

**CHAPTER 6**

**Your health rights**

<b>6.1</b>	<b>What are the rights of patients?</b> .....	<b>118</b>
	<i>The National Patients' Rights Charter</i> .....	118
<b>6.2</b>	<b>Confidentiality</b> .....	<b>120</b>
6.2.1	General principle .....	120
6.2.2	Ethical guidelines on confidentiality .....	120
	<i>SAMDC and HPCSA Guidelines</i> .....	120
	<i>Other Ethical Guidelines</i> .....	121
6.2.3	Legal rules on confidentiality .....	122
6.2.4	Common questions about confidentiality .....	123
	<i>Can a health care worker tell another health worker about your HIV status?</i> .....	123
	<i>Can a health care worker tell another health worker or health facility about your HIV status when referring you for treatment?</i> .....	124
	<i>Must a health care worker tell your sexual partner about your HIV status?</i> .....	124
	<i>Can a health care worker be sued for not telling sexual partners that they are at risk of HIV?</i> .....	126
	<i>Must a health care worker tell your family or care-givers about your HIV status?</i> .....	126
	<i>Can a court order a health care worker to give the court confidential medical information?</i> .....	126
	<i>What steps should a health care worker take if you say you do not have to tell your partner because you are having safer sex?</i> .....	126
	<i>Can a lay counsellor tell your sexual partner about your HIV status?</i> .....	127
	<i>What should be written on a sick certificate?</i> .....	128
	<i>What should be written on a death certificate?</i> .....	129
	<i>Do doctors have to report when they diagnose you with AIDS?</i> .....	130
6.2.5	What can you do if a health worker abuses your right to confidentiality? .....	131

---

<b>6.3</b>	<b>HIV testing and informed consent</b> .....	<b>132</b>
6.3.1	General principle .....	132
6.3.2	What does consenting to treatment mean.....	133
	<i>National Policy on Testing for HIV</i> .....	134
6.3.3	Common questions about HIV testing.....	136
	<i>When should a person be tested for HIV?</i> .....	136
	<i>When is testing for HIV not allowed?</i> .....	136
	<i>Must you sign a written consent form before an HIV test?</i> .....	136
	<i>If you go to hospital, can you be tested for HIV</i> <i>without your knowledge?</i> .....	136
	<i>If a hospital has wall posters saying they do</i> <i>HIV testing on all patients, is this consent?</i> .....	137
	<i>Can you be tested without consent after a health care worker</i> <i>has accidentally been pricked or cut while treating you?</i> .....	138
6.3.4	Exceptions to the rule of informed consent.....	139
6.3.5	Who can give consent?.....	142
6.3.6	What happens if you refuse to consent to an HIV test?.....	144
6.3.7	What can be done if the HIV test was done without your consent?.....	144
6.3.8	Testing checklist.....	145
<b>6.4</b>	<b>The right to medical treatment</b> .....	<b>146</b>
6.4.1	General principle .....	146
6.4.2	The right to treatment from a health care worker.....	146
6.4.3	The right to health care.....	146
	<i>Public health care services</i> .....	147
	<i>Private health care services</i> .....	147
6.4.4	What can you do if a hospital refuses to treat you?.....	148
	<b>Talking points</b> .....	<b>149</b>
	<b>References and resource materials</b> .....	<b>150</b>



## 6.1

# What are the rights of patients?

Many people complain that they are treated badly at hospitals and clinics. This happens especially when the staff at the hospital or clinic know that the people they are treating are living with HIV.

People complain about **confidentiality** not being respected and being tested for HIV without their knowledge and **consent** (agreement). In some cases, people are refused proper medical treatment.

This chapter looks mainly at:

- The rights of patients in hospitals and clinics, and
- The rights of people using public and private health services.

Patients have a number of rights in different laws, policies and guidelines:

- Our **constitutional law**
- Our **common law**
- **Statute laws** like the *Health Act*
- Health policies and charters (eg the National Patients' Rights Charter)
- Ethical guidelines of professional bodies (see 6.2.2 on page 120).

### ***The National Patients' Rights Charter***

During November 1999, the Department of Health launched a **National Patients' Rights Charter**. The Charter is very important because it lists the rights and duties of all patients that attend government hospitals and clinics.

The Charter is not a law – but it sets out guidelines which health care workers and patients are expected to follow. It is based on rights and duties in different health laws, and tries to explain these rights in an easy way, for example: it explains the constitutional right of access to health care services, so that patients know what they have the right to expect from state health care services.

For the National Patients' Rights Charter, see A2 on page 495.

The Charter says that all health care workers, like nurses and doctors, must treat all patients with human dignity, respect, courtesy, patience and tolerance.



**GUIDELINES**



### **YOUR RIGHTS**

**As a patient, your rights include the right to:**

- Have a healthy and safe environment.
- Take part in making decisions about your treatment.
- Get basic health care at government health facilities (eg emergency care, counselling, information).
- Have information about medical aid schemes.
- Make a proper choice about health services.
- Know the name of the doctor or nurse treating you.
- Enjoy confidentiality and **privacy** about your medical treatment.
- Give **informed consent** to medical treatment.
- Refuse medical treatment.

- Get a second opinion from another doctor.
- Have ongoing medical care.
- Complain about poor health services by health care workers.

### **YOUR DUTIES**

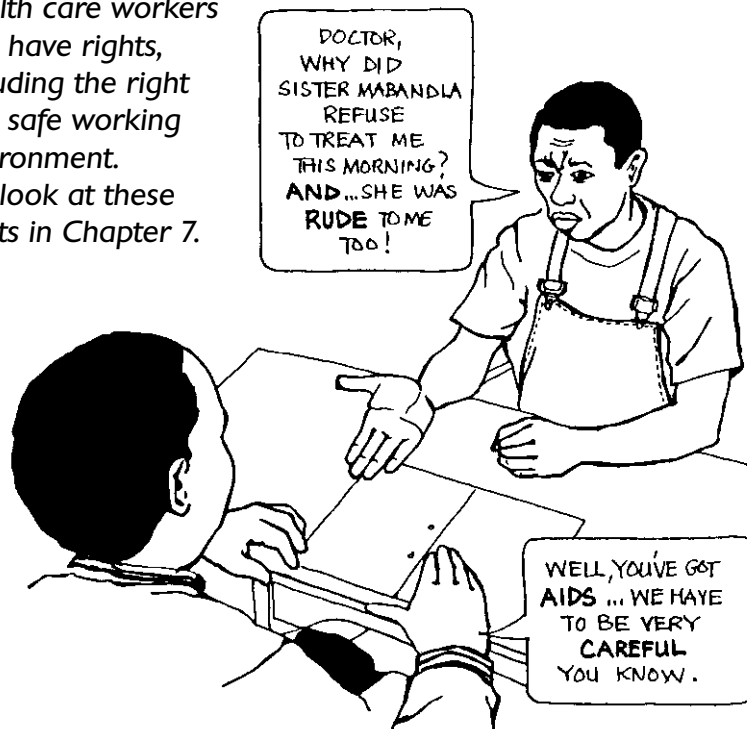
**As a patient, your duties include the duty to:**

- Take care of yourself.
- Respect other patients and health care workers.
- Use our health services, but not to abuse these services.
- Advise the doctor or nurse with correct information about your health.
- Follow treatment procedures.
- Pay for any costs of health services.
- Look after your personal medical records.

