

## **POSITIVE PREGNANCY**

### **Acknowledgements**

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## **Pictures**

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## **Editorial**

While HIV remains a confronting diagnosis, improvement in treatments are bringing hope to affected families. With advances, including antiviral treatments that are available, people with HIV are now able to live full active lives. The improved treatments have also produced dramatic improvements in the outlook for unborn babies of infected mothers. This booklet is designed to help couples living with HIV make difficult choices about pregnancy and having babies. The editorial team wishes to thank the many contributors, especially Amelia, and to acknowledge the generous assistance of GlaxoSmithKline who provide unrestricted support for this project.

### **A note from a parent**

*I'm really pleased to be making this contribution to a booklet specifically addressing issues around pregnancy for HIV positive women.*

*When I was first diagnosed with HIV I ruled out the possibility of children in my future. In 1994 it was shown that AZT reduced the risk of HIV transmission to the baby so I decided to explore the possibility of having a baby. This was a big decision to make and one I didn't make lightly. Information was scarce and I had to research a lot of it on my own.*

*I was fortunate to be living in Sydney and to have access to a knowledgeable HIV specialist and the Paediatric HIV Services at Sydney Children's Hospital, Randwick. I was also supported in my decision by family and friends; however I did encounter some people who were very judgemental about my decision to have a child as a positive woman, which was really upsetting.*

*Six years later I am just about to deliver my second child. I feel there is more information and support for positive women who decide that pregnancy is an option for them. I didn't know any other positive women when I had my first child. This time I have met 6 positive women having babies around a similar time to me!*

*This booklet brings together all the relevant information needed to make a decision on your pregnancy options and is in an easy to read format. I wish I had access to a booklet like this when contemplating my pregnancy.*

*Pregnancy and being a parent has been a fulfilling experience for me. I wish you well in the decisions you make.*

*Amelia.*

## **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.

There are many things that can reduce the risk of passing on the virus to your baby and these will be discussed in this booklet.

## **SOME BASIC INFORMATION ON HIV/AIDS IF YOU HAVE JUST BEEN RECENTLY DIAGNOSED.**

### **WHAT IS HIV AND WHAT DOES BEING HIV POSITIVE MEAN?**

If a person is HIV positive this means that the person has been infected with HIV. HIV is the Human Immunodeficiency Virus, the virus that causes the Acquired Immune Deficiency Syndrome (AIDS). Once HIV infects the body, it attacks the body's immune system (T cells or CD 4 count). The immune system is our defence system against diseases like infections and cancers.

### **WHAT IS AIDS?**

AIDS refers to a collection of illnesses and/or infections that can develop when the body's immune system has been severely weakened by HIV. This may occur several years after being first infected with HIV. Even after AIDS has developed, people may have long periods of being well between infections and other complications.

### **HOW IS HIV TRANSMITTED?**

HIV is a fragile virus and is therefore not easy to transmit. For a person to become infected, a large quantity of the virus must exit the blood stream or tissues of an

infected person, and enter the blood stream or tissues of an uninfected person. One bodily fluid that contains a large amount of the virus is blood. Semen, vaginal fluids and breastmilk also contain the virus.

### **THE MAIN WAYS IN WHICH A PERSON GETS HIV ARE:**

- Having unprotected sex with a person who is infected with HIV
- Sharing needles and syringes with a person who is infected with HIV
- From mother to baby, if the mother is infected with HIV

The virus can pass from mother to baby at any time during pregnancy or breast feeding however the risk is highest at the time of birth. During the birth process some mixing of mother's and baby's blood occurs. The exact process of infection is not known. The risk of transmission is higher if the mother's viral load is high and when the baby is premature. Breast-feeding adds substantially to the risk of transmission of HIV from mother to child.

The risk of transmission is lower when the mother is on anti-HIV therapy, when the baby is delivered by Caesarean section and when the baby is not breast-fed. In this booklet strategies to prevent the risk of HIV transmission from mother to baby will be discussed.

