



### Thinking of having a baby?

**Every woman has the right to have a baby and being HIV positive is no exception. If you are HIV positive and pregnant or you are considering having a baby, it is important that the choice you make is an informed one. Informed choice means knowing and understanding all of the options available to you and knowing what these options involve.**

# 6

1 Information for HIV positive women who are pregnant or considering pregnancy

### When is the best time to get pregnant?

If you are thinking of getting pregnant talk to your HIV doctor. It is better to become pregnant when your viral load (the amount of virus in your blood) is low, your T cell count (CD4 count) is high and you are feeling well. There are many other people you can speak to, such as other HIV positive women and others outlined under "supports" later on in this factsheet.

### Will pregnancy affect my health?

Being pregnant should not make your HIV worse, unless you are ill with an AIDS related condition. When you are pregnant your immune system is a bit weaker; this is true for all pregnant women. After you have had your baby, your immune system should return to the level that it was before you became pregnant.

Due to advances in HIV treatments and our knowledge of HIV, there are many strategies that can be used to minimise the risk of passing on HIV to your baby.

The chance of passing on HIV to your baby can be reduced to less than 2 per cent by using a number of strategies. This factsheet is for you if you are HIV positive and have questions about having a baby.

positive  
pregnancy

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### Will HIV affect my pregnancy?

If you are unwell with advanced HIV infection, there may be an increased risk of going into early labour. There is also an increased risk of passing on HIV to your baby.

### I'm not sure that I want to continue with the pregnancy.

For some women, continuing with an unplanned pregnancy may not be an option. You might not be ready to become a mother for a whole lot of reasons.

Some women feel that even a small risk of passing on HIV to their baby is too high, while some HIV positive women feel more comfortable about a pregnancy.

Whatever your feelings, the choice to continue or terminate a pregnancy is yours, but for some women the choice is a painful one. You can speak to your doctor and seek expert advice on HIV and pregnancy to help you decide. FPA Health (NSW), sexual health services and the Paediatric HIV Service at Sydney Children's Hospital, Randwick, can also provide you with counselling.

If you decide that you cannot continue with a pregnancy, you will need to speak to a doctor as soon as possible. Most terminations are performed within the first 12 weeks of pregnancy and your doctor will refer you to an appropriate place.

### What is known about HIV transmission from mother to baby?

Vertical transmission is the transmission of HIV from an HIV positive pregnant woman to her baby. Most transmissions happen around the time of the birth. HIV has also been found in breast milk and babies have become infected with the virus through breast-feeding. The chance of passing on the virus to your baby is about 20 per cent, but the good news is this risk can be reduced to less than 2 per cent by using a number of strategies.

Strategies to reduce the risk of transmission from mother to baby include:

- ❖ Taking antiviral treatment during pregnancy to reduce your viral load
- ❖ Giving your baby antiviral treatment for six weeks after birth
- ❖ Bottle feeding your baby with formula milk
- ❖ In some instances a caesarean section is recommended

### Who can help me now that I am pregnant?

It is really important that you start to get specialist care. This specialist care usually includes:

#### HIV specialist team

This team specialises in the care of people with HIV. They will talk to you about your treatment choices and monitor your health before, during and after your pregnancy.

#### Obstetric team

This team specialises in the care of pregnant women. They will care for you during your pregnancy and for a short time afterwards. Your HIV specialist doctor can make a referral to an obstetrician.

#### Paediatric team

This team specialises in the care of your baby. Even though your baby is not yet born, you can ask to see this team during your pregnancy. The team can counsel you on the risks of transmission from mother to baby and tell you what to expect once your baby is born.

These three teams can work closely together to provide you and your baby with the best care available. If you live in the country, don't worry; these specialist teams are available to talk to your local doctors, nurses and counsellors so that you can still be provided with the best care available to you.

**Tell me about the treatments that are available to me?**

If you require treatment for HIV infection it should be the best treatment for you, regardless of the pregnancy. A combination of three drugs is usually recommended and this is called triple combination therapy. It has been found that using a combination of three drugs is more effective in treating HIV than one drug alone or a combination of two drugs. Tablets are taken by mouth, up to three times a day.

To reduce the risk of passing on the virus to your baby, you can also receive AZT in a drip when you go into labour. Your baby will take AZT medicine by mouth in syrup form for six weeks after birth.

