

HIV/AIDS

A Resource for Journalists



Department of Health
Republic of South Africa



AIDS HELPLINE
☎ **0800-012-322**

This booklet is a resource to help busy journalists cover the issue of HIV/AIDS effectively. It is produced by Soul City: Institute for Health and Development Communication in partnership with the South African National Editors' Forum, Health-e and the Department of Health. It provides accurate information, reliable contacts and resources. The media can help or hinder attempts to address the AIDS epidemic. The booklet aims to strengthen the media's capacity to play a constructive role.



Department of Health
Republic of South Africa

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Soul City: Institute for Health and Development Communication in partnership with the South African National Editors' Forum, Health-e and the Department of Health.

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Design



Front Cover Photograph:

Close-up of isolated HIV viruses budding from cell protrusions of an infected white blood cell.

Photomicrograph by Lennart Nilsson

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Contents

- 4 Foreword**
- 6 Contacts for the Media**
- 13 Websites and Resources**
- 20 AIDS and the Media**
- 21 Ethical Issues for Journalists**
- 24 The Facts about HIV/AIDS**
 - What is HIV and AIDS?
 - How does HIV become AIDS?
 - Opportunistic Infections
 - How HIV is Transmitted?
 - Safer Sex
 - Myths and Stigma
- 28 Understanding Statistics and Predictions**
 - The National Ante-natal Survey
 - Predictions and Projections
 - The Economic Impact of HIV/AIDS
- 32 Gender & HIV/AIDS**
 - Notions of “Manhood”
 - Biological Vulnerability of Women
 - Violence Against Women
 - Pregnancy and HIV/AIDS
 - Mother-to-Child Transmission
- 35 Socio-economic Issues – Poverty and AIDS**
- 36 Children and AIDS**
- 38 HIV/AIDS and Education**
- 39 Vaccines**
- 40 Voluntary Testing and Counselling (VTC)**
 - Tests
 - Patient Rights
 - Informed Consent
 - Confidentiality
- 41 Care and Support for People Living with HIV and AIDS**
 - Keeping Healthy
 - Home-based Care
- 43 Treatment**
 - Basics on Anti-retroviral Drugs
 - Can South Africa Afford ARV Drugs?
 - MTCT*
 - Rape and Post-exposure Prophylaxis*
 - Treatment for Opportunistic Infections*
 - Triple Therapy*
 - Generic Medicines, Patents and TRIPS
- 49 HIV/AIDS and the Law**
 - Employment Practice
 - Laws and Policies Relating to Health Care
- 51 Addressing the Epidemic**
 - International Experience
 - The Department of Health’s Five-year Plan



Foreword



It is with great joy that I write this message, to support a venture that can only yield good results in the fight against HIV/AIDS.

We wholeheartedly welcome the partnership between the South African National Editors' Forum (Sanef), Soul City, Health-e news service and the Department of Health, which has led to the production of this resource booklet for journalists.

Reporting HIV/AIDS remains a serious challenge for the media in our country, and the intervention through this booklet is significant because it compels journalists to recognize that they have an important role to play in the fight against this epidemic. This level of enthusiasm from the media sector, particularly Sanef and Health-e, is encouraging. It shows that partners in the battle against the disease – from government to civil society – are all moving in the same direction.

In addition, the role of Soul City in bringing education to millions of households in our country, particularly relating to HIV/AIDS, is another unique contribution to the drive to disseminate life-saving information at all levels of our society. Therefore, a partnership between Soul City and the media is a recipe for success.

As Government, we have a clear vision of how to respond to the HIV/AIDS pandemic, and we value partnerships, as we believe all our actions count when it comes to dealing with HIV/AIDS. The partnership concept is seen in practice in the make-up of the South African National Aids Council, (SANAC), which is the highest body advising government on HIV/AIDS. SANAC leads a multi-sectoral strategy, which brings together 16 sectors of civil society and government, working together to combat the disease at different levels.

The SANAC intervention is in line with Government's five-year Strategic Plan for combating HIV/AIDS and other STDs – a framework that combines a range of interventions that have proved successful in other countries confronted with controlling the spread of the HIV virus.

The strategy consists of four priority areas:

- Preventing further HIV infections.
- Treatment, care and support for those who are HIV-positive and those close to them.
- Research and monitoring, including ongoing research into an AIDS vaccine.
- Asserting the human and legal rights of all affected by HIV/AIDS.

We therefore wish to congratulate the partners in this project, and pledge our support for this noble venture. If we strengthen partnerships and continue pooling our resources, we can neutralize this epidemic.

Jacob G. Zuma

A handwritten signature in black ink, appearing to read 'Zuma', with a stylized, circular flourish at the beginning.

Deputy President: Republic of South Africa

Chairperson: South African National AIDS Council



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AIDS – The Facts

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South African Human Rights Commission

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International Experience

Joint United Nations Programme on HIV/AIDS (UNAIDS)

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Ethical Issues for Media

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Treatment Action Campaign

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Websites and Resources

AIDS – The Facts

AIDS Education Global information System (AEGIS)

www.aegis.org

The largest HIV/AIDS website in the world updated hourly.

National Institute for Health, US

www.nih.gov

Extensive documentation on link between HIV and AIDS.

International Association of Physicians in AIDS Care

www.iapac.org

The Body (An AIDS & HIV Information Resource)

www.thebody.com

National Institute of Allergy and Infectious Diseases (USA)

www.niaid.nih.gov

Red Ribbon

www.redribbon.co.za

Aids Consortium

www.aidsconsortium.org.za

Southern African Aids Information Dissemination Service

www.safaids.org

AIDS Foundation of South Africa

www.aids.org.za

Contains general information about AIDS in South Africa.

SA Healthinfo HIV/AIDS module

<http://www.sahealthinfo.org>

iclinic's AIDS page

<http://www.iclinic.co.za/topics/aids/aids.htm>

Information on HIV/AIDS in South Africa & Africa

The Impact of HIV/AIDS

Health Systems Trust

www.hst.org.za

Joint United Nations Programme on HIV/AIDS

www.unaids.org

Love Life

www.lovelife.org.za

Health Economics and HIV/AIDS Research Division (HEARD)

www.und.ac.za/und/heard

Gender & HIV/AIDS

Women's Health Project

www.sn.apc.org./whp/

Panos Institute

www.panos.org.uk

Information on HIV/AIDS and development, and has good information on gender issues, particularly men and HIV/AIDS.

Mother To Child Transmission

Treatment Action Campaign

www.tac.org.za

Medscape

<http://hiv.medscape.com/>

Medecins Sans Frontieres

www.msf.org

Treatment Action Group, USA

www.aidsinfonyc.org/tag

Children & HIV/AIDS

Children in Distress (CINDI)

www.togan.co.za/cindi

An informal consortium of NGOs working with children affected by HIV/AIDS.

ACCESS (Alliance for Children's Entitlement to Social Security)

www.aces.org.za

Vaccines

Health Systems Trust

<http://news.hst.org.za>

UNAIDS

www.unaids.org

SA HIV Vaccine Action Campaign

www.sahealthinfo.org/modules/HIV_AIDS/hiv_aids.htm

Patient Rights

Lawyers for Human Rights

<http://lhrpmb@lhr.org.za>

Aids Law Project

www.hri.ca/partners/alp

African Counselling Network

www.geocities.com/kim1122a/

Treatment

Medecins Sans Frontieres (MSF)

www.msf.org

Treatment Action Campaign, South Africa

www.tac.org

Treatment Action Group, USA

www.aidsinfonyc.org./tag

Information on drugs, treatment, HIV/AIDS

Healthlink

www.hst.org.za

Department of Health

www.gov.za/dept/health

National Association of Pharmaceutical Manufacturers

<http://napmnet.org>

A US-based non-profit trade group representing the regulatory and legislative interests of independent generics manufacturers.

Consumer Project on Technology, USA

www.cptech.org

Aegis

www.aegis.com

Campaign for Access to Essential Medicines

www.accessmed-msf.org

Consumer Project on Technology

www.cptech.org

Information on international trade regulations, compulsory licensing, etc.