In this chapter, we will focus on some key patients' rights that are especially important for HIV/AIDS testing and treatment.

### **RIGHTS OF HEALTH CARE WORKERS**

Health care workers also have rights, including the right to a safe working environment. We look at these rights in Chapter 7.



The kind of situation that can happen at a hospital or clinic.



## 6.2.1 GENERAL PRINCIPLE

Ethical (moral) and legal rules say that doctors, nurses, psychologists, dentists and other health care workers must keep all patient information confidential. This means that any information about their patient's illness or treatment can only be given to another person with their patient's consent.

## 6.2.2 ETHICAL GUIDELINES ON CONFIDENTIALITY

Ethical guidelines are a set of moral rules or principles that are used to guide the work of professionals like doctors and nurses. Ethical guidelines are not the same as laws that are passed by Parliament. Sometimes, ethical guidelines become law, but generally they are principles to guide health care workers in protecting the people they serve from being abused during health care.



### EXAMPLES

#### **PROFESSIONAL GUIDELINES**

- Ethical guideline for lawyers: a lawyer may not tell a client to lie to the court.
- Ethical guideline for priests: they may not tell other people what they are told during confession.

### ***SAMDC and HPCSA Guidelines***

The Health Professions Council of South Africa (HPCSA) is a body set up to control the training, registration and conduct of doctors, dentists, psychologists and other health professionals who practise (treat people) in South Africa. The HPCSA replaced the South African Medical and Dental Council (SAMDC).

#### **EXISTING SAMDC GUIDELINES**

- In 1994, the SAMDC published ethical guidelines on the treatment and management of patients with HIV.
- In July 2001, the HPCSA revised and updated the old SAMDC Guidelines. The new Guidelines are included as A4 on page 504.



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The HPCSA Guidelines describe a doctor's duty to keep a patient's HIV status confidential:

*“ The results of HIV positive patients should be treated at the highest possible level of confidentiality. ”*

Health professionals must also follow the general SAMDC Rules of Practice, which say that:

*“ (no practitioner may) divulge verbally or in writing any information which ought not be divulged regarding the ailments of a patient except with the express consent of the patient or, in the case of a minor, with the express consent of his guardian, or in the case of a deceased patient, with the consent of his next-of-kin or the executor of his estate. ”*

Rule 16 of Rules of Practice 1994

### **Other ethical guidelines**

The **South African Medical Association (SAMA)**, previously called the Medical Association of South Africa (MASA), is a voluntary body for doctors and other health care workers. SAMA has its own set of guidelines on HIV/AIDS.

SAMA recommends that:

- Testing for HIV should only take place with the informed consent of the patient.
- Every effort should be made for pre- and post-test counselling to be given to the patient.
- A patient's medical information should be kept confidential.

The **South African Nursing Council (SANC)** is a **statutory body** that was set up to control the training, registration and practices of all nurses. Membership of the SANC is compulsory for all nurses. The SANC also have ethical guidelines that say that all nurses must respect a patient's right to confidentiality.

Another important statutory body is the **Chiropractors, Homeopathic and Allied Health Services Professions Interim Council**. This body is responsible for the registration, regulation and training of homeopaths, chiropractors or practitioners of a related health service profession, eg phytotherapy (medical herbalism).

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## **HEALTH CARE WORKERS AND CONFIDENTIALITY**

All health care workers must belong to a professional body and they must follow the professional body's rules to respect the confidentiality of their patients' medical information.



The ethical guidelines on confidentiality say that health care workers can only give another person information about a patient when:

- The patient has agreed to it, or
- If the patient is a child, the child's parents or guardian have agreed to it, or
- If the patient is dead, the **next-of-kin** (the person's closest family) has agreed to it.

### **6.2.3 LEGAL RULES ON CONFIDENTIALITY**

All patients have the legal right to confidentiality about their health and medical treatment.

#### **CONFIDENTIALITY ABOUT HIV STATUS**



In *Jansen van Vuuren and Another v Kruger* (1993), the Appellate Division of the Supreme Court (now called the Supreme Court of Appeal) decided that a doctor cannot **disclose** (give) the HIV status of a patient to other doctors without the consent of the patient unless there is a clear legal duty to do this. This case is better known as 'the McGeary case'.

#### ***What were the facts of the McGeary case?***

Mr McGeary wanted to apply for a life assurance policy. The insurance company told him he had to have an HIV test. So he went to his doctor and asked him to do the HIV test. When the doctor got the results of the test, he told McGeary that he was HIV positive.

The next day his doctor played golf with another doctor and a dentist. During the game they discussed AIDS, and McGeary's doctor told the other doctor and dentist that McGeary had tested positive for HIV.

Within days, the news of McGeary's HIV status had spread through his small community. McGeary made a **civil claim** to get compensation from his doctor for **breaching** (breaking) his legal and ethical rights to confidentiality.

During the trial, McGeary died of an AIDS-related illness. But the lawyers representing McGeary's **estate** continued with the case on his behalf.



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For more on civil claims,  
see 17.8 on page 428.

The Appellate Division decided:

- Dr Kruger (McGeary's doctor) had not respected McGeary's right to confidentiality.
- Dr Kruger should thus pay McGeary's estate compensation of R5 000 for breaching McGeary's right to confidentiality.

### **Why is McGeary's case important?**

The judgement in this case is important because it recognised that:

- If doctors do not keep their patient's medical information confidential, then patients will be too scared to go to them for treatment. This will not help to stop the spread of HIV.
- Patients have a legal right to expect that health care workers will obey the ethical guidelines of their professional body (eg HPCSA).
- Health care workers cannot breach a confidential doctor-patient relationship just because they think that there is a high risk of being infected with HIV at work.
- When a patient is HIV positive, it is even more important to keep this information confidential because people living with HIV or AIDS face **unfair discrimination and prejudice** (eg being dismissed from their jobs or rejected by their families). The stress of this discrimination and rejection negatively affects the health of people living with HIV or AIDS.

For more on unfair  
discrimination, see 4.2 – 4.4  
from page 67 onwards.

## **6.2.4 COMMON QUESTIONS ABOUT CONFIDENTIALITY**

### **Can a health care worker tell another health care worker about your HIV status?**

A health care worker must ask a patient's consent before giving any of your medical information to another health care worker – even when the patient is being treated by more than one person in a hospital.

If the health care worker explains why other doctors and nurses need to know about your HIV status, most patients will consent to this information being given out when it is in their best interests to get proper medical treatment.

**EXAMPLE**



#### **WHEN HEALTH CARE WORKERS NEED TO KNOW YOUR HIV STATUS**

Other health care workers may need to know a patient's HIV status if you need special treatment related to your HIV infection.

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If a patient refuses to agree to this information being given to other health care workers, then the health care worker must respect this decision. But the health care worker must warn you if this may lead to you getting unsuitable medical treatment, and if this may be dangerous for your health. The health care worker also has a right to refer you to another doctor.

**GUIDELINES**



**DECIDING TO TELL OTHER HEALTH CARE WORKERS**

The HPCSA Guidelines say that if a health care worker decides to inform other health care workers about a patient's HIV status, then they must only do this:

1. After carefully considering the decision,
2. After explaining their decision to the patient, and
3. After accepting full responsibility for their decision.