**The benefits of using a combination of drugs for you and your baby are:**

- ❖ The drugs working together will be more effective than working on their own
- ❖ The viral load is much more likely to decrease significantly
- ❖ The likelihood of passing on HIV to your baby becomes extremely small (less than 2 per cent)

**The goals of anti-HIV treatment are:**

- ❖ To maintain a healthy immune system
- ❖ To prevent complicating infections and cancers
- ❖ To improve your quality of life
- ❖ To prolong survival
- ❖ And for a pregnant woman, to protect the baby from HIV

**Will I experience any side-effects?**

The most common side-effects of anti-viral treatment are nausea (feeling sick), diarrhoea, headaches and feeling tired. However they vary from person to person. The side-effects can appear shortly after the medication has been started and they usually disappear after a few weeks. In almost every case the side-effects are not dangerous but sometimes do require that the doses of the drugs be reduced, or drugs be stopped or changed. Rarely some of the side-effects are dangerous and this will be explained to you.

**What if I am already pregnant and I'm on triple combination therapy?**

Do not stop taking your medication. The most important thing for you and your baby is to keep your viral load as low as possible. If you stop taking the medication your viral load might start to rise. Many women have now been through their entire pregnancies on triple combination therapy and have produced healthy babies. See your doctor to make sure that the tablets you are taking are safe for you and your baby.

**What happens if I don't want to take treatment?**

The choice to take or not take treatment for yourself is your decision, as is the decision on how to care for your child. Preventative treatment for your baby for six weeks and avoiding breast-feeding is strongly recommended.

**What if I don't want my baby to have treatment after he/she is born?**

If you choose not to treat your baby there is legislation that can intervene. Talk to your paediatrician and get advice from the HIV/AIDS Legal Centre (HALC).



The most important thing for you and your baby is to keep your viral load as low as possible.



Be guided by your obstetrician when decisions are being made about proceeding to a caesarean section and don't be afraid to ask questions.

You have the right to be treated the same as anyone would expect to be treated when having your baby.

### **Tell me about Caesarean Section delivery**

There are important reasons why caesarean section may be recommended for women with HIV infection. When there is a high risk of your baby getting infected with HIV (that is, when you have a high viral load) elective caesarean section is important in reducing the risk of your baby getting HIV during the birth process. Overall it is thought that the risk of passing on HIV can be halved by caesarean section before the waters break.

Of course HIV infection is not the only reason why women require a caesarean section. Other reasons include a mother's high blood pressure or a distressed baby. Be guided by your obstetrician when decisions are being made about proceeding to a caesarean section and don't be afraid to ask questions.

### **Is a vaginal delivery safe for my baby?**

If you are taking triple combination therapy and your viral load is undetectable, it is not clear that a caesarean section will provide your baby with any additional protection against HIV. However if your waters have been broken for more than four hours the risk of your baby getting infected with HIV start to increase.

### **If I have a caesarean section, what should I expect?**

You will either have a general anaesthetic or an epidural anaesthetic for the caesarean section. A general anaesthetic will put you to sleep and your partner or support person cannot be in the operating theatre.

An epidural anaesthetic involves an injection into your back, near your spine. It numbs you from the waist to your feet but you can be awake for the operation. Your partner or support person can stay with you for this. Speak with your obstetrician about your options.

## **2 Some information on the baby**

### **Are the treatments that I take, safe for my baby?**

Anti-viral medications are fairly new and the long-term effects on your baby are unknown. However many women living in Australia and elsewhere have been through pregnancies on triple combination therapy and have produced healthy babies.

There are some drugs that could be harmful to your baby such as efavirenz (Stocrin) or Ribavirin (used for treating Hepatitis C). In addition a combination of d4T and DDI used together could be harmful to you if you are pregnant. It is strongly recommended that these drugs not be used during pregnancy. Speak to your doctor if you are on this drug and you are pregnant or thinking of getting pregnant.

If you are not on anti-viral medication and you are already pregnant and worried about the effects of the treatments on your baby, you can discuss your options with your doctor, obstetrician or social worker. **Remember that it is important to start anti-viral treatment as soon as possible if your viral load is high.**

### **What happens once my baby is born?**

Your baby is dried off with a towel and given to you for a cuddle. Any blood on your baby is washed off as soon as possible by giving your baby a bath. Then your baby stays with you in your room. An exception to this is if you have been taking narcotics during pregnancy, or you are on methadone. Your baby may experience withdrawal symptoms and may be nursed in the special care baby unit where he/she is kept under close observation. Sometimes newborn babies can experience unexpected problems that are not related to HIV and these babies may also require a period of nursing in the special care baby unit.

Your baby will start on anti-HIV medicine as soon as possible. If your viral load is undetectable, then AZT syrup is usually enough to protect your baby (sometimes 3TC syrup is given as well). If your viral load is high around the time of delivery then an additional anti-HIV medication may be recommended and a paediatrician will discuss this with you. You will be taught how to give your baby the medicine before you go home.

