

HIV/AIDS

Current Law + Policy



Testing for
HIV – Know
your rights



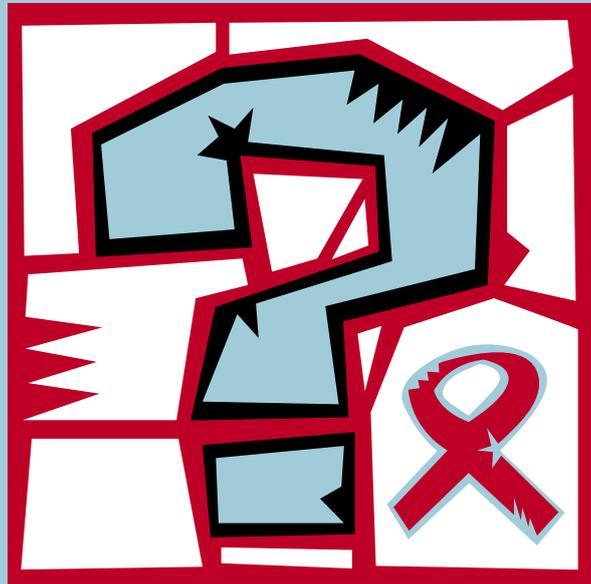
equality for all

**aidslaw
project**

Centre for Applied Legal Studies
University of the Witwatersrand

Revised April 2004

What are HIV and AIDS?



HIV is the “**H**uman **I**mmunodeficiency **V**irus”. It is the virus that eventually leads to AIDS.

AIDS is “**A**cquired **I**mmune **D**eficiency **S**yndrome”. Many 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 sometimes takes years for someone who has HIV to develop AIDS. During this time, people who have HIV **can** lead normal and productive lives.*

Today people with AIDS can also get treatment that can improve and prolong their lives.

Testing for HIV - Know your rights



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A brief summary of the rules for HIV testing

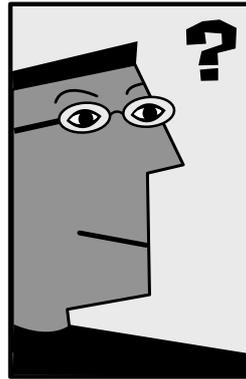
This booklet will look at all the current **laws** and **policies** that are in place dealing with HIV testing.

They can be summarised as follows:

- ⌘ An HIV test is a **medical procedure**.
- ⌘ You must give your **informed consent** to a medical procedure.
- ⌘ **Informed consent** means you must fully understand what the test is and what the consequences will be for you if you test positive or negative. To make sure you know this, you should be given counselling before the test. This is called "**pre-test counselling**".
- ⌘ Pre-test counselling should give you enough information to properly decide whether or not you want to have the test.
- ⌘ Once you have had counselling, you must be given time to decide if you want an HIV test.
- ⌘ If you decide **not** to have the test, no one can force you to.

If you decide to have the test, you must be given counselling when the results are given to you. This is called "**post-test counselling**".

Introduction



The decision on whether to have an HIV test, and when to do so, is **your decision** alone. Except in rare circumstances, you cannot be forced to take a test. Anyone who forces you to do so will violate your rights and may be breaking the law.

It is possible to have HIV without even being aware of it. This is because HIV can live in the human body for many years before it causes any illnesses. The only way of finding out is to have an HIV test. These tests are performed at many health clinics or you could ask your doctor or health care worker.

The benefits of knowing outweigh the risks. It is important that all people should think about going for an HIV test.



The window period

After someone is infected with HIV, it can **take up to 3 months** for it to show up in an HIV antibody test. This is because your body takes some time to develop antibodies to try to fight off the virus. An HIV test checks for the presence of these **HIV antibodies** in your blood and it might give a false negative result in this three-month period (the tests are called ELISA or Western Blot tests). These three months are commonly known as the "window period". To ensure that you get the correct results, do not take the antibody test during the "window period", - you should wait at least 3 months from the time of possible exposure before taking the test.

Another test is available that can tell you whether you have **HIV** in your blood, not just the antibodies. This test is called a PCR test and is more expensive than the ELISA or Western Blot tests. With the PCR test the virus can be detected within 12 days after exposure to HIV.

The benefits of knowing your HIV status



Knowing your HIV status is important. If you test HIV negative, you can make sure that you take more care not to contract HIV in the future. If, however, you test HIV positive, knowledge of your HIV status allows you to take better care of your life.



