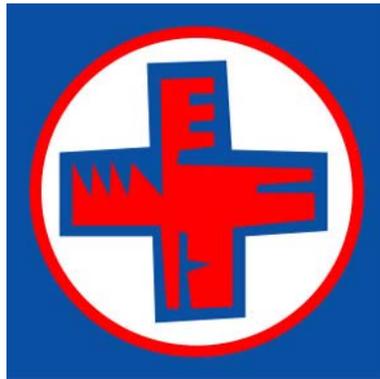


HIV/AIDS CURRENT LAW & POLICY



Your Rights to Health Care

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Glossary

What are HIV and AIDS?

HIV is the "Human Immunodeficiency Virus". It is the virus that eventually leads to AIDS.

AIDS is "Acquired Immune Deficiency Syndrome". People who have HIV eventually develop AIDS because the virus makes it difficult for their bodies to fight off diseases. It is not one sickness, but is a name given to many different illnesses, which people at this stage of the disease may get (such as TB and pneumonia).

It is very important to note that if you have HIV, it does not necessarily mean that you are sick. It can take years for someone who has HIV to develop AIDS. During this time, people who have HIV can lead totally normal and productive lives.

1 Introduction

There is no cure for AIDS but having HIV does not mean that you are going to die right away. Many people are able to live full lives with HIV for many years. Your ability to live with HIV has a lot to do with the kind of health care, treatment and support you get.

There are many treatments available that help people with HIV stay healthy for longer and live better lives. Unfortunately the majority of people with HIV and AIDS do not get the medical care they need and their rights are often violated.

All South Africans have the right of access to the health care services. Pregnant women and children under 6 have the right to free basic health care. These rights do not mean that all people with HIV and AIDS get all the medical treatment they need, but the law gives everyone the right to dignity, privacy and to make decisions about their health.

Many people experience discrimination because they have HIV or AIDS. This makes people scared of finding out if they have HIV and if they do, of being open about it. The stigma attached to AIDS means people with HIV and AIDS don't always get equal treatment or sympathetic care from health workers. Sometimes they get no treatment at all. Often their rights to privacy and confidentiality are violated.

There are laws and policies to protect you from these violations and they are dealt with later in this pamphlet.

Other problems that people with HIV and AIDS experience include:

- ✓ Not being informed about how to stay healthy.
- ✓ Not having access to affordable treatment.
- ✓ Very few doctors and nurses are trained to treat HIV and AIDS.
- ✓ Doctors who specialize in treating HIV are mostly in the private sector and charge high fees.
- ✓ The essential drugs needed to treat HIV are not available in most public hospitals.

2 How does HIV become AIDS?

Once you are infected with HIV, there are four stages that take place over a long period of time (between 5 and 12 years).

1 Being well with no signs of disease

This may last between 3 and 10 years. Even though there are no symptoms, HIV is busy spreading in your body and you can infect others.

2 Having mild symptoms

Between 3 and 7 years after infection, people with HIV may show symptoms of HIV infection like swollen glands, fevers, rashes, weight loss and chest infections.

3 Showing clear signs of HIV infections [AIDS-Related Complex (ARC)]

Eventually after many years of HIV infection, the immune system is deficient (broken down).

There is more HIV in your body fluids and if you have unprotected sex or are pregnant, the chances of you infecting the other person or your baby are much greater. Recurring cold sores and STDs, skin rashes, diarrhoea, weight loss, fungal infections (like thrush in the mouth, throat and vagina) and other opportunistic infections occur at this stage.

4 AIDS, severe HIV-related disease

Opportunist infections become severe as the immune system breaks down. Cancers, damage to organs and serious AIDS defining illnesses move in. People with AIDS can get very ill and die. These diseases show that your body is not coping at all.



How do I know which stage I am at?

The progression of AIDS is different for everyone. People who are poor and who have less access to medical care and information, or those who don't look after themselves are likely to develop AIDS faster. Some people take years to get sick, especially if they have the support and care they needs.

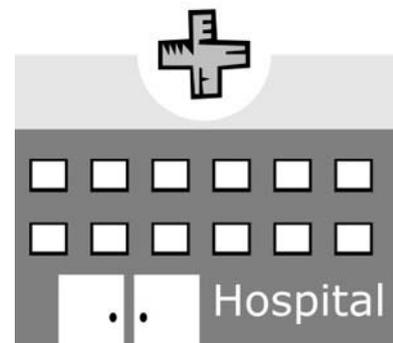
There are tests that can be done. These tests count the CD4 cells and "viral load" to see how damaged your immune system is. These tests are not normally done in public hospitals.

