



HIV/AIDS and TB

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Introduction

HIV has become a pandemic of massive proportions, particularly in Southern Africa. While there is less prejudice about HIV nowadays, there are still many untrue stories about AIDS, which causes people who are living with the disease to live with fear, prejudice and discrimination. People must understand what HIV and AIDS are and how to prevent the disease from spreading, but it is also important that we look at ways of undoing the prejudice that has built up around the disease. South Africa is still experiencing the largest HIV and AIDS epidemic in the world.

TB is a serious public health issue in South Africa, with about 450 000 people developing the disease every year, and of these, 270 000 are also living with HIV which is a key factor in the TB epidemic. HIV sufferers have a higher risk of contracting TB and are therefore at greater risk.

What are HIV and AIDS?

HIV stands for the Human Immune Deficiency Virus. This virus attacks the immune system, which is the body's defence against disease. HIV can live in our bodies for years without us looking or feeling sick in any way. Most people with HIV feel healthy and can work and live healthy lives for many years. It is only when a person develops an AIDS-related illness that they become very ill.

AIDS is caused by HIV. AIDS stands for Acquired Immune Deficiency Syndrome. It is the name given to a group of serious illnesses that are caused by your body being unable to fight infections. People with HIV or AIDS are more likely to get some diseases and infections because their immune system cannot fight them off.

The different stages of HIV

Once you test positive for HIV and Aids, you should get treatment as soon as possible. With the right treatment, you can live a normal healthy life for a long time.

Without treatment, the disease follows four stages:

STAGE 1: PRIMARY HIV INFECTION: The early symptoms of HIV may include a sore throat, swollen glands, headache, muscle aches or similar flu-like symptoms, and afterward you will return to feeling completely well. This stage may last several years, during which the person might have no HIV-related illnesses

STAGE 2: THE ASYMPTOMATIC OR “SILENT” STAGE: If you have the primary HIV illness, you can feel very well for many years without showing any major symptoms. A person with HIV who lives a healthy lifestyle by eating healthy foods, taking exercise, food supplements and anti-retroviral therapy (ART), can remain in Stage 1 or 2 of the illness for many years, living a normal life. Where the person does not live healthily and/or fails to take anti-retroviral treatment (ARVs), they will begin to develop minor illnesses in Stage 2. Ear infections, frequent flu and skin problems are common at this stage.

STAGE 3: EARLY HIV SYMPTOMATIC DISEASE: Gradually, after many years, the person’s immune system starts to break down, and the CD4 cell count drops lower and lower. (The strength of a person’s immune system is calculated by their CD4 cell count). Some people will begin to show mild symptoms of HIV disease, for example, shingles, swollen lymph glands, occasional fevers, mild skin irritations and rashes, fungal skin and nail infections, mouth ulcers, chest infections and weight loss.

STAGE 4: MEDIUM-STAGE HIV SYMPTOMATIC DISEASE: This is the stage when the CD4 cell count gets very low, and people use ARVs to boost their immune systems. In stage four, the person has illnesses due to a very weak immune system. These may include PCP (Pneumocystis pneumonia), pneumonia, chronic diarrhoea, toxoplasmosis and meningitis. It is at this stage that a person is said to “have AIDS.” A person is also said to “have AIDS” if their CD4 count (white blood cells) goes under 200.

How do you get HIV?

There are only three ways to get HIV/AIDS:

1. Unprotected sex (sex without a condom)
2. Contact between your blood and infected blood or body fluids
3. Mother-to-child transmission.

UNPROTECTED SEX

This is the most common way that people get HIV/AIDS. If you have sex with an HIV-positive person and there is direct contact between the penis and vagina or anus, you can easily get infected. The virus lives in the fluids inside the penis and

vagina and can easily enter your bloodstream. Using condoms properly is the only protection against this kind of infection.

You cannot get HIV from kissing someone on the lips, hugging, sharing food and drink or using the same bath or toilet as someone who is HIV-positive. Deep kissing or French kissing can pass on HIV if you have sores in your mouth.

CONTACT WITH INFECTED BLOOD

If you have an open wound and it is exposed to the blood of an HIV-positive person, you can be infected. This contact could be through using the same needles for drugs or unsafe instruments used for circumcision. It is possible to get HIV if you use the same razor blade or toothbrush as an HIV-positive person if there are any traces of blood on the implement. While you could easily contract HIV from a blood transfusion if the blood is contaminated, all blood in SA is tested for safety. Medical workers can get it from accidentally pricking themselves with needles they have used to inject HIV-positive people.

MOTHER-TO-CHILD TRANSMISSION

HIV-positive mothers can pass the infection to their babies. Without treatment, an estimated 25-45 % of HIV-positive mothers will transmit the virus to their infants. HIV may be transmitted during pregnancy, labour, delivery and breastfeeding. This happens because of the contact with blood. To reduce mother-to-child transmission during pregnancy, the HIV-positive mother should be initiated on treatment (ARVs) at 14 weeks, regardless of her CD4 count. This will ensure that the mother's CD4 count increases and the viral load drops. After birth, the baby is immediately administered with Nevirapine syrup. The mother continues to take treatment.

If the baby is taking Nevirapine syrup, the mother can practice exclusive breastfeeding. This reduces the chances of HIV transmission from mother to child. Exclusive breastfeeding means the feed cannot be mixed with other fluids or solids (even water) except for prescribed medicines.

Who is at most risk of contracting HIV?

Anyone can get HIV, but some people are more vulnerable because they do not have the power to negotiate the terms of sex or because of their risky sex lives.

The groups who are most vulnerable and have the highest infection rates are:

- Young women between 15 and 30 years old – some of the women in this age group are in unequal relationships where they cannot refuse unsafe sex or are exposed to sexual violence

- Sexually active men and women who have more than one partner. Although polygamy (having more than one wife) is a custom followed only by some men, many others have a wife and a girlfriend or casual sexual partners. They may get the virus from a casual partner and pass it on to their wife.
- Migrant and mine workers who are separated from their families for most of the year, and many of them have multiple partners
- Transport workers who travel a lot and have multiple partners, and many of them use the services of sex workers
- Sex workers who are exposed to many partners and are sometimes powerless to insist on safe sex
- Drug users who share needles – one HIV-positive person can infect a group of people who share the same needle unless it is sterilised in between usage. Many drug addicts also become sex workers to pay for their drugs.
- People who practice anal sex – the anus can easily be injured during sex because it has no natural lubrication (wetness), and the virus can be passed on unless a condom is used. Women who have anal sex, gay men and other men who have sex with men (for example, prisoners), are vulnerable to this form of transmission.)

Young women are the most vulnerable because they are often powerless to say no to unprotected sex with an HIV-positive partner. They have the highest infection rate of all in South Africa. They are also the most common victims of rape and sexual abuse. Young girls who are virgins are also at risk because of the myth that a person can be cured of HIV or AIDS by having sex with a virgin. This is completely untrue.

Women are more vulnerable to HIV infection than men. A woman's vagina has a larger surface area for HIV to enter. Some sexual practices are dangerous for women as they can increase the risk of getting HIV, e.g. dry sex, which can lead to vaginal tearing and can make it easier for the virus to enter the body. Rape, especially if it is violent, can also increase the risk of getting HIV, as the victim cannot make her rapist wear a condom.

Men and women who have other sexually transmitted diseases (such as syphilis or gonorrhoea) are also more vulnerable because they often have open sores on their private parts.

How do you treat HIV and AIDS?

You can find out whether you are HIV-positive by having a free blood test at any clinic, doctor, or hospital. The results will, and should, only be given to you. If you are positive, you should tell your sexual partner so that they can also be tested, and you should only practice safe sex by using a condom.

There is no cure for HIV, but there are many ways to help people living with HIV to strengthen their immune systems, for example:

- By treating people with anti-retroviral drugs
- By treating the opportunistic infections that are caused by HIV so that people can live longer, for example, by giving people antibiotics to fight diseases
- By following a healthy diet, exercising and living in a clean and healthy environment
- By providing counselling and emotional support to the person and their family

There are medications that can help to fight illnesses like pneumonia and stomach infections that easily kill people with AIDS. These infections are called opportunistic infections. Many of the medicines used to fight opportunistic infections are available at clinics and the government is working to get more affordable medicines to people who need them.

Anti-retroviral treatment (ART), when taken properly, can greatly reduce the level of HIV in the body, reduce susceptibility to HIV/AIDS illness, and extend the person's life – many years. ART prevents the virus from reproducing and helps prevent further damage to the body. Many people find that, after taking ART for a few months, the level of the virus in their blood is so low that it cannot be detected.

ART cannot, however, repair damage to organs and systems of the body that the virus has already made. Once a person goes on ART, they must accept that they will have to keep taking the medication for many years to come and probably for the rest of their lives.

PROPHYLACTIC ANTI-RETROVIRAL TREATMENT

If a person has been exposed to HIV-infected body fluids (for example, through being raped), then they should start with ART within 72 hours of possible post-exposure through rape or unprotected sex. This is called Post-exposure prophylaxis (PEP). PEP is a short-term anti-retroviral treatment that reduces the likelihood of HIV infection after exposure to HIV-infected blood or sexual contact with an HIV-positive person. The drug regimen for PEP consists of a combination of ARV medications that are taken for a period of four weeks. (*See pg 587: Sexual violence and HIV testing*)

How do HIV and AIDS impact on individuals and society?

THE IMPACT ON PEOPLE LIVING WITH HIV/AIDS

HIV can be treated. But there is still a lot of ignorance and prejudice about HIV and AIDS, and it is often seen as a “death sentence”. Most people are scared when they are first diagnosed. Some respond by feeling that their lives are over and become

very depressed. Many people cannot accept the diagnosis and deny that they are positive to their families and to themselves. Others react with anger and refuse to be responsible and practice safe sex. Many people feel ashamed of their HIV status and think that their partners and family will reject them or that their communities will isolate them if they are open about being HIV-positive.

It takes courage to face this disease, and a lot of support is needed to fight it. People with HIV/AIDS can live long and productive lives if they get emotional support, strengthen their immune systems, get proper medical treatment and take good care of their health.

Many HIV-positive people do not know it, although people are becoming more aware of the importance of voluntary counselling and testing (VCT). Many people only realise they are HIV-positive when they develop AIDS and get seriously ill.

THE IMPACT ON FAMILIES AND CHILDREN

The burden of care falls mostly on the families and children of those who are ill. Often, they have already lost a breadwinner, and the few resources they have left are not enough to provide care for the ill person and food for the family. Families also suffer the daily stress of looking after someone who is ill and, in some cases, facing death. Many children, especially older female children, have to leave school to look after ill parents.

Children who are orphaned are often deprived of parental care and financial support. Many orphans are living in child-headed families where no one is earning an income. Many of them leave school and have no hope of ever getting a decent education or job. These children who grow up without any support or guidance from adults may become our biggest problem in the future. They are more likely to become street children or turn to sex work or crime as a way of surviving.

Older female relatives, mostly grandmothers, are the most likely to take in orphans. Many of them survive on pensions and already live in dire poverty. When their children die, and they become responsible for grandchildren, they get a huge extra financial burden, and at the same time, they lose the financial support they may have received from their children. Although there are certain grants available for caregivers who are taking care of orphans, they may not be sufficient. (**See pg 463: Social grants**)

POVERTY, THE ECONOMY AND HIV/AIDS

People who carry the heaviest burden as a result of HIV and AIDS are the poor. AIDS increases poverty, and families are the first to feel the economic effects of having members of the family who have HIV and/or AIDS. Families lose income if the

breadwinner falls sick and is unable to continue working. Often, another family member stays at home to look after the sick person and further income is lost. Families also face increased costs, as they have to spend money on caring for the sick or on funeral expenses when the person dies.