Living with HIV

Some steps that can help you deal with having HIV include:

- ✂ Living a more healthy life by eating a balanced diet and getting lots of exercise.
- ✂ Planning properly for your future.
- ✂ Finding out what treatment is available and what you may need.
- ✂ Finding out about your rights to treatment and non-discrimination.
- ✂ Seeking counselling and support groups or service organisations that help people living with HIV/AIDS.

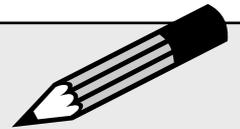
Having HIV does not mean you are about to die. You can have HIV and still be healthy and able to function as well as people who do not have the virus. This is one of the reasons why it is wrong to require people to test before employment.

While there is no cure for HIV, better medicines have made it possible for people to live longer and cope better with the disease. Some treatments, such as anti-retroviral medication, can delay or prevent HIV leading to AIDS. It is now government policy to provide people with HIV or AIDS with most of the medicines they need.

The risks of knowing your HIV status



There are risks involved in knowing you have HIV. Some people have been denied employment, fired and even been physically attacked by other people once others have found out that they have HIV. Discrimination is a result of prejudice, fear and ignorance and makes it hard for people to disclose that they have HIV.



There is no shame in having HIV/AIDS and your HIV status says nothing about who you are or what you are worth.

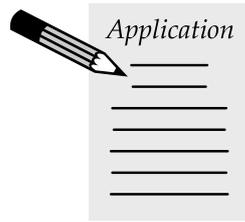
There are laws that make it unlawful to discriminate against you because you have HIV, including the Constitution. These are discussed briefly in this booklet.

It is also important to remember that your status is **confidential** (meaning only you can decide who else should know). There are both laws and policies to protect this right.

Since the benefits of knowing your status outweigh the risks, it is to your advantage to find out your HIV status. Again, the decision to have an HIV test is yours and yours alone and, except in very rare cases, you cannot be forced to take an HIV test. **In other words, you have the right to decide.**

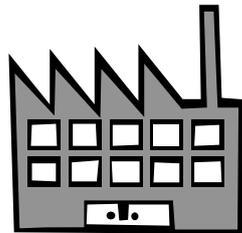
Know your rights

1 When applying for a job



Sometimes employers ask people applying for a job to take an HIV test. The Employment Equity Act says this is not allowed, except if your employer has permission from the Labour Court, or if you apply for a job with the South African Defence Force (SANDF), the National Intelligence Agency or the Secret Service. Some employers try to get around this by asking people to fill in a "health questionnaire", which may ask whether or not you have HIV. This, too, is not allowed.

2 At work



Some workers who have HIV have been dismissed, demoted or denied their employee benefits. The law on the rights of workers makes it quite clear that employers may not unfairly discriminate against workers who have HIV.

Domestic workers often suffer from unfair discrimination, especially when they are responsible for childcare. Domestic workers have the same rights as other workers and the

AIDS Law Project has successfully defended their rights in many such cases.



3 When applying for medical aid



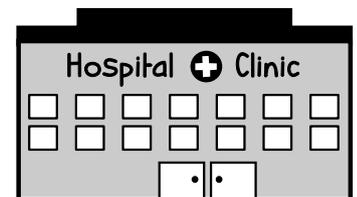
Medical aid schemes cannot deny you membership if you have HIV. They must now accept anyone who wants to join them as long as the person can afford the contributions. The premiums (the amount you have to pay) are based on how much you earn and how many people you wish to register as dependents and not on whether you are sick.

So, if you have HIV, you can still get medical aid and the fact that you have HIV makes no difference to how much you have to pay. For this reason, you do not have to have an HIV test when you apply for membership to a medical aid scheme.

Medical aid schemes are explained in more detail in the ALP booklet 'Your rights to health care'.

4 In hospital, at clinics and when visiting your doctor

While you are visiting your doctor or are a patient in hospital or at a clinic, you have the same rights as anyone else.



You may not be tested without your informed consent. Even so, the AIDS Law Project receives many complaints of this kind and has defended people and lodged complaints against doctors in such cases.

It is important to remember that, if you agree to have a test at a hospital, clinic or at your doctor, the person who does the test is not allowed to tell anyone the result except you.

Case

In one AIDS Law Project case in 2000, a doctor tested a person without his informed consent. Rather than go to trial, the doctor agreed to pay damages to this person. If you are tested illegally, make a complaint to the Health Professions Council of South Africa (HPCSA). Tell the ALP about your complaint.

