

HIV/AIDS

Current Law + Policy



Privacy and confidentiality



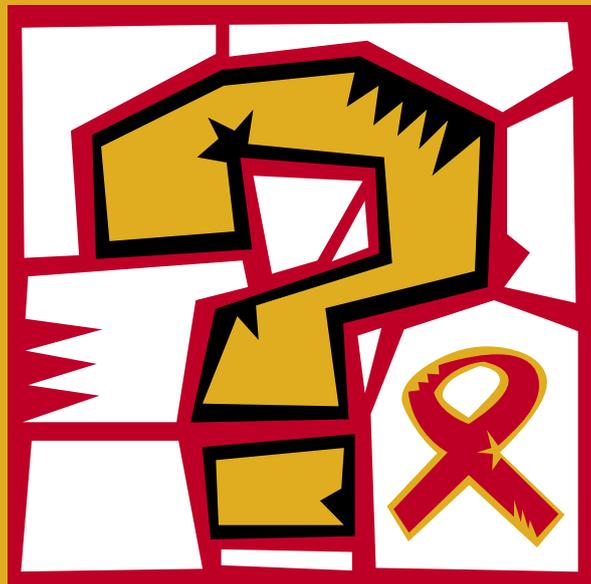
equality for all

**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.

Privacy and confidentiality



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Introduction - The Right to Privacy

You have a **right to privacy** and the decision about who you tell whether you have HIV or AIDS is yours and yours alone. Except in very few cases, you cannot be forced to tell anyone what your HIV status is.

Because of the stigma and ignorance that surround HIV and AIDS, people are often afraid to disclose their status. There are well known cases of people with HIV being terribly treated once people find out they have HIV. **These include:**

- ⌘ Being beaten by their husbands;
- ⌘ Being dismissed from work;
- ⌘ Being assaulted;
- ⌘ Being shunned by their family, friends and neighbours;
- ⌘ Being forced to move house; and
- ⌘ In one very famous case, a young woman, Gugu Dlamini, was killed by the people she told she had HIV.

There are laws and policies to protect your privacy and in the so-called "**McGeary case**", our courts recognised how important it is to protect this right.

Case

The "McGeary case" –
Jansen van Vuuren and Another NNO v Kruger
1993 (4) SA 82 (A)

Mr. McGeary went to his doctor for an HIV test. The test showed Mr. McGeary had HIV. The next day, his doctor was playing golf with another doctor and a dentist and told them that Mr. McGeary had HIV. **The court found that this was a violation of Mr. McGeary's rights because:**

- ⌘ Doctors must keep this information private or else people will not go to them for tests and treatment. Telling other doctors about a patient's HIV status will not stop the transmission of HIV;
- ⌘ Doctors must follow the South African Medical & Dental Council (SAMDC) Guidelines, which say that they should not tell anyone your HIV status unless you consent to this; and
- ⌘ It is important to keep this information private because people with HIV are often discriminated against.

We need to create a society where it is easier for people with HIV to be open with friends, family and colleagues.

We can do this by:

- ⌘ Treating people with HIV/AIDS with dignity and respect;
- ⌘ Learning about how HIV is and is not transmitted; and
- ⌘ Respecting everyone's right to privacy and not forcing people to disclose their status.

Only by doing this will we make it possible for people to be open about their status, to have HIV tests without fear, and to get the medical treatment they need. **As Justice Edwin Cameron, a Supreme Court judge, said when he announced that he had AIDS in April 1999:**

"The choice of speaking is available to me for very particular reasons: because I have a job position that is secure; because I am surrounded by loved ones, friends and colleagues who support me; and because I have access to medical care and treatment that ensures I remain strong, healthy and productive.

For millions of South Africans living with HIV or AIDS, these conditions do not exist. They have no jobs, or their jobs would be at risk if they spoke about their HIV. They not only lack community support, but face grave personal danger if they do so. And, most importantly, they do not have access to proper medical care and treatment. For them, in a still hostile climate, the choices are strictly limited. Their right to invoke confidentiality remains of critical importance to them. It is only by creating conditions in which people can speak out without fear that we can begin to end the silence surrounding South Africans living with AIDS and HIV."

- Judge Edwin Cameron

Laws and policies



Law and Policy

Laws must be followed by **everyone** in the country.

Policies are guidelines that **should** be followed by everyone. While policies are not laws, 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.

Because you have a **right to privacy**, only you can decide whom you want to tell. This right is in the **Constitution**, which is the highest law in the country. This means no law or policy is allowed to go against this right and everyone in the country has to follow it.

However, the rights in the Bill of Rights can be limited or reduced.