Government spending is affected since more and more of the taxes are spent on health care and welfare. Our social welfare system may not be able to cope with the number of orphans who need grants.

In addition, very poor people usually cannot afford the basic requirements for a healthy lifestyle - such as healthy food, a clean environment and clean water. They also cannot afford the costs of accessing basic health care services such as transport to clinics or hospitals. It is difficult for poor people to cope with the effects of HIV and to take their medicine regularly.

Most of the people who are dying from AIDS-related illnesses are between the ages of 25 and 44 - an age when most people are workers and parents. This has serious consequences for our economy and the development of the country.

BREAKING THE SILENCE AROUND HIV/AIDS

Although HIV/AIDS has become very common, it is still surrounded by silence. People are ashamed to speak about being infected, and many see it as a scandal when it happens in their families. People living with HIV or AIDS are exposed to daily prejudice born out of ignorance and fear. Fear leads to discrimination and victimisation against those living with HIV or AIDS. Some people still believe that only a certain group of people will be infected with HIV, such as gay men, sex workers, people who engage in risky sexual behaviour, and injecting drug users. This causes stigmatisation and discrimination against HIV-positive people. People become reluctant to test or disclose their status out of fear.

There are myths around HIV/AIDS that lead to people seeing it as something that should be kept secret. Many people see those with HIV/AIDS as people who are somehow to blame because they are promiscuous or homosexual. HIV is seen by some people as a plague that you can catch just from being in the same space with someone who is HIV-positive. In some communities, people with HIV or AIDS have been ostracised. This underlines the importance of widespread community education efforts because the ignorance and prejudice around HIV/AIDS can be almost as destructive as the disease itself. In some countries, AIDS activists have adopted the slogan "Fight AIDS, not people with AIDS." (See pg 665: *Running an HIV/AIDS and TB awareness campaign*)

There is a need to educate people to make responsible decisions that will prevent them from getting HIV. People should be encouraged to test and seek treatment if

they test positive. It is important to create awareness of HIV/AIDS in communities and encourage non-discriminatory practices for a more conducive environment that allows HIV-positive people to live more freely and openly.

HIV/AIDS and TB

What is TB?

Tuberculosis (TB) is an infectious disease caused by the bacteria known as *Mycobacterium tuberculosis*.

What is the association between TB and HIV?

TB and HIV form a lethal combination, each speeding the other's progress. It is essential to offer TB patients HIV testing with counselling. HIV weakens the immune system, increasing the susceptibility of an individual to TB infection and the progression of TB infection to disease. TB is a leading cause of death among people living with HIV. Early diagnosis and effective treatment of TB ensure a cure and stop transmission to others. Among HIV-infected patients, it is critical to diagnose and treat TB early.

How does TB spread?

Transmission occurs through the airborne spread of infectious droplets. When an infectious person coughs, sneezes, or spits, they propel TB bacteria into the air. Left untreated, a person with active TB can infect an average of 10 –15 people each year. People living with HIV are at a much greater risk of developing active TB once infected, which increases as the degree of immune suppression increases.

What factors affect TB transmission?

Businesses with a large migrant workforce, such as oil and gas companies, mining companies as well as health centres/hospitals, are workplace settings where there is an increased risk of TB. Transmission generally occurs indoors, where droplets can stay in the air for a long time due to poor ventilation.

TB is also more easily spread in crowded living, working or social conditions, such as in hostels, prisons, military barracks and shebeens.

What is the difference between TB infection and disease?

TB infection occurs when TB germs are breathed in and establish infection initially in the lungs. In most healthy individuals the immune system is able to keep the infection in check. This is referred to as latent TB infection.

TB occurs when conditions tip in favour of the TB germs because the immune system is weakened due to HIV infection, malnutrition, silicosis, cancer therapy or other chronic diseases such as diabetes, long-term steroid therapy, alcoholism, and physical and emotional stress. The TB bacteria then start replicating, causing increasing inflammation and tissue destruction until the person shows the signs and symptoms of TB.

What is drug-resistant TB?

Drug-resistant TB is when the bacteria that infected you are resistant to one or more anti-TB drugs. Drug resistance is possible in people getting TB for the first time (patients who have not received treatment with anti-TB drugs before), or they may have been infected with drug-resistant TB and not disclosed previous TB treatment. Drug resistance occurs much more commonly in patients with a history of previous treatment that was not completed properly.

How can TB be recognised?

If TB occurs following the initial infection, it is referred to as primary TB, which is common in children and HIV-positive individuals. Pulmonary TB (in the lungs) is the most common and contagious form of active TB. TB can occur in almost any other part of the body, including the lymph glands, lungs, joints, bones or intestines, and is called extra-pulmonary TB. In HIV-infected TB patients, TB often affects more than one organ, and pulmonary and extra-pulmonary TB commonly co-exist.

Why is early diagnosis important?

The systematic and early identification of adults with a persistent cough lasting two weeks or more (particularly among outpatients in health facilities) is important, as this reduces treatment delays and identifies infectious patients who are a risk to the community and others in their workplace. Early diagnosis and effective treatment reduce the chances of dying from TB and transmission of TB to others.

What are the symptoms of TB?

The most common symptom of pulmonary TB is a persistent cough for two weeks or more, where patients cough up bits of blood.

It may be accompanied by one or more of the following:

- Chest pain
- Loss of appetite and weight
- Tiredness
- Fever, particularly with a rise in temperature in the evening and night sweats
- Shortness of breath
- Coughing up blood may occur in complicated cases

Symptoms of extra-pulmonary (outside the lungs) TB depends on the organ involved. Chest pain from tuberculosis pleurisy, enlarged lymph nodes, and a sharp angular deformity of the spine are the most frequent signs.

How is TB treated?

The primary anti-TB medicines are Isoniazid (H), Rifampicin(R), Pyrazinamide (Z), Streptomycin (S) and Ethambutol (E). Apart from Streptomycin, the drugs are used in fixed-dose combination (FDC) tablets. Treatment regimens for new cases and retreatment exist for adult patients. Treatment is in two phases: an intensive phase (two or three months) and a continuation phase (four or six months). The initial intensive phase aims to kill the TB bacteria rapidly. The continuation phase of treatment aims to destroy any lingering bacteria that could trigger a relapse. Treatment in the intensive phase is directly observed by a treatment supporter.

HIV/AIDS and rights

The Bill of Rights has a list of fundamental rights of all people living in South Africa. In addition to the right of equality under the Equality Clause (Section 9 of the Bill of Rights), these rights are also extremely important. The Constitution includes many rights, but most important for people living with HIV and AIDS are the socio-economic rights such as the right to basic health care, education, social services, shelter, and so on. The government has a duty to provide as many of these services as it can afford.

WHAT RIGHTS MEAN FOR PEOPLE LIVING WITH HIV OR AIDS		
Section in the BILL OF RIGHTS	RIGHT	WHAT IT MEANS FOR YOU IF YOU ARE LIVING WITH HIV OR AIDS
10	HUMAN DIGNITY Everyone has inherent dignity and the right to have their dignity respected and protected	A person or institution, such as a hospital or company, may not insult or take away your self-respect by their words or actions.
12	FREEDOM AND SECURITY OF PERSON Includes the right to: <ul style="list-style-type: none"> • Make decisions about reproduction • Security and control over your body • Not be subjected to medical or scientific experiments without your informed consent 	You have the right to make your own decisions about medical treatment and pregnancy, e.g. you cannot be forced to have an HIV test. You may not be treated in a cruel or degrading way by any person or institution.
14	PRIVACY Everyone has the right to privacy	You have the right to keep the fact that you have HIV or AIDS to yourself. An employer or hospital cannot force you to tell them or force you to have an HIV test.
16	FREEDOM OF EXPRESSION Everyone has the right to freedom of expression, which includes freedom to receive or impart information or ideas.	Proper information can be made available in schools or prisons about how to prevent HIV.
18	FREEDOM OF ASSOCIATION Everyone has the right to freedom of association.	You can join any organisation you choose. You cannot be forcefully separated from other people.
21	FREEDOM OF MOVEMENT AND RESIDENCE Everyone has the right to: <ul style="list-style-type: none"> • Move about freely • Enter, remain in or leave the country • Reside anywhere in the country 	You are free to move around the country. You cannot be forced to live in a separate place, away from the rest of society.

22	FREEDOM OF TRADE, OCCUPATION AND PROFESSION Every citizen has the right to choose their work freely.	You can choose what kind of work you want to do, e.g. you may not be told that you cannot be a teacher or a health care worker.
23	LABOUR RELATIONS Everyone has the right to fair labour practices.	You may not be unfairly discriminated against at work.
24	ENVIRONMENT Everyone has the right to an environment that is not harmful to their health or wellbeing.	This right may be important for people living in a state institution such as a prison or psychiatric hospital.
26	HOUSING Everyone has the right to have access to adequate housing. No one may be evicted from their home or have their home demolished without a court order.	You may not be refused a subsidy or loan to buy a house because you have HIV or AIDS. It is unlawful to evict you from your home because of your health.
27	HEALTH CARE, FOOD, WATER AND SOCIAL SECURITY No one may be refused emergency medical treatment. Everyone has the right to access: <ul style="list-style-type: none"> • Health care services, including reproductive care • Social security, including appropriate social assistance if they are unable to support themselves and their dependants 	Hospitals or medical people cannot refuse to treat you. You have the right to a disability grant if you are too ill to support yourself or your family.
29	EDUCATION Everyone has the right to a basic education, including adult basic education.	You have the same right as anyone else to education. A school cannot refuse to educate you or your child because you have HIV or AIDS.
32	ACCESS TO INFORMATION Everyone has the right to see any information held by another person that they need in order to exercise or protect their rights.	If for example you feel your rights are being violated because of a company policy, you can demand to see the policy and may then challenge it in court. You have the same right with private institutions or the state, for example an organisation, or your medical records at a state hospital.
33	JUST ADMINISTRATIVE ACTION Everyone whose rights have been negatively affected by administrative action has the right to be given written reasons. This includes reasons for very long delays.	If you believe that you are being refused a social service (e.g. a house or education) for unjust reasons, you can demand to get the reasons in writing. You may then decide to challenge the decision.
35	ARRESTED, DETAINED AND ACCUSED PEOPLE Everyone who is detained, including every sentenced prisoner, has the right to conditions of detention that are consistent with dignity.	Prisoners cannot be discriminated against or treated in an undignified way just because they have HIV or AIDS.
Acknowledgements: HIV/AIDS & The LAW: A Resource Manual, 2nd edition. The AIDS Law Project & The AIDS Legal Network		

Health and medical rights

People also complain that information about their illness is not kept confidential. Healthcare workers also have rights, including the right to a safe working environment, while patients have rights to:

- Confidentiality
- Testing for HIV and informed consent
- Medical treatment

Confidentiality

Confidentiality means that doctors, nurses, psychologists, dentists and other healthcare workers have a moral and legal duty to keep all information about patients confidential. Any information about the patient's illness or treatment cannot be given to another person unless:

- The patient consents (agrees) to this
- The information is about the illness or treatment of a child – then health workers can tell others but only with the permission of the child's parent or guardian
- The patient is dead – then the doctor must get permission from the next-of-kin (the person's closest family)

EXAMPLE

THE McGEARY CASE

In the McGeary case, the Supreme Court of Appeal said that a doctor cannot tell other doctors about the HIV status of a patient without the patient's consent. Mr. McGeary applied for a life assurance policy. The insurance company told him to have an HIV test before they could approve his application. The doctor got the results of the test and told McGeary that he was HIV-positive. The next day, the doctor played golf with another doctor and a dentist. During the game, they discussed AIDS and McGeary's doctor told the other two that McGeary was HIV-positive. The news of McGeary's condition spread around the small community. McGeary began a civil claim to get compensation from his doctor for breaking his rights to confidentiality. The Court said the doctor had to pay



McGeary compensation for breaking his right to confidentiality. The Supreme Court of Appeal said that a doctor cannot tell other doctors about the HIV status of a patient without the patient's consent.