**Can a health care worker tell another health care worker or health facility about your HIV status when referring you for further treatment?**

Yes, but only with your permission. For example, if a doctor refers you as a patient from a clinic to a Tuberculosis (TB) hospital for further care, they cannot tell the TB hospital your HIV status without first getting your permission.

If this information is going to be important for your future medical treatment and care, this must be explained to you. You must then give permission for your medical information to be passed on to the other health care worker or health facility.

**Must a health care worker tell your sexual partner about your HIV status?**

No. All people must get counselling on the advantages of telling sexual partners about their HIV status. After proper pre- and post-test counselling, most people will realise the need to protect themselves and their sexual partners.

**GUIDELINES**



**WHEN CAN A HEALTH CARE WORKER TELL YOUR SEXUAL PARTNER?**

A health care worker may only tell your sexual partner about your HIV status when:

- 1** The sexual partner is clearly known and identifiable – in other words, a specific person, eg “your husband William”.
- 2** The sexual partner is at risk of being infected with HIV by you, and you have refused to inform the partner of your HIV status or you have refused to have safer sex.
- 3** You have been counselled on the need to inform your sexual partner or have safer sex.
- 4** The health care worker has told you of your duty to protect your sexual partners.
- 5** The health care worker has warned you that if you do not inform your sexual partner or have safer sex, then the health care worker will have to breach confidentiality.

**GUIDELINES**



**STEPS BEFORE DECIDING TO TELL A PATIENT'S SEXUAL PARTNER**

We recommend that health care workers take these minimum steps before deciding to inform a person's known sexual partner:

- 1** Give in-depth counselling on why it is important to tell a sexual partner. If a healthcare worker is unable to give this counselling, then the patient should be referred for HIV/AIDS counselling at a local counselling centre or another suitable place.
- 2** Give an explanation of a health care worker's duty to warn sexual partners at risk of HIV infection.
- 3** Tell the patient that a health care worker may have to breach a patient's right to confidentiality in the circumstances, and then offer him/her the opportunity to inform his/her sexual partner with or without help.
- 4** Make the decision on whether or not it is necessary to tell the sexual partner that the patient is living with HIV.

To contact counselling or other HIV/AIDS service organisations, see R8 on page 483.



**KEY POINT**

**THE LIKELY APPROACH OF THE COURTS**

*It is unlikely that the courts would expect health care workers to act as police in the HIV/AIDS epidemic by making them responsible for telling all sexual partners of all patients.*

*To find these draft regulations, see References and resource materials on page 150.*

**Can a health care worker be sued for not telling sexual partners that they are at risk of HIV?**

It is possible that a health care worker can be sued (taken to court) by a sexual partner if they do not tell a patient's sexual partner that the partner is at risk of HIV. This is because the person at risk of HIV could bring a civil claim against the health worker for not warning them.

A health care worker is only under a duty to protect a sexual partner from possible infection if:

- The health care worker knows the sexual partner is in danger, and
- The health care worker has followed the Guidelines on page 125 in trying to deal with the situation.

**Must a health care worker tell your family or care-givers about your HIV status?**

There is no legal duty on a health care worker to tell your family or care-givers that you are living with HIV. You should decide who to tell. The health care worker can advise you on why it may be useful or important to tell your care-giver or family members about your HIV status.

In April 1999, the Department of Health published draft regulations on AIDS, which said that if a health care worker **diagnosed** a patient with AIDS, they should tell the patient's family and care-givers. This law has not been finalised and is not in force.

**Can a court order a health care worker to give the court confidential information?**

If a health care worker is called to give evidence in court, they should tell the judge that they cannot give out confidential patient information. If the judge says the health care worker must give the court this information, then they have to breach the confidential relationship between patient and health care worker. They should tell the judge that they are only giving out this information because the court ordered this.

**What steps should a health care worker take if you say you do not have to tell your partner because you are having safer sex?**

If you say your sexual partner is not in danger because you have safer sex, the health worker must accept this.

**RESPECTING THE DOCTOR-PATIENT RELATIONSHIP**

*The doctor-patient relationship can only be breached in very serious circumstances. Therefore the patient must be trusted if they say they will be having safer sex unless it is clear that they are not telling the truth.*



**KEY POINT**



EXAMPLE

### **A DIFFICULT SITUATION FACED BY A DOCTOR**

Bruce has HIV and he told the doctor that he would protect Thandi by using condoms when he sleeps with her. But the doctor also knows that Bruce has spoken before of their wish to have a second baby.

If the doctor thinks that Thandi is at risk of being infected with HIV, he can tell her that Bruce has tested HIV positive. But the doctor can only do this if he/she is completely convinced that Thandi is in real danger of being infected and the doctor has discussed this with Bruce beforehand.

This is a serious and difficult decision to make so it must be done with great care and after following the Guidelines on page 125.

Health care workers should keep a written record of discussions and the suggestions they have made to their patient.

### **Can a lay counsellor tell your sexual partner about your HIV status?**

No. A lay counsellor must also respect your rights to privacy and medical confidentiality. Because **lay counsellors** are not accredited (formally recognised) health professionals registered with a professional body, they are not directly covered by the bodies and ethical guidelines for doctors, psychologists, dentists or nurses. But they still have to respect the **common law** and the constitutional right of the patient to confidentiality.

Lay counsellors are usually supervised by a health professional (eg a registered psychologist). The supervisor should guide the lay counsellor and make sure that he/she follows the same ethical rules and principles that the supervisor follows.

The Department of Health recently finalised guidelines on lay counsellors so that the work of lay counsellors will be more controlled. The guidelines recommend:

- Selection standards for lay counsellor trainees
- Minimum training standards for lay counsellors
- Minimum supervising standards for lay counsellors
- Accreditation of lay counsellors through certificates.



To check on the Department of Health guidelines, see References and Resource Materials on page 150.

## **GUIDELINES FOR LAY COUNSELLORS**

Lay counsellors should be guided by:

- Nationally accepted guidelines of professional bodies, such as the HPCSA and SANC.
- Constitutional and common law rules on privacy.
- Department of Health guidelines for lay counsellors.

This means that lay counsellors may not tell other people things that were discussed during counselling sessions.

## **What should be written on a sick certificate?**

A medical certificate for being off sick must be drawn up after discussion with the patient because it gives an employer confidential information on the person's medical condition.

You can ask for private information to be left off the certificate.



## **THE RIGHT NOT TO DISCLOSE PRIVATE INFORMATION**

You may not want to disclose that you have a sexually transmissible disease (STD), a life-threatening illness like cancer, or a substance-abuse problem like alcoholism.

This does not mean that a health care worker is allowed to write false information on a sick certificate – this would be unethical and illegal. But they must be sensitive to a person's wishes when completing the certificate.



For more information on the Basic Conditions of Employment Act, see 7.2.6 on page 167.

## **WHAT HEALTH CARE WORKERS CAN WRITE**

If you do not want your HIV status known, the health care worker must not write it on the medical certificate. They must simply write that you are sick and not injured.

When an employee needs a sick certificate, the Basic Conditions of Employment Act says that the person who completes the certificate must put down the reason for the absence – in other words, sickness or injury. Again there is no legal duty on the health care worker to write HIV or AIDS on the certificate.

## **What should be written on a death certificate?**

In July 1998, new Regulations were made under the *Birth and Death Registration Act*. The Regulations change the way that deaths are reported, and say that all deaths must be registered with the Department of Home Affairs.