The rule for this is:

- ⌘ Rights can only be limited by a law that applies to people generally; and
- ⌘ There must be a reason to limit the right and it must make sense to do so.

For Example:

The Criminal Law Amendment Act of 1997 says a court can be told whether a person convicted of rape has HIV. This is clearly a limitation of the right to privacy.

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.

Even though you have the right to privacy, you will **still** be asked your HIV status in many situations. Some of these situations, and the laws and policies dealing with them, are set out below.

Remember that the Constitution protects your right to privacy in all of the following cases:

Who has the right to know...

- at home?
- when I am in hospital or at a clinic?
- at work?
- in prison?
- when I apply for medical aid?
- when I apply for life insurance?

Who has the right to know... at home?

There may be benefits to disclosing your HIV status to your wife, husband or sexual partner.

For example:

- ⌘ Your partner may not be infected and you will be able to take steps jointly to protect yourselves.
- ⌘ Your sexual partner may want to have an HIV test. It may be important that they know so that they can get treatment.
- ⌘ Unsafe sex between people who are both infected sometimes leads to "re-infection". Re-infection, that is being infected with HIV again, makes your body weaker, may lead to drug resistance and makes it easier for HIV to become AIDS;
- ⌘ You will be able to support each other and plan for your future needs.

However, decisions about disclosure are always difficult and must be made on an individual basis. Disclosure by people with HIV is not a substitute for both partners in sex always taking responsibility to protect themselves and to protect others.

A simple guide to safer sex:



Safer sex is the responsibility of **everyone** who is sexually active whether you have HIV or not. Because it can take many years before a person with HIV develops symptoms and because many people are scared to have an HIV test, a lot of people with HIV do not know they are infected. To avoid being infected or infecting others, we all need to take care to reduce the risks to others and ourselves.



HIV is carried in bodily fluids like blood, semen and the fluid inside the vagina. HIV infection happens most often during sex, when the semen of an infected person comes into contact with the inside of the vagina or anus, or when the fluids or blood inside the vagina or anus of an infected person enter openings on the penis. Blood, semen and the fluids inside the vagina contain a high concentration of HIV and may transmit HIV to other people who come into unprotected contact with these fluids. Safer sex is about knowing the risks involved and taking precautions against HIV infection.



Why are some kinds of sexual activity more risky than others?:



When a penis penetrates a vagina or anus there may be small tears in the soft, absorbent tissues of the vagina or anus and other mucus membranes. If sperm or blood that contains HIV enters your blood stream, the chances of infection are much higher.



The risk of HIV infection through oral sex is very small. If you swallow vaginal fluid or semen there is a chance of getting infected, but only if you have open sores in your mouth or throat. To have safer oral sex, use protection and do not swallow semen or vaginal fluid.



People with HIV can still enjoy sex without putting their partners at risk, by practicing safe sex. Even if you and your partner both have HIV, you should still practice safer sex to avoid re-infection, which can accelerate the progression to AIDS.



Reducing the risk - some choices:

- ⌘ Have sex that does not involve the penetration of the penis into the vagina or anus, for example oral sex, mutual masturbation.
- ⌘ Use male or female condoms or other barrier methods.

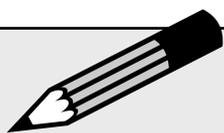


Universal precautions:

Regardless of whether or not you choose to tell your wife, husband, sexual partner or family members about your HIV status, you **should** practice universal precautions. Universal precautions mean that you treat all bodily fluids as if they contain HIV. **There are a number of things you and your family can do to reduce the risk of HIV infection, such as:**

- ⌘ Treating **all** blood and body fluids (such as semen and vaginal fluid) with care by wearing gloves or plastic bags over your hands.
- ⌘ If there is an accident where blood is spilt, **immediately** wash blood and bodily fluids away with water and bleach.

NOTE



Members of your family are at **no risk** from using the same knives and forks, cups and plates as you, or from sharing your bath, shower or toilet. You can also hug, kiss and touch people without any risk.

Does your health care worker have to tell your family?



HIV and AIDS are not notifiable diseases. There is **no law** that says a health care worker **must** tell your family. The question of whether a health care worker **should** help you to tell your family is discussed later in this booklet.

Who has the right to know... when I am in hospital or at a clinic?



Because HIV is in your blood and bodily fluids, some health care workers ask you to tell them that you have HIV, because they worry that they may get infected. **You do not have to tell them.** As long as health care workers follow universal precautions, the risk of them being infected with HIV from treating patients is extremely low. Also, because of the **“window period”**, a patient could have HIV even if he or she has tested negative. A health care worker should treat all patients as if they have HIV.