Generally, health workers look for symptoms to show them how sick you are, but they are not all trained to spot them.

3 Treatment for HIV and AIDS - what is available?

There are five main types of treatment:

- a Post exposure prophylaxis
- b Anti-retrovirals to reduce mother-to-child transmission
- c Combination therapy
- d Treatment and prevention of opportunistic infections
- e Palliative care



a Post exposure prophylaxis

If someone has been recently exposed to HIV, **anti-retroviral drugs** can be taken to reduce the risk of **sero-conversion**. But these drugs must be taken within 3 days of the exposure. Sero-conversion takes place when HIV begins to successfully reproduce in your blood and when the body develops **anti-bodies** to fight HIV. When this happens, a test for HIV will give a positive result although you probably will not show any symptoms.

At the moment, these drugs are only given to health workers who are exposed while working, for example, after an injury with an injection that has been used on another person. Women who have been raped are allowed to receive this treatment in the public and private health service.

b

Anti-retrovirals to reduce mother-to-child transmission

Anti-retroviral drugs, such as AZT and Nevirapine, can be used to reduce the risk of babies being infected by their HIV-positive mothers.

The government has 'pilot sites' where Nevirapine is available. They say they will make this service available to all pregnant women after December 2002.



Anti-retrovirals and protease inhibitors

The drugs that work best against HIV are "anti-retrovirals" and "protease inhibitors". They are most effective when they are taken together, which is why they are called '**combination therapy**'.

They work by attacking HIV and reducing down the speed at which HIV reproduces in your body, which prevents or slows down the weakening of your immune system. This way, a person can avoid many of the illnesses that normally come with AIDS.

But combination therapy is very expensive. Work is being done to make these medicines more affordable.

c

Combination therapy

Certain medicines (**anti-retrovirals** and **protease inhibitors**) can be used together to stop or slow down the way the virus weakens your immune system.

These drugs help your body fight other infections that move in when it is weak. These medicines can slow down the change from HIV to AIDS but they do not cure HIV.

d

Treatment and prevention of opportunistic infections

After several years, people with HIV usually get common illnesses (like thrush, TB and pneumonia) because their immune systems are weakened. These are called "**opportunistic infections**".

These illnesses can lead to time in hospital but can be treated and prevented with medicines known as "**prophylactics**", which are often cheaper than the drugs that are used to fight HIV.

e.g. People with AIDS often get pneumonia, which can lead to death. The drug Bactrim can be used to treat pneumonia and save the patient's life. It can also be used to prevent pneumonia for less than R20 a month.

The government has published Standard Treatment guidelines for health workers on how to treat these infections. At the moment, many opportunistic infections are not treated. Even if the medicines are available, many health care workers are not trained to spot and treat them.

e **Palliative care**

Because there is no cure for HIV/AIDS, the disease eventually leads to death. If someone is terminally ill (so sick that they will not get better) they can be cared for so they are made as comfortable as possible. This is called "**palliative**" care.

Hospitals cannot look after all the people who are dying from AIDS-related infections so the use of homecare is encouraged. This means that people who are very ill and dying are looked after at home and are treated as outpatients at hospitals and clinics.

⌘ 4 Laws and Policy

Law and Policy

Laws must be followed by everyone.

Policies are not laws. They are **guidelines** that **should** be followed by everyone. They are often based on laws and can become law in time. If a Judge in a court case uses a policy to reach a decision, it becomes law. If the government sets the policy, all government employees must follow it.



This is a list of laws and policies that contain your rights to health care:

- a The Constitution and the Bill of Rights
- b Promotion of Equality and Prevention of Unfair Discrimination Act
- c Free Health Care for pregnant women and children under 6
- d Medical Schemes Act
- e The National Patients Rights Charter
- f The Health Professions Council (HPC) Guidelines for the management of patients with HIV or AIDS
- g The "Five Year Plan"
- h International Guidelines – The United Nations International Guidelines on HIV/AIDS and Human Rights

a

The Constitution and the Bill of Rights

The Constitution (which contains the Bill of Rights) is the highest law. This means everyone must follow it and no laws can go against it.