SOME RULES ABOUT CONFIDENTIALITY

Telling other health care workers: A health care worker must get a patient's permission before giving any of that patient's medical information to another health care worker.

Telling a patient's sexual partner: A healthcare worker may not tell the patient's sexual partner that the patient has HIV unless the partner appears to be at risk because the patient refuses to practice safer sex. The health care worker must counsel the patient on the need to tell their sexual partner and to practise safer sex. The health care worker must then warn the patient that if they do not tell their sexual partner or practise safer sex, then the health care worker will have to tell the partner about the person's HIV status.

Telling a court: A court can order a health care worker to give them confidential information.

CONFIDENTIALITY AND OPENNESS

HIV/AIDS is not an open issue mainly because people living with the disease fear the prejudice and discrimination they will suffer if they tell people about it. Communities need to be educated about HIV and AIDS and the supportive role they can play in the lives of people living with the disease. In this way, people may be encouraged to be open about their HIV status. Some people choose to be open about their HIV status to certain people, but this does not mean they lose their right to confidentiality with a doctor, nurse, health care worker, employer or friend. A person's personal right to privacy and confidentiality must always be respected.

WHAT CAN YOU DO IF A HEALTHCARE WORKER ABUSES YOUR RIGHT TO CONFIDENTIALITY?

You can complain to the Health Professions Council of South Africa (HPCSA). You can also make a civil claim for damages (compensation) against the healthcare worker, hospital or clinic, or any member of the public who has abused your rights. (See: pg 1078: Resources)

HIV testing and informed consent

Everyone has the right to make their own decisions about their body, so no patient can be given medical treatment without their consent. Consenting to medical treatment has two parts to it: information (understanding) and permission (agreeing).

With an HIV test, you must know what the test is, why it is being done and what the result will mean for you before you agree to the blood sample being taken. This is called pre-test counselling. After the HIV test results have been received, you must be counselled again to help you understand and accept the effect that a negative or positive result will have on your life. This is called post-test counselling.

EXAMPLE

Thami is a caregiver in a children's home. The matron informs him that all staff in the hospital must have a Hepatitis B test. Thami agrees to this. But, the hospital does an HIV test, too, saying it saves time and money to do both tests at the same time. The matron tells Thami he is HIV-positive. Thami is furious because he only gave permission for the Hepatitis B test. The matron did not have a right to do the test. She should have discussed it with Thami first and obtained his consent.

SOME RULES ABOUT HIV TESTING AND CONSENT

Here are some rules to remember:

- You can give verbal or written consent to have an HIV test
- If you go to hospital, you cannot be tested for HIV without your consent

EXCEPTIONS TO THE RULE OF INFORMED CONSENT

These are the only exceptions to the rule that a person must give their consent to treatment or an operation:

- If a patient needs emergency treatment
- Testing done on blood donations
- Mentally ill patients - In this case, the mental hospital must get permission from one of the following people: the patient's husband or wife, parent, child (if the child is 21 or older), brother or sister

- HIV tests are routinely done on the blood of all pregnant women for health research, but the name of the woman is not attached to the blood sample, so no one knows whose blood it is

WHO CAN GIVE CONSENT?

A person who is directly affected must give consent. Only in exceptional circumstances can it be given by another person, e.g. on behalf of mentally ill patients. In the event that a person is unable to consent, consent can be given by a person who has a legal right to consent on behalf of another person, e.g. guardian or curator.

Adults who have a legal capacity (the ability to make legal decisions) and who are of “sound and sober mind” can give valid consent to medical treatment (consent recognised by law). Adults without legal capacity (e.g. people who are mentally ill or have a mental disability) cannot give consent without assistance. Couples must consent to treatment individually – one partner in a relationship cannot consent to treatment on behalf of the other partner.

Children over 12 years can also give their consent to medical treatment. When a child is too young to consent, either one of their parents or guardians must give consent. (See pg 643: *Children and youth and HIV/AIDS*)

WHAT CAN YOU DO IF AN HIV TEST WAS DONE WITHOUT YOUR CONSENT?

If an HIV test was done without consent, your rights have been abused. You can complain to the Health Professions Council of South Africa (HPSCSA). You can also bring a civil claim for invasion of privacy and a criminal charge of assault against the health care worker or the person they were acting on behalf of.

CASE STUDY

HOFFMAN v SOUTH AFRICAN AIRWAYS (SAA)

Mr Hoffman applied for a job as a cabin attendant with South African Airways (SAA) and was asked by SAA to take an HIV test. He tested HIV-positive. SAA refused to give Mr Hoffman the job because, they said, part of his job involved travelling to different countries, and he would need to have a yellow fever vaccination. It is not advisable for someone with HIV to have these vaccinations. SAA said that this was an inherent requirement of the job in the airline and, therefore, they couldn't employ him. The Constitutional Court was asked to decide if SAA had gone against Hoffman's rights to equality, dignity and fair labour practices. The court decided that:

- SAA had discriminated against Hoffman
- The discrimination was unfair and infringed on his dignity

Being HIV-negative was not an inherent requirement of the job of being a cabin attendant; they should have taken greater steps to investigate how Hoffman's immune system could have dealt with travelling and the possibility of getting a strange disease.

The right to health care and medical treatment

Everyone has the right of access to health care services and medical treatment, including access to affordable medicines and proper medical care. The right to access to health care services includes the right to proper care from a health care worker, which means it is against the law for a health care worker to:

- Refuse to treat a person because they have HIV
- Treat people with HIV differently from other patients.

If a hospital or clinic refuses to treat someone living with HIV/AIDS, they can be reported to the Department of Health, the Public Protector, the South African Human Rights Commission or Legal Aid South Africa. The case can also be taken to the High Court, which can review and cancel the hospital's decision to refuse to provide treatment. (*See pg 629: The right to health care and medical treatment*)

The right to health care includes the provision of medical treatment to people in need. The government has committed itself, as part of its strategic plan, to making anti-retroviral treatment available to all people who have reached a certain stage of their illness. A doctor must medically certify a person who wants to receive anti-retroviral treatment.

HIV/AIDS and TB in the workplace

Laws that give employees with HIV, AIDS and/or TB rights at work

Employers, supervisors or colleagues often discriminate against employees living with HIV, AIDS or TB. The following laws give people rights at work:

THE CONSTITUTION

The Constitution gives all employees the right to be treated fairly at work, including the right to fair labour practices and the right to equal treatment and non-discrimination.

THE LABOUR RELATIONS ACT (LRA)

The LRA covers all employees and employers and treats everyone the same. This means that domestic workers now have the same rights as factory workers.

The only employees who are not covered by the LRA are people working for the South African National Defence Force (SANDF) and the State Security Agency. But these employees are protected by the Constitution and therefore have the right to fair labour practices and equality. The LRA gives employees the right to be treated equally. It is an unfair labour practice to discriminate against an employee on any grounds, including race, gender, sex, colour, sexual orientation, age, disability and so on. Discrimination is 'automatically unfair' if it violates any of the basic rights of employees, such as discrimination on grounds of a person's disability. (See pg 361: *Automatically unfair dismissals*)

CASE STUDY

GARY SHANE ALLPASS v MOOIKLOOF ESTATES (PTY) LTD (2011)

Mr Allpass was employed by Mooikloof Estates as a horse riding instructor and stable manager. At the time of his recruitment, he had been living with HIV for almost 20 years. Before being hired, Mr Allpass had an interview where he informed his employer that he was "in good health".

Shortly after he was hired, he – along with other employees – was asked to complete a form requiring him to disclose whether he was taking any "chronic medication."



Mr Allpass complied and disclosed that he was taking, among other things, daily medication to manage his HIV condition.

When his employer found out about his HIV-positive status, he immediately terminated his employment on the grounds that he had fraudulently misrepresented his condition and that he was, in fact, “severely ill”.

The court decided that Mr Allpass had been discriminated against and unfairly dismissed due to his HIV status. The court also considered that the dismissal violated the equality rights.

THE EMPLOYMENT EQUITY ACT (EEA)

The EEA is more specific about the rights of people living with HIV or AIDS. The EEA explicitly prohibits unfair discrimination against people at work on grounds of their HIV status. The EEA also prohibits testing for HIV in the workplace unless this is authorised by the Labour Court. (See pg 345: *Employment Equity Act*)

An employer cannot:

- Force a person who is applying for a job to have an HIV test
- Automatically make an HIV test part of a medical examination
- Force someone who is already working for them to have an HIV test

The EEA doesn't cover members of the South African National Defence Force or the State Security Agency. But members of these organisations can still take their cases to any court with jurisdiction including the High Courts.

THE OCCUPATIONAL HEALTH AND SAFETY ACT AND MINE HEALTH AND SAFETY ACT

Sometimes, an accident at work can cause a bleeding injury. If the injured person is HIV-positive and someone who tries to help the person also has an open wound, there is a small chance of the helper becoming infected if the wound comes into contact with the injured person's blood. The employer has a responsibility to make sure that the workplace is safe and that employees are not at risk of HIV infection at work. (See pg 346: *Occupational Health and Safety Act*)

There are regulations issued by the Department of Employment and Labour which say:

- Employers must keep rubber gloves in the first aid box
- All staff must be trained so that they know what safety measures to take if an accident happens

COMPENSATION FOR OCCUPATIONAL INJURIES AND DISEASES ACT (NO. 130 OF 1993) (COIDA)

COIDA gives employees the right to compensation if they are injured or become ill at work. If you get infected with HIV because of a workplace accident, you can claim for compensation. (See pg 394: *Compensation Fund*)

THE MEDICAL SCHEMES ACT NO. 131 OF 1998 AND REGULATIONS: GOVERNMENT GAZETTE 20556, 20 OCTOBER 1999

Medical aid as a form of insurance is an important employee benefit in the workplace. In the past, the majority of medical schemes refused to cover illnesses that were linked to HIV infection.

