

HIV/AIDS

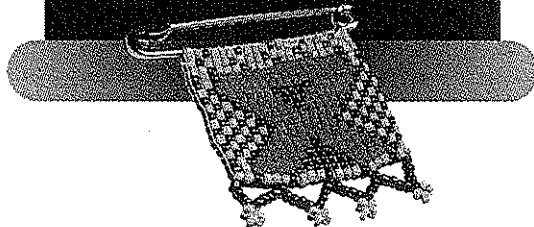
AND THE LAW

A RESOURCE MANUAL • 3RD EDITION

PUBLISHED BY THE AIDS LAW PROJECT AND THE AIDS LEGAL NETWORK

HIV/AIDS AND THE LAW

A resource manual



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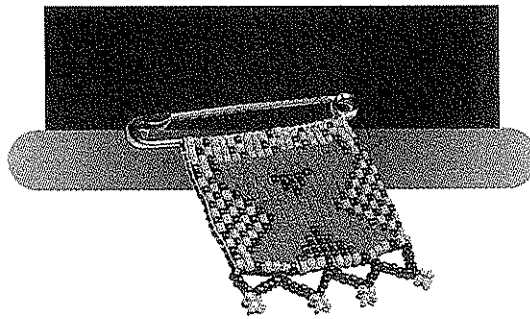
Introduction & updating of third edition

Kitty Barrett-Grant
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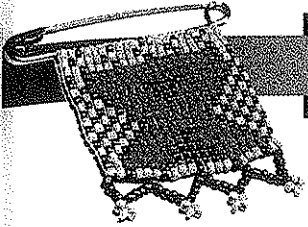
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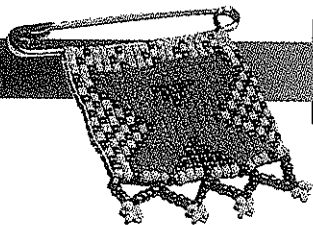
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One essential thing learned in the HIV/AIDS epidemic is that universally recognised human rights standards should guide policy-makers in formulating the direction and content of HIV-related policy and should be an integral part of all aspects of the national and local response to HIV/AIDS.



Guidelines on HIV/AIDS and Human Rights, UNAIDS and the United Nations High Commissioner for Human Rights, 1997



Foreword

As a people we have much to be sad about in this grievous epidemic. The insufficiency of much of our response, and the misdirection of too many of our thoughts and utterances and plans, have resulted in many avoidable infections – and in too much avoidable grief, suffering and bereavement.

But sadness and grief, if not acted on, result in despair. And despair is a response that we cannot permit. That is why the appearance of the second edition of this admirable book is so welcome.

HIV/AIDS and the Law: A Resource Manual symbolises the best in our nation's response to HIV and AIDS. It is truthful, clear, practical, well-directed and helpful. It is filled with accurate and useful information. But above all, the manual embodies a call for action – rejecting unfair discrimination and affirming claimable rights. Such responses can improve the lives of those living with or affected by HIV or AIDS. This is the point of the manual.

The second edition – nearly four years after the first appeared – is enhanced, improved and enlarged. Those in the AIDS Legal Network and in the AIDS Law Project who originally conceived and who have now updated the manual (together with allies in Lawyers for Human Rights and other human rights organisations) are to be applauded for their forethought, hard work and courage.

The second edition of the manual, like its predecessor, will prove invaluable to those in government, business and the non-governmental sector who are committed to dealing with this epidemic in the most effective way. That is, as we know from our own experiences and those of others worldwide, through recognising and enforcing the rights of all South Africans to dignity and autonomy, and to just equality in resources, opportunities and medical treatment.

Justice Edwin Cameron
SUPREME COURT OF APPEAL

May 2001

REFLECTING ON THE AIM OF THE MANUAL

The first edition of *HIV/AIDS and the Law: A Resource Manual* was published in May 1997. Six years later, stigma, unfair discrimination and human rights violations against people living with HIV or AIDS remain common in our society. This is an attack on the rights of thousands of people to dignity and equality, and also a serious obstacle to effective HIV prevention, treatment and care.

Since 1997, the number of people living with HIV in South Africa has more than doubled and is now close to 5 million. Yet the threat of human rights violations makes many people afraid to be tested to HIV and fear disclosure of their HIV status, even to close friends and family. This means that, with a few brave exceptions, there is still little openness about HIV.