Essential Drugs Lists (EDL)

www.sadap.org.za/edl/

Ethical Issues for Media

Health–e News Agency

www.health-e.org.za

News agency producing health news and analysis for the South African media.

Panos Institute

<http://oneworld.org/panos/>

Southern African Aids Information Dissemination Service

www.saf aids.org

General

Beyond Awareness Campaign

(Government website)

www.aidsinfo.co.za

The AIDS Consortium

www.aidsconsortium.org.za

Information on all aspects of the epidemic & assistance with sourcing appropriate information.

World AIDS Statistics

<http://167.160.195.60/html/aidsstatworld.html>

Health Global Access Project Coalition, US

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Coalition campaigning for treatment access.

The Joint UN Programme on HIV/AIDS

www.unaids.org

The Joint United Nations Programme on HIV/AIDS is cosponsored by UNICEF, UNDP, UNFPA, UNESCO, WHO, UNDCP and the World Bank.

The World Health Organisation

www.who.int

HIVNet

www.hivnet.ch/e/

Swiss information and exchange site on HIV/AIDS, created by the Fondation du Présent, Geneva.

Grateful Med:

<http://igm.nlm.nih.gov/>

A gateway interface for assisted searching of medical and health journals.

Kaizer Daily HIV/AIDS Report

<http://report.kff.org/hiv aids/>

International Association of Physicians in AIDS Care

www.iapac.org

The Lancet Publishing Group

www.thelancet.com

The Aids Memorial Quilt

<http://www.aidsquilt.org/>

Contains information on World Aids Statistics

Department of Health website

www.health.gov.za

Treatment Action Campaign

www.tac.org.za

AIDS Information Dissemination Site Southern Africa

<http://www2.wn.apc.org/sahivaids/>

SAFAIDS

www.safaids.org

Information on HIV/AIDS in Southern Africa

Health-link

www.healthlink.org.za

Health Systems Trust website for health workers in South Africa.

Metropolitan Life AIDS information site:

www.redribbon.co.za

SANBI HIV Africa

www.sanbi.ac.za/hivafrica/

MEDSCAPE's AIDS MedPulse

<http://hiv.medscape.com>

South African Medical Journal

www.samedical.org

Soul City

www.soulcity.co.za

South Africa's innovative multimedia health promotion project.

AIDS Law Project

www.hri.ca/partners/alp/index2.shtml

Working to combat discrimination against People Living With HIV/AIDS

SA Medical Association

www.samedical.org

Gender and AIDS

Speakout

www.speakout.org.za

A South African site with information on rape and post exposure HIV prophylaxis.

Women's Net

www.womensnet.org.za

A South African site with local and international information.

United Nations Development Program

www.unifem.undp.org

UN AIDS

www.unaids.org

Averting AIDS and HIV

www.avert.org

This site includes interalia, statistics, information for young people, personal stories.

United States Centre for Disease Control and Prevention

www.cdcnpin.org/topic/woman.htm

US Department of Health and Human Services

www.hrsa.dhhs.gov

Offers, inter alia, a guide to the clinical care of women with HIV.

Henry J Kaiser Family Foundation

www.kff.org

This site has a section on AIDS that includes articles about women and a women's health policy section.

Stories on HIV/AIDS

Health-e News Agency

www.health-e.org.za

This website is a source for the media of stories and photographs on AIDS and other health related matters.

AIDS and the Media

The media is a powerful source of information for people in South Africa. For this reason, it can also be a powerful tool in the fight against AIDS. Journalists have a particularly important role to play in:

- Providing the public with accurate information about the causes, spread, impact and prevention of the disease.
- Helping to destigmatise the epidemic.
- Monitoring and pressurising those in positions of power – in government, business and elsewhere – to deal adequately with HIV/AIDS.
- Presenting a human face to the epidemic by reporting on South African stories.
- Presenting informed debate on difficult ethical questions.
- Providing information on living positively with HIV/AIDS.
- Influencing public opinion against behaviour and trends that help to spread HIV/AIDS.

The media has a very powerful role to play in shaping people’s perceptions about HIV/AIDS, particularly in destigmatising the epidemic. Discrimination against those with HIV/AIDS is often based

on ignorance and fear. Sometimes this ignorance causes dangerous rumours to spread – especially about causes and cures.

Discrimination helps spread the epidemic – fear of discrimination promotes secrecy and non disclosure of one’s HIV status, which may lead to unsafe sexual practices and the spread of HIV.

Journalists have a huge responsibility to set the record straight, but are often called in at short notice to write about HIV/AIDS issues without the necessary background knowledge or time to research the issue properly.

Knowledge about the disease is growing constantly as researchers bring new facts to light. For this reason, it is important for journalists to ensure that their information is up-to-date and accurate. The best way to do so is to check your facts with an expert.

It is not easy reporting on HIV/AIDS. Fear, prejudice, ignorance and denial, and a reluctance to talk openly about sex, in addition to AIDS related politics and economics, are all powerful factors associated with the epidemic. Other conflicts – such as those between the public interest and the individual interest, for example – are not easy to resolve. In addition,

it is a challenge to keep the issue newsworthy and topical, rather than repetitive.

Sensitivity to people living with HIV/AIDS and a commitment to preventing the further spread of HIV are important touchstones as we weave our way through this minefield.

Ethical Issues for Journalists

Reporting on HIV/AIDS provides many challenges. Some of the issues that frequently cause problems are:

Sensationalism

South African society is not used to open discussion about sex. As the epidemic deals with both sex and death, there is a temptation to sensationalise reports.

Sensationalism relies on emotion, usually offering a shallow view of issues and presenting people as either “good” or “bad”. Babies who get HIV, for example, are often described as “innocent” – implying others are somehow “to blame” for contracting the disease. Gay men are a frequent target for sensation.

In reality, no one “deserves” to get

HIV. A sensational approach fails to analyse issues and inform readers of complexities. It also makes it harder to deal with the epidemic and fosters a culture of fear, silence, prejudice and discrimination, and can adversely influence the setting of national priorities and resource allocation.

Relating to Subjects

Subjects of reports and sources should be approached as human beings who have the right to respect.

Aside from damaging people’s lives, fixation on the story without thinking through its consequences on people’s lives may prevent the journalist/any media from being allowed to return to that story again. (For example, after women taking part in an HIV prevention project in Carletonville were exposed in the press as sex workers, the future of the project was jeopardised and all media was barred from that project.)

Under apartheid, the lives and experiences of poor black people were devalued in the media. As the effects of HIV/AIDS are most visible in these communities (poor nutrition hastens the advent of AIDS; people have no resources to conceal the disease;

demographically, 80% of our population is African), there is a danger that this practice will continue. Journalists need to ensure that they treat every subject with respect.

Confidentiality

An ethical reporter should not publish the names of people with HIV without their permission as this could have significant implications for them. This could include rejection by family and deprivation of support. This sometimes poses dilemmas, for example:

- what happens if a government official takes anti-retrovirals but argues that they should not be provided by the health system to others who cannot afford to buy them?
- what about the person with HIV who wilfully infects others?
- what is the line between public interest and the right to privacy? "Outing" people is a matter for debate, but will sometimes do little more than perpetuate the stigma associated with HIV.

The way in which the media covered the death of Presidential spokesperson Parks Mankahlana raised considerable debate. A complaint was laid against a TV station for broadcasting that he

had died of an AIDS-related illness. However, the Broadcasting Complaints Commission of SA dismissed the complaint, ruling that a dead person "had no legal right to privacy or dignity and that the report did not intend to attack Mankahlana". The BCCSA said while many might find the broadcast "in questionable taste", Mankahlana's involvement in the AIDS debate as a public official justified the report.

The debate still rages on amongst media practitioners particularly because of the role Parks Mankahlana played in the controversy around the cause of Aids. But as a general rule, a person with HIV should not be named unless they agree to this. In the case of a person who has died, the family should be consulted.

Language/Terminology

The words used to describe HIV/AIDS play an important role in shaping perceptions and should be used with care. Use words that do not carry value judgements. Language should be inclusive rather than creating a "them/us" or "innocent/guilty" mentality – nobody deserves to get AIDS.