The *Medical Schemes Amendment Act of 1998* prohibits discrimination on the grounds of 'state of health'. This covers a person living with HIV or AIDS. It means that the medical scheme cannot refuse to cover reasonable care that could prolong the health and lives of people living with HIV or AIDS. The *Medical Schemes Act* stops medical schemes from discriminating against people living with HIV or AIDS. It states that all schemes must offer a minimum level of benefits, decided by the government, to employees with HIV or AIDS. The minimum levels of benefits include:

- They must diagnose and treat all opportunistic infections for HIV or AIDS
- They must provide anti-retroviral treatment

General rules about HIV and AIDS that apply in the workplace

- An HIV-positive person does not have a duty to give this information to their employer because of their right to privacy
- If you tell your employer about your HIV status, the employer cannot tell anyone else without your consent. If the employer tells anyone else, this is violating your right to privacy, and it is possibly an unfair labour practice
- A doctor or health care worker who tells an employer about an employee's HIV status without their consent is acting against the law. This is a violation of the employee's right to confidentiality
- An employer cannot demand to know if the cause of an illness is HIV infection
- An employer cannot refuse to employ you because you have HIV
- An employer cannot dismiss you because you have HIV
- An employer cannot dismiss you because you have HIV, even if other employees refuse to work with you

- The *Promotion of Equality and Prevention of Unfair Discrimination Act* also protects an HIV-positive person from unfair discrimination in the workplace

CASE STUDY

SOUTH AFRICAN SECURITY FORCES UNION AND OTHERS v SURGEON GENERAL AND OTHERS

The AIDS Law Project (now SECTION27) represented the SA Security Forces Union (SASFU) and three individual people with HIV who were denied recruitment or promotion in the SANDF based on their HIV status. The old HIV testing policies of the SANDF were used to exclude all people with HIV from recruitment, promotion and foreign deployment.

The court declared that the blanket exclusion practised by the SANDF was unconstitutional. The case was important because it showed that there is no medical evidence to justify a blanket ban on all people with HIV.

Code of Good Practice on HIV/AIDS and Employment

The Department of Employment and Labour has published a *Code of Good Practice on Key aspects of HIV and Employment*. This Code gives employers and trade unions guidelines to ensure that HIV-positive people are not unfairly discriminated against in the workplace.

This includes provisions dealing with:

- Creating a non-discriminatory work environment
- HIV testing, confidentiality and disclosure
- Providing equitable employee benefits
- Dismissals
- Managing grievance procedures

The Code also provides guidelines for employers, employees and trade unions on how to manage HIV/AIDS in the workplace.

For a copy of the Code, go to the [website: www.labour.gov.za](http://www.labour.gov.za); click on 'Resource Centre'; click on Codes of Good Practice'; click on 'Employment Equity', then on the specific Code of Good Practice.

What happens if you become too ill to work?

All employees have a right to sick leave, and an employer has no right to discriminate against or dismiss an employee who uses these rights. The *Basic Conditions of Employment Act* says an employee can have 6 weeks' paid sick leave over any 3-year cycle.

However, people with HIV could eventually start to become ill, and this will affect their capacity to perform their work. An employer is allowed to dismiss an employee on grounds of incapacity and poor work performance, even if the employee has not used all their sick leave. This means if an employee is unable to do their job properly because of their illness, then the employer will eventually be able to dismiss them.

The *Labour Relations Act* sets out clear procedures for employers and employees when dealing with dismissals for incapacity.

The Code on HIV states, "Where a worker has become too ill to perform their current work, an employer is obliged to explore alternatives, including reasonable accommodation and redeployment". It is unlawful for an employer to dismiss an employee simply because he/she suspects that the employee may have AIDS but cannot show any evidence of incapacity.

When can TB patients return to work?

Since patients with active TB may be sick and infectious, they may be advised not to work during the initial stages of treatment until they are no longer infectious. Most patients are no longer infectious after approximately two weeks of treatment. Such patients should continue treatment and can return to work; they are not a threat to other employees.

TB patients where multi-drug resistance is confirmed or strongly suspected should not be allowed to return to work until they have had tests that confirm that they do not have resistant TB. Adequate sick leave should be available to employees to allow them sufficient time to recover, especially those with drug-resistant TB, as they may require hospitalisation for a few months.

Can TB patients go on leave?

TB patients, particularly those with workplace DOT treatment, should be encouraged not to take annual leave during the intensive phase of treatment. Prior to going on leave, the patient should be re-counselled on the importance of continuing treatment while on leave.

The patient should be supplied with adequate treatment for days away and be encouraged to use an alternative treatment supporter while on leave. Employees with TB going on extended leave should be transferred to their nearest clinic.

How can TB be prevented in the workplace?

The three underlying principles of TB control are: find, treat/cure and prevent.

1. Prompt identification and diagnosis of TB
2. Regular and correct treatment and cure of TB
3. Prevention of TB

In addition to promptly identifying TB cases and ensuring they are treated and cured, TB can also be prevented by TB preventive therapy targeted to those who are at a high risk of developing TB, such as HIV-infected workers or those with silicosis, an occupational lung disease that results from silica dust exposure. Silica dust exposure may occur in mines, quarrying, sandblasting, tunnelling and smelting.

Infection control is essential to prevent transmission of TB in the workplace. The elements of a workplace infection control programme include:

- Developing an infection control plan following a risk assessment
- Implementing environmental controls, such as ensuring adequate ventilation by having outdoor waiting areas and windows that open or through simple architectural modifications to improve ventilation, cough hygiene for coughing patients and the use of ultraviolet-light air disinfection
- Identifying workers that may have TB as soon as possible and referring them for prompt diagnosis and treatment
- Collecting sputum samples in a safe manner. This is best achieved by collecting sputum samples outside but not in direct sunlight. If this is not possible, sputum should be collected in a well-ventilated room
- Relevant training for administrators and healthcare workers
- Offering HIV testing for those working in high-risk situations and alternative jobs for HIV-infected workers
- Ensuring the use of personal respirators (masks), particularly for those working with drug-resistant TB patients (*See pg 365: Dismissal for incapacity*)

What can you do to protect your rights at work?

Employees can take disputes about dismissals or discrimination to a Bargaining Council or the Commission for Conciliation, Mediation and Arbitration (CCMA). The Bargaining Council or CCMA will try to settle the dispute by conciliation, mediation or arbitration. (See pg 370: *Solving disputes under the Labour Relations Act*)

Cases about unfair discrimination and automatically unfair dismissal will be referred to the Labour Court. Employees can appeal against decisions of the Labour Court by going to the Labour Appeal Court. (See pg 628: *Case Study: Hoffman vs South African Airways*)

Women and HIV/AIDs

The impact of the HIV pandemic has been far greater on women than men. There are many reasons for the vulnerability of women to HIV:

- **Physical reasons:** Women are more vulnerable to HIV infection than men. A woman's vagina has a larger surface area for HIV to enter. Some sexual practices are dangerous for women as they can increase the risk of getting HIV, e.g. dry sex, which can lead to vaginal tearing and can make it easier for the virus to enter the body. Rape, especially if it is violent, can also increase the risk of getting HIV because the victim cannot make the rapist wear a condom.
- **Social and economic reasons:** Because women are often financially dependent on their partners, it can be difficult for a woman to tell her partner to use a condom because she may be afraid that he might reject her and leave her with no financial support. The unequal position of women in society also means that it is often difficult for women to get access to good health care and information about how to prevent HIV.
- **Sexual reasons:** Many men do not believe that women have the right to make decisions about their bodies and when to have sex. This makes it difficult for women to be assertive (to make their own decisions) about sex and to demand that their partners have safer sex. Many women do not know that they have the right to refuse to have sex with their husbands. If a woman does not consent to sex with her husband, the husband can be charged with rape.

Rape and HIV infection

If a woman has been raped, she should ask for an HIV test. Even if the result is negative, she should go for another test after 3 months. If she tests positive, this may be proof that she became positive as a result of the rape. However, the rapist has to take an HIV test. The *Sexual Offences and Related Matters Amendment Act* allows a person accused of a sexual offence where there is a risk of HIV transmission to be tested without his permission and his HIV status to be disclosed to the victim.

A rape survivor can also make a civil claim against her rapist. If she can prove that she became HIV positive as a result of the rape, she can make a claim against the rapist for her medical expenses and for pain and suffering because of the rape. (*See pg 601 Problem 1: Reporting rape or assault and going to court; See pg 587: Sexual violence and HIV testing*)

Termination of pregnancy (Abortion)

The *Choice of Termination of Pregnancy Act* gives women the right to have safe and legal terminations.

APPLYING FOR TERMINATION

To apply for an abortion, the woman should:

- Ask her doctor to refer her to a hospital or clinic where terminations take place
- Go to a non-profit clinic that assists women with advice and care on issues around pregnancy and reproduction
- Go to the hospital in her area that the government has set aside to do terminations (called 'designated hospitals')
- Go to the nearest doctor or nurse at the local primary health care clinic
- Consult a counsellor at a community centre
- Visit a social worker in her district

Sometimes, healthcare workers do not give women the right information because they think that it is wrong for a woman to terminate her pregnancy. At other times, healthcare workers have forced pregnant women living with HIV or AIDS to have a termination. This is against the law, as only a woman has the right to decide whether she wants to continue with her pregnancy or not. If this happens to you, you should make a complaint to the Commission on Gender Equality (CGE) or the Department of Health.

WHERE WILL THE TERMINATION TAKE PLACE?

The termination will take place at a hospital or clinic that has been authorised to do terminations by the health minister. Social workers, doctors, nurses and midwives will be able to advise a woman where the nearest facility is.

TERMINATION BY HIV-POSITIVE WOMEN

A woman living with HIV or AIDS may apply for a termination, as without treatment, there is a nearly 20% risk of infection to her child. It is possible that she may be able to have a termination even after the 20th week of pregnancy. A woman can only have a termination after the 20th week of her pregnancy if a doctor, after discussing it with another doctor or a registered midwife, believes that the pregnancy could be dangerous for the woman or could result in a deformed baby.

CONSENT FOR TERMINATION OF PREGNANCY

The *Choice on the Termination of Pregnancy Act* says that a woman doesn't need to ask her husband before she decides to end her pregnancy. Healthcare workers cannot refuse to do a termination because a woman has not told her husband.

TERMINATION FOR A GIRL UNDER THE AGE OF 18 YEARS

The law says that a young woman under 18 may apply for a termination without the knowledge or consent of her parents. Doctors and midwives should advise her to discuss this with her parents, but they cannot force her to do this. Healthcare workers cannot refuse to terminate her pregnancy if she does not want to discuss her decision with her parents.

Sterilisation

A woman with HIV cannot be sterilised unless she agrees to this. All women, including women with HIV, have the right to have children. If a woman with HIV chooses to get sterilised, the hospital must respect her decision. She does not have to discuss her decision with her husband or get his consent.

CONSENT TO STERILISATION

A woman of 18 years or older can consent on her own to sterilisation. As sterilisation is a medical operation, a girl under 18 must have the consent of her parents or legal guardians before a hospital will agree to the operation.

Commercial sex work

In South Africa, it is a crime to be a commercial sex worker. This is sometimes still referred to as 'prostitution'. It is also a crime to solicit (get customers). Although both men and women can be sex workers, it is usually women working on the streets who are most often prosecuted and who are most vulnerable to violence and abuse.

Commercial sex workers are vulnerable to HIV because:

- They are not always able to insist that their customers use condoms, and the sex is often violent
- Because sex work is illegal, it is difficult for sex workers to get information about HIV and safer sex practices
- Sex workers are often scared to say that they are sex workers and are not able to go to organisations where they could get help and information
- They are also not able to protect themselves from rape and abuse because they cannot report these crimes to the police

Customary practices and HIV/AIDS

For many people, customary law is the most important law in their lives, controlling areas of their lives like their marriages, their property, and their right to inherit.

But some customary laws discriminate and make people vulnerable to HIV and AIDS because, for instance, it traditionally gives women less power than men. Various customary practices have been linked to HIV and AIDS, e.g. ritual male circumcision, healing scarification and virginity testing.

