

Pregnancy and HIV/AIDS

A PRACTICAL GUIDE

Treatment Action Campaign/AIDS Law Project

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This booklet sets out standards of care, counseling and treatment that all pregnant women are entitled to. It is in keeping with the Department of Health's National *Patient's Rights Charter* and the Health Professions Council *Guidelines on The Management of Patients with HIV Infection or AIDS*, which state the general rules for health care workers /doctors when treating patients with HIV.

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1. Introduction

This booklet is meant to give you important information about pregnancy and HIV/AIDS. You may be pregnant, you may be the partner, relative or friend of a pregnant woman, or you may be a health worker. The information in these pages will help you to make decisions about getting the best health care for mother and baby.

The statistics about HIV/AIDS in South Africa are so alarming that it can be easier not to think about them – especially during pregnancy when there are so many other important concerns. This booklet explains some of the facts about HIV/AIDS and pregnancy. It describes in a simple way how HIV can be transmitted to a baby. It sets out a HIV infected woman's rights to proper care, how to reduce the risk of transmitting HIV and how to increase the chances of giving birth to a healthy baby.

Being well-informed is the first step to taking control of your health and supporting those you care about.

At the end of the booklet you will find the contact details for organisations that can give you more information and advice.

2. Why worry about HIV/AIDS and pregnancy?

South Africa has one the fastest growing HIV epidemics in the world. In 2000 it was estimated that about 4.7 million South African people were infected with HIV, the virus that causes AIDS. Of these, 2.2 million were girls and women aged between 15 and 49 years – that is, women of child-bearing age.

Women are more at risk than men of becoming infected with HIV/AIDS, for several reasons:

- vaginal tissue is very fragile. It can tear easily during sexual intercourse, allowing the virus to enter the blood;
- many men have more than one sexual partner but refuse to wear a condom, so if they are HIV positive they can infect and reinfect their wives and girlfriends;
- rape is common in South Africa so women face a high risk of getting HIV regardless of their own behaviour;
- women are still not treated equally in South Africa and are less likely than men to have access to appropriate health care and information.

A woman who has HIV faces many obstacles to receiving appropriate information and treatment. The pregnant woman with HIV faces the additional worry that she may pass the virus to her baby. At least 30 of every 100 HIV positive pregnant women in South Africa will transmit HIV to their babies. This is called **mother to child transmission**. It mostly happens during delivery, but may also occur while the baby is in the womb or after birth during breastfeeding.

The risk of a mother with HIV passing the virus to her baby can be reduced by medication.

3. Basic Rights to fair and proper care

South Africa's Constitution includes a Bill of Rights, which is a list of the basic human rights we all have as South Africans. The law protects these rights, which say that all people must be treated fairly. No one can take away these rights to fair treatment. They apply to everyone – women, men and children, regardless of whether a person is single, married or pregnant.

The Bill of Rights states: “everyone has the right to freedom and security of the person”. This means that we all have the right of control over our bodies and to make decisions about reproduction. This includes the rights to:

- Decide how many children we will have and when;
- Receive information about contraception so we can decide what is best for us;
- Receive the best possible health care during pregnancy; and
- Make decisions about reproduction without being discriminated against or put under pressure.

In 1999, the Government issued the National Patients' Right's Charter, which supports the Bill of Rights by providing guidelines on rights of access to health care services. All government health care workers must follow these guidelines.

Patients' rights are especially important for women since they are linked to other valuable rights, such as the rights to equality, dignity and privacy.

4. Health rights and HIV

The Department of Health, in its National AIDS Five Year Plan, has committed itself to improving access to reproductive health services for women with HIV, to help reduce the rate of mother to child transmission.

We all have the right to confidential (private) counseling and testing for HIV. However, women are sometimes discriminated against in the health system when they are tested. Often women are tested without their **informed consent** – that means without being told exactly what they are agreeing to. Some health workers tell other people about a woman's HIV status. They do not respect the right to **confidentiality** – that means the right to keep personal information private.

Women are sometimes not given enough information about their health and possible treatments to make the choices that are best for them. Health care workers can impose their own views and prejudices on patients who don't have accurate information. For

example, some women undergo abortions or are sterilised without knowing enough about their rights and options to make the most suitable choice.