Our society is now well aware of the worst cases of human rights abuse and discrimination. Gugu Dlamini, a NAPWA activist, who was killed in December 1998, is a household name. But less concern is shown about the many unnamed people who, on a daily basis, lose their jobs, are refused houses and are denied treatment because of their HIV status. For example, in February 2001, the Sowetan newspaper reported the tragic story of Nosipho Xhape, who died alone under a tree in a Soweto street. Before she died, she told a journalist that after her lover found out she had HIV:

“ He said I was useless because I could no longer cook, wash or clean his house. He also did not want me to die in his house. It was at night that he threw me out. I managed to crawl to a toilet and slept there. ”

HIV/AIDS and the Law: A Resource Manual aims to help people living with HIV and people affected by HIV (all of us) to navigate their way through the law on human rights and discrimination. The manual presents the law in a way that is easy to understand and use. It combines practical information with guidance on where to get further assistance. It aims to assist many different types of people, including paralegals, judges, politicians, trade unionists, and people offering pre- and post-test counselling for HIV.

Since the first edition in 1997, there have been many changes to the law and its interpretation. Many of these changes were captured in the second edition in 2001. For example, in 1997 the Constitution and the Bill of Rights still had to be tested.

Since then, the Constitutional Court and many lower courts have passed judgments that widen our understanding of the meaning of human rights in relation to HIV/AIDS. One of the most important of these was the Constitutional Court's judgment in 2000 in *Hoffman vs SAA*, where the Court decided that it was a violation of a person's right to dignity and equality to refuse him employment just because he was living with HIV. In this case, the judge spoke out strongly against unfair discrimination, stereotyping and "economic death" for people with HIV who are forced to have a pre-employment HIV test.

The third edition of this manual has again been updated, although there are a number of important developments that we refer to below which are not yet reflected in the relevant chapters in this manual. In particular, we draw the reader's attention to the following:



THE CONSTITUTION AND BILL OF RIGHTS (CHAPTER 4)

Since 2001, there have been numerous new judgments from the Constitutional Court. However, there are three that are of particular importance to HIV/AIDS. The first is a judgment now known as *Grootboom*, in which the Constitutional Court stated that the government had a duty to have clear plans to realise the socio-economic rights that are given to people under our Constitution.

In particular, it said that these plans must be "reasonable" and that the test of reasonableness must include ascertaining whether there are specific measures in place that address the needs of those who are most vulnerable and at risk because of poverty or other socio-economic circumstances. This was a judgment in relation to Section 26 of the Bill of Rights – "The right to have access to adequate housing", as well as Section 28(1)(c) – "The rights of children to shelter". This judgment is considered to be a fundamental judgment on socio-economic rights.

In 2002, the Constitutional Court handed down judgment in the case between the Treatment Action Campaign (TAC) and the Minister of Health, finally concluding the dispute over the extent of the government's duties to take steps to prevent mother-to-child transmission of HIV (MTCT) by using the anti-retroviral drug Nevirapine. This case was an appeal brought by the government to challenge an order that had been made by the Pretoria High Court in December 2001 instructing the government to allow doctors to dispense Nevirapine after consultation with hospital superintendents, and also ordering the national and provincial governments to develop a coherent plan on MTCT within a timeframe of three months.

In response to the appeal, the Constitutional Court declared that the government's MTCT policy was unreasonable and that it did not meet the duties they had under Section 27(1) and 27(2) of the Constitution – the rights of everyone to have access to health care services and the duty of the state to take

 reasonable legislative and other measures within its available resources, to achieve the progressive realisation of each of these rights. 

In the light of this finding, the Court ordered the government to lift restrictions on the availability of Nevirapine and to implement concrete measures to assist with the training of counsellors as part of a MTCT programme. This judgment, too, is very important and is seen as a deepening of the Court's jurisprudence on socio-economic rights. In it the Constitutional Court went further than in *Grootboom*, because the judgment was more than just a declaration that the government was wrong – it included specific orders that the government had to carry out. Both of these cases are cited in references at the end of this chapter.

The third important case that has direct consequences for the management of the HIV/AIDS epidemic that came before the Constitutional Court was not so positive. This case, known as *Jordan and Others v S and Others* was an appeal to uphold the finding of the Pretoria High Court that the criminalisation of prostitution under the Sexual Offences Act (23 of 1957) was a violation of the constitutional right to equality because it unfairly discriminated against women. In its judgment on this matter, the Constitutional Court wrote majority and minority judgments. The majority judgment declined to find that the prohibition on prostitution and the running of brothels in the Sexual Offences Act is unconstitutional.