Attention should be paid to how people prefer to describe

themselves. HIV-positive people reject descriptions such as “infected person”, “AIDS carrier”, “sufferer” or “victim” as these stigmatise and imply that they should be avoided or are powerless. The preferred term is “People living with HIV/AIDS” (PWA).

Words such as “scourge”, “dreaded disease”, “plague” etc contribute to a climate of fear which has been shown to perpetuate stigma. This makes it harder to speak openly about the disease and is a barrier to addressing the epidemic.

Similarly, referring to people as “suspected” of having AIDS or “admitting” they are HIV positive only adds to stigma.

Often a journalist may have used appropriate language, but an editor or sub-editor changes the article to include offensive terminology. This should be challenged by journalists.

Myths and Misconceptions

Inaccurate reporting fuels the epidemic. If in doubt, check your stories with an expert. In addition, if members of the public are quoted repeating myths about the

disease, these should be refuted by experts in the same article.

Journalists should exercise caution when reporting on treatments and “cures”. These should be scrutinised carefully, and a distinction should be made between those aimed at “treating AIDS” and those that treat opportunistic infections. In the past, inaccurate reporting on such claims has raised expectations among PWAs, and damaged the credibility of health care providers who are unable to meet these expectations.

Sources

There are many sources about the disease, often contradictory. Powerful forces often try to influence the agenda and may pressurise journalists to report issues in a particular way. For example, politicians may put pressure on reporters or pharmaceutical companies may try to use their financial muscle to influence what gets reported on. The stakes are very high, for example, in the search for a vaccine and for effective anti HIV drugs. Ideally, all information should be independently verified, even though this may take time and energy.

The Facts About HIV/AIDS

What is HIV and AIDS?

AIDS stands for Acquired Immune Deficiency Syndrome. It was first recognised in 1981 and has since become a major worldwide pandemic.

A syndrome is a collection of symptoms and illnesses. Although there are other causes of less severe immune deficiency, like cancer, malnutrition, diabetes and even the common cold, the cause of the severe and progressive immune deficiency in this pandemic has been conclusively shown to be caused by the Human Immunodeficiency Virus (HIV).

How does HIV become AIDS?

HIV causes AIDS by directly killing CD4+ T cells or interfering with their normal function. CD4+ T cells are the white blood cells that orchestrate and control the body's immune response. This process takes place over a long period during which the person is HIV positive (i.e. carrying the HI Virus) but looks and feels well. In this period, the virus multiplies and

eventually overpowers the body's immune system. It may be anything between 5 – 15 years before the immune system becomes so compromised that the syndrome of AIDS becomes manifest.

By definition, AIDS begins when a person's CD4+ T cell count is less than 200 cells per microlitre of blood, or s/he develops AIDS related opportunistic infections (infections that don't usually cause severe or life threatening diseases in people with a healthy immune system).

HIV infection typically follows the following course:

- **Initial infection, usually going unrecognised or marked by mild flu-like symptoms.** Prolonged period without visible symptoms. For a while the body's defence system tries to fight off the AIDS virus, but eventually the virus multiplies and overpowers the body's immune system. Often this decline is evident on laboratory tests (eg CD4 cell counts, HIV viral load) even though the individual may appear well.
- **With moderate immune deficiency** the body becomes more prone to illnesses. These can usually be simply diagnosed and treated, the immune status

improves, and the person can return to reasonable health again.

- **Severe immuno-deficiency** resulting in the development of opportunistic infections and some cancers, represent the major causes of death in AIDS patients. These can often also be treated if detected early, but the weaker the immune system the poorer the outlook.

The vast majority of people who get the HIV Virus die of AIDS. There is no cure for AIDS. However, in the industrialised world, the affordability of combination therapies of drugs to inhibit the virus have made HIV/AIDS a manageable, almost chronic, disease.

Opportunistic Infections

People with AIDS die from sicknesses – called opportunistic infections – that take advantage of weak immune systems. Many of these infections can be cured through drugs. However, many of these drugs are expensive and patent laws render generic versions unavailable (see section on Treatment). This makes it difficult for people with AIDS to manage their opportunistic infections.

Common Opportunistic Infections include:

Tuberculosis (TB) – the most common life-threatening opportunistic infection in people with HIV in Africa.

Candidiasis (thrush) – a fungal infection, affecting the mucous membranes around the mouth, vagina, oesophagus, and skin.

Gastrointestinal infections that cause chronic diarrhoea.

Cryptococcal meningitis – a fungal infection of the brain lining.

Pneumocystis carinii Pneumonia (PCP) – a lung infection characterised by coughing, high fever and difficulty in breathing.

Cytomegalovirus (CMV) – a viral infection that can cause infections of the eyes, oesophagus and intestine.

Herpes and shingles – viral infections.

Cancers such as Kaposi's sarcoma and non-Hodgkin's lymphoma may also develop. Other cancers are also more likely to develop in immune-suppressed people, particularly cervical cancer in women and rectal cancer in men.

A number of these diseases (such as Kaposi's sarcoma) are almost unknown in people with adequate immune systems.

How HIV is Transmitted?

Sex

In South Africa, HIV is spread most commonly during unprotected, penetrative sex with an infected partner. During sex the virus can enter the body through the mucosal linings of the vagina, vulva, penis, rectum or, in rare cases, via the mouth (if there are open sores). Oral sex is less risky than vaginal or anal sex because saliva contains chemicals that help kill HIV in your mouth.

The presence of Sexually Transmitted Diseases (STDs) increases the risk of HIV transmission. In addition to causing open sores, STDs bring immune cells to the site of the infection. The presence of the immune cells enhances the ability of the HI Virus to penetrate the body. In women STDs are often symptomless, placing them at greater risk, as they do not know they have the STD.

Blood

HIV can also be transmitted through infected blood, most often by the sharing of needles or syringes contaminated with infected blood. Transmission can also occur through sharing of instruments used for circumcision and tattooing.

Mother-to-Child

Most HIV-infected children acquire the virus from their mothers before or during birth. The virus may also be transmitted from a breastfeeding HIV infected mother to her infant.

Safer Sex

As there is no cure for HIV and as most transmission of HIV takes place during sexual intercourse, the best ways to prevent infection is to abstain from sex or to use a condom during anal or vaginal penetrative sex.

Without condoms, penetrative sex is only safe if you are in a relationship in which both of you have been tested as HIV negative; both only have sex with each other; and both are not exposed to HIV through drug use or other activities.

Condoms are effective barriers to HIV as well as other sexually transmitted diseases. Condoms must be used correctly, however, in order to be effective. Common problems include failure to use a new condom after each ejaculation, not unrolling condom completely, putting it on after genital contact and using with oil-based lubricants that weaken latex.

“Pulling out” before ejaculation is not safe. HIV is also in the fluid that comes out of the penis before orgasm.

Oral sex is only a risk to either partner if there are open sores or blood (bleeding gums) in the mouth. Saliva helps to protect the body during oral sex. However, it is still best for the man not to ejaculate in his partner’s mouth.

Female condoms (femidoms) are currently the only female-applied choice that a woman has to protect herself from HIV and other STDs. Scientists are currently trying to develop microbicides – a foam or gel applied vaginally to protect against HIV transmission.

Myths and Stigma

Myths and stigma present major barriers when dealing with HIV/AIDS.

Many South Africans incorrectly view HIV/AIDS as a “black disease” or a disease that only affects white, gay men. These stereotypes are mostly perpetuated by images in the media and by the profiles of those willing to speak out about their status. The truth is that potentially anyone can get AIDS.

Lack of accurate information and fear of the consequences of infection, as well as reluctance to talk openly about sex, has led to the disease becoming highly stigmatised. Infected people are “blamed”, labelled as “bad” people who in some way deserve AIDS as a punishment. Many people living with HIV / AIDS have been rejected and abandoned by families, friends and colleagues at a time when support and care is most needed. The stigma shrouding AIDS is a barrier to prevention and treatment programmes and is making disclosure to partners, family or communities extremely difficult. The most tragic example of this is Durban AIDS activist Gugu Dlamini, who was murdered by neighbourhood youths in KwaMashu after revealing her status.