It is a woman's reproductive right to be given information that will allow her to make the best decisions about her pregnancy and her health.

If you are living with HIV/AIDS, or providing care or health services to someone living with HIV/AIDS, it is very important that you have up-to-date information on HIV and pregnancy, and on how to lower the risk of mother to child transmission of HIV.

Health care workers have a duty to provide the public with access to the following information:

- why women have a higher risk of getting HIV infection;
- steps that can be taken to lessen this risk;
- how having HIV or being involved with someone who has HIV can affect decisions about reproduction;
- a woman's right to end or continue with a pregnancy whether or not she has HIV;
- steps a pregnant woman can take to lessen the effect of HIV on her health and to reduce the risk of HIV being passed on to the unborn baby;
- steps that can be taken during delivery of the baby to reduce the risk of HIV being passed on to the baby;
- whether these steps are available and how much they would cost;
- the risks and advantages of breastfeeding a baby if the mother has HIV.

5. Step by step guide to testing and counseling

If you decide to go for an HIV test, you must be properly counseled – that means you should be given information and advice – about what the test is, why it is being done and what the result will mean for you. This is known as **pre-test counseling**. It is important because it helps you to understand how HIV is transmitted and how a positive or a negative result may change your life, before you actually have a test.

Pre-test Counseling (counseling before an HIV test)

You must be offered counseling (advice and information) before an HIV test.

- If, after counseling, you decide *not* to have an HIV test, the health care worker must respect your decision.
- The counseling before the test must provide you with all the information necessary to understand what an HIV test involves and the possible effects the results may have on your life.
- You must be counseled in a language that you understand.
- You must be given clear information about when and where you can obtain your results.

If you are pregnant, when you go for your first check-up, you should request to a pre-HIV test counseling session. It should follow these steps:

- HIV testing should be offered early in your pregnancy. Knowing your HIV status is important when you decide to continue or end your pregnancy. It affects the treatment options available for your health, the medical steps that can lessen the possibility of HIV passing on to the baby and the decision to breastfeed or bottlefeed.
- You may only be tested for HIV after you have given **informed consent** – remember, that means after you have been given enough information to decide whether you want to be tested. You cannot be forced to take an HIV test and a doctor or health worker can only accept your consent if she or he has given pre-test counseling as set out in the National Testing Policy.
- The baby may only be tested when the doctor or nurse believes that this information may influence his/her further care and treatment. This may only be done after the mother, father or legal guardian has received pre-test counseling and given their informed consent.

When the doctor or health worker tells you the result of your HIV test, he or she must give you information and advice about the effect the result may have on your life. This is called **post-test counseling** and it must be done whether the result is negative or positive. It is important because if you are negative, the counsellor will advise you how to stay that way. If you are positive, the counsellor will advise you how to stay healthy, how to protect your partner and how to deal with your emotions and mental well-being.

Post-test Counseling (counseling you receive after your test)

Anyone who has an HIV test must be given post-test counseling.

Negative HIV Test Results:

If your result is negative (meaning that no evidence of the virus was found in your blood at the time of the test), post-test counseling should include information on:

- the importance of safer sex and how to practice it;
- that you could still test positive in the future

Positive HIV Test Results:

If your result is positive (the test shows that the virus is present in your blood), post- test counseling should include the following information:

- available treatment and steps you can take to support your health, such as the importance of eating healthily;
- the number of years you can expect to live healthily as a person living with HIV/AIDS and the way the disease progresses in women, men and children.
- the importance of practising safer sex. The higher the level of HIV in your blood, the greater the risk of passing on the virus; so avoid re-infecting yourself and your partner, or infecting yourself with a different type of virus, especially during pregnancy and breastfeeding;

If you are pregnant:

- the effect of birth control methods and pregnancy on the development of HIV;
- your right to end the pregnancy (abortion) and the effect this may have on your health;
- the possibility of the HIV passing to the unborn baby (fetus) during your pregnancy and to the baby during delivery and breastfeeding;

- available treatment options and medical steps to reduce the risk of passing HIV just before childbirth, during delivery and just after childbirth (postpartum)
- the importance of completing the full course of treatment (compliance) and the possible side effects of the drugs taken for your health or used to prevent the passing of HIV to the baby;
- the advantages and disadvantages of breastfeeding if you are infected with HIV, including correct information on the risks of passing HIV through breastmilk and the conditions necessary to be able to feed the baby milk formula safely.