The new death certificate has 2 pages:

- Page 1 is for the registration of the death with the Department of Home Affairs so that they can issue a burial order. This death certificate only needs to say if the cause of death was:
  - ‘Natural’ (eg due to illness or old age), or
  - ‘Unnatural’ (eg murder).
- Page 2 is a confidential document that is only used for data (information) collection. It is not a public record. This page asks for information about the **deceased** (like his/her occupation) and the medical cause of death (the underlying illness or condition).

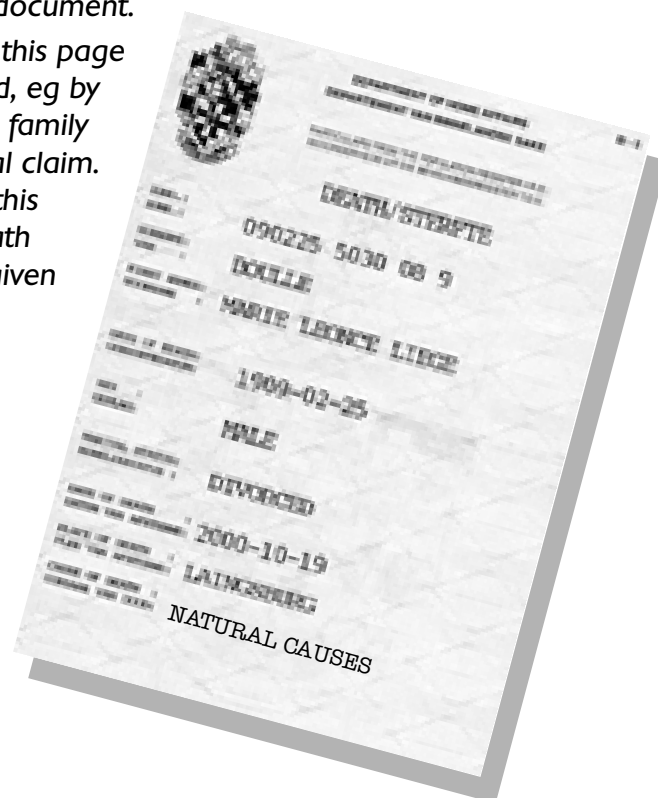
### **CONFIDENTIAL PART OF DEATH CERTIFICATE**

*Remember: even if the second page of the death certificate shows that a person died of an AIDS-related illness, this part of the death certificate is a confidential document.*

Sometimes this page may be needed, eg by the deceased’s family to make a legal claim. Only then will this part of the death certificate be given to the family.



To find these regulations, see References and resource materials on page 150.



## **Do doctors have to report when they diagnose you with AIDS?**

No, AIDS is not a notifiable disease. This means that when a health care worker diagnoses a person with AIDS, or when a person dies of AIDS, they do not have to report this to the health authorities.

In April 1999, the Department of Health sent out draft regulations to make AIDS a notifiable condition, but these have not been passed as law.

To find these draft regulations, see References and resource materials on page 150.

### **WHY AIDS SHOULD NOT BE A NOTIFIABLE CONDITION**

Because of the opposition to making AIDS a notifiable condition, it does not seem that the Government will go ahead with making AIDS notifiable. People and organisations opposed to the Government's proposals argued:

- Notification unfairly limits the human rights of all people with HIV or AIDS, especially the right to privacy, confidentiality and dignity. There are other better and cheaper ways of collecting important information about causes of death while still respecting human rights to privacy and dignity.
- In South Africa, we do not have good systems in place to collect medical information. Other medical conditions that are already notifiable (like TB) are often under-reported or not properly reported.
- Making AIDS notifiable does not give us information about how many people are HIV-infected, only about how many people have AIDS.
- Making AIDS notifiable does not help to stop the spread of the disease.
- It is difficult for health care workers to trace family members and care-givers.
- It is not always safe to tell family members that someone in their family is living with AIDS. The family members may reject the person and this can lead to violence against the person.
- If health care workers have to tell family members and care-givers when a person has AIDS, many people will not go and ask for medical treatment because they may not want anyone to know that they have AIDS.
- It may not always be possible to decide when a person has developed 'AIDS' based on the person's physical appearance or symptoms.



For more on AIDS-defining conditions, see 1.5.2 on page 21



## 6.2.5 WHAT CAN YOU DO IF A HEALTH CARE WORKER ABUSES YOUR RIGHT TO CONFIDENTIALITY?

If your right to confidentiality has been abused (not respected), you can make a civil claim for damages (compensation) against the health care worker or the hospital/clinic which abused your rights.



### TIME PERIODS FOR STARTING A CIVIL CLAIM

- Against a government hospital: within 12 months of the incident
- Against a private clinic: within 36 months of the incident.

For more on civil claims, see 17.8 on page 428.

For more on criminal charges, see 17.7 on page 425.

For more on complaints against health care workers, see 17.4 on page 407.

You can also make a criminal charge against the health care worker, or the head of the hospital or clinic employing the worker.

In addition, you can report the doctor, nurse or any other health care worker to their professional body, eg HPCSA or SANC. There is no time limit for this. The HPCSA, SANC and other professional bodies have the legal power to discipline their members by giving them a fine, suspending them temporarily or stopping them from practising.



**6.3.1 GENERAL PRINCIPLE**

Every person has the right to privacy, dignity, autonomy (to make your own decisions) and bodily integrity (protection of your body from harm by others). These rights are protected by the **Constitution** and our common law.

In other words, every person has the right to be treated with respect and as an individual who makes their own decisions about their body. This means a patient must consent to all medical treatment.

**CONSENT TO TREATMENT**

- 'Consenting to medical treatment' means a person must give their express permission before they are examined, tested, treated, given medicine or operated on.
- 'Express permission' is when a person clearly says or shows that they are agreeing to treatment.
- People have the right to refuse medical care.



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## 6.3.2 WHAT DOES CONSENTING TO TREATMENT MEAN?

Consenting to medical treatment means a person:

- Must understand the nature of the treatment that is proposed, and
- Must give their permission for the treatment verbally or in writing.

### **GIVING A PATIENT THE INFORMATION NEEDED TO MAKE A DECISION**

*Julie, a 25 year old teacher, went to her doctor for a check-up in the fourth month of her pregnancy. Her doctor told her that there was a possibility that the baby could develop complications (like heart disease or blindness) as she had come into contact with a person who had German measles.*

 **EXAMPLE**

*Julie's doctor carefully explained what German measles could do to an unborn baby. She gave Julie some books to read on this and asked Julie to contact her with any questions.*

*After giving Julie all the information, the doctor told her that she should decide whether to continue with the pregnancy or not.*

Many people speak about **informed consent**. In other words, the person makes a decision to agree to the medical treatment, but only after they have been given all the information they need to make their decision.

The HPCSA Guidelines say that doctors should not do an HIV test on a person without informed consent:

*“ The patient should be given information regarding the purpose of the laboratory test; what advantages or disadvantages testing may hold for him or her as patient; why the surgeon or physician wants this information; what influence the result of such a test will have on his or her treatment; and how his or her medical protocol will be altered by this information. The psychosocial impact of a positive test result should also be addressed. ”*

## National Policy on Testing for HIV

The Department of Health's National Policy on Testing for HIV (2000) says the patient should:

- Understand and be aware of the test.
- Know the benefits, risks, alternatives (other choices) and social implications of the test result.