Many myths exist around modes of transmission. The facts are: you cannot get HIV from mosquito bites, someone coughing or sneezing, sharing household items, from close physical contact (touching, hugging) with an infected person that is non-sexual, or swimming in the same pool as someone with HIV. You also can’t get it from kissing, masturbation and mutual masturbation.

HIV is not transmitted via sweat, saliva or tears. The only body fluids

which can transmit HIV are sexual fluids, blood and breastmilk.

HIV cannot pass through the protective barrier of your skin. If your skin is not cut, it protects you against infection from blood or sexual fluids. Therefore, you can't get infected if you help someone who is bleeding if you make sure to protect any cuts or open sores on your skin as well as your eyes and mouth.

There is some evidence that male circumcision reduces the risk of HIV infection, but this should not be interpreted to mean that circumcised men do not need to practise safer sex.

Extremely harmful is the myth that an HIV positive man will be cured by having sex with a young virgin.

Understanding Statistics and Predictions

National Ante-natal Survey

The national ante-natal survey involves the anonymous unlinked testing of pregnant women for HIV at state health facilities countrywide. Although not fully

representative of all women or generalisable to the broad population, the national ante-natal survey provides the best available trend of the epidemic and allows for reasonable calculations to be done to determine the extent and magnitude of the HIV epidemic in South Africa. These data also provide the basis for the future projections of the severity of the epidemic, and for planning a response.

It is important to emphasise that pregnant women who use public sector ante-natal clinics do not represent all pregnant women in the South African population, nor the population in its entirety. The survey results only reflect the sexually active women of reproductive age attending these public health clinics. The survey obviously excludes children, the elderly (who are at a relatively insignificant risk of HIV infection), and sexually active adult men. Also excluded from these surveys are pregnant women from higher socio-economic communities using the private sector. Journalists commonly misrepresent the ante-natal data, extrapolating the figures to all of the population, and to men and women in older age groups. Also teenage pregnant girls are not necessarily representative of all teenage girls and the ante-natal data in this respect needs to

be interpreted with extra caution.

Using the ante-natal survey results, and combining these with knowledge of the relative risks of contracting HIV infection in those who do not attend ante-natal clinics, it is possible to estimate HIV infection rates in the total sexually active population. An example of this is the estimate provided by UNAIDS. It suggested that 19.9% of the total sexually active population were infected with HIV at the end of 1999, compared to 22.4% of those who attended ante-natal care at that time.

The findings of the ante-natal survey, conducted by the National Department of Health are updated yearly: ¹

“Prevalence” is a measure of all existing cases of HIV infection.

	National
HIV rates 2000 (%)	24.5
HIV rates 1999 (%)	22.4
HIV rates 1998 (%)	22.8
HIV rates 1997 (%)	17.04

National prevalence figures such as those above obscure the fact that the extent of the epidemic varies widely between provinces. In

KwaZulu-Natal, the worst affected province, HIV prevalence rates were over 36% in 2000 while in the Western Cape they were around 8.7%. (Northern Cape – 11.1%; Northern Province – 13.2%; Eastern Cape – 20.2%; North West – 22.9%; Free State – 27.9%; Gauteng – 29.3%; Mpumalanga – 29.7%.) Rather than simply quoting the national figures, the striking differences between provinces need to be understood and explained. Trends over one year periods should also be interpreted with caution as longer periods of time present a more reliable picture.

Current Debate Regarding the Ante-natal Survey Results

No one contests the extent or severity of the epidemic in the study population of South African women of reproductive age as indicated by the survey data.

However, some researchers argue that the epidemic may be worse among sexually active women of reproductive age than the data from the ante-natal survey suggests. One of the reasons for this is that HIV is known to cause infertility. Pregnant women sampled in the ante-natal survey

may therefore be less likely to be HIV infected than the sexually active population of women they are supposed to represent.

AIDS epidemiologists have also argued that while the survey *data* may be valid, *interpretations* of that data may not be. For example, it has been argued that a stabilising in prevalence rates from one year to the next means the epidemic itself is levelling off. But some epidemiologists caution that if the overall number of infections starts to stabilise and remain constant, this may well be because many HIV infected people are dying rather than because less new people are becoming infected.

These issues regarding the *interpretation* of the survey data need to be understood. But to query the interpretation of data is not the same as to query the validity of the data itself.

Predictions and Projections

Foretelling the future is not an exact science. The underlying assumptions, theoretical models and mathematical equations upon which epidemiologists base their predictions and projections of the future impact of AIDS are subject to healthy ongoing debate and are

constantly improving.

However, projections made in the past by leading epidemiologists from reputable institutions – which were loudly disputed at the time as alarmist doomsday scenarios – have indeed proven to be largely accurate as the epidemic has unfolded.

Most epidemiologists use a demographic model maintained and updated by Metropolitan Life Ltd (the “Doyle model”). This model has also been used by the Actuarial Society of South Africa, as the basis for its own projection tool.²

Below are some key projections regarding the future impact of the South African epidemic derived from the Doyle model:

HIV prevalence in the general population: On the basis of the national ante-natal survey, it is estimated that 4,5 – 5 million people were living with HIV in the year 2000. This is the largest number of people in any one country living with HIV/AIDS in the world.^{3/4}

Mortality: In 10 years time, the epidemic will probably claim up to 635 000 people in a single year.⁴
Child Mortality: AIDS is likely to double the child mortality rate by

2010.⁵

Orphans: By 2005, there may be 800 000 children orphaned by AIDS. This figure could rise to more than 1,95 million in 2021. This is an increase of about 75% in the orphaned child population within a decade.⁶

Life Expectancy: Before HIV, the probability of dying before the age of 60 was 30%. This is estimated to have already gone up to 75% as a result of AIDS. By 2010, life expectancy will be 43 years, 17 years less than it would have been without AIDS.⁷

The Economic Impact of HIV/AIDS

The impact of AIDS on households' economies is particularly severe; 30% greater than deaths from other causes.⁴ This is partially because most diseases predominantly affect the very young and very old, but HIV affects the economically active section of the population which provides for their families and communities.

In South Africa, the epidemic is projected to reduce the economic growth rate by between 0,3% and 0,4% annually, resulting by the year 2010 in a gross domestic

product (GDP) 17% lower than it would have been without AIDS and wiping US\$22-billion off the country's economy.⁴

If levels of care were to remain constant, acute health care costs in the public sector would double by 2010.⁴

Around 40% of employees will be lost to AIDS over the next 10 years.⁴ 15% of highly skilled employees are expected to be HIV positive by 2010.⁴

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7. World Health Organisation Bulletin, Oct 1999

Gender & HIV/AIDS

Gender has a significant impact on the transmission of HIV. Women are more vulnerable to HIV infection than men because of their biological make-up. Women's unequal status in relation to men puts them at greater risk of infection, as many women lack the power to control their sexual relations – particularly to refuse sex or insist that their partners use condoms. Women are often financially dependent on men, resulting in the exchange of sexual favours. There is also societal pressure on women to have babies, making it difficult to insist on condom use. Women also bear the brunt of caring for people with AIDS and orphans – both as healthcare workers and relatives.

Notions of “Manhood”

Many South Africans believe that men are the heads of households and decision-makers. In sexual relations, men are expected to be the initiators and women the receivers of sex.

“Manhood” is often equated with qualities such as virility, strength and dominance. “Proof” of “manhood” often requires a man to have multiple sexual partners,

and condoms are often seen as undermining manhood. In addition, there is a pervasive belief that men's natural sex drives are far stronger than women's, so men need more than one sexual partner. All these views encourage men to engage in risky sexual behaviour.

Biological Vulnerability

A woman is at least twice as likely to contract HIV from a male partner with the virus than the other way around because of her body's structure. During sex between men and women, the woman is the receptive sex partner. Semen infected with HIV stays in the vagina for some time after sex and has more opportunity to enter the blood stream.

Risk is multiplied if a woman has sores or cuts in her vaginal wall, as these enable HIV to go straight into the blood stream. These sores can be caused by cancer of the cervix or sexually transmitted diseases (STDs) such as chancroid or herpes, which frequently go unnoticed and untreated as they are often symptomless in women. Dry sex – relatively common in parts of South Africa – also places women at greater risk of HIV infection. Some women use herbs, roots and even bleach, vinegar and snuff to dry out their vaginal secretions to tighten

the vagina. This is believed to increase male pleasure during sex. However, penetrative sex under such conditions can cause cuts to the vagina, which makes it easier for HIV to pass into the bloodstream.