The result of this is that sex work and the running of brothels in South Africa remains illegal and, therefore, a criminal offence. In this case, a number of organisations, including the AIDS Law Project, had acted as *amicus curiae* (friend of the court) and argued that criminalising sex work exposes prostitutes, who are mostly women, to higher risks of HIV infection. This is because people who are engaged in unlawful acts have less power to insist on safer sex. Prostitutes who are forced to have sex without a condom or who are raped are unable to seek protection from the police or the legal system because of the unlawful nature of their work. Unfortunately, this argument was not accepted by the Constitutional Court.

In addition to the cases above there are other cases on HIV/AIDS and constitutional law, which have not yet been decided. In June 2002, for example, the Johannesburg High Court, heard a case where it is being claimed that a pre-primary school's refusal to admit a three year old child because she had HIV was a violation of her right to equality.

INTERNATIONAL LAW (CHAPTER 5)

In this manual international law is mainly looked at through the right to health. Since 2001, there have been two developments of particular importance. The first was a meeting of the Council of Ministers of the World Trade Organisation, which took place in Doha in November 2001. This meeting led to a ministerial declaration of the TRIPS agreement and public health which aimed to clarify the powers of governments to override patents by issuing compulsory licences on essential medicines. Specifically, the declaration stated that governments have a right to issue these licences as well as to

“ determine what constitutes a national emergency or other circumstances of extreme urgency, it being understood that public health crises, including those relating to HIV/AIDS, tuberculosis, malaria and other epidemics, can represent a national emergency or other circumstances of extreme urgency. ”

This declaration is a milestone in advancing the rights of health. Unfortunately, however, by early 2003, no governments had taken advantage of this statement. Indeed, late in 2002, there were efforts at the WTO, driven by the United States, to try to limit the applicability of this statement and restrict the powers of developing countries to import generic medicines.

The next important development was the publication in September 2002 of a revision of Guideline 6 of the *International Guidelines on HIV/AIDS and Human Rights*. The new guideline on *Access to Prevention, Treatment, Care and Support* recommends explicitly that governments have a duty to take steps to ensure that all people have access to health services essential for the prevention and treatment of HIV/AIDS. It specifically mentions that people have a right to have access to “antiretroviral and other safe and effective medicines” and recommends that:

“ States should develop and implement national plans to progressively realise universal access to comprehensive treatment, care and support for all persons living with HIV/AIDS ... ”

The *International Guidelines* are recommendations, that is, they are not ‘hard law’ or legally binding on states. Nevertheless, they are important and it is likely in the years ahead that aspects of these guidelines will find their way into national legislation and jurisprudence.

HEALTH RIGHTS (CHAPTER 6)

The major development in relation to health rights has already been referred to, that is, the case concerning the prevention of mother-to-child HIV transmission. This judgment made clear the duty on government to take reasonable measures to progressively realise people's rights to access to health care services.

In 2003, after the 3rd edition of this manual has been published, it is likely that Parliament will pass a new National Health Act. This Act will set out the structure of the health system, the powers of the Minister of Health, as well as the powers of various levels of the health service and institutions such as the Medical Research Council. The National Health Act will be the most important law, other than the Constitution, setting out the duties of government. The AIDS Law Project hopes to produce a new resource manual that deals extensively with health law and policy.

YOUR RIGHTS AT WORK (CHAPTER 7)

Since 2001, there have been a number of important Labour Court cases that have tested the meaning of Section 7(2) of the Employment Equity Act, that is the Section that prohibits HIV testing in the workplace unless permission is granted by the Labour Court (see page 163).

For some time, there was some controversy about the breadth of this prohibition, with the emergence of two interpretive camps: on the one hand, those that argued that the Act created a prohibition on any and all kinds of HIV testing (including voluntary counselling and testing). On the other hand, those who argue that the purpose of the Act was only to prohibit testing that was discriminatory in its intent. Orders that were handed down by the Labour Court in relation to Section 7(2) included cases known as *Ndebele Mining* (unreported), *Rand Water Board* (unreported), *Joy Mining Machinery* and, most recently, *Irvin & Johnson*. Proper references to these cases are given in Chapter 7.