Life insurance



When applying for life insurance

Some insurance companies will ask you to have an HIV test when you apply for life insurance.

You cannot be forced to have an HIV test but if you refuse, they will probably not give you life insurance. Some insurance policies do not require you to have an HIV test, but these policies only give very low cover.

If you do agree to have an HIV test, the insurance company must follow all the rules of HIV testing. This means you must be given pre-test and post-test counselling. Also, the results of your test must be treated with confidentiality. This means that your right to privacy must be respected and the result of your test may not be given to anyone else unless you agree to this.

Know the law



South African law is made up of two main parts, **common law** and **legislation**, both of which are equally important and have to be followed by everyone.

The common law, legislation and policies have been developed to stop violations on the grounds of HIV status and to set out the rules around HIV testing.

Common law is laws and rules that have been passed down over the years without having to be written down. It includes things like the crimes of murder and theft.

Legislation is written law. Because the common law comes from long ago, governments write new laws to cover new situations. These written laws are known as **Acts**.

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.

The LAW on HIV testing



The common law rule of informed consent

Testing for HIV is a medical procedure and the common law says a medical procedure can only be done on you if you **consent** (agree) to it. This was decided in a very old case from 1922, known as **Stoffberg v. Elliot (1023 CPD 148)**.

To say that you have consented to a test, you must know what it is you are agreeing to and must actually agree to it. This is called **informed consent** and, as will be seen, there are very few cases where a test can be done on you without your informed consent.

To make sure your consent is informed consent, policies dealing with HIV testing all say you must be given **pre-test** and **post-test counselling**.

The decision in **Stoffberg v Elliot** has been followed in many cases, including **Castell v de Greef** and **C v Minister of Correctional Services**. Even so, people are still tested without their informed consent. This is why new laws and policies have been put in place.

Case

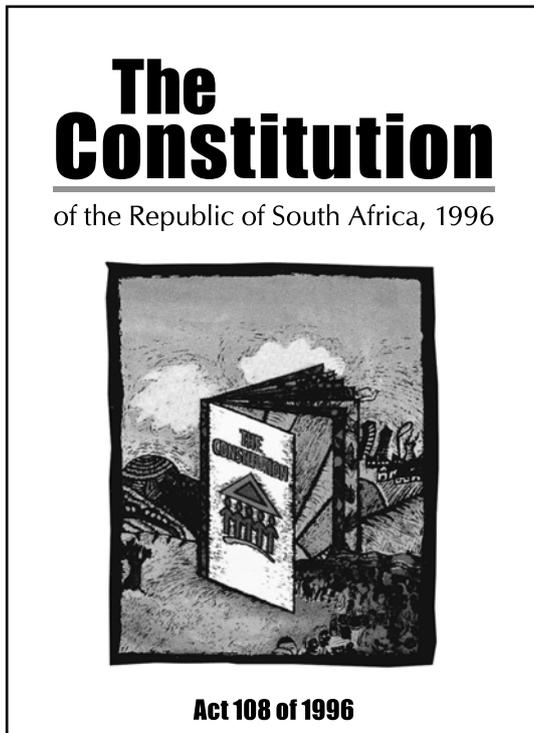
Castell v De Greef
1994 (4) SA 408 (C)

In this case, the judge said that in order for informed consent to exist, a person must:

- ⌘ Know the nature and extent of the harm or risk;
- ⌘ Have understood the nature and extent of the harm or risk;
- ⌘ Have agreed to the harm or risk;
- ⌘ Have agreed to all parts of the harm or risk, including the consequences.

The Constitution and the Bill of Rights

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



The most important human rights with regard to HIV testing are:

Freedom and Security of the person

You have the right to “bodily integrity”, which means you decide what happens to your body. So, you cannot be forced to take an HIV test. You also have the right not to be made part of a medical experiment unless you give your informed consent. This means you must know what will be done to you and what the consequences will be for you.

Privacy

Your privacy must be respected. Only you can decide who should know the result of your HIV test.

Criminal Law amendments

The rights of survivors of rape and sexual assault



According to South African law and the draft policy on HIV testing of the Department of Health, no-one can be tested for HIV without their informed consent.

There is a new draft law that is not yet in operation that will allow alleged rapists and perpetrators of sexual assault to be tested for HIV at the request of the survivor of the rape or sexual assault. When this law comes into effect, a survivor will be able to ask that the suspect be tested and even if he does not agree to have the test, he can be forced to do so.