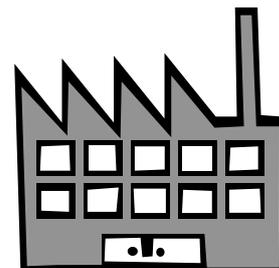
The window period

After someone is infected with HIV, it can take up to three 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 one does not take the antibody test during the “window period”; one should wait at least three 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 of infection with HIV.

The **AIDS Law Project (ALP)** has received many complaints of health care workers testing patients without their knowledge or consent, and of health care workers giving out this information without the consent of the patient. This goes against all the laws and policies dealing with HIV testing and confidentiality and **is not allowed.**

Who has the right to know... at work?



1 Can I be asked what my HIV status is when I apply for a job?

No. No one may test or question you about your HIV status when you apply for a job, unless you are applying for a job with the South African National Defence Force (SANDF), the National Intelligence Agency or the Secret Service.

2 Can my employer ask me?

No. The Employment Equity Act says that you cannot be compelled to take an HIV test at work **unless** the Labour Court has given your employer permission to do so.

If you trust your employer or if your workplace has a clear policy on HIV/AIDS, you may decide to tell your employer. This may make it possible for you and your employer to discuss ways of making it easier for you at work or getting hold of treatment.

3 When I take sick leave?

Most employers require a certificate when you take sick leave. While your health care worker is not allowed to lie on the certificate, they should not disclose private information – particularly your HIV status – without your agreement. A doctor or nurse can state your illness without referring to whether it may be caused by HIV.

Who has the right to know... in prison?

Even in prison, you **cannot** be tested for HIV **without** your consent. If you volunteer to have an HIV test, only you can decide who knows your HIV status.

Who has the right to know... when I apply for medical aid?

Medical aid schemes must accept anyone who wants to join them 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 dependants 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 Medical Schemes Act says medical aid schemes must give a minimum benefit (which is set by government) to people who have HIV/AIDS. Many medical aid schemes have special options or programmes for people who have HIV/AIDS. People who have HIV should 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 dependants (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/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 do not have to wait a year to get all the extra benefits that the scheme offers for a pre-existing illness.
- ⌘ Unlike before, workers can choose to join any option offered by a medical aid scheme (as long as you can afford it). So, you can join special programmes the scheme may have for people with HIV/AIDS.
- ⌘ You may be asked to have a medical exam (including an HIV test) to qualify for extra benefits.

So, even though you do not have to take an HIV test to get medical aid or to say that you have HIV when applying, it may well be to your benefit to do so.

Who has the right to know... when I apply for life insurance?



Usually insurance companies will ask you to have a test when you apply for life insurance. **You cannot be forced to have a test** but if you refuse to have one, they will probably not give you life insurance.

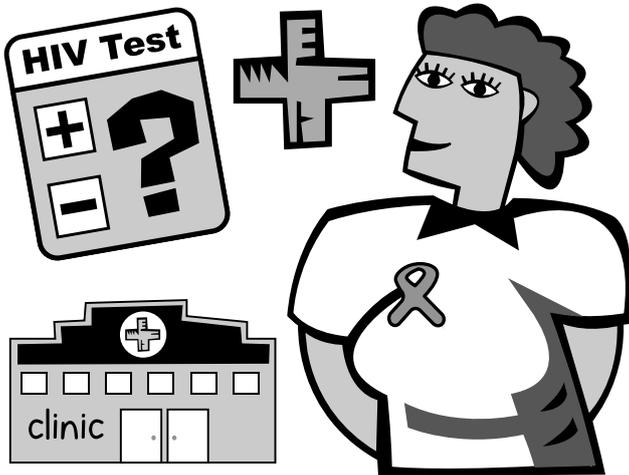
If you do agree to have a test, the insurance company must follow all the rules of HIV testing. This means you must be given pre-test and post-test counselling. Also, the results of your test must be treated with confidentiality. That is, your right to privacy must be respected and the result may not be given to anyone else unless you agree to this. Insurance companies must also protect the information they have about you.

IMPORTANT NOTE

Your responsibilities:

While there are very few people that you need to tell about your status, you must remember that you have a **responsibility** to other people and you should not do anything that would place another person at risk. So, practice safer sex **at all times**. Try to prevent people (such as people you work or play sport with) from coming into contact with blood or body fluids. For example, do not share razors or needles with anyone.

Health care workers - can they tell anyone else the result of your HIV test?