In the judgment handed down in *Irvin & Johnson*, the Labour Court dispelled this uncertainty by stating that the Employment Equity Act was not applicable to testing in the workplace that is voluntary and takes place with informed consent. The meaning of this is that, in future, applications to the Labour Court will only be necessary in circumstances where the HIV testing may be thought to be discriminatory, for example as a condition for employment or promotion.

In 2002 an important amendment to the law governing employees in government departments was made through an amendment to the Public Service Regulations – a new regulation was inserted dealing specifically with HIV. The purpose of this amendment was to create a safe and supportive environment that takes into account the impact of HIV on the workplace. The new regulations are included in Appendix 7.

It creates rules and guidelines governing occupational exposure, non-discrimination, HIV testing, confidentiality and disclosure, and health promotion. The effect of this amendment is to make the recommendations of the Code on HIV/AIDS and Employment compulsory for the public service. For example the amendment states that:

“ A head of department shall ... ensure that no employee or prospective employee is unfairly discriminated against on the basis of his or her HIV status ... ”

This is a very positive step.

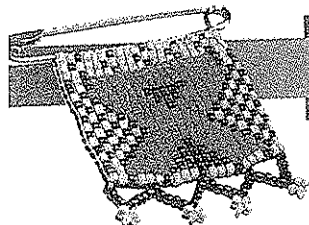
CRIMINAL LAW AND PROCEDURE (CHAPTER 14)

Since the 2nd edition of the manual, there has not been any new jurisprudence relating to criminal law and HIV/AIDS. However, there have been a number of important developments. Firstly, in early 2003, Parliament passed the Compulsory Testing of Alleged Sexual Offenders Act, a new law which allows people who have been accused of sexual offences, particularly rape, to be tested for HIV without their consent, if an HIV test is requested by the victim of the sexual offence. This is recognised to be a limitation on the rights of the person accused of the sexual offence, but is justified on the grounds of bringing some peace of mind to the victim, as well as on the grounds that permission to test is only given after an application to a Magistrate and with certain strict conditions concerning issues such as confidentiality. A reference to this Act can be found in Chapter 14.

In addition, debate has continued on the merits of using criminal law to prevent HIV transmission. This is reflected in an early 2003 report of the South African Law Commission that is making recommendations on changes to the Sexual Offences Act. Controversially, this report recommends that people who have sex without disclosing that they have a sexually transmitted infection, including HIV, should be guilty of the offence of rape. As previously explained, the problems with this kind of proposal are:

- that there are many people who are unaware that they have HIV
- that there are many people who, even though they might be aware, have not been properly counselled about disclosure to sexual partners or fear violence if the partners are men
- that this kind of law takes the responsibility off both people to practice safer sex.

A detailed analysis of the problems of using criminal law to try to prevent HIV infections was published by UNAIDS in late 2002 and is listed in the references in the chapter on criminal law.



Contents

Sharpening our focus	1
How to use this manual	5

Chapters


1. Understanding HIV and AIDS	7
2. HIV/AIDS, power and discrimination	29
3. Introduction to the legal system	45
4. The Constitution and Bill of Rights	63
5. International law	93
6. Your health rights	115
7. Your rights at work	153
8. The rights of women	181
9. Customary law	207
10. The rights of lesbians and gay men	225
11. The rights of children	247
12. Social assistance	271
13. Insurance	291
14. Criminal law and procedure	313
15. The rights of prisoners	343
16. Future planning	365
17. Legal remedies: Using the law to protect your rights	393

Reference lists

R1. Abbreviations	449
R2. Key words	451
R3. Laws	469
R4. Policy documents	471
R5. Cases	474
R6. Reports, manuals and other useful materials	477
R7. Websites	481
R8. Contacts	483

Appendices

A1. Charter of Rights on AIDS and HIV	491
A2. National Patients' Rights Charter	495
A3. National Policy on Testing for HIV	500
A4. Health Professions Council Guidelines: The Management of Patients with HIV Infection or AIDS	504
A5. Code of Good Practice on Key Aspects of HIV/AIDS and Employment	514
A6. National Policy on HIV/AIDS for Learners and Educators	529
A7. Amendment of Public Service Regulations, 2001	548


 Human rights matter most when they are most at risk.

That is when lawyers and lawmakers have a special responsibility.