**Is there other treatment that my baby requires?**

Babies who are HIV positive are prone to pneumonia called PCP. PCP pneumonia can be life threatening in babies. Because it is difficult at first to tell if your baby has HIV, your paediatrician will recommend an antibiotic. This starts at six weeks of age and is given once a day. It helps to protect your baby from PCP pneumonia. Treatment with the antibiotic can stop at three months of age if the PCR test for HIV infection in your baby is negative.

**How do I know if my baby is HIV positive or negative?**

All HIV positive mothers pass HIV antibodies on to their baby. This does not mean that your baby has the virus. It can take up to eighteen months for your baby to clear your antibodies. A more detailed test called a PCR test is used to test babies from birth. This test can tell the difference between antibodies and the virus.

Your baby is tested regularly in the first three to six months. Babies are considered uninfected at three months of age if all of the PCR tests have been negative and your baby has been exclusively bottle-fed. Testing becomes less frequent after the first three months, but it is important to continue testing until your baby is 18 months old, or until your baby has cleared all of your antibodies.

Testing your baby for HIV can be an emotional roller coaster ride. Becoming acquainted with the testing procedure while you are pregnant and talking through an experience with another HIV positive woman or health professional, can alleviate your concerns.

**Can you tell me a little more about how these tests are done?**

The PCR test is a blood test and is usually taken from a vein in your baby's arm. The frequency of the tests may be a little different from hospital to hospital, but the first tests are usually done when your baby is one day old and again when your baby is one week old.

Before you leave hospital, you will be given an appointment to come back and see the paediatrician when your baby is six weeks old. The doctor will examine your baby, the anti-viral medicine will be stopped and another blood test will be taken. Your baby will be given an antibiotic to take until the next visit to the doctor at three months of age. This is the medicine that protects your baby from getting PCP pneumonia.

If the 3-month test on your baby is PCR negative (ie. HIV is not found) you will be asked to stop all the medicines being given to your baby.

Ongoing testing of your baby is required to make sure that all of the mother's antibodies have cleared and this can take up to 18 months.

If the result is PCR positive (ie. HIV is found) your doctor will need to advise you on the next step.



The frequency of the tests may be a little different from hospital to hospital, but the first tests are usually done when your baby is one day old and again when your baby is one week old.



Your baby's health will be monitored regularly and you can expect to be provided with lots of support.

### Immunisations

There is no reason why your baby cannot follow the routine immunisation schedule for newborns. Speak to your doctor or nurse about getting your baby immunised during the visits for blood tests. It will save another trip to the doctor.

### If my baby is HIV positive, what should I expect?

If your baby is HIV positive then he/she will be seen by a paediatrician. Your baby's health will be monitored regularly and you can expect to be provided with lots of support. We suggest you read the booklet called *Your Child and HIV* for a really good idea on what happens next.

### My baby is HIV negative. What happens if I get sick?

It is really important to think about this, painful though it may be. If you have a support partner and/or family, then they can help out. If you don't, you will probably want to tell a close friend or relative, so that they can help out when you are sick. If you have not already disclosed to friends and family, you might want to make arrangements in advance for someone to look after your child if you are no longer able to do it yourself.

These are really difficult things to think about, but you can talk to your social worker or to the family support worker at the AIDS Council of NSW (ACON) for assistance. The social worker in the Paediatric HIV Service at Sydney Children's Hospital, Randwick can also help.

### 3 What support is available to me?

All women experience times in their pregnancy where they worry about whether their baby will be all right. It is normal to worry about your unborn child during pregnancy.

It is well recognised that having a baby is one of life's major milestones and stresses. Don't do it alone. There are many supports out there and many positive women who have pioneered the way.

#### Speak to another positive woman

Positive women's support networks provide you with the opportunity to meet and develop a circle of friends who not only live with HIV, but may be pregnant or have had a child since becoming HIV positive. This support is invaluable and allows you the opportunity to air your fears and concerns in a safe and confidential way with someone who has been in a similar situation.

#### Speak to health care workers

Any established relationships with your doctor, nurse, social worker or counsellor will help you with your concerns.

#### Speak to the Family Support Worker

After having a baby you need some recovery time, particularly if your baby was delivered by caesarean section. It is important that you have people around you who are able to support you in your new role as a parent. If there is no support within your network of family and friends, speak to the Family Support Project at the AIDS Council of NSW (ACON) for assistance or your social worker about a referral to a family support agency in your area.

### Speak to the Family Assistance Office

It is worthwhile making an appointment with the Family Assistance Office at your nearest Centrelink or Medicare Centre. Talk to them about financial benefits that you may be eligible for, such as, the one-off Maternity Allowance, Maternity Immunisation Allowance, Family Tax Benefit and Childcare Benefit.

