be trained to end discrimination against people with HIV.

But providing adequate treatment for people with HIV requires more than anti-retrovirals and better training. Taken as a whole, the public-health system is underfunded and understaffed. That is one of the legacies of apartheid, which created wonderful hospitals for the rich but left poor communities and regions with completely inadequate health care.

COSATU has called for a substantial improvement in government spending on health. In the long run, we want government to establish a National Health System. This system would incorporate the private sector, which now takes up two thirds of health resources for about a fifth of the population. It would ensure adequate healthcare for all South Africans, including people with HIV.

Finally, several provinces have begun to set up systems of homecare for people with AIDS. If there is sufficient support for families, this system could give people more comfortable circumstances when they are ill. But too often, it is just a way to save money on hospitals. Homecare systems must be designed to ensure that people with AIDS continue to get quality care. They should work with the public health programs.

Discuss/Talk about it!

- Beyond workplace negotiations, COSATU affiliates are working directly to force employers to create jobs through the Sector Job Summits. Is your union working toward a Sector Summit? How can you support it?

Together, we can win!

- End discrimination against people with HIV
- Teach our children and ourselves to prevent HIV
- Win treatment for people with HIV

Appendix 1: Glossary

AIDS (Acquired Immune Disease Syndrome): a group of illnesses that develops after the HIV virus has weakened the body's immune system (see p. 9 – 13.)

Alternative medicines: any form of medicine which does not come from the main body of Western scientific knowledge (including African traditional medicine, Chinese herbal medicines, disciplines such as yoga, etc.) (see p. 72.)

Anti-bodies: particles produced by a person's immune system in their blood to fight against specific illnesses (for instance, you can have anti-bodies in your blood to fight against HIV)

Anti-retroviral medicine (also HAART, ART, ARV, Combination Therapy): medicines that attack HIV directly (see p. 78 – 86)

AZT: the oldest and most well-known anti-retroviral medicine. Now used mostly as one drug in combination therapy (see p .81)

Blood count: laboratory tests can count the different types of blood cells in a sample of blood, and find out how many of each kind there are in the blood. These can be done for many illnesses as well as for HIV and AIDS (see CD4-count and viral load, p. 9 and 10)

BIG (Basic Income Grant): proposed grant to all citizens in South Africa to improve welfare delivery (see p. 102)

CD4-cells (also called T-cells and fighter cells): cells in a person's blood that work to defend the body from harmful germs, bacteria, and viruses (see p. 11)

CD4-count (CD4-cell count): The number of CD-4 cells that can be measured in a small amount of a person's blood; the figure is given in thousands of CD4- cells in each millilitre of blood (see p. 11)

Combination therapy: taking several different medicines to ensure HIV is stopped effectively (see p.82)

Confidentiality: every person has a legal right to privacy about their own health status, including whether they have HIV or not (see p.37-40)

Cryptococcal meningitis: when the fungus that causes thrush infects the brain

Drug resistance: when a person who is taking a drug gets a bad reaction to the medicine, or it stops working well for them (see p. 83)

Elisa test: standard HIV test used in South Africa; a blood test done in the laboratory, which looks for the presence of anti-bodies to HIV

Fluconazole: the drug which is used against fungal infections that cause thrush and cryptococcal meningitis (see p. 75)

Generic drugs (generics): “no-name” medicines, with the same contents as brand-name drugs but produced by a different company; often much less expensive than brand-name products (see p 74)

HIV (Human Immuno-Deficiency Disease): the virus that causes AIDS (see p.7)

HIV-positive (sometimes called “sero-positive”): HIV is present in the person’s blood: a person is called HIV-positive when a blood test shows that their blood has anti-bodies to HIV, which means HIV is present in the body. (Some more recent tests identify the HIV directly in a person’s blood.)

HIV-negative: when there is no sign of HIV in the blood when it is tested in a laboratory

Immune boosters: things that you can eat – some kinds of food, vitamins, herbs, and minerals - which help to strengthen the body’s immune system and fight disease

MCTC (Mother-to-Child Transmission): when HIV passes from a mother to her child during pregnancy, birth, or breast feeding

Nevirapine: one of the anti-retroviral drugs, used mostly in South Africa for prevention of HIV in mother-to-child transission

Nutritional additives: small amounts of minerals (such as zinc or selenium), vitamins, or other foods which are added to meals to strengthen the body

Opportunistic disease: illnesses which take advantage of a person’s immune system when it has been weakened by HIV (see p.73)

Patent: any new idea, object, process or medicine can be registered with government and internationally as the property of the person who made it. This registration is called a patent. No other person, company or even country is then supposed to make it, use it or sell it without the patent owner’s permission. (This often means paying the owner for permission to use their product.)