### THE MEANING OF CONSENT

Consent has two parts to it – information and permission.

With an HIV test, a person must know what the test is, why it is being done and what the result will mean for him/her before agreeing to their blood being taken.

A person may not be forced, or tricked into consenting to testing or treatment.



In this case, Thami's blood has been taken **unlawfully**, as Thami had agreed to his blood being taken and tested for Hepatitis B and not HIV.

If the matron had wanted to test his blood for HIV, she should have discussed this with him first and got his consent.

Before an HIV test, a person should receive **pre-test counselling**, followed later by **post-test counselling**:

- **Pre-test counselling** is a counselling session which is held before the HIV test is done. As a patient, it helps you look at the effect the test will have on you and your family.
- **Post-test counselling** is counselling which takes place after the HIV test results have been received. It helps you understand and accept the effect a negative or a positive result will have on your life.

The Government's testing policy will be attached to the new National Health Act, which will become law in 2003.

**GUIDELINES**



### **NATIONAL POLICY ON TESTING FOR HIV**

*The National Policy on Testing for HIV sets out the circumstances when HIV testing can take place, and how HIV testing should be done:*

1. *Testing for HIV may only be done with informed consent (except in a few cases, set out in the Policy).*
2. *Pre-test counselling must be given to each person before the test.*
3. *Post-test counselling must be given after the person gets the test result:*
  - *If the result is negative, then the person should be told how to stay negative and about the possibility of the **window period**.*
  - *If the result is positive, the person should be given emotional support, and discussions can take place about who to inform and how to reduce the risk of HIV infection to their sexual partner/s.*
4. *If a hospital or clinic is not able to do counselling, it must refer the person to another place for counselling (like ATIC).*

*For more on the window period, see 1.5.1 on page 19.*

*For more on when HIV testing may not be done, see 6.3.3 on page 136.*

*For the National Policy, see A3 on page 500.*

*For contact details for ATIC, see R8 on page 483.*

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### 6.3.3 COMMON QUESTIONS ABOUT HIV TESTING

#### ***When should a person be tested for HIV?***

The Department of Health's National Policy on Testing for HIV says:

- Testing for HIV should only be done at the request of the person who wants to be tested.
- Where a doctor recommends testing for HIV, this should be done in consultation with the person – as long as the testing is necessary to make a **diagnosis** or for treatment.
- Testing for HIV can also be done for research purposes, but it must follow the ethical guidelines on research.
- With workplace injury (eg a needlestick injury), testing for HIV should also only be done with the person's informed consent.

*For more on testing at work, see 7.2.3 on page 161 and 7.3.1 – 7.3.3 from page 168 onwards.*

*For more on testing after a needlestick injury, see 6.3.4 on page 141.*

*For the National Policy, see A3 on page 500.*

#### ***When is testing for HIV not allowed?***

- A person cannot be tested for the purpose of protecting a health worker who thinks they may be at risk.
- An employer cannot make an employee or a job applicant take an HIV test to find out his/her HIV status, unless this is authorised by the Labour Court (under s7(2) of the *Employment Equity Act*).

#### ***Must you sign a written consent form before an HIV test?***

Not always. The law does not say that all people must give their consent to an HIV test in writing. But it is better if you sign in writing that you have received pre-test counselling and that you agree to have an HIV test after the pre-test counselling.

#### ***If you go to hospital, can you be tested for HIV without your knowledge?***

No. If you go to a hospital for treatment, you must still consent to all treatment and testing. The law says that hospitals must treat people with respect and allow them to make their own decisions about their bodies.

#### ***SPECIFIC CONSENT NEEDED FOR AN HIV TEST***

- *If you go into hospital to take your appendix out, the hospital must get your consent if they want to do an HIV test.*
- *Even if you agree to the appendix being taken out, that does not mean that you agree to the hospital doing any other test without your consent.*

**EXAMPLE**





CASE

## THE RIGHTS OF ALL PATIENTS

In *Stoffberg v Elliot* (1923), the Supreme Court said:

“ By going into hospital (a person) does not give up their right to security of the person ... patients remain human beings with the right to control their own body. ”

The right to security and control of your own body is now also protected in our Constitution.

### ***If a hospital has wall posters saying they do HIV testing on all patients, is this consent?***

No. Wall posters saying a hospital is doing testing on all patients are not consent because:

- Not all patients are literate and can read the poster.
- Not everyone will see the poster.
- You cannot be sure that after reading the poster, a person has understood what an HIV test is and what it will mean for him/her.

For more on informed consent, see 6.3.2 on page 133.

So, after reading a wall poster, a person may not have the necessary information and understanding needed to agree to an HIV test.



Here the doctor is wrong. Reading a poster does not mean that a person has consented to having an HIV test.

## Can you be tested without consent after a health care worker has accidentally been pricked or cut while treating you?

For more on exceptions to informed consent, see 6.3.4 on page 139.

For the National Policy, see A3 on page 500.

No. The Department of Health's National Policy on Testing for HIV says that a person should only be tested for HIV with informed consent. But, if you refuse to give consent, and there is an existing blood sample (you have already given blood and that blood is available), then that blood can be tested for HIV, even if you do not consent.



Sister Cele can't demand that Mrs Green take an HIV test. She should ask for Mrs Green's consent to the HIV test. But discussion about an HIV test should never take place on the phone.



### 6.3.4 EXCEPTIONS TO THE RULE OF INFORMED CONSENT

These are the only times a health care worker does not have to get informed consent to do an HIV test:

- Emergencies
- Testing done on blood donations
- Mentally ill patients
- **Anonymous, unlinked testing**
- Testing when there's a needlestick injury
- If the law allows for testing without informed consent.

We will look at each of these examples in more detail:

#### ***Emergencies***

If a patient needs emergency treatment, the doctor or hospital does not need to get consent before carrying out essential treatment (treatment that will save the patient's life).

#### GUIDELINES



#### **EMERGENCY TREATMENT**

*The law says that doctors can only treat a patient in an emergency situation if:*

- *There is a real emergency which makes the treatment necessary.*
- *The patient is unaware of the treatment required because he/she is unconscious.*
- *The doctor tries to get consent from the patient's relatives or loved ones.*
- *The treatment is not against the wishes of the patient, (eg Jehovah's Witnesses believe that they should not be given blood at any time – this means in an emergency, a hospital may not give a Jehovah's Witness a blood transfusion as this would be against their wishes.)*
- *The treatment is in the best interests of the patient.*

#### KEY POINTS



#### **HIV TESTING IN EMERGENCIES**

- *In an emergency, health care workers can only do an HIV test if the test is necessary to save the patient's life.*
- *It is unlawful to do an HIV test for the mistaken purpose of protecting a health care worker operating on a patient.*
- *It is unlikely that an HIV test can ever be part of emergency life-saving medical treatment.*

---

## ***Testing done on blood donations***

The voluntary donation of blood at a Blood Transfusion Service Centre is controlled by the *Human Tissue Act*. This law says that all donations of blood must be voluntary – in other words, people cannot be forced to donate blood and they cannot be paid for donating their blood.

If you give blood at a Blood Transfusion Centre, you will be asked to fill in a form. You will answer questions which are used to find out if your blood is likely to have any viruses or infections.

After the blood is taken, it is screened and tested for HIV, Hepatitis B and C, and sexually transmitted diseases. If any of these tests are positive, the blood donor will be informed of the results.