But although a woman is more at risk than a man during sex, she can still pass HIV to uninfected partners (male and female) through sex, as HIV is present in blood (including menstrual blood), vaginal secretions and cells in the vaginal and anal walls.

Women under the age of 20 are more vulnerable to HIV than older women as their genital tracts are more prone to infection.

Violence Against Women

Violence against women in South Africa is widespread, and contributes to the spread of HIV. In 1997, there were 244 reported incidents of rape per 100 000 women, while research conducted by Medical Research Council with women aged 18 – 49 in the Eastern Cape, Mpumalanga and Northern Province found 2070 incidents of rape and attempted rape of women per 100 000 women that year.¹

Girl child rape has doubled in

recent years with one third of reported rapes of girl children under 15 perpetrated by school teachers.²

Almost 4 in 10 sexually experienced girls (39%) between the ages of 12 and 17 say they have been forced to have sex.³

Domestic violence is widespread. Many women know that their partners are unfaithful and that they are at risk of HIV. But they fear violence if they raise questions about infidelity, or ask partners to use condoms. Some women are accused of being unfaithful themselves or lacking in trust if they try to insist on condom use. Some women also face violence when they reveal their HIV status to their partners.

References

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2. South African Demographic & Health Survey, Department of Health, 1998
3. "Hot Prospects, Cold Facts: A Portrait of Young South Africa". Henry J. Kaiser Family Foundation, 2000.

Pregnancy and HIV/AIDS

Many South African women only learn that they are HIV positive when they are tested during an antenatal check-up. Apart from the

implications for herself and her partner, the woman faces the possibility of transmitting a fatal disease to her unborn baby. Moreover, this places an additional burden on women as men are not routinely tested. Careful counselling is necessary to help and support pregnant women to explore their options in these circumstances, including:

- Should she terminate the pregnancy?
- Who to tell and how.
- How to practise safe sex to protect her partner, if he is not infected, and to protect herself from reinfection if he is.
- How to care for a baby who may be HIV positive and become sick.
- Whether to breastfeed or not (breast milk can transmit HIV).
- How to plan for the future, based on the knowledge that she (and her partner) may both die when their child is young.
- How to access anti-retroviral drugs to help prevent mother to child HIV transmission.
- How to live a positive life, through good nutrition, exercise etc.

Mother-to-Child Transmission

A pregnant woman with HIV has about a one in three (33%) chance

of passing the virus on to her baby. This is called mother-to-child transmission (MTCT) or vertical transmission.

Most transmission (about 70%) takes place during labour, when the baby is exposed to blood and amniotic fluids from its mother. Anti-retroviral drugs can cut the vertical transmission rate by at least half. Delivery by elective caesarian section and avoiding traumatic procedures at birth (such as forceps deliveries) can also reduce the risk. Transmission can also occur during pregnancy and breast feeding.

The Department of Health estimates that some 14 000 babies a year could be spared HIV through the use of anti-retroviral drugs. The Department estimates that a MTCT programme using nevirapine could save the state about R270-million a year.

A single tablet of nevirapine taken during labour and another dose given to the baby soon after birth is as effective as a four-week course of AZT, and only costs about R30.

However, these babies can subsequently become infected through breastfeeding. This issue remains controversial and emotive. Different studies put the risk of

transmission from breastfeeding at between 1 – 22%, and at almost 30% if the mother becomes infected while breastfeeding. A recent study conducted by the University of Natal found that exclusive breastfeeding for six months (without giving the baby even water) and then immediate weaning can protect the baby from HIV. It appears that mixed feeding too early may cause irritation of the new born's bowel and facilitate HIV transmission. However there are questions about the design of this study, and the results are inconclusive.

If a woman does not breastfeed, she needs to bottle or cup feed using formula milk. This is expensive. In addition, unless the mother has access to clean water (or cheap fuel to boil and sterilise water) and enough resources to ensure an adequate supply of formula milk, her baby is probably at greater risk of dying from malnutrition, diarrhoea and dehydration (all strongly associated with formula feeding in conditions of poverty) than HIV. Many women find it difficult not to breastfeed because of an associated stigma. Also, if women run out of formula feed they may end up mixed feeding, which appears to be the most risky practice.

If a MTCT programme is to

succeed, it has to go hand-in-hand with an improvement in resources at primary health clinics – including enough nurses to provide counselling and conduct HIV tests. The Department of Health is soon to pilot two operational research sites per province to explore the practical requirements of using nevirapine to prevent MTCT before rolling this out as a full scale service.

Socio-economic Issues — Poverty and AIDS

While HIV is the actual cause of AIDS, poverty creates a social and economic environment conducive to the spread of the virus. For example, in communities where there is little work (particularly in rural areas), men are often forced to leave their homes to seek employment. A migrant who is away from his wife, family and community for long periods may engage in casual sex, including with sex workers or multiple partners, which puts him at risk of infection.

Many migrants such as mineworkers and soldiers also live in all-male environments. They are also at greater risk than men who

live with their partners. Truck drivers are also at a higher risk, as they spend long periods away from home.

Poverty forces women to enter into unequal relationships with men, on whom they are dependent for their economic survival. This dependence makes negotiations for safer sex very difficult. Poverty may also force a girl or woman to exchange sex for money or goods. A recent survey showed that 16% of sexually experienced girls between 12 and 17 years old had sex for money, drinks, food or other gifts. One in five (20%) sexually experienced boys had given a girlfriend pocket money or bought her drinks or food in return for sex.¹

However, it is a myth that HIV/AIDS is simply a disease of the poor. Anyone who has unprotected sex with an infected person is at risk.

Reference

1. Kaiser Family Foundation report, "Hot Prospects, cold facts: A portrait of young South Africa".

Children and AIDS

AIDS impacts on children in various ways. Some children are infected with HIV during pregnancy, birth, breastfeeding, child abuse and sexual assault. Others are affected

by the epidemic through caring for sick parents, losing their parents and increasingly, heading up households.

According to UNAIDS, 600 000 children were infected with HIV during 2000 worldwide, most of them in sub-Saharan Africa and 500 000 died of AIDS-related illnesses in 2000.

Children are also more vulnerable to the virus and progress much faster from being HIV positive to having symptomatic AIDS than adults. Those born with HIV usually display AIDS symptoms within the first year of life and most will die before their third birthday.

Caring for children who have lost parents to AIDS has become one of the greatest challenges facing South Africa. It is estimated that by 2005 there will be nearly a million children under the age of 15 who have lost their mothers through AIDS (UNAIDS).

As a result of the epidemic, children are caring for the sick and assuming adult responsibilities before they are ready to do so. When the extended family either does not exist or simply cannot cope, siblings who have lost their parents often end up living together with no adult supervision. Many orphans will grow up as

street children or will form child-headed households to avoid being separated from siblings. Surviving family members, in many cases only the children, may also be forced into low paid work, crime or sex work.

Problems identified in child-headed households by a University of Natal study include poverty, lack of supervision and care, stunting and hunger, educational failure, lack of adequate medical care, psychological problems, disruption of normal childhood and adolescence, exploitation, early marriage, discrimination, poor housing and child labour. Additionally, orphans have to deal with the trauma of losing parents and the stigma surrounding HIV/AIDS. Some studies have shown that death rates among AIDS orphans are 2,5 to 3,5 times higher than children with parents.

Even if orphans cope in the short term, the longer-term impact for the affected children and society as a whole is significant. As children under stress grow up without adequate parenting and support, they may be at greater risk of developing anti-social behaviour and of being less productive members of society.

In the face of dwindling family networks and the increased

number of children needing help, community solutions with support from both government and the private sector, will have to be found to care for the needy and impoverished children. Some countries in the region such as Zimbabwe have done extensive research and produced excellent policies.