Customary law is the written and unwritten rules which have developed from the customs and traditions of communities. They are laws that apply to certain cultures or ethnic groups. The ordinary courts use customary law. For customs and traditions to become law, they must be:

- Known to the community
- Followed by the community
- Enforceable (able to be carried out)

Three important ways that the Constitution and Bill of Rights have changed the way customary law is used:

1. Customary law must be in line with the principles in the Bill of Rights. The Bill of Rights protects the right to culture, but it also protects the right to equality and non-discrimination and the right to dignity
 2. Identify cultural practices that deserve to be protected because they do not discriminate and those that should be done away with because they discriminate unfairly.
 3. Customary law should not be used to discriminate
-

Mother-to-child transmission of HIV

Research has shown that giving anti-retroviral drugs to HIV-positive pregnant mothers before they give birth decreases the risk of passing HIV on to the baby.

The Constitutional Court has said that the national government must make it possible for all pregnant mothers to have access to drugs that will prevent mother-to-child transmission of HIV.

LGBTQI+ persons and HIV/AIDS

The gay, lesbian, bisexual, transgender, queer and intersex (LGBTQI+) communities have faced much of the blame, discrimination and prejudice linked with HIV/AIDS. A gay person with HIV or AIDS will, therefore, suffer a double burden of discrimination and negative attitudes towards them – because of having the disease and because of being gay. As a result of the general prejudice and discrimination against gay and lesbian people, important ways of educating people about HIV and AIDS are lost. For example, sexuality education in schools ignores or avoids discussion about lesbian or gay relationships.

Social prejudice: There is still a lot of social prejudice against lesbians and gay men from their families in the community, workplace, schools, churches, and public services.

The effects of double discrimination: LGBTI people often experience double discrimination:

- Discrimination because of their sexual orientation and
- discrimination because of HIV/AIDS

This discrimination can put them at more risk of getting infected with HIV and make prevention and care work much more difficult. It can also worsen the impact of HIV on their lives.

Reasons for greater risk and vulnerability:

- It is harder to do direct and open, safer sex education because many people still think that same-sex acts are immoral.
- Many men and women who have same-sex relationships believe their behaviour is illegal or socially unacceptable – as a result, many deny to themselves, to their close family and friends, and to the broader community that they love or have sex with people of the same sex.
- Many LGBTQI+ persons cannot, or are afraid to, use public services (like health care and welfare, sexuality education) that would help to reduce the risk of HIV infection or would help them to cope with HIV infection.

SEXUALITY EDUCATION AT SCHOOL

Sexuality education ignores, avoids or misrepresents same-sex practices or relationships. Most of the HIV/AIDS prevention materials aimed at school students and youth do not discuss same-sex relations. They are silent about the needs of young people who are not heterosexual, and often, young people cannot get access to any information about same-sex practices.

Most of the safer sex tools – like condoms – that are available in South Africa are not suitable for lesbian or gay safer sex. Lesbian safer sex tools like dental dams and rubber gloves are not distributed widely by the health department. Some of the condoms available in South Africa are not suitable for anal sex and do not come with lubricants such as KY jelly.

The Constitution prohibits unfair discrimination on the basis of sexual orientation. LGBTQI+ students and youth have a right to get suitable information, sexuality education or life skills training on how to protect themselves.

THE WORKPLACE

LGBTQI+ persons face a lot of discrimination at work, for example, in hiring, promotion and benefits. The *Labour Relations Act* specifically prohibits discrimination on the grounds of sexual orientation and marital status, in line with the Constitution.

MEDICAL AID ASSISTANCE

Lesbian and gay employees were often not allowed to register their same-sex partners on their medical aid schemes, and many companies still exclude

same-sex partners from their schemes. The *Medical Schemes Act* says it is against the law for medical aid schemes to refuse to register a same-sex partner.

CASE STUDY

LANGEMAAT v MINISTER OF SAFETY AND SECURITY (1998)

In Langemaat v Minister of Safety and Security (1998), a lesbian who worked for the police wanted to add her partner to her medical aid as a dependant but was not allowed to because the medical aid scheme did not include same-sex partners as dependants. The High Court said that this was discrimination on the basis of sexual orientation.

MEDICAL CARE

Doctors need to know the sexual orientation of their patients. But once doctors know this, they have to respect the privacy and confidentiality of the patient.

If a doctor or any health care worker discriminates against you because you are lesbian, gay, bisexual, transgender or intersex, they are breaching:

- Their duty to give the best care and treatment to patients
- Their constitutional duty to equal treatment of all patients
- The *National Health Act*, which prohibits discrimination on the basis of sexual orientation

Challenging unfair discrimination by a medical professional

If you do not receive adequate medical treatment or care because a healthcare worker is homophobic, you can:

- Make a civil or constitutional case against the hospital or clinic, or
- Complain to a professional body such as the Health Professions Council of South Africa (HPCSA)

MATERNITY LEAVE

The *Basic Condition of Employment Act* currently does not make provision for parental leave or maternity leave for gay couples.

CASE STUDY

A v STATE INFORMATION TECHNOLOGY AGENCY

In March 2015, a gay man challenged his employer's refusal to grant him four months' paid maternity leave on the grounds that he was not the child's biological 'mother'. The man married his partner in a civil union in 2010, and a year later, the couple entered into an agreement with a woman to carry a baby for them. However, the employer refused on the grounds that its policies and the Basic Conditions of Employment Act made provision for maternity leave only for female employees and was silent on leave for people who became parents through surrogacy.

The Labour Court ordered that the employer:

- *Recognise the status of parties to a civil union and prohibit discrimination against couples who have become parents by entering into a surrogacy agreement.*
- *Pay him for the two months' unpaid leave he took to care for his newborn baby.*

COMPASSIONATE LEAVE

The *Labour Relations Act* allows for compassionate leave. This is an equal right for people in same-sex relationships. Compassionate leave makes it possible for people to take leave when their partner or a close relative dies or is very ill.

If a company discriminates on the grounds of sexual orientation in giving compassionate leave, this is an unfair labour practice. You can challenge this at the Commission for Conciliation, Mediation and Arbitration (CCMA). (See pg 623: *Chart: What rights mean for people living with HIV and AIDS*)

Children and youth and HIV/AIDS

HIV and AIDS can affect children in the following ways:

- Where they are infected from birth or from sexual abuse
- Where their parents have HIV or AIDS, and they have to live with the illness and loss

- Where they have to live with the illness and loss of friends, teachers, and other family members

Children who have HIV or whose parents are ill because of HIV or AIDS are often shunned and discriminated against by people in the community. Many suffer from neglect or are abandoned as babies. There are many examples of children being refused access to crèches, schools and bursaries. Orphans of parents who have died from AIDS are particularly vulnerable, and many survive in child-headed households. Many of them turn to crime, drugs, or the streets to survive.

Discrimination and abuses faced by children (relating to HIV/AIDS)

Children are often discriminated against and abused in the following ways:

- They are often tested for HIV without their consent or the consent of their parent or guardian
 - Young boys and girls are denied access to adequate sexuality education and sexual health care services
 - Children orphaned by AIDS struggle to find suitable caregivers
 - Children living with HIV or AIDS are sometimes denied access to pre-schools
-

How does the law protect children (relating to HIV/AIDS)?

Children are protected by various international, regional and local human rights documents. These are some of their major rights. (*See pg 45: Section 28: Children's Rights*)

The Constitution of South Africa and the United Nations (UN) Convention on the Rights of the Child that South Africa signed and agreed to on 16 June 1995 protect the rights of children. The Constitution sets out the human rights of all people. Children also have these general rights, for example:

- The right to equality and non-discrimination
- The right to privacy and dignity

CHILDREN'S RIGHTS AND THE LAW

The Constitution also recognises that children need special protection. Section 28 of the Constitution sets out special rights just for children - these include:

- The right to appropriate care (if they are removed from their parents)
- The right to basic health care services
- The right to basic shelter

- The right to basic social services
- The right to be protected from abuse or bad treatment
- The right to be protected from child labour
- The right to a basic education (Section 29)

THE BEST INTERESTS OF THE CHILD

Whenever a person does something that concerns and affects a child, this must be done in the best interests of the child. The 'best interests of the child' is a very important standard that we must use to measure everything that is done for a child. Sometimes, it is difficult to decide what a child's best interests are, as you often have to weigh up different issues carefully.

If a child is identified as being in need of care by the law, then the Children's Court must hold an inquiry to decide how to protect the child.

Just because a child's parents or caregivers are living with HIV or AIDS does not mean that the child should be placed in alternative care. It depends on the circumstances.

CASE STUDY

A MOTHER LIVING WITH HIV

In 1999, a mother living with HIV turned to the AIDS Law Project (ALP, now called SECTION 27) for help. A social worker had removed her 3-year-old twin children on the grounds that she was a bad mother because she was living with HIV and wasn't looking after the children properly.

The ALP represented the mother in the Children's Court and showed that she was healthy, was earning money through informal work and that the children were well cared for.

The Department of Social Development made it clear that removing a child should be a last resort.

The case shows that when decisions are made about removing a child, discrimination and prejudice about HIV/AIDS should not be a deciding factor.

Dealing with HIV/AIDS in schools

The South African Schools Act says that schools must admit all learners and must not discriminate against any learner. Thus, a child cannot be excluded from school only because of their HIV status. This is the law for private and government schools. The

Constitution also says that everyone has the right to a basic education. If a child is stopped from going to school because of their HIV status, this can be challenged in court.

Parents do not have to tell the school authorities if their child has HIV, even if the school asks them to fill this in on the application form. Schools are also not allowed to test learners for HIV before they are admitted to the school or while they are at school. A learner cannot be tested for HIV without their consent (if over 12 years) and/or a parent's or guardian's consent (if younger than 12 years.)

With the increasing numbers of learners and teachers becoming infected with HIV and AIDS, all schools need to have an HIV/AIDS policy so that:

- The rights of all learners and teachers are respected
- Learners and teachers with HIV are managed in an appropriate way
- Further HIV infection is prevented
- A non-discriminatory and caring learning environment is created

THE NATIONAL POLICY

The *National Policy on HIV/AIDS for Learners and Educators in Public Schools and Students and Educators in Further Education and Training Institutions* (1999) sets out some important policy issues on children with HIV or AIDS in schools.

IMPORTANT PRINCIPLES

- Learners and students with HIV or AIDS should live as full a life as possible and should not be denied an opportunity to receive education that fits their ability
- No learner or educator can be forced to disclose their HIV status. If anyone knows about the HIV status of a learner or educator, this information must be kept confidential
- No learner or educator may be asked to have an HIV test
- Learners and educators should not be discriminated against, for example, this means that no learner or educator can be refused to join or stay at a school because of their HIV status
- If a learner becomes incapacitated through illness, the school must take steps to arrange home study for the learner

RULES REGARDING TESTING AND CONFIDENTIALITY FOR CHILDREN

- Children who are 12 years or older can consent to medical treatment or a surgical operation on their own
- If the child is younger than 12 years, the child cannot consent to an HIV test without the consent of the parent or guardian. The test results must be given

to the parents or guardian unless the child is of sufficient maturity to understand the benefits, risks and social implications of such a test.

- If a child consents to an HIV test, they have the right for the information to be kept confidential, even from the child's parents
- A school does not have to be told about a child's HIV status
- A children's home or place of safety can be told of a child's HIV status if the child is under 12, and it is in the child's best interests for this information to be passed on. The information must be kept confidential by the staff of the home, and the child must not suffer any kind of discrimination because of it.