The most important rights with regard to HIV and healthcare are:

✓ Equality

Everyone is equal and must be treated equally. You may not be **unfairly discriminated** against for any reason.

✓ Freedom and Security of the Person

You have the right of **control over your body** and to make any **decisions about reproduction**. You can choose to have an abortion and you may not be forced to have an HIV test or be sterilized. You cannot be forced to take part in **medical experiments** (like the testing of new medicines) without your **informed consent**. That is, you must know exactly what the test involves and what the consequences will be for you.

✓ Privacy

You have the right to privacy. Only you can decide who should know the result of an HIV test.

✓ Access to Health Care

While some people are able to afford medical aid, many others cannot. This makes sure that the government must try to provide health care to people who cannot afford it.

What does "Access to Health Care" mean?

The Constitution says "everyone has the right to have **access** to health care services, including reproductive health care". It then says that government "must take reasonable legislative and other measures, within its available resources, to achieve the progressive realisation of this right".

This does not mean that you have a right to health care or to treatment regardless of the cost. Instead, it means that:

- ✓ The government must use the money it has to **try** to give everybody health care. If the government cannot afford certain treatments or drugs, the courts will not force it to give these to people.
- ✓ The government must do what it can to make medicines available and must do other things – like build clinics in rural areas – to make it possible for more people to get access to health care.
- ✓ The government can pass laws to make it easier to people to get health care.

Preventing Mother-to-Child Transmission

If a woman with HIV is pregnant the virus can infect the baby during childbirth or breastfeeding. This is called mother-to-child transmission. The risk of this can be reduced by up to 50% by the use of anti-retrovirals. The Medicines Control Council has said that the anti-retroviral drugs to reduce mother-to-child transmission are safe and can be used. The government has not yet decided to use them in all hospitals.

The government's refusal to make some kinds of medical treatment available because they don't have the resources (they can't afford it) has been challenged in court, for example, in the following two cases.

Cases

Van Biljon and others v Minister of Correctional Services and Others 1997 (4) SA 441 (C)

In this case, four prisoners with HIV took the Minister of Correctional Services to court to force the prison to give them anti-retroviral drugs. Two of them had been given the drugs and then the prison stopped providing them. The other two had not been given these drugs at all. The Minister argued that the prison could not afford this. The judge ordered the prison to keep giving the drugs to the first two because the Minister had not shown that the prison could not afford it.

This does **not** mean that all prisoners with HIV have a right to these drugs or that all people with HIV have a right to the treatment. This is because, in terms of the Constitution, prisoners have the right to "adequate medical treatment" while other people have the right to access to health care services. What this case did decide was that government has to prove that it can't afford to provide certain kinds of treatment – it can't just refuse to provide them, by claiming (without evidence) that they are too expensive.

Soobramoney v Minister of Health 1998 (1) SA 765 (CC)

Mr Soobramoney was a diabetic with a serious kidney disease. To stay live he needed to have special treatment twice a week. The treatment he needed is very expensive and the government cannot afford to give it to everyone who needs it. They have to decide who will benefit most and Mr Soobramoney did not qualify for it.

After spending all his money on treatment at a private hospital, he asked a High Court to order the government to give him treatment based on his right to emergency medical treatment and his right to life.

The court decided that the treatment he needed was not emergency medical treatment because he needed ongoing care, which is different to emergency care. The court also said that it could not interfere with the difficult decisions that government must make when it decides where to spend money. Mr Soobramoney appealed to the Constitutional Court to reverse this decision. But the Constitutional Court upheld the original decision.

These decisions may show that the courts are not keen to interfere with government policy if decisions about where resources should go are made rationally.

b

Promotion of Equality and Prevention of Unfair Discrimination Act (No 4 of 2000)

This law has been written to strengthen the right to Equality in the Constitution. It says no one may be unfairly discriminated against and explains how you can protect this right.

c

Free Health Care for pregnant women and children under 6

(Notice 657 of 1994)

In 1994, the Minister of Health issued a notice that said all pregnant women and children under the age of six (except those on medical aid) can get free public health care, even for health problems that are not connected with the pregnancy.

d

Medical Schemes Act (No 131 of 1998)

In the past, medical aid schemes could refuse to take people who were already sick or they could make them pay more than other people. This is no longer allowed. Now, medical aid schemes must accept anyone who wants to join as long as the person can afford the contributions. The "premium" (the amount you have to pay) is based on how much you earn and how many dependents you want to add and not on whether you are sick. So, if you have HIV, you can still get medical aid. You will not have to pay a higher premium.