The results of the HIV test will only be made known to the survivor, and also to the suspect if he wants to see his HIV test result. It will be an offence for the survivor to disclose the HIV status of the suspect to any other person and the results of the HIV test cannot be used in the criminal case against the suspect.

Disclosure to a sexual partner

The law at the moment does not require you to disclose your HIV status to your sexual partner, although if you infect your partner with HIV and you knew your HIV status at the time that you had sex, you may be charged with murder, attempted murder or assault. A new draft law dealing with sexual offences states that it is a criminal offence not to disclose your HIV status to your sexual partner. This law has not yet come into effect, but if it does, it will mean that if you know that you have HIV, you will have to tell your partner about your HIV status before you have sex with them. If you do not, you may be charged with an offence even if your partner does not contract HIV.

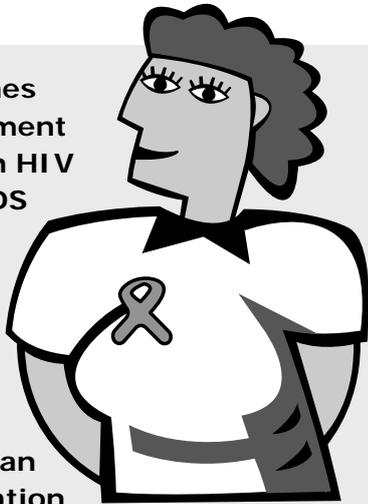
If this provision becomes a new law, it will create many problems, especially for women, who are often not able to disclose their HIV status because they are afraid of violence or abandonment.

Policies on HIV testing

⌘ HPCSA Guidelines on the Management of Patients with HIV infection or AIDS

⌘ The National Policy on Testing for HIV

⌘ The South African Medical Association (SAMA) Human Rights and Ethical Guidelines on HIV: A Manual for Medical Practitioners



⌘ HPCSA Guidelines on the Management of Patients with HIV infection or AIDS

The HPCSA was set up by Parliament. All doctors have to belong to it and if a doctor breaks the rules set by this body, a complaint can be made to the HPCSA. The HPCSA has the power to discipline doctors, including not allowing them to practice medicine anymore.

These guidelines were written to advise doctors on how to deal with patients with HIV/AIDS. These guidelines say clearly that HIV testing can only be done with your **informed consent**.

To make sure you know what you are consenting to, doctors must give you **pre-test** and **post-test counselling**.

Pre-test counselling

Doctors must **discuss** the test with you or must arrange for you to discuss the test with a counsellor before you are tested.

During this discussion, they must explain:

- ⌘ What the purpose of the test is (that is, that the test is to see whether you have HIV);
- ⌘ The advantages and disadvantages of testing;
- ⌘ What effect treatment and support you may need if you have HIV; and
- ⌘ How to cope with a positive test result (such as who to tell, what your needs will be and what support services there are).

Post-test counselling

You must be given counselling when the result of the test is given to you (post-test counselling). This is to help you understand and deal with a positive or negative result and **includes discussing the following issues:**

- ⌘ What health care facilities and other support structures there are to help you; and
- ⌘ Who can help your family or sexual partner to cope.

Case

C v Minister of Correctional Services 1996 (4) SA 292 (TPD)

In this case, a prisoner was given an HIV test. He had been told what the test was and that he could refuse. But he was not given pre-test or post-test counselling and had very little time to decide whether or not to have the test. When he found out he had HIV, he sued the Minister for violating his rights. The court agreed and said that, because he had not been given proper pre-test and post-test counselling and had little time to decide, he had not given informed consent to the test.

Testing without informed consent

The HPCSA Guidelines say that testing **without** your informed consent can only be done **in the following circumstances**:

In an emergency



In an emergency, where it is impossible to get your consent (such as when you are unconscious). However, the AIDS Law Project believes that such testing must only be done if it is in the interests of the patient.

After a needle stick injury



Where a health care worker has been exposed to a possible risk of HIV infection, such as where they have pricked themselves with a needle that has already been used. Because there are anti-retroviral medicines (known as **post exposure prophylaxis or PEP**) that may prevent HIV infection, the guidelines say the health care worker should be able to find out what your HIV status is if the needle was first used on you.

⌘ If you refuse to give consent to an HIV test after a needle stick injury and if there is already a sample of your blood available, it can be tested, even if you don't give your permission. If you would like to know what your HIV status is, you must be given counselling before and after you are given your result.