The **only** people who know the result of your HIV test are you and the health care worker who does the test. **Can this person ever tell anyone other than you the result?**

Generally, a health care worker may only give this information to anyone else if you consent (agree) to it.

This is set out in the following laws and policies:

- ⌘ The right to privacy in the *Constitution*.
- ⌘ The Health Professions Council Guidelines for the *Management of Patients with HIV or AIDS* say "the results of HIV positive patients should be treated at the highest level of confidentiality".
- ⌘ The *Patient's Rights Charter* (which is a policy of the Department of Health) says information about your health can only be given out with your **consent**.

Our courts approved this rule in the so-called "McGeary Case", which is discussed on page two.

The principle is that when health care workers counsel you, the counselling has to include advice and assistance with disclosure. However, health care workers must also accept that we have 'bodily autonomy'. There are usually very good reasons why people do not want their sexual partners to know their HIV status (such as fear of being beaten up or kicked out of the home).

"Patient confidentiality is one of the cornerstones of the medical profession. It ensures that a patient divulges all the information relevant to his/her health care to the practitioner, thereby ensuring the best appropriate health care."

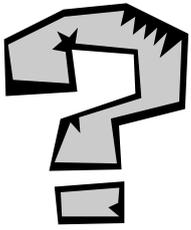
- The South African Medical Association
"Human Rights and Ethical Guidelines on HIV: A Manual for Medical Practitioners" November 2001

Unless there is strong reason to believe that you will put another person at risk – then the decision about **how**, **when** and **if** to disclose must be made by you.

Many health care workers may be put under pressure by third parties (such as family members, sexual partners or employers) to give them information about a patient's HIV status or whether the patient has gone for an HIV test.

The South African Medical Association (SAMA) suggests that the health care workers give the following response:

*"Patient confidentiality is protected by legislation and ethical rules binding medical practitioners. **Unless the patient** (or in the case of a deceased person his/her next of kin) **provides informed consent** (among others, by knowing what will happen if the status is disclosed), **no medical information may be provided to third parties**. If you are relying on any existing legislation, contract or agreement binding on yourself and the patient, please provide us with a copy thereof so as to facilitate a proper evaluation as to the possibility of disclosure."*



However, the question of what a health care worker should do if you intend to endanger your husband, wife, sexual partner or partners is clear.

Although there is no law that says a health care worker must tell them, there are internationally recognised guidelines on disclosure without consent.

To deal with situations in which health care workers may find themselves where someone might endanger his/her sexual partner(s), policies and guidelines have been developed by the United Nations, World Health Organisation, the Health Professions Council and the South African Medical Association.

These policies say a health care worker CAN tell a sexual partner if:

- ⌘ The health care worker has more than once explained why it is important for the partner to know;
- ⌘ The health care worker is able to clearly identify who the partner is;
- ⌘ There is a real risk that this partner will become infected;
- ⌘ The health care worker has told the person with HIV that the health care worker will have to tell their partner if the person with HIV refuses to do so; **and**
- ⌘ The health care worker has taken steps to protect the identity of the person with HIV from the sexual partner the health care worker is going to tell.

The **AIDS Law Project (ALP)** recommends that health care workers take these minimum steps before they decide to inform a person's known sexual partner:

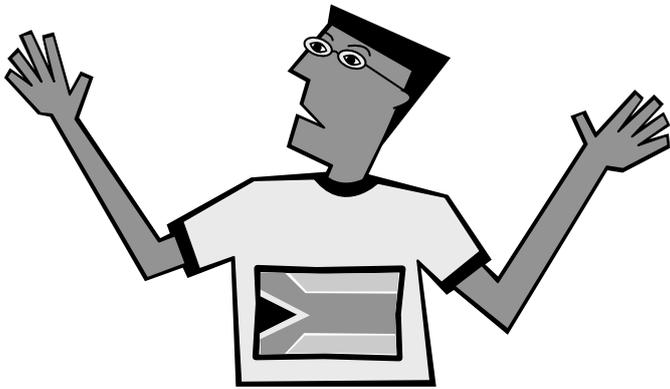
- 1 Give in-depth counselling on why it is important to tell a sexual partner. If the health care worker is unable to give counselling then the patient should be referred to outside counselling at another suitable place.
- 2 Give an explanation of the health care worker's duty to warn sexual partners in danger.
- 3 Tell the patient that the health care worker may have to breach confidentiality, and then offer him/her the opportunity to inform his/her sexual partner with or without help.
- 4 After trying these three steps, the health care worker can make the decision on whether or not it is necessary to tell the sexual partner.