The Act says the medical aid schemes must give minimum benefits (which are set by government), including to people who have HIV or AIDS. Many medical aid schemes have special options or programmes for people who have HIV or AIDS. By paying an extra amount, you become part of this option and are entitled to more than the minimum benefits (such as more money each year for medicine). Workers who have HIV could check with their medical aid schemes to see if they can get this extra cover.

If you are a member of a medical aid, you can add dependents (such as blood relatives, your wife, husband, same sex partner, customary wife or husband, and children) to it, which means they are covered too (although you will have to pay more).



NOTES

- ▶ If you have HIV or AIDS when you join a medical aid scheme, you may have to wait a year before you get any of the extra benefits the scheme offers. So, for the first year, you can only get the minimum benefit.
- ▶ If you change jobs and join a new medical aid scheme within 3 months, and you were a member of your previous scheme for at least 2 years, you will **not** be subject to the late joinder penalty, but you will also not have to wait a year to get all the extra benefits that the scheme offers for pre-existing illness.
- ▶ Unlike before, workers can choose to join any option offered by a medical aid scheme (as long as they can afford it). You too can join any special programmes your medical aid scheme may have for people with HIV or AIDS.
- ▶ You may be required to have a medical exam (including an HIV test) to qualify for extra benefits.

e

The National Patients Rights Charter (1999)

This policy explains what your right of access to health care services means. All government health care workers must follow the policy, but it is not legally binding.

It says all patients have a right to health services that include:

- ✓ **Emergency care** at any open health care facility, even if you cannot pay for it.
- ✓ **Treatment** that is explained properly to you so that you understand how it works, what it costs and what it does to you. You must also be told about what is wrong with you in a way that you understand.
- ✓ **Proper treatment** of people with **HIV or AIDS**.
- ✓ **Counselling** on reproductive health, HIV and AIDS without discrimination, force or violence.
- ✓ **Palliative care** that is affordable and effective for people with incurable or terminal illness (like AIDS).
- ✓ **Health care workers** must treat you **politely**, they must respect your **dignity** and they must be **patient and tolerant**.
- ✓ **Health information** in your own language about where to find health services and how to use these services.

It also says that:

- ✓ Any information about your health and medical treatment may only be given out with your **informed consent**.
- ✓ If a health care worker, hospital or clinic starts to treat you they must continue to treat you. You also have the right to choose where you want to be treated.
- ✓ You have the right to complain about health services to the Department of Health and to have your complaints investigated and responded to.

f

The Health Professions Council (HPC) Guidelines for the management of patients with HIV or AIDS

The Guidelines set the rules for doctors, dentists and psychologists to follow when treating patients with HIV or AIDS. This body is created by Parliament and all doctors have to be members. You can make complaints to this body against any doctor breaking the rules.

In the so-called McGeary Case, the Appeal Court used these guidelines to reach a decision. As a result, the guidelines are now legally binding.

The Guidelines say that:

- ✓ Health care workers cannot refuse to treat you or treat you differently to others because you have HIV.
- ✓ You must give informed consent (which means you must understand and agree to what they are doing) to any kind of treatment or test.
- ✓ Information on your health can only be given to someone else if you agree.

The **ALP** knows of cases where people have been refused medical treatment by health workers who think that treating people with AIDS would be a waste of medicine. **This is illegal.** Health care workers can **not** refuse to treat you or discriminate against you because you have HIV or AIDS



g
The "Five Year Plan" (2000-2005)

The Department of Health has a new plan that aims to:

- ✓ Strengthen efforts to stop new HIV infections and stop the epidemic from getting any worse. This includes encouraging people to use condoms, improving treatment of sexually transmitted diseases and TB, and finding affordable ways to reduce mother-to-child transmission.
- ✓ Trying to develop a vaccine against HIV.
- ✓ Providing affordable care.
- ✓ Caring for and supporting children orphaned by AIDS.
- ✓ Increasing the use of community and home-based care.
- ✓ Finding better ways to educate and inform people.
- ✓ Increasing access to and acceptability of voluntary HIV testing and counselling.
- ✓ Improving care and treatment of people with HIV and AIDS.