Pneumonia: a lung infection where liquid fills the lungs; a common opportunistic disease with HIV

PCP pneumonia: a form of pneumonia. PCP is an opportunistic illness more common in people with HIV

PEP (Post Exposure Prophylaxis): Giving people anti-retrovirals right after they have been exposed to HIV, through rape, needlestick injury, or to newborn babies.

Prevelance Testing (or Surveillance testing): mass testing of the workforce to find out how many people are HIV-positive (see p. 39)

Primary health care: basic measures to ensure people and communities maintain health , including basic medical clinics, clean water and sanitation, immunisations and antenatal care (for primary health care and HIV issues, see p. 71)

Safer Sex: measures to prevent the spread of HIV by stopping infected body fluids from passing between people during sex (see p. 17 - 25)

Selenium: a mineral found in food, which can be taken as a food additive for people with HIV

Surveillance testing: mass testing or of the workforce to find out how many people are HIV-positive (see page 39)

T-cells: another name for CD4 cells

TB (tuberculosis): a bacterial infection, usually but not always of the lungs; most common opportunistic disease with HIV in South Africa (see p.76)

Thrush: fungal infection; common in small babies (without HIV); common opportunistic disease; mostly in the mouth and vagina, but can occur in throat, stomach and brain

Traditional medicine: term used in South Africa to refer to African traditional medicine, although it can cover medicine and healing systems from other non-Western cultures (see alternative medicines, and p.72)

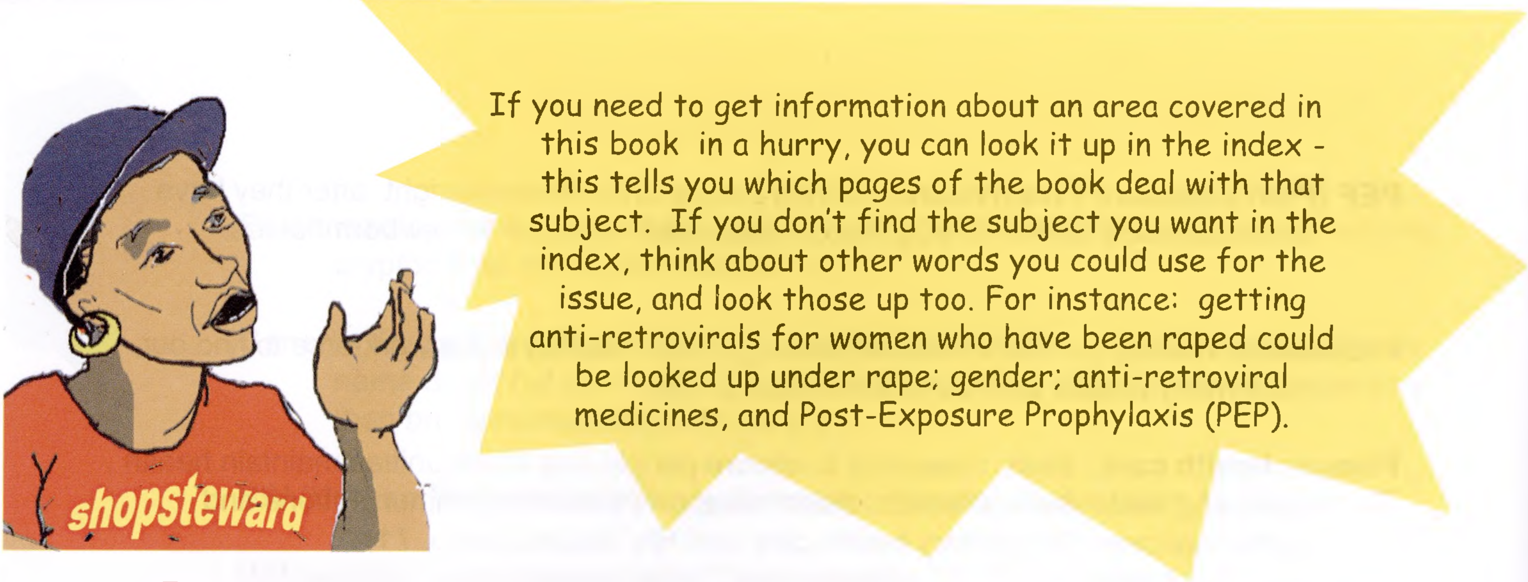
Vaccine: a small amount of a modified virus given to people who are well to build up resistance to the illness; the vaccine then prevents infection by the full disease. There is currently no vaccine available for HIV