The **South African Medical Association's (SAMA)** Human Rights and Ethical Guidelines on HIV: *A Manual for Medical Practitioners* notes the following:

"Where the patient firmly believes that his/her disclosure to a partner will put his/her life at risk, the medical practitioner's primary duty is to protect the life of the patient and act in his/her best interests. In some communities people living with HIV are persecuted. SAMA recommends that the patient's HIV status is not disclosed to the partner in these circumstances."

What can I do if someone gives out information about my HIV status?



If anyone tells another person your HIV status **without your consent**, they will have **violated your right to privacy**. You will be able to sue them (bring a case against them) and they may have to pay you damages. "Damages" is a legal term that means money given to you to make up for the harm you have suffered. You can also lay a **complaint** against them.

⌘ **Complaints against doctors, psychologists and dentists can be made to:**

The **Health Professions Council of South Africa (HPCSA)**, which used to be known as the South African Medical and Dental Council (SAMDC). They will follow this up and can even conduct a disciplinary enquiry that may decide that the doctor is no longer allowed to practice.

⌘ **Complaints against nurses can be made to:**

The **South African Nursing Council (SANC)**.

⌘ **You can also make a complaint to:**

The **South African Human Rights Commission (SAHRC)**.

What if I am unfairly discriminated against because I have HIV?



The Constitution and the Promotion of Equality and Prevention of Unfair Discrimination Act make it **illegal** for anyone to **unfairly discriminate** against you (treat you unfairly or unequally) because you have HIV. The Promotion of Equality and Prevention of Unfair Discrimination Act also gives you quick, cheap and easy ways of making complaints about this and having them worked out. Some sections of this Act are not active yet, so check with your local magistrate's court or the AIDS Law Project whether you can rely on this Act.

You can also make a complaint to the SAHRC.

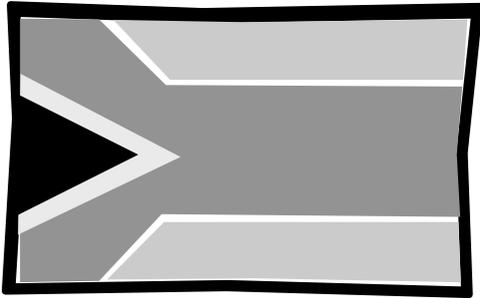
At work?

There are many laws protecting your rights at work. For example, the Employment Equity Act says you cannot be fired on unfair or arbitrary grounds just because you have HIV/AIDS. The Commission for Conciliation, Mediation and Arbitration (CCMA), the Department of Labour and your trade union may also be able to assist you.

"In the long run, preservation of confidentiality is the only way of securing public health."

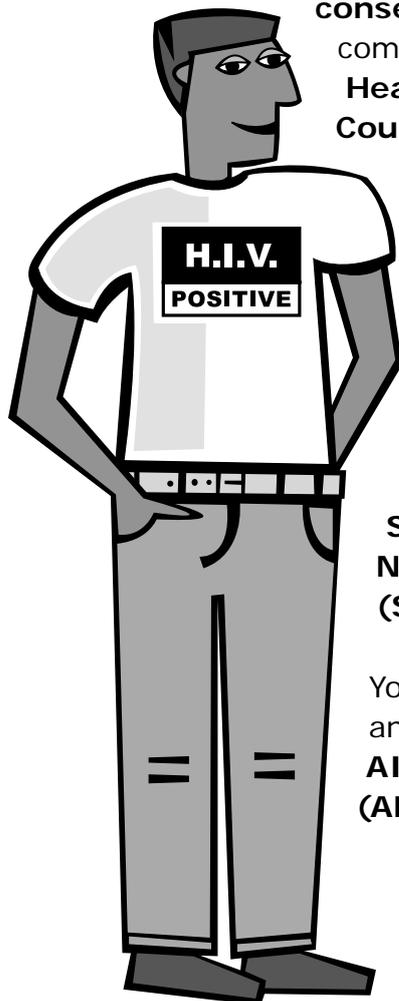
*- Judge Harms,
(Acting Judge of the Appeal Court in
the "McGeary Case")*

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.

Contact details

⌘ AIDS Consortium

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⌘ AIDS Law Project (ALP)

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www.alp.org.za

⌘ 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)

PO Box 1123, Pretoria 0001
TEL: 012 420 1000
FAX: 012 343 5400
www.sanc.co.za



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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www.tac.org.za

Glossary

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

HIV

Human Immunodeficiency Virus. The virus that causes AIDS.

AIDS

Acquired Immune Deficiency Syndrome. 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.

Who has the right to know your HIV status? Can a health care worker tell anyone other than you the results of your HIV test? Do you have to tell your employer? 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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