Confidentiality is a common law right and also protects children. The law does not say that a child's HIV status must be disclosed to a school. We recommend that parents or caregivers think carefully about what is in the child's best interests before deciding whether to disclose this information. (*See pg 625: Confidentiality*)

Adoption, fostering and HIV/AIDS

ADOPTION

Adoption is when a couple or a single person agrees to permanently take care of a child who is not their own. The law then treats the child as the child of the new parent or parents. The adoptive parents (the new parents) become the child's legal guardians. (*See pg 551: Adoption of Children*)

TESTING FOR HIV BEFORE ADOPTION

There is no legal requirement for prospective parents to be tested for HIV. However, some adoption agencies will not consider parents who are HIV positive and may demand that the applicants, child and birth mother be tested before they will proceed with an adoption. It is important to remember that HIV testing is not something that the law demands when it comes to adoption. The *Children's Act* does not say whether or not HIV testing should take place before an adoption. This means that different welfare organisations may have different HIV testing policies. It is worth noting that the practice of compulsory HIV testing of parents and children before an adoption violates the right to privacy. (*See pg 551: Adoption of Children; See pg 568: Problem 3: Adopting a child*)

FOSTER CARE

Fostering is usually for a short period, so children are not tested for HIV before they are fostered. When a child's HIV status is known, and the child is under 12 years old, this may be told to the foster parents if it is in the child's best interests, for example, the child needs special medical care. Adoption agencies are not required by law to disclose the child's HIV status to the prospective parents. (See pg 560: Foster care; See pg 480: Social grants for children below the age of 18 years; See pg 914: Exemptions from school fees)

INSTITUTIONAL CARE

The *Childrens Act* allows a police officer to remove a child from a parent or any other person if they believe that the child is in need of care (e.g. if the child is neglected) and to take the child to a place of safety. After this, the Children's Court will decide what is in the best interests of the child. Where no person can be found to take care of the child, the child may be sent to a children's home until he/she is placed with a family or reaches the age of 18 years.

CAN A CHILDREN'S HOME REFUSE TO ADMIT A CHILD WHO HAS HIV?

A children's home, place of safety, or any other institution (including schools and pre-schools) may not refuse to admit a child simply because of the child's HIV status. This is unfair discrimination.

CAN A CHILDREN'S HOME OR PLACE OF SAFETY HAVE INFORMATION ON CHILD'S HIV STATUS?

A children's home or place of safety does not have a right to have information on a child's HIV status. Sometimes, it may be in the best interests of the child if the caregiver knows the child's HIV status. Children who are 12 years or older can decide whom to tell about their HIV status.

Children's health rights and HIV/AIDS

The United Nations Convention on the Rights of the Child (CRC), which South Africa ratified in 1995, says the State has a duty to:

- Recognise the right of the child to the highest possible standard of health
- Take steps to lower infant and child mortality, ensure that all children receive necessary medical assistance and health care, and ensure suitable pre-natal and post-natal care for mothers.

CONFIDENTIALITY AND HIV TESTING

HIV TESTING 12 YEARS OR OLDER

If a child is 12 or older, the child has the same rights to confidentiality as an adult. This means that a child who consents to an HIV test has the right to keep their result private. Nobody is allowed to disclose (tell anyone) the HIV status of someone who is 12 or older without their consent.

HIV TESTING 12 YEARS OR YOUNGER

When a child is younger than 12, the child cannot consent to an HIV test. The consent of a parent or guardian is necessary. The parent or guardian has a right to decide whether to disclose the results of the test to the child. A lot depends on:

- Whether the child is old enough to understand the results
- What is in the child's best interests

If the child does not have parents or a guardian, the parents or guardian are not available, or they cannot be found in time, then consent to general medical treatment or operation (which is not risky to the child's life or health) can be given by one of these people:

- A person with parental power over the child (e.g. a teacher or relative)
- A person who has custody of the child (e.g. a foster parent or the head of a children's home)
- The social development minister

EMERGENCY MEDICAL TREATMENT

When there is an emergency where the child's life or health is in danger, there may not be time to consult the parents/guardian or the minister for consent. Then, the *Children's Act* says that one of these people can consent to the treatment or operation:

- The person with parental power or custody
- The medical superintendent of the hospital

REPRODUCTIVE HEALTH

Reproductive health is the health of your body's reproductive system – the parts of the body that are used for having sex and giving birth to babies.

The Constitution says that all children have a right to health. The right to health includes a right to reproductive health.

CONTRACEPTION

The *Children's Act* says that a child of 12 years or older can consent to medical treatment. This means that a 12-year-old girl can choose to take an oral contraceptive (the pill) to control her reproductive system.

TERMINATION OF PREGNANCY

The *Choice on Termination of Pregnancy Act 1996* governs the law about terminations of pregnancy – often referred to as 'abortions'. The Act says that when a girl wanting an abortion is under 18, the doctor or midwife must advise her to speak to her parents or other family members before having the abortion. But the girl does not need to follow this advice and she does not need their consent for the procedure.

An exception is that if the girl is severely mentally ill or has been unconscious for a long time, then the consent of a parent or legal guardian is required.

Prisoners and HIV/AIDS

In many cases, prisoners with HIV or AIDS and Tuberculosis (TB) continue to be strongly discriminated against. The *National Strategic Plan 2012 – 2016* in Section 3.1.2 states that the Department of Correctional Services (DCS) must ensure the provision of appropriate prevention and treatment services – including HIV, STI and TB screening, and prompt treatment of all inmates and correctional services staff – ensuring a continuum of care through proper referral.

Prisoners' rights and HIV/AIDS

THE CONSTITUTION

Prisoners are also protected by the Constitution:

- Section 27 protects the right to access to health care services
- Section 35(2)(e) provides that a detained, including every sentenced prisoner, has the right to conditions of detention that are consistent with human dignity, including at least exercise and the provision, at state expense, of adequate accommodation, nutrition, reading material and medical treatment

THE CORRECTIONAL SERVICES ACT

- Section 12(1) – The DCS must provide adequate healthcare so that inmates can “lead a healthy life.”
- Power to make (1) regulations (to the Minister) and (2) “orders” (to the National Commissioner).

CORRECTIONAL SERVICE REGULATIONS

Section 7 of the correctional services regulations states:

- 7(1) Primary healthcare must be available at least on a level as rendered by the state to the public
- 7(2) A dental practitioner must be available at every prison

Standing correctional orders on health promotion and disease prevention are:

- Each prison should have health education sessions at least once a week
- The topics must include HIV and reducing the risk of communicable diseases like TB
- External stakeholders such as the health department and civil society must be involved in these sessions
- The division head of nursing services must check that these sessions are diarized and displayed so that prisoners can know about them

Some rights and rules about prisoners and HIV/AIDS

- It is against the law for a prisoner to be tested for HIV against their wishes or knowledge. A prisoner does not have to take an HIV test even if the prison authorities demand this. Informed consent must always be given for an HIV test. (See pg 627: *HIV testing and informed consent*)
- It is against the law to force a person to make a confession or admission, for example, about their HIV status so that this can be used against them
- The courts cannot use evidence that was forced out of a prisoner in a way that goes against the person's rights
- Prisoners have the right to receive healthcare, including preventative measures, equivalent to the care available in South African communities. This means prisoners with HIV and TB should have access to the same kinds of treatment and care that are available to non-prisoners. (See pg 652: *Case Study: Dudley Lee v The Minister of Correctional Services*)

- Prisoners have the right to confidentiality about their HIV status (*See pg 625: Confidentiality*)
- Prisoners have the right to TB and STI screenings and treatment
- Policies and practices should be put in place to create a safer environment and diminish the risk of transmission of TB, HIV and sexually transmitted infections (STIs) to inmates
- It is against the law to segregate (separate) a prisoner with HIV, AIDS or TB from other prisoners. Segregation is only allowed if ordered by the medical practitioner on medical grounds (e.g. communicable diseases such as TB). The periods for segregation should not exceed 37 days.

CASE STUDY

DUDLEY LEE v THE MINISTER OF CORRECTIONAL SERVICES

This is a landmark case that highlights the state's responsibility for ensuring that the constitutional rights of detainees are maintained and safeguarded. Lee sued the state because he contracted TB in Pollsmoor's overcrowded, poorly ventilated cells. His case succeeded in the Cape High Court but was overturned by the Supreme Court of Appeal.

Lee appealed to the Constitutional Court, where he eventually won in December 2012.

The majority of the Court found that the Department of Correctional Services (DCS) negligently caused Dudley Lee to become infected with tuberculosis (TB) while it detained Lee in Pollsmoor prison from 1999 to 2004. The Court, therefore, held that the DCS should be liable to Lee.

The rights of accused people and HIV/AIDS

Accused people are people who have been charged with crimes but who have not yet been found guilty or not guilty. In terms of the *Sexual Offences and Related Matters Amendment Act*, the victim of a sexual violence crime can apply to court for an order to have the perpetrator have an HIV test if they do not know the HIV status of the perpetrator. The results of the test should only be given to the victim in writing and should not be disclosed to others. This application can also be brought by any person who has an interest in the victim's well-being or the investigating officer investigating the case. The application must be brought within 90 days after the act of sexual violence was committed. (*See pg 587: Sexual violence and HIV testing*)

Bail and sentencing for rape accused with HIV/AIDS

All accused people have a right to apply for bail. However, where the crime is very serious, for example, rape, the law makes it more difficult to get bail particularly – where the accused knew that he was HIV-positive or had AIDS at the time of the rape. The minimum sentence for a person accused of rape who is HIV-positive is much higher than the minimum sentence for a person accused of rape who is not HIV-positive. (See pg 209: *The Criminal Procedures Second Amendment Act (Bail law)*)

Social support and medical care for people living with HIV/AIDS

If people are unable to support themselves and their dependants, they have the right to social assistance. People living with HIV can work and support themselves during the first phases of their illness. However, eventually, many people with HIV become sick and unable to look after themselves and will require palliative care. Social support includes the right to healthcare and medical treatment.

There are different types of social grants available to people living with HIV and AIDS or people caring for someone with HIV or Aids:

- Disability grants
- Grants-in-aid
- Foster care grants
- Care dependency grants

HIV or AIDS are also disabling conditions. People living with HIV or AIDS will qualify for social security and assistance such as nutrition, transport, rent, burial costs and school books where necessary. (See pg 470: *Social grants for adults who are 18 years and older*; See pg 480: *Social grants for children below the age of 18 years*)

Disability grants for people with HIV/AIDS

A person who has HIV- or an AIDS-related illness will only get a disability grant if they become too sick to work. If that person is unemployed but still fit for work, they will not get a grant. The social development department will look at the medical report to make sure

that the disability will prevent the person from working for more than 6 months. Usually, a person will lose their grant if they become healthy enough to work. (See pg 472: *Disability grant*)

Grant-in-aid for people with HIV/AIDS

A grant-in-aid is help in the form of nursing care. This grant is given to people who are too sick to take care of themselves at home. When a person applies for a grant-in-aid, they must bring the same forms to the SASSA office as they would for a disability grant. The applicant:

- Must receive a grant for older persons, a disability grant or a war veterans grant, and require full-time attendance by another person owing to their physical or mental disabilities
 - Must not be cared for in an institution that receives a subsidy from the state for the care/housing of such beneficiary (See pg 475: *Grant-in-Aid*)
-

Fast-tracking grants

The government has created a facility for 'fast-tracking' grants for people who are urgently in need of social support. The district office is responsible for processing disability grants and for deciding on the policy on 'fast-tracking'. These policies might differ from province to province. However, these are some of the standard rules about fast-tracking:

- Both disability grants and care-dependency grants, in respect of children, can be 'fast-tracked' for a person who is sick with AIDS. However, only if a person is in stage 4 of AIDS will they qualify to have the grant fast-tracked. (See pg 613: *The different stages of HIV*)
- If a grant is to be fast-tracked it means it should take no more than five (5) working days to be processed. The procedure for applying to have a grant fast-tracked is as follows:
 - A prescribed medical form is issued AND stamped by the District Office of the provincial social services department. The person must take this form to a state doctor (not their own private doctor) to have it completed. The person either has to take the medical form back to the social services department or the doctor sends it. The grant should then be available within 5 days.