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Social Security

South Africa's formal welfare system includes institutional care of orphans and foster care support. However, government has acknowledged that drastic measures are needed to improve the system and to ensure that children affected and infected by AIDS are covered. Organisations in civil society such as ACESS (Alliance for Children's Entitlement to Social Security) are calling for a basic income grant for all people in South Africa to help alleviate the economic impact of AIDS on families. ACESS is also calling for the immediate implementation of this basic income grant for all children through the existing Child Support Grant (by extending its coverage to include all children up

to 18 years. Currently this Child Support Grant is R110 for children 0 to 7 years).

Mechanisms must be established to ensure AIDS orphans and child headed households have urgent access to the grants. Administrative delivery must be improved to ensure the grant reaches those in need.

Recommendations also include extending the Care Dependency Grant to include children infected with HIV/AIDS. Subsidised adoptions and making the foster grant available to extended families will also help assist communities caring for children affected by AIDS. Support for children affected by AIDS should include indirect social services (such as subsidized housing, improved access to health services, education etc).

HIV/AIDS and Education

With no cure or vaccine for HIV/AIDS, prevention education remains a cornerstone of HIV programmes. As a vital source of information to the public, the media has a key role to play in this regard. Education is needed at all levels of society – from parents to

children, at schools, health settings, industry and business. However, in order for education to be effective, it must be part of a comprehensive intervention that creates an enabling environment for behaviour change and access to treatment. This includes bold policy and implementation, addressing underlying issues such as poverty and gender inequities and support for community mobilisation.

HIV infection is growing fastest amongst those between 15 and 35 years of age. Research shows the average age of sexual debut is 14.¹ Ideally, comprehensive safer sex education for youth should be available from pre-puberty. Youth are in the process of learning sexual behaviours and are therefore more receptive to adopting safer sex practices than older people.

Concern that educating children on sex will make them promiscuous is unfounded. Research shows the opposite. For example, Dutch children – who have access to explicit sex education – start having sex later than young people living in other parts of Europe, Africa and the USA with no access to sex education.²

The National Policy on HIV and AIDS for Learners and Educators in Public Schools and Students and

Educators in Further Education and Training Institutions (1999) states that: "Sexuality education is obligatory at all institutions of learning". In reality, however, the implementation of the Life Skills programme in schools is erratic and HIV/AIDS is inadequately covered in the curricula of teachers, nurses and doctors.

Many preventive messages around sex are aimed at women who are often unable to make changes for fear of violence or rejection especially if financially dependent on partners for survival. More programmes are recognising the importance of targeting men and gender violence.

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Vaccines

The development of a prophylactic HIV vaccine, which would end the HIV epidemic, is the Holy Grail of HIV/AIDS research.

Vaccines cause an immune response against an invading virus

and are therefore a form of prevention and not a cure. Those already infected with HIV will not benefit from a vaccine, although therapeutic vaccines to reduce the progression of HIV are also on the agenda.

HIV is not an easy candidate for vaccine development. The HI virus incorporates its own genetic material into the immune system, which is the very system designed to fight off viruses. It is therefore difficult to eliminate or neutralise the virus without destroying the immune system itself.

HIV also mutates very fast. It has sub-types that vary between geographical areas, from person to person or even within the same person over time. One vaccine may well not work against all sub-types. There are currently ten different clades (sub-types) of the main subgroup HIV-1.

But even if a candidate vaccine was to enter clinical trials tomorrow and prove to be safe and effective, it would still not be available to the general public for at least five to seven years, perhaps even longer for developing countries. In addition, most vaccine research internationally has targeted Clade B, the sub-type most common in developed countries. Funding for research into Clade C, most

common in developing countries, has been limited.

The South African AIDS Vaccine Initiative (SAVI), part of the International AIDS Vaccine Initiative (IAVI), is co-ordinating vaccine trials in South Africa. The goal is the development of an affordable, subtype C-based vaccine, owned by the public sector.

Vaccine trials, like clinical drug trials, raise a range of difficult ethical questions on issues such as informed consent.

Voluntary Testing and Counselling (VTC)

There is no scientific reason to doubt the accuracy of HIV tests used in the public sector. All positive tests are routinely repeated and confirmed.

However, the most common tests check for *antibodies* to the virus rather than the virus itself. In some people, antibodies can take up to three months to develop, and these tests can therefore fail to pick up the presence of HIV in the early stage of infection. This is referred to as the “window period”.

ELISA (enzyme-linked immunosorbent assay): The most commonly used test is the ELISA. This tests for the presence of antibodies (an immune system response) to the HI virus.

PCR (Polymerase Chain Reaction): The PCR tests for the presence of the virus itself, and can therefore be used from two weeks after infection. It can also establish the presence of the virus in infants under the age of 18 months. PCR becomes more reliable in infants approximately 2 – 4 weeks after infection. It is an expensive test (approx R350.00) and is out of reach of most South Africans.

Rapid Tests: Rapid HIV tests look for antibodies to the virus, but do not require specialised laboratory equipment and are both cheaper and quicker than the ELISA. These tests are generally reliable approximately 4 – 6 weeks after infection.

The Department of Health warns against purchasing rapid HIV tests from pharmacies because in order to give informed consent to an HIV test, there should always be pre- and post-test counselling and because quality control of all the brands on the market is not yet assured.

Patient Rights

Informed consent

HIV testing without informed consent is unlawful in South Africa. No one can be forced to have an HIV test (or disclose their HIV status). Exceptions are in an emergency when s/he is unconscious and it is in their interests to be tested.

Adoption of universal precautions against infections will significantly protect health professionals from HIV infection and as such health professionals have no right to ask patients their HIV status. Except, however, in the case of needle-stick injuries in health workers, when available blood samples may be tested for HIV if the patient does not consent to testing. In children under the age of 14, consent from parents or guardians is required.

The policy guidelines of the Department of Health prohibit any HIV test which is used to discriminate against an individual.

At the time of print, the South African Law Commission was debating the constitutionality of mandatory testing of alleged sexual offenders.

Confidentiality

HIV test results are confidential and cannot be disclosed to others

without the individual's consent. Such disclosure is regarded as breach of confidentiality, and legal action may be taken.

The only exception to this is when a patient intends to endanger a sexual partner. In this case, a health professional must follow clear Health Professions Council of SA (HPCSA) guidelines before telling the sexual partner at risk.

Care and Support for People Living with HIV and AIDS

The epidemic affects us all. People living with HIV/AIDS have the right to live in a caring community. A supportive environment will help people living with HIV/AIDS cope better and live longer. The media has an important role to play in nurturing this climate.

Keeping Healthy

It is very important that a person diagnosed HIV positive realises that s/he can still live a healthy life for some time. A person living with HIV needs advice on how to:

- Recognise HIV-related infections and seek early treatment.

- Monitor his/her immune system to gauge the progression of the disease. This enables those who can afford it to go onto anti-retroviral drugs when necessary.
- Use safer sex practices to avoid infecting others and re-infecting themselves.
- Adopt healthy lifestyles, including eating well and avoiding smoking and drinking a lot of alcohol.
- Promote a more positive outlook on life.
- Prevent re-infection.
- Avoid overuse of medication which in turn can be harmful.
- Avoid depression and stress which in turn can result in ill health and cause the virus to progress faster.

For many people with HIV, lack of resources makes it difficult to eat healthily, supplement their diets with vitamins and avoid stress.

Home-based Care

As the HIV epidemic progresses, more people are becoming sick and dying of AIDS-related illnesses. The promotion of home based care is partly an acknowledgement that existing health facilities cannot cope with the sheer numbers of people with HIV and AIDS who require care. It is also based on the view that hospital care is often not

the most appropriate form of care. To meet the challenge of caring for people living with AIDS (PWAs), a number of non-governmental organisations, in partnership with communities (some with government support) have set up home-based care projects to offer care and support for AIDS patients in their homes. Currently in South Africa, volunteers are largely driving home-based care initiatives. Often the care offered is "palliative" – where the emphasis is on improving the quality of the patient's life (comfort and dignity) rather than their recovery.

Home based care should not place the burden solely on communities. There needs to be a strong element of support from formal health and social institutions. Although it is a cheaper option than hospital care, government has accepted that there will be substantial costs to home-based care. There are various models of home-based care. Some involve hospice care for patients at the end of their lives. Some are run by local government, others by NGOs.