## ***Mentally ill patients***

The Mental Health Act says that, if a mentally ill person is unable to consent to treatment or testing, you can get consent from their:

- **Curator** (person appointed by law to look after them)
- **Spouse** (husband or wife)
- Parent
- Child (if the child is 21 or older)
- Brother or sister.

If the person is in a mental institution, the medical superintendent can, in serious cases, consent on behalf of the patient if the next-of-kin (eg child) cannot be found.

But, the patient can only be tested for HIV if this information is necessary for his/her medical treatment. The medical superintendent is not allowed to consent on the patient's behalf if the results are going to be used to **unfairly discriminate** against the patient.

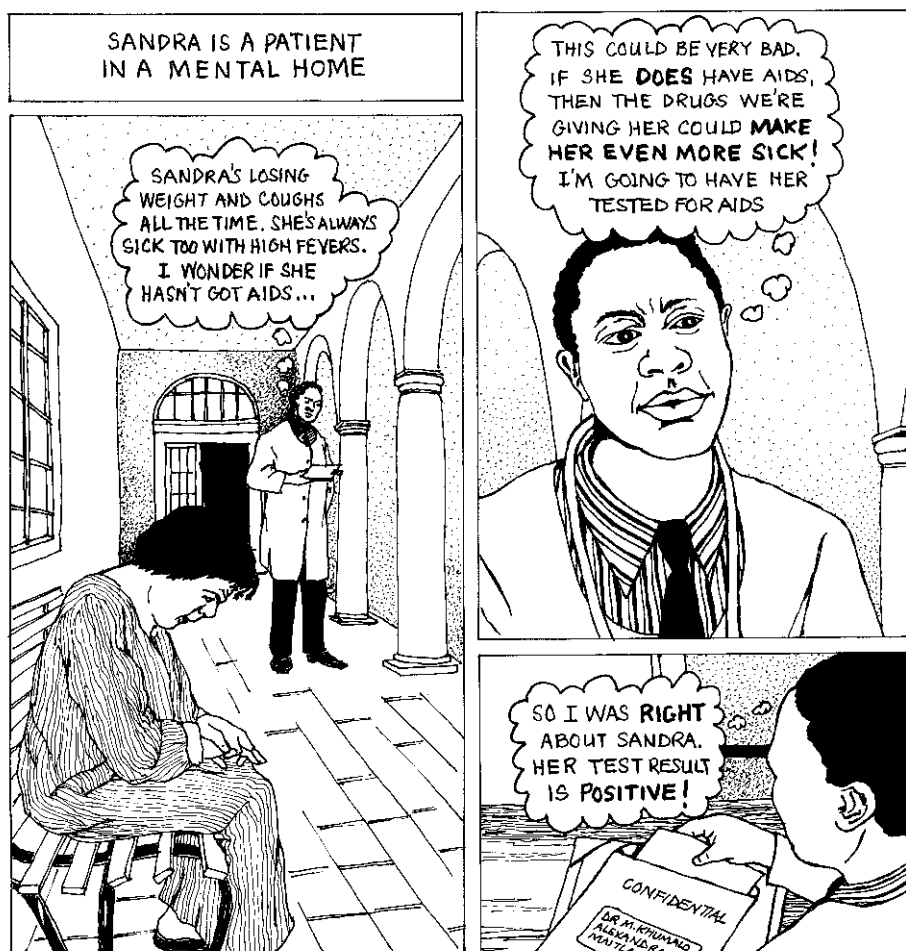
### ***UNFAIR DISCRIMINATION AGAINST MENTAL HEALTH PATIENTS***

EXAMPLE



*The medical superintendent at a mental health hospital outside a large city decides to consent to the testing of all the patients for HIV in order to place all patients who test positive in a separate building. This is against the law.*

It is legal to get the medical superintendent to consent on Sandra's behalf.



### ***Anonymous, unlinked testing***

Testing is sometimes done for research purposes to find out how HIV is spreading in the population, it is usually:

- Anonymous (no names are used), and
- Unlinked (it can't be traced back to the person who was tested).

The annual survey of the number of pregnant women with HIV is an example of this kind of testing, which can be done without informed consent.

### ***Testing after a needlestick injury***

A person can be tested for HIV without informed consent if a health care worker has a needlestick injury and the person, whose blood sample is available, refuses to give informed consent to test the blood.

The person must be told that the blood sample will be tested, but will not get the results of the test unless he/she asks for them. The person must be told that the results of the test may be **disclosed** (given) to the health worker – otherwise it will remain confidential.

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For the SALC Discussion Paper on compulsory HIV testing, see References and resource materials on page 150.

### **Where the law allows for testing without consent**

If a statute law allows for testing without informed consent, this can take place. For example, the **South African Law Commission** has recommended passing a law to allow for the compulsory HIV testing of people accused of sexual offences (like rape).

## **6.3.5 WHO CAN GIVE CONSENT?**

Consent must be given by the person who is directly affected. Only in exceptional (very unusual) circumstances, can it be given by another person, eg on behalf of mentally ill patients.



### **PROXY CONSENT**

The Department of Health's National Policy on Testing for HIV allows for "proxy consent" – the consent given by a person who has a legal right to consent on behalf of another person, eg guardian, curator.

### **Adults**

All adults who have **legal capacity** (the ability to make a legal decision) and who are of "sound and sober mind" can give **valid** consent to treatment (consent recognised by law).

Adults without legal capacity (eg 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 and youth**

Under the *Child Care Act*, children who are 14 or older can consent on their own to medical treatment. For example: a child of 14 can consent to treatment for an STD or for an HIV test. Children and youth of 18 and older can consent to an operation.

When a child is too young to consent, consent must be given by either one of their parents or guardians.