A care-dependency grant will only be paid if a child's physical condition stops them from going to school. The child must be in the full-time care of a caregiver at home.

Other forms of relief for people with HIV/AIDS

PALLIATIVE CARE

Palliative care tries to help people who suffer from illnesses that may cause death to have a better quality of life. It helps to prevent suffering and helps patients and families cope with pain and emotional and physical problems.

RIGHT TO PALLIATIVE CARE

Section 27 of the Constitution gives every person the right of access to health care services. The *National Health Act of South Africa* aims to promote the health of all people, and the *South African Patients' Rights Charter* states that "Everyone has the right of access to healthcare services that include provision for special needs in the case of ... patients in pain... palliative care that is affordable and effective in cases of incurable or terminal illness"

In order to realise these rights, the government needs to put in place a policy on palliative care so that this can form part of the comprehensive healthcare system in both the formal and informal healthcare sectors.

Access to healthcare depends on access to doctors, nurses, dentists and pharmacists. In South Africa, as well as internationally, there are several different problems confronting human resources within health care services, including:

- Shortage of professional staff in rural areas and poor urban areas
- Many healthcare workers leaving the public health system and going to rich countries where payment and conditions are much better
- The impact that HIV is having on the capacity of the health system by greatly increasing the numbers of people in need of care

Organisations such as the Hospice Palliative Care Association of South Africa (HPCA) provide palliative care and support. It is difficult for these organisations to find adequate resources to meet the growing needs.

See www.apcc.org.za and click on 'Find a Hospice or Palliative Care Centre' to find hospices in your province.

OBSTACLES TO ACCESS TO PALLIATIVE CARE

While organisations such as HPCA continue to provide palliative care and support there are a number of obstacles standing in the way of people accessing their right to palliative care. These include:

- Lack of access to an appropriate place of care, for example, a hospice or a home-based care service
- Lack of integration of palliative care into government health programmes
- Lack of palliative care education and training for doctors and nurses resulting in professionals who are not able to deal with the clinical and emotional issues in caring for patients for whom cure is no longer an option
- A shortage of trained palliative care staff
- Legislation that only allows doctors to prescribe specific medication that can provide pain relief. This limits access to pain medication for many patients in need, as it is homecarers – not doctors – who are attending to patients in their homes. The South African Nursing Council (SANC) and civil society are working on regulations that will allow professional nurses to prescribe and administer medication in cases requiring pain management.
- Geographic challenges in rural areas where the infrastructure is bad, for example, poor road conditions and no public transport, make it difficult to reach people in need and to provide the appropriate medication
- Fear of the stigma attached to terminal illnesses means families often delay contacting an organisation such as HPCA to treat the sick person at home, or they prefer to treat the person on their own without support
- Language barriers between caregivers and patients
- Cultural barriers where some cultures believe that talking about death invites death, or not acknowledging their illness leads to a delay in accessing palliative care
- Religious beliefs where some people believe in the power of prayer and not medical care
- Women generally play the nurturing role, and men often distance themselves from caring for the very ill as they see this as a woman's task. This puts a burden on female members of the family and limits the responsibility of the male in the home in caring for ill members of a family.

- In child-headed households where the child replaces the parent, it places a big responsibility on the child if a member of the household is very ill, and this often leads to poor compliance with the medication and other logistical problems

Information for this section was taken from *Legal Aspects of Palliative Care*, developed by the Association of Palliative Care Centres (APCC). Download a copy of the Law Manual from www.apcc.org.za, and click on Resources/Law Manual.

MEDICAL COSTS

Public healthcare offers free access to anti-retroviral treatment nationwide. However, people living with HIV/AIDS may also want to use private health care, especially if they are on a private medical scheme. Private healthcare offers prescribed minimum benefits (PMBs). PMBs are a set of minimum benefits which, by law, must be provided to all medical aid scheme members and include the provisions of diagnosis, treatment and costs of ongoing treatment for a list of 27 chronic conditions including HIV/AIDS.

CHILD SUPPORT

Under the *Social Assistance Act*, the following grants are available for the support of children, including children living with HIV or whose parents are living with HIV or AIDS:

- Foster Care Grant (*See pg 484: Foster Care Grant*)
- Child Support Grant (*See pg 482: Child Support Grant*)
- Care Dependency Grant (*See pg 486: Care Dependency Grant*)

Insurance and HIV/AIDS

Insurance is a contract (agreement) between an insurance company (e.g. Santam) and a person. It is meant to protect the person and their family from financial hardship in case something very serious like an accident or unexpected death happens.

The insured person pays a monthly premium, and the insurance company in turn promises to pay the insured or their dependents money to cover the loss when the event happens. Insurance policies may be especially important to families where there is only one breadwinner or where there are still young children.

The Association for Savings and Investment South Africa (ASISA) is the umbrella body of the insurance industry. ASISA represents the majority of South Africa's asset managers,

collective investment scheme management companies, linked investment service providers, multi-managers, and life insurance companies. It was formed in 2008, combining several key players in the saving and investments industry, including the Association of Collective Investments (ACI), the Investment Management Association of South Africa (IMASA), the Linked Investment Service Providers Association (LISPA) and the Life Offices' Association (LOA).

ASISA comprises voting and non-voting members. The following insurance companies are among its members:

- Liberty Group Ltd
- Hollard Life Assurance Company Ltd
- Old Mutual (South Africa) Ltd
- Discovery Holdings Ltd
- OUTsurance Life Insurance Company Ltd
- Lombard Life Ltd
- Clientèle Life Assurance Company Ltd
- Sanlam Ltd

There are 2 main types of insurance contracts:

- Indemnity insurance
- Non-indemnity insurance

People living with HIV or AIDS can also speak to their insurance company about what other financial planning options there are (besides a life insurance policy). For example, it may be better to consider an education policy to make sure that children are provided for.

INDEMNITY INSURANCE

Indemnity insurance is when the insurance company agrees to compensate you for a loss that you may suffer as a result of the event you have insured yourself against – for example, if you insure your house against fire and your house burns down, you will be compensated. When the contract is taken out, a maximum amount that the insurance company will pay out is agreed upon in the contract, and your monthly premiums are based on this maximum amount. But the actual amount that the insurance company will have to pay in the end is not known, and will depend on the value of your loss.

NON-INDEMNITY INSURANCE

Non-indemnity insurance is a type of insurance where the insured and insurer agree on the amount that the insurance company will pay if something happens to you – for example, life insurance or disability insurance. The higher the amount you want

you or your dependants to receive, the higher the premium that you will have to pay.

THE APPROACH OF MOST INSURANCE COMPANIES

Your decision to apply for life insurance or disability insurance is voluntary. Equally, the insurance company does not have a duty to accept your application. Before entering into an insurance contract, the company needs information from you to help assess the risk to the company of issuing a contract. This information also helps the company to decide what premiums to charge. Insurance companies check applicants for serious diseases (e.g. diabetes) or habits (e.g. smoking) that may affect their life expectancy (how long you are likely to live). This is done through questionnaires, medical examinations, urine, blood and other tests.

HIV TESTING PROTOCOL

The ASISA HIV Best Practice Testing Guidelines (1 November 2021) encourage the insurance industry to provide life cover for HIV-positive applicants. The purpose of the HIV Testing Best Practice Guideline is to ensure that the life industry follows the highest standards in all aspects of HIV screening of applicants for life insurance. This guideline applies to all HIV tests performed by ASISA members. It addresses issues such as identification, confidentiality, informed consent, pre-and post-test counselling transmission of test results and approval of test kits and laboratories.

THE RIGHT TO PROPER COUNSELLING

The ASISA Testing Guidelines state that an applicant has the right to give informed consent. The Guidelines say the insurer must cover:

- Costs of pre-test counselling
- One session of post-test counselling.

This means it is your right to ask the broker for proper counselling before and after the HIV test.

CHALLENGING VIOLATIONS OF YOUR RIGHTS

If you are asked to sign a consent form without pre-test counselling and informed consent, this violates your right to autonomy (to make decisions for yourself). If you do not receive pre-and post-test counselling, you can make a civil claim against the company.

APPLICANT'S DUTY TO DISCLOSE MATERIAL FACTS

When entering into an insurance contract it is important to fully disclose one's medical history in order for a claim not to be rejected.

CASE STUDY

SOUTHERN LIFE ASSOCIATION v JOHNSON (1993)

Mr Johnson applied for life and disability cover. When he applied, he was asked to say if he had had a blood test in the last 5 years. He did not disclose a blood test that was carried out on him to decide if he had a blood disorder. He was not aware that he suffered from the blood disorder. No symptoms had developed at the time of the application, and he believed that he was in good health.

Only later, when his health got worse, his doctor told him what the problem was. The insurance company decided not to pay him the disability cover.

The Supreme Court decided that Mr Johnson should have disclosed the fact that he had the blood test. The undisclosed fact was 'material', and thus, the company was allowed to refuse to make any payment under the insurance policy.

PROCEDURES FOLLOWED BY MOST INSURANCE COMPANIES

CONSENT FORM: You will be asked to fill in an application form. This form will probably include a consent form – the form that says you give your permission for an HIV test to take place.

DOCTOR DETAILS: You will also be asked to give details of your doctor (your family doctor or a doctor who you trust). The results of the HIV test will be sent to this doctor, so it is important that their details are correctly written down.

THE TEST: A doctor or laboratory chosen by the insurance company will do an HIV test. They will tell you where to go for the test.

TEST RESULT: The result of the HIV test is then usually sent to a doctor employed by the insurance company. This person is usually called the 'chief medical officer'. The chief medical officer will open a file for you. The file will include all medical information relevant to the application, including the results of the HIV test.

Positive test result – life register: If a test result is positive, your insurance application may be rejected. If it is rejected, your name will be put in the code on the LOA's life register as someone who has been refused insurance. This means that if you apply for insurance at another company, they will also reject your application. 'In code' means that the information about your HIV status will not be able to be read by anyone, except those people who know

what the code is. This is done to stop unauthorised people from getting to know your status.

Positive test result – telling your doctor: If the result is positive, your personal doctor will be told in writing. This doctor is expected to contact you to tell you the result. An insurance company will not tell you directly.

Negative test result: If the results are negative and all the other conditions of the insurance company have been met, you will be told that your insurance application has been successful. Your doctor is not contacted if the results are negative.

HIV/AIDS strategic plan for South Africa

In 2003, the South African government approved a *Comprehensive National Plan on HIV/AIDS Care, Management and Treatment*. A new plan is developed every four years after the evaluation of the previous four-year plan.