If you have HIV, you can and should continue going for counseling regularly to discuss any problems or questions you have. These might be questions about your health but also about your legal rights, money matters, employment issues and other concerns.

6. Who should know your HIV status?

We all have a legal and ethical right to **confidentiality**. This means that information about anyone's state of health, or the treatment they are receiving, is private. Health care workers have no right to tell another health care worker about anyone's HIV status. If this information is necessary for your treatment and care, the healthcare worker must first get your permission (**informed consent**) before telling another health care worker.

During counseling, you should be told about the advantages and possible problems of disclosing your HIV status. You need to understand these before you give your consent for a health care worker to tell another health care worker your status.

Your records, which show your HIV status, must be safely stored to protect your privacy.

You should be given information about group counseling and organisations that can offer support. If it is possible, it is advised that your partner/s and or your close family members be included in the counseling, so that you can have someone close to you who understands and supports you. It is also advised that your sexual partner should attend post-test counseling with you, so that you can support each other. However you must give your consent to this.

A health care worker may only inform your sexual partner of your HIV status *against your wishes* if:

- you have been counseled on the need to inform your sexual partner of your HIV status or to practice safe sex and you refuse to do so; or
- the health care worker has informed you of their duty to protect other people at risk and has warned you that if you do not inform your sexual partner or practice safer sex, they will disclose (tell) your status.

7. Pregnancy, HIV and health care

Everyone has the right to information about all available medical treatment to maintain or improve their health. Pregnant women living with HIV have the right to such information, including the availability of such treatment, whether it is provided free, if it is not free what the costs are and what are the benefits and possible side effects. Any treatment given to a pregnant woman should be concerned with *her* health and well-being, as well as that of her baby.

Since HIV can be transmitted to a baby during pregnancy, during birth and during breastfeeding, we need to consider the best treatment options at each of these stages:

During your pregnancy (prepartum)

Very few babies are infected during the pregnancy itself. However, the way that you live your life while you are pregnant can help to reduce the risk during delivery or breastfeeding. This is the time when it is very important to eat well, stay healthy and avoid re-infection with HIV.

It is your right to ask for and be given information on the risks and benefits of any tests to check the development of the baby inside the womb. Some tests, such as an amniocentesis (a test that checks for Downs Syndrome by pricking the amniotic sac and withdrawing some amniotic fluid) may increase the risk of the virus passing to the baby and you can refuse them if you wish. If your health care worker feels any test is necessary, then you should be offered anti-HIV therapy first, to help reduce the risk of HIV passing to your baby

There are treatments/medication that reduce the amount of HIV in the body. These are known as **antiretroviral** drugs. It is your right to have access to such treatment. You should be given information including:

- What treatment is recommended for women with HIV;
- The rates of success and how effective these treatments are in reducing mother to child transmission;
- What is known or not known about the effects of such drugs on yourself and the baby fetus;
- The importance of completing the course of treatment correctly.

Your **immune status** (your body's ability to fight off illness) should be checked in case you need medication against the many infections that can affect people with HIV. You should be treated immediately if you get an infection, to avoid harming the developing baby.

You must be given information on the importance of **nutrition** (eating well, taking iron and folate) and stress management in staying healthy. Poor nutrition and low weight gain from the mother can increase the risk of a premature or underweight baby, which increases the risk of transmitting HIV.

You must be told of all known risks and benefits of any treatment offered.

During your labour and delivery

Use of anti-retroviral medicines can reduce the risk of passing on the infection to your baby by nearly 50%. At the moment the government is using these medicines only at certain 'pilot sites' across the country. ***However, you have the right to ask for this medicine.***

Treatment that reduces the risk of HIV passing from mother to baby

The current treatment options recommended for the prevention of mother-to-child transmission are:

- **AZT (Zidovudine):** A dosage of 300mg is given to you twice a day from 36 weeks of your pregnancy. This is taken orally. During labour you must be given 300mg every 3 hours. Your baby should be given a liquid dosage of 4mg/kg, twice daily for 7 days.
- **Nevirapine:** This is currently the cheapest and most effective treatment. A single dose of 200mg is given at the onset of your labour and then one dose of 0,6 mls (2mg/kg) Nevirapine syrup is given to your baby within 72 hours of birth.