Government's preferred model is to establish care teams at the district level, coordinated by a professional worker and comprising trained lay workers. Ideally, a PWA or his/her family, would be referred by a hospital or clinic to a home-based

care organisation in their area. The organisation, supported by government, would assign one of its carers to visit the person and see what his/her needs are. Where possible, family members would be trained to care for the PWA. The carer would visit the family regularly to assist. The district health authority would support home-based care by providing training to carers, medicine, dressings and, where necessary, expert advice, attention and referrals.

The main advantages of home-based care are that it saves hospitals a huge amount of money, frees beds for those who are not terminally ill and enables a person to spend their last days at home with people they love.

The disadvantage is that home based care places a huge responsibility on the carers, many of whom are not paid, or are children who should be in school.

Carers and family members involved in care-giving often suffer from stress and exhaustion and receive little support.

In poverty-stricken areas, unresourced home-based care runs the danger of transferring responsibility for care to communities least able to afford

any extra pressure. In such settings, families of PWAs often lack food and live in places that are not accessible to vehicles.

It is thus essential that home-based care is well co-ordinated and resourced. However, at present there are no national guidelines on how home-based care should be implemented.

Treatment

Basics on Anti-retroviral Drugs

Until recently, it was believed that after infection, the virus remained dormant in the blood and only became active after a person had lived with HIV for years. A few years ago, scientists discovered that in fact the virus is active from the moment of infection, replicating constantly, and being fought off by the body's immune system. This places an enormous burden on the immune system.

Anti-retroviral (ARV) drugs stop the replication of the virus, keeping the viral count in the blood stream down to below 50 copies of HIV RNA per millilitre of blood, which is undetectable in tests. The virus is still present, but the immune system gets a chance to repair

itself as it is not fighting an active virus. Access to triple therapy has led to AIDS becoming almost a chronic, manageable illness in developed countries.

There are three main classes of ARV drugs:

- Nucleoside analogue reverse transcriptase inhibitors (NRTIs), which target an HIV protein called reverse transcriptase, (eg AZT, ddI, ddC, 3TC and d4T). These were the first anti-HIV drugs developed, and form the backbone of treatment.
- Protease inhibitors (PIs) which target an HIV protein called protease (eg. Saquinavir, indinavir, amprenavir).
- Non-nucleoside reverse transcriptase inhibitors (NNRTIs), which also target reverse transcriptase (eg. nevirapine, delavirdine and efavirenz).

Each class of drugs attacks HIV replication in a different way. Generally, drugs from two (and sometimes three) classes are used in combination (as a drug "cocktail") to attack HIV. However, HIV reproduces very fast, making billions of new viruses every day. As it often makes errors in copying itself, each generation of virus is slightly different from the previous one. This means that the drugs will have to tackle a variety of viruses, some of which may be resistant to

the drug. The resistant viruses will then continue to reproduce, resulting in the dominance of the drug-resistant strain.

To be effective at least 2 and preferably 3 different drugs need to be used together, to reduce the likelihood of resistance developing. The medication needs to be taken every day for life and monitored regularly with laboratory tests (viral load and CD4 cell counts) to determine whether the drugs are effective. Potential side effects, costs, limitations of the health services and insufficient laboratory services to monitor the therapy are all issues which need to be considered.

Some confusion has been created in South Africa regarding the safety of ARV drugs. Like most drugs, ARVs do have side-effects. Chemotherapy drugs used to fight cancer can also cause side-effects but the benefits of their use outweigh the costs; similarly for ARVs. Moreover, side effects have not been shown in the short course dosages of AZT or nevirapine necessary to prevent Mother-to-Child Transmission.

Can South Africa Afford ARV Drugs?

The issue of drugs and access to treatment is complex and arouses strong emotions. Up until recently, it was generally accepted that drug therapy, particularly expensive ARV drugs, would never be affordable or accessible to developing countries. Many people regarded it as elitist to consider the issue at all. However, over the past two years, this is an area where real progress has been made, largely due to international and local activism and advocacy.

Arguments against triple drug therapy include:

- Cost of drugs
- Cost of diagnostics to monitor
- Infrastructure for health service delivery
- Equity issues
- Patient adherence to treatment
- Development of resistant strains

Counter-arguments include:

- the cost of not treating
- the prices of drugs and diagnostics can be dramatically reduced, still allowing for a profit margin
- infrastructure will never be developed adequately until a commitment is made to provide the service
- an incremental approach to access to treatment

- patient adherence and development of resistance are problems globally, not just in South Africa.

Developments over the past few years have highlighted unacceptable levels of profiteering by drug companies. Large pharmaceutical multinationals have actively obstructed moves to make their drugs more affordable, even in developing countries which represent an insignificant percentage of their profit margin.

Internationally there has been a groundswell of resistance, challenging the protection of drug company profits under international trade regulations, and the inclusion of health as a trade issue.

The fight for access to treatment covers MTCT, rape and post-exposure prophylaxis, treatment for opportunistic infections, and triple therapy.

Mother-to-Child Transmission:

Trials have proved that both short course AZT and Nevirapine (NVP) can be used to prevent up to 50% of MTCT. AZT is more expensive (around R400/intervention) than Nevirapine (around R30/intervention) and more complicated to administer. Side effects are limited and although

long term resistance is not known in NVP, it appears that unlikely as it is a single dose to mother and child. Internationally, NVP is recommended for use in developing countries.

Studies have proved that it would be both cost effective and cost saving to provide NVP to all pregnant women with HIV. Hidden costs in a MTCT programme include counselling and HIV tests to establish HIV status; and formula feed for women who choose not to breastfeed. There are also difficult ethical questions about providing antiretrovirals for prevention in babies but not for the treatment of their mothers.

Rape and post-exposure prophylaxis: The current state of scientific evidence supporting the efficacy of post-exposure prophylaxis following sexual and/or occupational exposure is incomplete, but raises many ethical considerations. Research on health care workers following occupational exposure found an 81% reduction in risk of HIV transmission using a regimen of AZT alone. There is consensus within both the Centre for Disease Control (CDC) and the World Health Organisation (WHO) that this result can be applied to sexual exposure as it would be unethical to perform a controlled trial with placebos

once there is information about effective prophylaxis. Cost and adherence are factors to be considered and the use of NVP is also being explored, following its success in preventing MTCT.

Treatment for opportunistic infections: Much of the treatment for opportunistic infections is off patent. Where it is not, for example in the case of Fluconazole (a drug used to treat systemic thrush and cryptococcal meningitis), the profiteering of drug companies has been exposed: the same drug that sells at R120 through the private health system and R29 through the public health system is available at less than R2 for the generic equivalent in Thailand. The Thai company is still making a profit at this price.

Triple therapy: In the industrialised world, the affordability of combination therapies of drugs to inhibit the virus have made HIV/AIDS a manageable, almost chronic, disease. However, anti-HIV drugs are the most expensive and therefore the most profitable market. The lowest prices publicly quoted for triple therapy work out to around R800 per person per month (\$1 200 per year). However, generic manufacturers have offered a reliable triple therapy package at less than R233 per month. In Brazil,

where a court case forced government to offer universal access to triple therapy, they have successfully offered ARVs to thousands of citizens and have reported a significant saving to the health system. Local insurance firms and managed health companies have calculated that providing triple therapy would be cost saving to medical schemes and companies.

Government faces difficult questions of priorities and equity especially in view of the extensive scale of the epidemic. However, an incremental approach is possible: the option could be for government to use its massive purchasing power to bring down the prices of a range of drugs, whether through the private or public sector. Medical aids could then assume a larger part of the cost of managing HIV by offering affordable triple therapy to their members, thus avoiding the cost of managing opportunistic infections, and the costs of illness. In this way, a larger number of the workforce could be kept active as well.

In the court case between the Pharmaceutical Manufacturers' Association (representing numerous multinational pharmaceutical companies) and government, government has demonstrated its commitment to affordable

medicines. The Medicines and Related Substances Control Amendment Act, allows four new practices:

- the parallel importation of patented medicines sold cheaper in another country by their manufacturing companies or licensees;
- generic substitutions for medicines no longer protected by patents;
- the establishment of a pricing committee to ensure transparent pricing mechanisms and to compel pharmaceutical companies to justify the prices they charge;
- international tendering for medicines used in the public sector.