Viral load: a laboratory can count the amount of HIV virus in a sample of blood (see p. 70)

Virus: an organism that can cause a disease (this are too small to see)

Window period: the period between infection with HIV and the time when the person's blood will show as HIV-positive on a standard HIV test (about 6 weeks)

Universal precautions: measures to be taken by any person providing care to a person who is ill (whether they have HIV or not), to prevent infection



Index: where to find it

Why this book avoids using the term HIV/AIDS

People talk about something called "HIV/AIDS". This joined phrase covers all the things that can develop when you have HIV. By joining the two words together, it implies that HIV is the first part of a road to illness and death. Using this joined phrase can make it harder to understand the different ways that HIV and AIDS affect a person's health over time - and to learn how to keep one from becoming the other.

In this book, we use the terms "HIV" and "AIDS" separately, because they are different conditions.

HIV is the virus which causes AIDS. It is too small to see. It can live in people's blood and other body fluids. It can pass from one person to another through sex, and from a mother with HIV to her baby when it is born. We say someone is **HIV-positive** when they have the HIV virus in their body. People can live for long periods, and remain healthy, with the HIV virus.

AIDS is the illness (or group of illnesses) that develops after HIV weakens a person's immune system. Most people in Africa get AIDS (which is defined as being very ill) when they get another disease, or several diseases – such as TB, pneumonia, or thrush – as well as the HIV. People who get AIDS who do not get treatment for their opportunistic illnesses, and for their HIV, are likely to die quite quickly.

Organisations that work on issues of HIV and AIDS:

TAC (Treatment Action Campaign)
Website: http//.www.tac.org.za
Email: info@tac.org.za
National Offices: 021 - 788 -3507
Regional offices:
Gauteng: 011 - 339 - 8421
KZN: 031-304-3673
Western Cape: 021-364-5489
Eastern Cape 043-760-0050.

AIDS Consortium:
Website: http//www.aidsconsortium.org.za
Tel. 011-403-0256 Fax: 011-403-2106

National Association of People with AIDS (NAPWA)
Gauteng: Tel: 011-982-5451
KZN: Tel: 031- 300- 3914
Western Cape: Tel: 021 -637-2190
Eastern Cape: Tel: 041 - 487- 3397
Free State: Tel: 051 - 405-8817
Mpumalanga: Tel: 013 -759-2167
North-West: Tel: 014- 597-2266

Department of Health Directorate: HIV/AIDS and STDs: 012-312-0121

National Network on Violence Against Women (tollfree helpline): 0800- 150 - 150

AIDS Helpline (toll-free helpline): 0800 - 012- 322

COSATU regional offices:

Eastern Cape: Tel: 0437-43-1951/2

Western Cape: Tel: 021- 448- 0045

Northern Cape/Free State: Tel Free State: 051 - 447 - 5499

KZN: Tel: 031- 304- 1690

Mpumalanga: Tel: 013 - 656-0298

Northern Transvaal: 015-291-2981

Wits : Tel: 011 - 873 - 2610

Western Transvaal region: Tel: 018 - 462 - 2406

AN INJURY TO ONE IS AN INJURY TO ALL

This handbook talks to workers and unions about living with HIV and AIDS – in our homes, in our workplaces, and in our communities. It talks about the basic facts, issues, and challanges that confront us every day with this epidemic. It looks at:

- what is HIV and AIDS
- how do we stop the spread of the epidemic
- knowing your status and HIV testing in the workplace
- living healthy with HIV and AIDS
- fighting discrimination
- treatment and medical care
- fighting the epidemic in our society.

Whether you have comrades and friends who are HIV-positive, whether you have it yourself, whether your co-workers fear losing jobs from this illness: this handbook is for you. It gives a first step in understanding the epidemic, and finding strategies to survive.

We do not face these issues alone. We must organise to deal with the epidemic – together.

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