⌘ If there is no blood sample available, you can be asked to give a sample. If you refuse, the health care worker must ask the Medical Officer of Health to agree to this being done and blood can be taken from you.

Comment *The ALP does not agree with HIV testing without consent. This is because a person could be in the window period and a negative test result would not prove anything. Instead, we recommend that health care and emergency workers are counselled about the possible risk of infection and that all cases of possible exposure are treated as if the person had HIV. That is, they should be offered voluntary counselling and testing and if the injury carried a risk of infection, post exposure prophylaxis.*



Post exposure prophylaxis

Taking medicines that reduce the risk of HIV infection after rape, or a needle-stick injury in a hospital setting is known as **post exposure prophylaxis** or **PEP**. Anti-retroviral medicines like AZT and 3TC can reduce the risk of HIV transmission as long as they are taken within 3 days of the needle-stick injury or rape, and for 28 days thereafter.

What if you cannot consent?

Where you cannot consent to a test (for example, if you are too young or you are unconscious) someone else may do so for you. This “proxy consent” is consent by a person who is legally entitled to give consent on behalf of another person – for example, a parent or guardian of a child below the age of 14 years.

⌘ The National Policy on Testing for HIV

This policy has been developed by the Department of Health. The government says that the policy will be made part of the National Health Act.

Government health care workers must follow it. This policy also provides useful guidance to private doctors and health workers, employers and people employed outside of government.

According to this policy, informed consent is required for testing, for example, when:

- ⌘ You ask for a test;
- ⌘ A doctor says you should have a test;
- ⌘ The test is for research purposes; or
- ⌘ The test is done to screen blood being donated. However, if you do not give consent to this, you will not be allowed to donate blood.

To make sure your consent is informed consent, the Policy says you must be given pre-test and post-test counselling. The rules here are very similar to those in the HPCSA guidelines, but have more detail on post-test counselling.

They say post-test counselling should involve at least two sessions and should include discussions on:

If the result is negative:



- ⌘ How to reduce the risk of being infected with HIV in the future; and
- ⌘ There may be a possibility that you are still in the window period.

If the result is positive:



- ⌘ What this means for you and your family;
- ⌘ How to deal with difficulties you may encounter;
- ⌘ Who you would like to tell about the result; and
- ⌘ What medical care you need and how to get it.

The National Policy on Testing also includes provisions for testing for “**epidemiological purposes**”. Even though informed consent is not required here, the testing must be unlinked and anonymous (for example, your name must not appear on the blood sample).



HIV testing for “**epidemiological purposes**” means testing to get information about the distribution of HIV infection in society so that this information can be used to monitor and control HIV infection.

This Policy says **you can never be tested as a matter of routine in hospitals or clinics**. This is to stop hospitals testing all patients regardless of why they are there.

You may only be tested for HIV when applying for a job if the Labour Court has granted your employer **permission** to carry out testing.

The South African Medical Association (SAMA) Human Rights and Ethical Guidelines on HIV: A Manual for Medical Practitioners

SAMA is a type of trade union for doctors. Its membership is voluntary and it has no statutory or disciplinary powers. At present some 70% of doctors in both the public and private sectors are members of SAMA.

The SAMA manual draws on the HPCSA Guidelines as well as the World Medical Association’s International Code of Medical Ethics. It provides detailed guidance to medical practitioners on pre- and post-testing counselling, informed consent, confidentiality, access to treatment, medical certificates and other topics.

Post-test counselling

On post-test counselling, the Manual notes that the duty to provide post-test counselling falls on the medical practitioner who commissioned the HIV test. This means that you have to get post-test counselling from the person who asked for the HIV test to be done. The practitioner cannot shift the duty to others by just referring the patient to a counselling service.

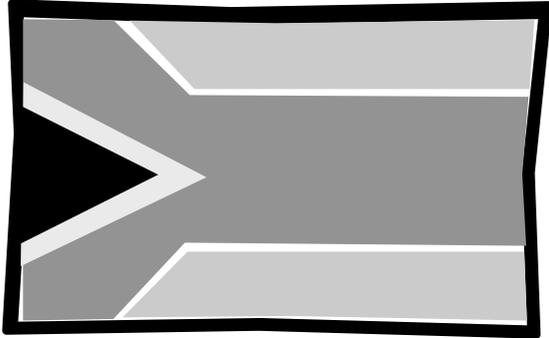
Home-tests

There are home-test HIV kits available from pharmacies. The problem with these tests is that they do not provide pre- and post-test counselling.