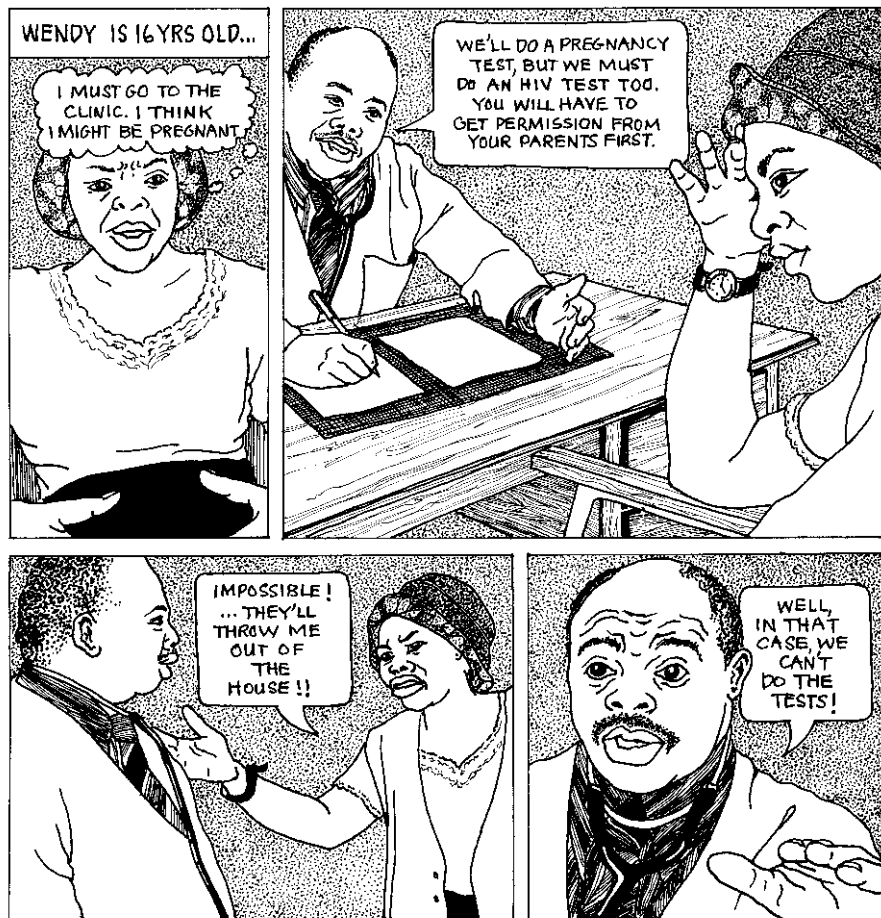
## CONSENT BY CHILDREN

- Children of 14 or older can consent to medical treatment, which includes different kinds of contact with a health care worker, eg asking for contraceptives, receiving injections, asking advice, having stitches and getting antibiotics.
- But medical treatment does not include consenting to a surgical operation. Children have to be 18 years or older to be able to consent to a medical operation.
- With abortion, the Termination of Pregnancy Act has changed the general law. Even though this is an 'operation', the Act says that a girl of any age can consent to an abortion.



For more on testing children, see 11.5.1 on page 262.

For more on abortion, see 8.3 on page 187.



The doctor is wrong to refuse to do the pregnancy test.

### 6.3.6 WHAT HAPPENS IF YOU REFUSE TO CONSENT TO AN HIV TEST?

If you refuse to have an HIV test, but a health care worker believes you should be tested to make a proper diagnosis, the SAMDC Guidelines recommend that the health care worker should advise you to get a second opinion (another view) on whether the test is necessary.

If you refuse to get a second opinion and the health care worker cannot make a diagnosis without the test results, then they can end their professional relationship with you. However, they still have a duty to refer you to another doctor and to ensure that you are cared for.

### 6.3.7 WHAT CAN BE DONE IF AN HIV TEST WAS DONE WITHOUT YOUR CONSENT?

If an HIV test was done without your informed consent, your rights have been abused.

*For more on making a criminal charge, see 17.7 on page 425.*

*For more on making a civil claim, see 17.8 on page 428.*

You can get advice from a lawyer or paralegal on:

- A civil claim, eg for invasion of privacy, dignity and bodily integrity.
- A **criminal charge**, eg of assault, against the health care worker and any person they were acting on behalf of, such as an employer.

#### TESTING WITHOUT INFORMED CONSENT

In *A v South African Airways* (2000), 'A' applied for a position with South African Airways (SAA) as a cabin attendant. He was tested for HIV without his informed consent. He was asked to sign a consent form and the HIV test was not explained to him. He was therefore tested without any pre- or post-test counselling.

In May 2000, the case went to trial at the Johannesburg Labour Court. On the third day of the trial, SAA admitted:

- It should have got the informed consent of 'A' before the HIV test, and
- It should have offered pre- and post-test counselling.

SAA agreed to pay R100 000 in compensation to 'A'.



**CASE**

A health care worker can also be reported to the HPCSA or SANC. They should hold an enquiry to find out what happened, and to decide how to discipline the health care worker.

EXAMPLE



### **AN HPCSA ENQUIRY**

In February 2000, an enquiry by the HPCSA was held against a medical practitioner who tested a patient for HIV without his knowledge or consent.

The HPCSA committee decided that the doctor did not act wrongfully or unethically, and decided that the doctor was not guilty.

## **6.3.8 TESTING CHECKLIST**

GUIDELINES



### **TESTING AND CONSENT**

#### **Informed consent**

Testing that must take place with informed consent:

- Testing authorised under the Employment Equity Act
- Testing for insurance purposes
- Voluntary testing
- Testing to make a diagnosis.

#### **Consent of another person**

Testing that can take place with the consent of another person:

- Emergency testing
- Certain mentally ill patients
- Children under 14.

#### **Without consent**

Testing that can take place without consent:

- Anonymous, unlinked testing for research purposes
- Testing of an existing blood sample
- Testing where the law allows for testing without consent.



## 6.4 The right to medical treatment

### 6.4.1 GENERAL PRINCIPLE

The Constitution gives every person the right of access to health care services.

### 6.4.2 THE RIGHT TO TREATMENT FROM A HEALTH CARE WORKER

#### ***Ethical guidelines***

The HPCSA Guidelines say that no health care worker can refuse to treat you just because you have HIV. This means that health care workers working in government hospitals and in private health care clinics cannot refuse to treat people living with HIV or AIDS.

All patients have the right to be treated with respect. The HPCSA Guidelines say that health care workers must not treat patients who are living with HIV differently to other patients.

EXAMPLE



#### ***THE RIGHT OF PEOPLE LIVING WITH HIV TO TREATMENT***

*No health care worker can refuse to feed or clean a patient living with HIV just because they are afraid of being infected with HIV.*

#### ***Legal guidelines***

The law says that doctors must obey the Ethical Guidelines drawn up by the HPCSA. This means that it is against the law for a health care worker to:

- Refuse to treat a person just because they are living with HIV.
- Treat patients living with HIV differently to other patients.

### 6.4.3 THE RIGHT TO HEALTH CARE

Every person in South Africa has a constitutional right to access health care services. Our health care system is also governed by the Health Act, which aims to:

*“ promote the health of the inhabitants of the Republic so that every person shall be enabled to attain and maintain a state of complete physical, mental and social well-being. ”*

This means that the Government must promote health by providing hospitals, clinics, medicine and staff to give health care services to all people in South Africa.





## **A NEW HEALTH ACT**

At the moment, a new Health Act is being finalised, based on the Draft National Health Bill. When the new Act is passed in 2003, it will replace the 1977 Health Act.

### **Public health care services**

People living with HIV or AIDS have a right to access any health care services that are available. The State also has a duty to promote every person's right to access to health care services, and to improve the range of health care services and treatments available to people living with HIV or AIDS.



### **DEPARTMENT OF HEALTH HIV/AIDS POLICY GUIDELINES**

In October 2000, the Department of Health released a series of HIV/AIDS Policy Guidelines, including guidelines for managing and treating patients with HIV or AIDS.

These Department of Health HIV/AIDS Policy Guidelines are now being used in government hospitals to help doctors treat patients with HIV or AIDS.

Every patient with HIV or AIDS will have a right to receive these treatments.

For more on access to health care as a socio-economic right and the Department of Health HIV/AIDS Policy Guidelines, see 4.7 on page 79.

For details of the Department of Health's series of HIV/AIDS Policy Guidelines, see References and resource materials on page 150.

### **Private health care services**

People living with HIV or AIDS may also want to use private health care, especially if they are on a private medical scheme.

In February 1999, the *Medical Schemes Act* was passed. The Act made some important changes to the law:

- A scheme is no longer allowed to exclude persons living with HIV or AIDS from membership.
- Every scheme must provide minimum benefits, including for people living with HIV or AIDS. Government decides these benefits in regulations under the Medical Schemes Act. They are known as 'Prescribed Minimum Benefits'.
- There is no waiting period for getting minimum benefits. But if you already have HIV when you join, you may have to wait 12 months before you can claim any extra benefits that the scheme has for HIV/AIDS.
- Trustees of medical schemes have to be more responsible for their actions and their conduct. Schemes can also no longer change their rules as they please. They have to register all rule changes with the Registrar at the Council for Medical Schemes.