KEY POINTS:

Both of these medicines are safe for you and your baby, and are registered in South Africa.

It is important to note that these medicines do not totally prevent the risk to your child, but they do reduce that risk. You must make the decision about whether you want to take them.

Even if you take these medicines, there is still a risk that your baby can be infected through breastfeeding. Discuss with your doctor or nurse about safe ways of feeding your baby.

You must also be given information on safe practices to reduce transmission of HIV during delivery. These are important points to consider:

- The length of time the baby is exposed to HIV through the mother's ruptured (torn) membranes must be kept to a minimum (not longer than four hours). For example, the midwife or doctor should avoid breaking the water (amniotic sac).
- Caesarean delivery (cutting through the mother's stomach muscles and uterus to remove the baby) *before* the start of labour has been shown to reduce the risk of transmission of HIV.
- Where it is not vital, forceful suctioning of the baby's mouth and throat should be avoided.
- The baby must be cleaned soon after delivery to remove any HIV-containing fluid from the skin.

After your baby is born (postpartum)

If you have HIV, your baby should be given the drug called **cotrimoxazole** (also known as Bactrim or Septrin) , from four weeks of age until he/she reaches one year of age. If your baby tests HIV negative at one year, the cotrimoxazole can be stopped.

Even if HIV is not passed to a baby before or during birth, there is a risk that the baby can become infected through breastfeeding.

Breastfeeding:

Exclusive formula feeding is the best way to prevent transmission after birth. Mothers with HIV should ask for access to milk formula, feeding bottles and information on safe infant feeding practices – especially the importance of clean water.

If you live in an area where there is no clean water, or have limited ability to heat water, or where living conditions are bad, meaning that there is a lot of disease and dirt that can threaten your babies health, then it may be safer to breastfeed. This is because breast-milk contains vitamins, and proteins that can help fight natural illnesses.

But, if you decide to breastfeed, you must be informed about the importance of *exclusive* breastfeeding (that is breastfeeding only, not even giving any water) for six months and then completely stopping breastfeeding. . Mixed feeding i.e. breast and formula should be avoided.

All infants born to HIV positive mothers should receive regular check-ups for up to 18 months.

8. Points to remember

As a pregnant woman, a partner or friend, or a health worker, there is a lot we can all do to protect mothers and babies – and everyone else – against HIV/AIDS.

- Demand your right to information – and meet your responsibility to inform others.
- Exercise your right to HIV testing and counseling – and take responsibility for the result.
- If you have HIV, protect yourself against infections by eating as well as you can and taking vitamins and food supplements if possible.
- Go for regular check ups to get information and advice about treatment options.
- Protect yourself and your partner/s against infection or re-infection, by practising safer sex.
- If you have HIV and are pregnant, exercise your right to information and advice on treatment options to keep you and your baby as healthy as possible.
- If you are HIV negative, stay that way. Protect yourself and your partner/s by practising safer sex.

9. Where to get advice

If you want advice on pregnancy and HIV you can contact your local clinic and speak to a doctor or nurse.

You can call the AIDS Helpline: 0800 012 322 or an AIDS Training and Information Centre at one of the numbers below:

Cape Town	(021) 797 3327
Durban	(031) 300 3104
East London	(043) 705 2620
Johannesburg	(011) 725 6711/2
Lowveld	(013) 759 2167
Mpumalanga	(013) 759 2167
Pietermaritzburg	(033) 395 1612
Port Elizabeth	(041) 506 1415

You can also contact the Treatment Action Campaign:

Cape Town **Tel: (021) 364-5489**
Fax: (021) 361-7051

Durban **Tel: (031) 304-3673**
Fax: (031) 304-3673

Johannesburg **Tel: (011) 403-7021**
Fax: (011) 403-2106

Email Address: info@tac.org.za

Website: <http://www.tac.org.za/>

The TAC is a campaign for affordable and quality treatment for people living with HIV/AIDS.

The ALP is a non-governmental organization that campaigns for the rights of people living with HIV/AIDS, offers legal advice and support and helps with policy development.