The AIDS Law Project recommends that people who want to use these home-test kits, discuss it with their doctors first and seek counselling before using the test. Employers are not allowed to test their employees for HIV without permission from the Labour Court, and this includes the use of home-test kits.

SAMA notes that a medical practitioner must inform the patient of the reliability of a home-test if the patient tells the practitioner that she/he has taken such a test. The practitioner should encourage the patient to undergo a second test and the practitioner should adhere to all other principles relating to good patient care even if the patient refuses to take a second test. SAMA notes that it is likely that the duty to provide post-test counselling to the patient may fall on the practitioner, even though the practitioner did not ask for the test to be performed on the patient.

Enforcing your rights

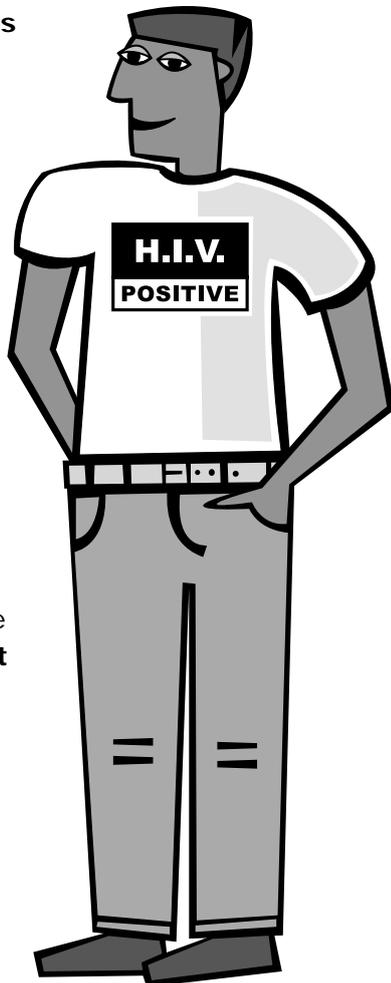


Testing without your informed consent is an **assault**, and you can lay a charge with the **police**. You can also sue (bring a case against) the doctor or nurse who tested you.

If a doctor tests you **without your informed consent**, you can lay a complaint with the **Health Professions Council of South Africa (HPCSA)**.

If a nurse tests you **without your informed consent**, you can lay a complaint with the **South African Nursing Council (SANC)**.

You can also contact an NGO, like the **AIDS Law Project (ALP)** for help.



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⌘ Commission for Conciliation, Mediation and Arbitration (CCMA)

TEL: 011 377 6600
www.ccma.org.za

⌘ Health Professions Council of South Africa (HPCSA)

PO Box 205, Pretoria 0001
TEL: 012 338 9300
FAX: 012 328 5120
www.hpcsa.co.za

⌘ Life Line 24-hour counselling

TEL: 0861 322 322
www.lifeline.org.za

⌘ South African Human Rights Commission (SAHRC)

Private Bag 2700, Houghton 2041
TEL: 011 484 8300
FAX: 011 484 1360
www.sahrc.org.za

⌘ South African Nursing Council (SANC)

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FAX: 012 343 5400
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TAC is an activist NGO. Its main objective is to campaign for greater access to treatment for all South Africans, by raising public awareness and understanding about issues surrounding the availability, affordability and use of HIV treatments.

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Glossary

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

HIV

Human **I**mmunodeficiency **V**irus. The virus that causes AIDS.

AIDS

Acquired **I**mmune **D**eficiency **S**yndrome. This means the body cannot fight infections because the immune system is weakened.

Antibodies

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

Anti-retroviral drugs

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

Disclosure

Make information known to others.

Immune system

The body's way of fighting infection and disease.

Opportunistic infections

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

Post exposure prophylaxis (PEP)

These anti-retroviral medicines reduce the risk of HIV infection after an incidence of rape or a needle-stick injury.

Sero-conversion

When your body makes antibodies 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.

Window period

This is the period of up to 3 months between HIV infection and when the body makes antibodies 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.

Why should you have an HIV test? What are the benefits of knowing your HIV status? What rules have to be followed by people who conduct HIV tests? This booklet answers these and other questions.

This booklet forms part of the following series:

-  Women, HIV and AIDS
-  Your rights to health care
-  Your rights in the workplace
-  Testing for HIV – Know your rights
-  Privacy and confidentiality

These booklets are available from the ALP:

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