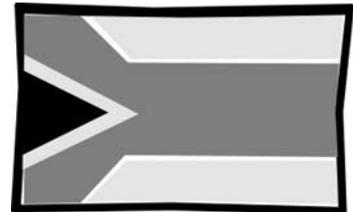
The health ministry is also looking into the way "clinical trials" (using people in experiments with new drugs) are done because of concerns that the rights of the people who take part may be violated. For this reason the rules about these trials may be changed. At the moment South Africa has no laws governing the conduct of clinical trials.

h

International Guidelines – The United Nations International Guidelines on HIV/AIDS and Human Rights

This international policy says governments should deal with HIV and AIDS in a way that respects human rights. Governments should pass laws to make sure that all people can get access to medicines, healthcare and information about HIV and AIDS. This means that everyone should have access to ways of preventing HIV infection, information about care and treatment, and effective medicine at an affordable price.

5 What can I do if my rights are abused?



If a doctor or health care worker tests you without your informed consent?

- ✓ You can lay a criminal charge.
- ✓ You can sue (bring a case against) the person.
- ✓ You can lay a complaint with the Health Professions Council (HPCSA) or South African Nursing Council.
- ✓ You can report this to the AIDS Law Project (ALP).

If a health care worker, doctor, clinic or hospital refuses to treat you?

- ✓ You can go and get a court to order that they treat you.
- ✓ You can lay a complaint with the HPCSA.
- ✓ You can complain to the Department of Health.
- ✓ You can report this to the South African Human Rights Commission.
- ✓ You can report this to the AIDS Law Project (ALP).

If a health care worker or doctor tells anyone else about your state of health without your informed consent?

- ✓ You can sue the person who did it.
- ✓ You can lay a complaint with the HPCSA or SANC.
- ✓ You can report this to the AIDS Law Project (ALP).

If anyone unfairly discriminates against you because you have HIV or AIDS?

- ✓ You can approach the AIDS Law Project.
- ✓ You can complain to the SAHRC.
- ✓ You can complain to the Department of Health.

| & Contact details

AIDS Law Project (ALP)

Center for Applied Legal Studies
University of the Witwatersrand
Private Bag 3, WITS, 2050, South Africa
Tel: 011 717 8600 Fax: 011 403 2341
www.alp.org.za

Health Professions Council of South Africa (HPCSA)

P O Box 205, Pretoria 0001
Tel: 012 338 9300 Fax: 012 328 5120
www.hpcsa.co.za

South African Human Rights Commission (SAHRC)

Gauteng

Private Bag 2700, Houghton 2041
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P O Box 1854, Port Elizabeth 6001
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P O Box 3563, Cape Town 8000
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South African Nursing Council (SANC)

P O Box 1123, Pretoria 0001
Tel: 012 420 1000 Fax: 012 343 5400

Glossary

The following medical terms are often used when people talk about HIV and AIDS:

Antibodies

These are produced by the immune system to fight against the causes of disease.

Anti-retroviral drugs

Drugs that stop or reduce the rate that HIV spreads through the body. Use of these drugs is known as anti-retroviral therapy.

CD4

A CD4 cell count refers to a test that measures the impact of HIV on a person's immune system. A person who has a CD4 cell count of less than 200 is classified as having developed AIDS.

Immune System

The body's way of fighting infection and disease.

Opportunistic Infections

Infections that people with HIV or AIDS get because their immune system is weak.

Prophylactic medicines

These are medicines that help you not to become infected by a certain illness or virus.

Sero-conversion

When your body makes anti-bodies to fight HIV, this is called "sero-conversion". After this, an HIV test will give a positive result. Sometimes people get sick when this happens (sero-conversion illness). Many people don't notice and, because there are no signs, they do not know they have HIV unless they have a test.

Viral Load

This refers to a test that measures the volume (amount) of HIV in a person's blood. A high viral load usually indicates that a person has been infected with HIV for a long time and may have AIDS.

Window Period

This is the period of up to 3 months between HIV infection and when the body makes anti-bodies to fight it (when sero-conversion takes place). During this time, an HIV test can give a negative result even if you are infected with HIV. This is because a HIV test looks for anti-bodies to HIV.