Bottle feeding your baby can be expensive but some states in Australia can provide you with financial assistance, so speak to your social worker or nurse about this and they will make the referral.

### Speak to people who deal with childhood problems

The Tresillian and Karitane hotlines provide valuable 24-hour advice on issues such as feeding, settling and routines. They offer day and overnight stay programs if you are having problems settling or feeding your baby.

A specialist paediatrician will monitor your baby and all of the testing for HIV will be performed at the hospital. However, your local early childhood centre can monitor your baby's general health and we would recommend that you go there regularly. They will weigh your baby, assess your baby's development and provide really good advice on looking after your baby. Most baby health centres run education and support groups for new mothers. **It is important to remember that you are not obliged to disclose your HIV status to your early childhood nurse and this information does not need to be recorded in your baby's blue book.** If you would like to disclose, you could do this with the assistance of the specialist doctor or nurse caring for you and your child.

### Camp Goodtime

Camp Goodtime is a national camp for families living with HIV. It is coordinated by the social worker from the Paediatric HIV Service at Sydney Children's Hospital, Randwick. Speak to your social worker or nurse about the possibility of your family being included in this exciting annual event.

### Support groups

Support groups are run throughout the year for families living in NSW living with HIV. Contact the Paediatric HIV Service at Sydney Children's Hospital, Randwick for more information. Assistance can be provided to families living in NSW to attend the groups.



It is important to remember that you are not obliged to disclose your HIV status to your early childhood nurse and this information does not need to be recorded in your baby's blue book.

### Further reading

- **Women and HIV – Pregnancy** This factsheet (No.5) is produced by FPA Health (NSW) and the AIDS Council of NSW. ☎ (02) 9716 6099 or 9206 2079
- **Women and HIV – Parenting** This factsheet (No.6) is produced by FPA Health (NSW) and the AIDS Council of NSW. ☎ (02) 9716 6099 or 9206 2079
- **Your Child and HIV – Be Positive About Being Positive** Written by M. Goode, L. Maurice, Sarah and David, C. Romberg and A Stewart. Published in 1999. Available from GlaxoSmith Kline.

### Websites

- [www.pedhiv aids.org](http://www.pedhiv aids.org)
- [www.babycentre.com](http://www.babycentre.com)
- [www.epregnancy.com](http://www.epregnancy.com)

### Other services that can help

- **Paediatric HIV Service, Sydney Children's Hospital, Randwick, NSW** Clinical Nurse Consultant ☎ (02) 9382 1654; Social Worker ☎ (02) 9382 1580
- **National Association of People Living With HIV/AIDS (NAPWA)** Level 1/222 King Street, Newtown, NSW 2043. ☎ (02) 9557 8825 Freecall 1800 259 666
- **Women's HIV Support ACON** ☎ (02) 9206 2012 Information, education, support and referral services for women living with HIV/AIDS.
- **Heterosexual HIV/AIDS Service (Pozhet)** ☎ (02) 9515 3095 Freecall 1800 812 404 (national). Men and women living heterosexually with HIV/AIDS.
- **Sexual Health Information Line (Mon–Fri 9–5)** ☎ (02) 9382 7440 Freecall 1800 451 624.
- **Sexual Health Centre** ☎ (02) 9382 7440
- **Multicultural HIV/AIDS Service** ☎ (02) 9515 3098 Freecall 1800 108 098 (Mon–Fri 9–5). Bilingual/bicultural co-workers providing emotional support, advocacy and information to people living with HIV/AIDS from non-English speaking backgrounds.

### Family planning

- **FPA Healthline (NSW)** ☎ 1300 658 886
- **FPA Health (NSW)** ☎ Health Promotion Officers (02) 8752 4300 [www.fpahealth.org.au](http://www.fpahealth.org.au) Full range of sexual health services – clinics in seven locations – HIV specific projects for women, men and people with intellectual disabilities.

### Legal assistance

- **HV/AIDS Legal Centre (HALC)** Principal Solicitor ☎ (02) 9206 2060/1800 063 060 (Freecall outside Sydney area) [www.halc.org.au](http://www.halc.org.au) Free legal advice for legal problems relating to HIV/AIDS.

### For Regional NSW HIV/AIDS and related services

- **Contacts. A Directory of Services for People Living With HIV/AIDS.** Available from People Living With HIV/AIDS (NSW) Inc. ☎ (02) 9361 6011 Freecall 1800 245 677 (outside Sydney area) or [www.plwha.org.au](http://www.plwha.org.au)

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**Pictures of Amelia and her baby** were taken by the Medical Illustrations Unit, Prince of Wales Hospital, Randwick

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