Generic Medicines, Patents and TRIPS

Most anti-HIV drugs and some of the drugs to treat opportunistic infections are patented. Patent protection gives the company that developed the drug exclusive production rights. The World Trade Organisation's agreement on Trade-Related Aspects of Intellectual Property Rights (TRIPS) is the most important international agreement on the protection of patents, copyright and trademarks. TRIPS obliges all WTO member states to provide 20 years of patent

protection for medicines. The production of generics (cheaper forms of the same drug) during this period is prohibited in member states. Increasingly, there is massive economic pressure on developing countries to join the WTO in order to participate in the global economy.

Although generic manufacture is generally prohibited during the period of patent protection, TRIPS acknowledges that there are instances where patents may be overridden "in the case of a national emergency or other circumstances of extreme urgency or in cases of public non-commercial use". TRIPS allows for the use of compulsory and voluntary licences. With voluntary licensing, the government grants a production licence to a third party to produce a generic version of a patented drug with the consent of the patent holder. The patent holder usually receives a token royalty. With compulsory licensing, the production licence is granted without the consent of the patent holder.

Brazil has argued that the HIV/AIDS pandemic is such an emergency and used this tactic to enable local drug companies to make generic anti-retroviral drugs which it has dispensed free to citizens.

Without requiring emergency conditions, the South African Patents Act provides for compulsory licensing for purposes of public non-commercial use or if the patent holder can be shown to be abusing the patent. The provision, and the pharmaceutical industry's reaction to its use, has not been tested in practice. However, an Indian generics manufacturer has indicated a strong interest in seeking a compulsory license for six antiretroviral drugs on grounds of patent abuse.

Parallel importing allows government to import a patented product that is available domestically from the same producer in another country where the drug is sold cheaper. This process (which is not restricted to emergency situations) is provided for in the Medicines and Related Substances Control Amendment Act, the law which the drug multinationals unsuccessfully challenged in protracted court action. Parallel importing is practiced by a number of countries bound by WTO agreements.

Pharmaceutical companies argue that strong intellectual property incentives and high prices are needed to maintain investment in new research. While it is true that research and development costs of new drugs are high, the following

points must also be considered:

- most research into new essential medicines, particularly anti-retroviral (AIDS) drugs, has taken place in the public sector. Pharmaceutical companies usually invest money in the final stages of research and development, when a new drug looks promising. Most of the research into drugs like AZT was paid for by American taxpayers' money. Often, companies simply buy patents from public institutions or other companies.
- Africa accounts for about 1.3% of global pharmaceutical sales, so issuing compulsory licences will not significantly affect industry profits. For the past 10 years, the pharmaceutical industry has been the most profitable in the USA, with profit rates more than three times those of other big companies. (Public Citizen's Congress Watch. Analysis of Drug Industry Profits - [www.citizen.org/congress/drugs/factsheets/pharm\\$graphs.pdf](http://www.citizen.org/congress/drugs/factsheets/pharm$graphs.pdf))
- Internationally, there is growing resistance to the notion that health is a trade issue. It appears unlikely that the pharmaceutical industry will be allowed to continue to make excessive profits at the expense of millions of lives.

HIV/AIDS and the Law

There are a range of laws to protect people with HIV/AIDS (PWA). **The Bill of Rights and the Promotion of Equality and Prevention of Unfair Discrimination Act** protect the rights of all people, including those with HIV/AIDS, not to be unfairly discriminated against.

Although discrimination against PWA is not specifically outlawed by the Constitution, government has succeeded in creating an enabling legal environment through the promulgation of laws specifically protecting the rights of people with HIV/AIDS.

Employment Practice

Various labour laws ensure that HIV positive workers in all sectors, including the agricultural and domestic labour sectors, have comprehensive and explicit protection against discrimination in the workplace. These include:

- **The Employment Equity Act** (No. 55 of 1988), which states that you cannot be asked to take a test at work or when applying for a job (pre-employment testing) unless specific permission has been granted to

your employer by the Labour Court.

- **The Labour Relations Act** (No.66 of 1995), which states that you cannot be dismissed because of HIV infection. The Act specifies the fair procedures to be followed when people living with HIV/AIDS can no longer do their work, including changing the nature of the work expected.
- **The Occupational Health and Safety Act** (No. 85 Of 1993) and **the Mine Health and Safety Act** (no. 29 Of 1996), which both specify that employers must reduce the risk of being infected with HIV at work, especially in health care settings, in occupations where injury is common and in laboratory workers.
- **The Compensation for Occupational Injuries and Diseases Act** (No.130 of 1993), which allows you to claim compensation if you become infected with HIV because of a work-related accident.
- **The Code of Good Practice on HIV and AIDS and Employment** describes the proper management of HIV/AIDS in the workplace.

Laws and Policies Relating to Health Care

Since 1999, medical aid schemes

can no longer refuse cover to people living with HIV/AIDS or make them pay higher premiums than other people, as proclaimed by the Medical Schemes Act (No. 131 of 1998).

However, medical aids may ask you to have an HIV test if you want to apply for extra benefits above the minimum set by government. Many medical aid schemes also have special options specifically for people living with HIV/AIDS.

Health professionals can be taken to court when the following guidelines of the Health Professions Council (HPCSA), are broken:

- Health professionals cannot refuse to treat people with HIV/AIDS or treat them differently.
- An individual’s informed consent is required for any treatment, test or disclosure of any medical information to others.

The Patient’s Rights Charter outlines what the right to health care actually means. If a patient’s rights are contravened, they should report this to the AIDS Law Project, lay a complaint with the Health Professions Council of SA and consider laying criminal charges or suing the health professional concerned.

Addressing the Epidemic

International Experience

To succeed in preventing HIV transmission, countries need to work simultaneously on many fronts. Priority activities cover prevention, monitoring and surveillance, treatment, care and support.

UN Secretary Kofi Annan's report on AIDS calls on governments to meet the following critical challenges:

- effective leadership and coordination
- alleviating the social and economic impact of the epidemic
- reducing the vulnerability of particular social groups to HIV infection
- achieving agreed targets for the prevention of HIV infection
- ensuring care and support available to those infected and those affected by AIDS
- mobilising financial resources needed to fight the disease.

He also stresses that important elements include MTCT prevention, strengthening health care systems and the affordability of medicines for opportunistic infections and ARV therapy. Other areas where best practice policies, strategies

and projects have been identified include youth lifeskills and school sexuality programmes, youth-friendly health services, public education, condom promotion, women-controlled barriers to HIV and voluntary HIV counselling and testing.

UNAIDS strongly advocates political will as an essential element. It defines this an expression of "the national commitment and overall leadership to the nation in response to AIDS". It requires political commitment from community leadership up to a country's highest political level, and "results in high-profile advocacy and helps bring in all the sectors and players, along with the necessary human and financial resources".

As the tide of illness and death from AIDS rose in Africa, a few countries reacted quickly, mobilising people from all walks of life to join forces against HIV. Success stories have been recorded from Senegal, Uganda and Zambia.

Department of Health's Five-year Plan

The Department of Health's HIV/AIDS and STD 5 year strategic plan includes the following priority areas:

1. Prevention

- Promote safe and healthy sexual behaviour.
- Improve management and control of STDS
- Reduce mother to child transmission
- Address issues relating to blood transfusion and HIV
- Provide appropriate post exposure services
- Improve access to voluntary testing and counselling

2. Treatment, care and support

- Provide treatment, care and support services in health facilities
- Provide adequate treatment, care and support in communities
- Develop and expand the provision of care to children and orphans

3. Research, monitoring and surveillance

- Ensure vaccine development
- Conduct policy research
- Conduct regular surveillance

4. Human and legal rights

- Create an appropriate social

environment

- Develop an appropriate legal and policy environment

Copies of the full text of the strategy can be obtained from the Government's "Beyond Awareness Campaign" website:

www.aidsinfo.co.za