*South Africa, with its beautiful land and people,
has had occasion to learn from the
great wrongs of discrimination and the burden
of the viruses of ignorance and prejudice.*

*As South Africa now faces a new and special test
with the advent of AIDS,*

*there will be many observers who will hope that,
learning from its past,*

it will do better in its future. 

Justice Michael Kirby, Chairperson of the International Commission of Jurists,
address to the first National Conference on Legal Rights and AIDS, Johannesburg 1992.

ACCESS TO TREATMENT

The biggest change of all since the first edition of this manual has been the emergence of activism and heated debate around rights of access to health care, and particularly access to effective and affordable treatments, for people with HIV.

In 1997, South Africa still faced a largely invisible HIV epidemic with relatively small numbers of people becoming ill and dying as a result of AIDS. But by 2003, the scale of South Africa's epidemic has become a lot clearer. The Department of Health now believes that over 200,000 people die every year as a result of AIDS. In 2002, an investigation into causes of death by Statistics SA found that HIV was the leading cause of death among young women, and one of the main causes of death of adult men. Some analysts predict that, by next year, as many as 500,000 people will die each year.

Preserving human life and well-being is a duty facing the Government and all health professionals in South Africa. Back in 1997, there was a hope that this would become a relatively simple duty as a result of the growing scientific understanding of HIV and the development of increasingly effective ways of treating HIV. However, for people in South Africa and in all poor countries, access to effective treatment is being blocked by the cost of medicines and the lack of public and private investment in health care services for all people.

Improving access to life-saving medicines changes the way people look at HIV and AIDS. A lot of stigma exists because of fear of death, and the perception that HIV is automatically a death sentence. Providing people with effective medicines is a strategy to protect other human rights. Doing this will also encourage more voluntary HIV testing and openness about HIV infection.

This is why access to treatment has become such a burning human rights issue. It raises many questions of law, for example:

- What does the "right to have access to health care services" actually mean?
- What powers can the Government use to bring down the price of medicines?
- What medicines do people have a right to get from clinics and hospitals?
- What medicines are available to people who can afford them?
- Why are patents a barrier to the production and sale of affordable medicines?



ISSUING OF NEVIRAPINE

As we saw in the mother-to-child transmission of HIV (MTCT) case, bringing these issues before the court can help to answer some of these questions.

● See pages iii & iv.

In April 2002, partly because of the pressure of legal action, the Cabinet developed its policy on HIV. It said that nobody should be refused treatment for 'opportunistic infections' caused by HIV. It announced that anti-retrovirals would be provided to rape survivors as post-exposure prophylaxis (PCP), and promised a universal roll-out of an MTCT programme from 2003. It recognised that anti-retroviral treatment does improve health, but that ways needed to be found to reduce the cost of these drugs.

IMPLEMENTING THE NEW MEDICINES ACT

In April 2001, the legal action brought by the Pharmaceutical Manufacturers' Association (PMA) against the *Medicines and Related Substances Control Amendment Act of 1997* ('the Medicines Act') ended unexpectedly when the PMA unconditionally withdraw its legal action.

The withdrawal took place because of mounting international pressure and the likelihood of the companies being humiliated in the court. On 6 March 2001, for example, Judge Ngoepe dismissed PMA objections to the participation of the Treatment Action Campaign (TAC) as *amicus curiae* (friend of the court), and ordered the PMA to respond to the evidence and arguments made in the TAC's affidavits.

The Government is now free to implement the Medicines Act and some of its measures will have an impact on the affordability of medicines. For example, the *Sunday Times* of 22 April 2001 estimated that "South Africans would benefit to the tune of R2,5 billion" through the radical overhaul of the medicines industry that the Medicines Act will encourage. They quoted Aspen Pharmacare, a listed South African generic medicines manufacturer as saying that the Medicines Act would make compulsory the generic substitution of off-patent drugs for diabetes, depression, blood pressure and other illnesses. This would lead to significant savings to the consumer.

The Medicines Act is due to come into effect in 2003. It will alter the balance of power in the relationship between the research-based companies and the Government. This will be achieved through:

- Generic substitution of off-patent medicines if there are generic alternatives already registered in South Africa.
- Setting up a statutory Medicines Pricing Committee.
- Setting a "single exit price" for a medicine that is sold in the private sector.
- The power of the Minister to authorise parallel importing of medicines that are needed in the public interest.