- The monthly **premium** (fee) that you pay to the scheme is not based on how sick you are or how old you are. The premium is now based on how much you earn and how many **dependants** you add on to your scheme under your membership.
- The Act now makes it easier to register and add more dependants.



**EXAMPLES**

**EXTENDED DEFINITION OF 'DEPENDANT'**

- You can register your partner in a **same-sex relationship** or your partner in a customary, religious or traditional marriage
- You can register the children of a customary, traditional or religious marriage, or same-sex relationship.



**KEY POINTS**

**MEDICAL SCHEME BENEFITS**

- The Minister of Health has the power to issue regulations on the minimum benefits that medical schemes must give.
- On 1 January 2000, minimum benefits for HIV/AIDS were introduced.
- The minimum benefit for HIV or AIDS covers treatment for opportunistic infections and costs of hospitalisation.
- At the moment, the minimum benefits for HIV or AIDS do not include **anti-retroviral drugs**. However, the Council for Medical Schemes will **review** these minimum benefits during 2001.

For taking up disputes with your medical scheme, see 17.4.4 on page 409.

**6.4.4 WHAT CAN YOU DO IF A HOSPITAL REFUSES TO TREAT YOU?**

To contact the Department of Health, see 17.3 on page 406.

To contact the Public Protector, see 17.2.3 on page 401.

If a hospital refuses to treat you, you must immediately report this to the Department of Health or the Public Protector. The High Court can review and set aside (cancel) the decision of the hospital to refuse to treat you.



# Talking points



**1** If there were no rules about confidentiality, and every person who was tested for HIV was forced to disclose his/her HIV status, what do you think would happen?

- *Would this reduce the spread of HIV?*
- *Why or why not?*

**2** When do you think it may be in a patient's best interests to disclose his/her HIV status?

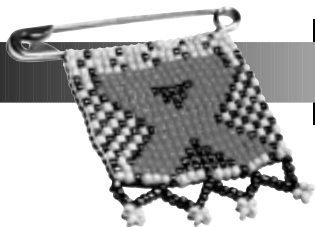
- *When do you think it may not be in the best interests?*
- *What do you think you would do in the situation?*

**3** The Human Tissues Act says that a blood donation can only be given with informed consent. But the Act doesn't say anything about consent for an HIV test. The National Policy on Testing recommends that blood donors should give informed consent for their blood to be tested for HIV.

- *What do you think?*

**4** The South African Law Commission has recommended that the law should be amended to allow for the HIV testing without consent of a person accused of a sexual offence, in certain circumstances.

- *Do you think this is important? Why?*
- *Do you think this is constitutional?*



## References & resource materials

### **LAWS**

- Basic Conditions of Employment Act, No 137 of 1993.
- Birth and Death Registration Act: Regulations, 1998.
- Child Care Act, No 74 of 1983.
- Choice on Termination of Pregnancy Act, No 92 of 1996.
- Employment Equity Act, No 55 of 1998.
- Health Act, No 63 of 1977.
- Human Tissue Act, No 65 of 1983.
- Medical Schemes Act, No 131 of 1998 & Regulations: Government Gazette No 20556, 20 October 1999.
- Mental Health Act, No 18 of 1973.
- Draft National Health Bill, 9 November 2001.
- National Policy for Health Act, No 116 of 1990.

### **POLICY DOCUMENTS**

- Department of Health: Minimum Standards for Counselling and Training, (Policy for Lay Counsellors).
- Department of Health: National Policy on Testing for HIV: Government Gazette No 20710, December 1999.
- Department of Health: HIV/AIDS Policy Guideline: Testing for HIV, August 2000 (based on National Policy).
- Department of Health: Standard Treatment Guidelines for the Management of HIV-related Opportunistic Infections in Adults and Children, August 2000.
- Department of Health: HIV/AIDS Policy Guideline: Prevention and Treatment of Opportunistic and HIV-related diseases in Adults, August 2000.
- Department of Health: HIV/AIDS Policy Guideline: Managing HIV in Children, March 2000.
- Department of Health: HIV/AIDS Policy Guideline: Prevention of Mother-to-child HIV transmission and management of HIV positive pregnant women, May 2000.
- Department of Health: Guidelines for Couple Counselling, no date.
- Department of Health: Guidelines for Pre-test, Post-test and Ongoing Counselling and Group Intervention Sessions, no date.
- Department of Health: Rapid HIV Testing, August 2000.

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Department of Health: HIV/AIDS Policy Guideline: Tuberculosis (TB) and HIV/AIDS, August 2000.

Department of Health: HIV/AIDS Policy Guideline: Feeding of infants of HIV positive mothers, August 2000.

Department of Health: The National Patients' Rights Charter, 1999.

Department of Health: Draft Regulations relating to Communicable Diseases and the Notification of Notifiable Medical Conditions, SA Government Gazette, R485 and R484, 23rd April 1999.

HPCSA Guidelines: The Management of Patients with HIV Infection or AIDS, 2001.

Medical Association of South Africa (MASA): HIV/AIDS Guidelines (revised), 1995.

SAMDC Rules of Practice, 1994.

## **CASES**

A v SAA, (unreported), Case No. J1916/99, Labour Court, Braamfontein.

Jansen van Vuuren and Another NNO v Kruger, 1993 (4) SA 842 (A).

Stoffberg v Elliot, 1923 CPD 148.

## **REPORTS, MANUALS AND OTHER USEFUL MATERIALS**

AIDS Law Project (ALP) and Lawyers for Human Rights: HIV/AIDS and the Law – A Trainer's Manual (First Edition), July 1997.

ALP: HIV/AIDS Current Law & Policy booklet 2: 'Knowing your HIV status – issues around testing', July 2000.

ALP: HIV/AIDS Current Law & Policy booklet 3: 'Who has the right to know?', July 2000.

AIDS Legal Network (ALN): ALQ – The AIDS Legal Quarterly (quarterly magazine).

Community Law Centre: Socio-Economic Rights in South Africa (A Resource Book), October 2000.

Department of Health: Patients' Rights – your right to dignity (pamphlet), 1999.

South African Law Commission: The Compulsory HIV Testing in Persons Arrested for Sexual Offences, Fourth Interim Report (Project 85), 2000.

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## **WEBSITES**

AIDS Law Project: [www.alp.org.za](http://www.alp.org.za)

AIDS Legal Network: [www.redribbon.co.za/legal](http://www.redribbon.co.za/legal)

Council for Medical Schemes: [www.medicalschemes.com](http://www.medicalschemes.com)

Department of Health resources: [www.aidsinfo.co.za](http://www.aidsinfo.co.za)

Health Professions Council of South Africa: [www.hpcs.co.za](http://www.hpcs.co.za)

South African Law Commission: [www.law.wits.ac.za/salc/salc.html](http://www.law.wits.ac.za/salc/salc.html)

Treatment Action Campaign: [www.tac.org.za](http://www.tac.org.za)

UNAIDS: [www.unaids.org](http://www.unaids.org)

World Health Organisation: [www.who.org](http://www.who.org)