The South African National Aids Council (SANAC)

The South African National AIDS Council (SANAC), is the main official body co-ordinating the government's HIV/AIDS programme.

It is chaired by the deputy president of South Africa and has members from government, civil society (NGOs), the private sector and trade unions. People living with HIV/AIDS and women's groups are also represented. SANAC is engaged in shaping, influencing and implementing policies and programme interventions.

ACKNOWLEDGEMENT

*The contents of certain sections of this chapter were originally based on relevant chapters in the publication *HIV/AIDS and the Law*, published by the AIDS Law Project (now SECTION27) and Lawyers for Human Rights.*

For more information, see www.section27.org.za

Problems

1. Keeping medical information confidential

Dr Vincent is a doctor at Langa Day Hospital. He has a patient called Themba, who is HIV-positive. Dr Vincent tells two other doctors about Themba's HIV status. Themba is very angry about this. He believes Dr Vincent should have kept his HIV status confidential. Themba wants to take action against the doctor.

WHAT DOES THE LAW SAY?

Doctors, nurses and other medical professionals have a legal and moral duty to keep information about a patient confidential. (See pg 625: Confidentiality)

WHAT CAN YOU DO?

You can refer Themba to a lawyer who will make a civil claim on his behalf against the doctor. (See pg 237: Steps in a civil claim in a magistrate's court)

You can also help Themba draw up an affidavit complaining about the doctor's conduct. Send the affidavit to the Health Professions Council of South Africa (HPCSA) (Go to the website: www.hpcsa.co.za). (See pg 974: Affidavits)

2. Entry to school refused because of HIV status

The principal of the local high school, Mrs Shabangu, refuses to admit a student, Melanie, to the school because Melanie is HIV-positive.

WHAT DOES THE LAW SAY?

It is an act of discrimination to keep a child out of a school because of HIV status, and every child has a right to education.

WHAT CAN YOU DO?

You can help Melanie and her parents by first setting up a meeting with the chairperson of the school governing board. If this doesn't help, you can write a letter of complaint to the South African Human Rights Commission about the school's actions. The SAHRC must investigate the complaint. (See pg 63: Problem 1: Taking a case to the South African Human Rights Commission; See pg 645: Dealing with HIV/AIDS in schools)

3. Dismissing a worker who is HIV-positive

Susan is a machine operator in a factory. She tells her employer that she is HIV- positive. The employer tells Susan that she will have to leave her job because the other workers will complain if they find out, and he doesn't want any trouble in his factory.

WHAT DOES THE LAW SAY?

Everyone has the right to be treated equally and fairly at work. There can be no discrimination against a person because they are HIV-positive. The *Labour Relations Act* and the *Equality Act (Promotion of Equality and Prevention of Unfair Discrimination Act, 2000)* protect people living with HIV or AIDS from being discriminated against in the workplace.

An employer cannot dismiss a person because they are HIV-positive, even if other employees refuse to work with this person. (See pg 630: *Laws that give employees with HIV and AIDS or TB rights at work*)

WHAT CAN YOU DO?

You can help Susan fill in the correct form for her to refer her case to the Commission for Conciliation, Mediation and Arbitration (CCMA). (See pg 370: *Solving disputes under the LRA*)

4. Refusing to employ an HIV-positive person

Brian applies for a job with the South African Police Services (SAPS). On the application form, he fills in that he is HIV-positive. The SAPS refuses to employ him and gives him no reasons to explain their refusal.

WHAT DOES THE LAW SAY?

The SAPS must give Brian reasons why he didn't get the job. The *Labour Relations Act* and the *Equality Act* say an employer cannot refuse to employ a person because they have HIV. This is discriminating against the person. that give employees with HIV and AIDS or TB rights at work) (See pg 47: *Section 33: Just Administrative Action*)

WHAT CAN YOU DO?

You can help Brian find out the reasons why he didn't get the job. If the SAPS refuses to give the reasons, Brian can complain to the Department of Safety and Security.

If the reasons do not seem valid, and Brian suspects that the real reason he didn't get the job is that he is HIV-positive, he can take up a case of an unfair labour

practice involving arbitrary discrimination against the SAPS. You can help Brian fill in the correct form to refer his case to the Commission for Conciliation, Mediation and Arbitration (CCMA).

The CCMA will investigate the allegation of discrimination. (*See pg 370: Solving disputes under the LRA*)

5. Making a complaint about being refused medical care

Tina was in an accident and is a patient at the Lagunya Hospital. Tina agrees to an HIV test. The test is positive.

Tina's wounds need to be treated every day, but the nurse treating her finds out the results of the HIV test and refuses to treat her again. She also tells all the other nurses. They, too, refuse to touch Tina, and she is left in pain with blood-soaked bandages for many hours. When she recovers, she wants to take action against the hospital for the degrading way in which they treated her.

WHAT DOES THE LAW SAY?

Everyone has the right of access to health care services. It is against the law for a healthcare worker to refuse to treat a person because they have HIV or to treat people with HIV differently from other patients. (*See pg 629: The right to health care and medical treatment*)

WHAT CAN YOU DO?

There are a number of ways to respond to this problem:

1. You can refer Tina to a lawyer to make a civil claim against the health workers or the hospital on behalf of the patient. A High Court can review and set aside the decision of a hospital to refuse to treat a patient. (*See pg 238: Steps in a civil claim in a Magistrate's Court*)
2. You can help Tina draw up an affidavit explaining her complaint. Include the names of the health workers involved. Send the affidavit to the relevant medical council, which can discipline their members. This includes the South African Nursing Council (SANC) if the complaint is against a nurse, or the Health Professions Council of South Africa (HPCSA) if the complaint is against a doctor. (*See 974: Affidavits; Go to the HPCSA website: <https://www.hpcsa.co.za/complaints-investigation> to lodge a complaint*)
3. You can also help Tina send a letter of complaint to the South African Human Rights Commission (SAHRC). (*See pg 63: Problem 1: Taking a case to the South African Human Rights Commission*)

4. A letter of complaint can also be sent to the Public Protector (*See pg 63: Making a complaint to the Public Protector*)
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6. Applying for a disability grant

Nobantu and Sipho are married with three young children below the age of 10. Both partners are HIV-positive. Sipho has lost his job because he became too ill to work. The doctor says that he could die within 6 months. Nobantu earns R4,800 per month doing part-time domestic work, but she has also become increasingly ill, and her employer has warned her on a number of occasions that she will have to find someone else to do the work.

WHAT DOES THE LAW SAY?

Both Sipho and Nobantu can apply for a disability grant. The social development minister has also notified the department and SASSA that applications from HIV-positive people for disability grants should be 'fast-tracked'. This means that these applications should be given priority and processed faster than any other grant applications. The parents can also apply for child support grants for the three children. (*See pg 470: Social grants for adults who are 18 years and older; See pg 480: Social grants for children below the age of 18 years; See pg 482: Child support grant*)

WHAT CAN YOU DO?

You should find out from the provincial SASSA office that processes disability grants what the policy is on 'fast-tracking'. Then you should write a letter setting out the particular circumstances of Nobantu and Sipho and ask the provincial office to 'fast-track' their applications. You should also help them apply for child support grants for their three children (who all qualify for the grant because of their ages).

Community action

Running an HIV/AIDS and TB Awareness Campaign

These guidelines will help you to run an HIV/AIDS campaign in your community – when you are planning your campaign you must keep them in mind.

WHAT IS THE AIM OF THE CAMPAIGN?

The aim of the campaign says what you want to achieve at the end of the campaign. To think about your aim ask yourself this question: What do I want to achieve with this campaign? So, for example, your aim(s) for an HIV/AIDS campaign could be that you want to: Reduce the rate of HIV infection in my community and Ensure that people with HIV or AIDS and their families in my community are given care and support

HOW ARE YOU GOING TO ACHIEVE YOUR AIMS?

SETTING OBJECTIVES FOR THE CAMPAIGN

Objectives are more specific than aims; they help you to achieve your aims. You can ask yourself the question: What must we do to achieve our aims? Your objectives could be as follows:

To build openness and awareness around HIV/AIDS & TB

We will do this in the following ways:

- Wear a red ribbon
- Act as role models to show support for the campaign
- Organise AIDS awareness-raising events, for example, marches, cultural events, protests, prayer meetings, loudhailers, and information tables in public places
- Openly support people who are open about their HIV status and encourage people to be tested for HIV
- Print posters, pamphlets or use graffiti
- Encourage and support people living with aids to go public about their illness
- Encourage voluntary counselling and testing by organising testing drives and ask community leaders who are willing, to go public about their results
- Encourage leaders and other influential people who are HIV-positive to become role models for other people by being open about their status

To educate people about prevention, care and treatment:

We will try to get people to change their sexual behaviour in the following ways:

- Public meetings – invite people to speak on HIV/AIDS, particularly people who are HIV-positive and willing to speak in public about their illness

- Speeches – ask institutions like schools, churches, workplaces, etc if we can send a speaker to talk about HIV/AIDS and TB
- Workshops – present community education workshops
- Chat shows – ask to be invited to speak on chat shows of local radio stations
- Newspapers – write articles for newspapers on the prevention of aids, non-discrimination and care for people living with HIV and AIDS and TB or ask journalists to write them
- Plays and songs
- Distribution of pamphlets, booklets, etc.

To develop community care projects

We will try to help community members living with HIV/AIDS or infected with TB, their families and orphans in the following ways:

- Openly organise support and care for people living with HIV/AIDS and TB
- Start vegetable garden projects to help provide the right food to people who cannot afford it
- Make sure the local health services keep supplies of cheap medicines that can be used to fight common infections that harm people with HIV/AIDS or TB
- Organise support groups where people living with HIV or AIDS can meet and talk to each other
- Train volunteers in basic home care and counselling so that they can help with house visits and also provide training to home caregivers
- Work with the social services department or the Child Welfare Society to encourage people in the community to take care of orphan children, for example, by providing foster care

WHO ARE WE GOING TO TARGET?

The campaign should reach everyone in the community but we can also target specific sectors which are more vulnerable.

THE EDUCATION AND PREVENTION PART OF THE CAMPAIGN

- Sexually active youth, particularly young girls
- Migrant and transport workers
- Sex workers Women, particularly those in relationships with HIV-positive men
- Men who are HIV-positive
- Anyone infected with TB or caring for someone with TB

- Drug users
- LGBTQI+ persons
- Men who have sex with men (MSM)

THE AWARENESS AND OPENNESS PART OF THE CAMPAIGN

These groups are most likely able to influence people's attitudes:

- The local mayor
- Ward councillors
- Members of national and provincial parliaments
- Local leadership
- Religious leaders
- Traditional leaders
- Sports and cultural stars
- Popular business people
- Community organisation leaders
- Union leaders
- Teachers
- Community radio DJs and newspaper reporters

THE SUPPORT AND COMMUNITY CARE PART OF THE CAMPAIGN

People who need information, care and/or support:

- People who are HIV-positive
- People who are sick with AIDS and need home care
- Children whose parents are dying or have died of AIDS
- Anyone infected with TB or caring for someone with TB

People who can help provide information, care and/or support -

- Community structures and leaders
- Community welfare organisations
- Religious leaders
- Women's groups
- Local business
- Schools
- Individual volunteers for home care or foster care projects

You need to give the campaign an identity and decide what the main messages will be. For example, the Treatment Action Campaign encourages people to wear T-shirts with the slogan 'HIV-positive' or 'TB-Suspect' to help bring AIDS awareness to the public.