To read the legal papers in the TAC Complaint to the Competition Commission, visit the TAC website: www.tac.org.za

Efforts to use the law to reduce medicine prices have continued. In 2002, for example, a number of people with HIV, doctors and trade unions laid a complaint with the Competition Commission against the behaviour of two multi-national pharmaceutical companies. They allege that these companies are abusing their monopoly over the market, gained through their patents, to set excessive prices for essential medicines. They claim that this impacts on the rights to life and dignity of people with HIV/AIDS. At the time of writing the Competition Commission had not reported on whether it had found evidence to justify this complaint. An introduction to some of the issues around patents and the prices of medicines can be found in Chapter 5 of this manual.

BUILDING OUR UNDERSTANDING AND ACTION

We need to know and understand the law on HIV/AIDS to challenge discrimination, abuses and lack of access to treatment. Continuing to stand up for our rights also depends on a full understanding by all people of:

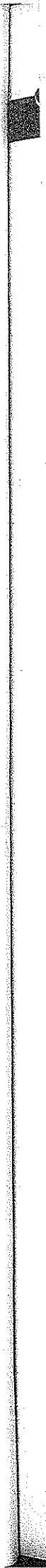
- The science of HIV
- The impact of HIV on the human immune system
- The different approaches to treating illness caused by HIV and to preventing HIV from destroying the immune system.

Organisations such as the Treatment Action Campaign (TAC) are developing much experience and knowledge on these issues and are attempting to pass on this knowledge to affected people and communities. You can contact the TAC for more information and to get actively involved in its campaign work.

In this context, it is fitting to remind ourselves of a comment made by Justice Edwin Cameron, whose leadership in fighting for equality for people with HIV and AIDS is now universally recognised. In 1992, Judge Cameron said:

“Discrimination in the allocation of health resources is the most debilitating discrimination of all ... The deepest violation of another person's humanity is to deprive that person of the means to remain healthy, to fight illness and to live – or die – in reasonable comfort and dignity.”

MARCH 2003



FINDING INFORMATION

Contents

- Manual contents: find the chapter you need by checking the Contents page at the front.
- Chapter contents: each chapter has a more detailed Contents to help you find information quickly.

Numbering in chapters

Using Chapter 3 as an example:

- Main sections are numbered 3.1, 3.2 and 3.3 etc.
- Subsections are 3.1.1 and 3.1.2 etc.

Cross-references

Look in the left margin for references to information in another part of the chapter, at the back of the chapter, or in another part of the manual, eg: For more on confidentiality, see 6.2 on page 120.

Chapter talking points

You will find *Talking points* at the back of each chapter. You can use these for discussion and workshops in your organisation, office or community.

Chapter resource materials

Also look at the back of each chapter for a list of *References and resource materials* used in the chapter, under these headings:

- Laws
- Policy documents
- Cases
- Reports, manuals and other useful materials
- Websites.

NOTE: We use *italics* the first time we mention a law, policy document or case in a chapter.

Resource materials at the back of the manual

See Reference lists R3, R4, R5, R6 and R7 from page 469 onwards for combined lists of manual resource materials, under the same headings used at the end of chapters (see *Chapter resource materials*).

Contacts

Check R8 on page 483 for our selected list of resource and support organisations on HIV/AIDS and the law.

ABBREVIATIONS AND KEY WORDS

Abbreviations

See R1 on page 449 for our A to Z list of abbreviations used in the manual.

Key words

See R2 on page 451 for our A to Z list of key words, terms and structures used in the manual.

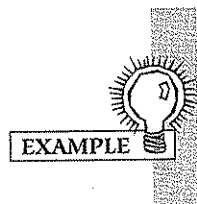
NOTE: The first time we use a key word, term or structure in a chapter, we put it in **bold**.

SYMBOLS TO GUIDE YOU



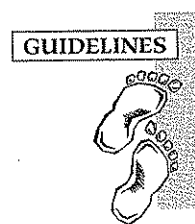
CASE

Important court cases on HIV/AIDS and the law.



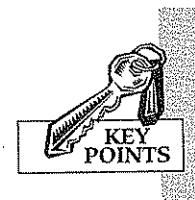
EXAMPLE

Practical examples to explain laws, policies or issues.



GUIDELINES

Steps or checklists to follow in handling problems and situations.



KEY POINT

Important points or lessons to remember.