### **WHAT IS THE HIV TEST?**

This is a blood test. Normally when you are infected with a virus, even a cold, your body produces antibodies to fight off the infection. The HIV test checks if you have been infected with HIV by seeing if you have produced antibodies to HIV. If your test comes back HIV antibody positive you are said to be "HIV positive".

### **DON'T ALL WOMEN WHO ARE PREGNANT GET TESTED FOR HIV?**

It is not lawful to perform an HIV test without your knowledge and permission. The midwife or doctor will recommend the test and women need to give informed consent

for the test to be conducted. Current policy recommends that all pregnant women are offered HIV testing and there should be a discussion about HIV before the test and after the test is performed. A midwife, doctor or counsellor will want to make sure that you understand and think about the test before you agree to it.

## **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 (CD 4 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 booklet.

### **WILL PREGNANCY AFFECT MY HEALTH?**

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

### **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 for them. If you have just found out that you are HIV positive you might want time to think about you, without having to worry about a baby too. 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 the pregnancy.

Whatever your feelings, the choice to continue or to terminate a pregnancy is yours, but for some women the choice is very difficult. You should speak to your doctor and seek expert advice on HIV and pregnancy to help you decide. Family Planning Clinics, Women's hospitals 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 or 'mother to child transmission' (MTCT) is the transmission of HIV from HIV positive pregnant woman to her baby. Most transmissions happen around the time of the birth. HIV is also found in breast milk and babies can become infected with the virus through breast feeding. The risk of HIV transmission from an HIV positive mother to the baby is about 25%, and even higher if with breastfeeding. However the good news is that this risk can be reduced to 1-2%. by using a number of strategies. The lower the mother's viral load the lower the risk but there is no known circumstances where the risk is zero.

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 four to six weeks after birth.
- Feeding your baby with formula milk (completely avoiding breastfeeding)
- A caesarean section may also be recommended.

In developed countries such as Australia, the recommendation is for HIV positive

women to exclusively formula feed their infants to reduce the risk of HIV transmission via exposure to breast milk.

## **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 will counsel you on the risks of transmission of HIV from mother to baby and tell you what to expect once your baby is born.

These three teams 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.

## **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

most combinations of two drugs. Tablets and capsules are taken by mouth, usually one or two times a day.

To reduce the risk of passing on the virus to the baby most women also receive AZT in a drip when they go into labour. Your doctor will discuss this with you. The baby will take AZT medicine by mouth in a syrup form for 4-6 weeks after birth. If your baby is having difficulty tolerating oral feeds, it may be necessary to give AZT via a drip.

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

- The drugs work more effectively together than on their own.
- The viral load is much more likely to decrease significantly.
- The likelihood of transmission of HIV to your baby becomes extremely small (even less than 2%).
- It reduces the mother's risk of resistance. This can stop the drugs from working if the mother needs to keep taking them, or needs to start them again in the future.

**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 and depend on which drugs are used. 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. These side effects are rarely 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 medications. 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 of taking or not taking treatment during pregnancy for you, rests with you. However preventative treatment for the baby for six weeks and avoiding breast feeding is strongly recommended.

### **TELL ME ABOUT CAESAREAN SECTION DELIVERY**

There are important reasons why caesarean section may be recommended for some women with HIV infection. When there is a high risk of the baby getting infected with HIV, an elective caesarean section (planned caesarean section carried out before labour begins) produces a very important reduction in the risk of the 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. In this context a vaginal delivery may be the better option. However, if your waters have been broken for more than 4 hours the risk of the baby getting infected with HIV starts 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 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; however you can be awake for the operation. Your partner can stay with you for this. Speak with your obstetrician about your options.

## **SOME INFORMATION ON THE BABY**

### **ARE THE TREATMENTS THAT I TAKE SAFE FOR MY BABY?**

These anti viral drugs 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. Precautions are

necessary for the use of nevirapine (Viramune) in pregnancy. Speak to your doctor if you are on any of these drugs 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 should discuss your options with your doctor. A growing foetus makes all of its major organs (kidneys, heart, liver, brain) by the first 12 weeks of pregnancy so putting off taking the medication until after then may be something to consider. Remember though, 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?**

The 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 the baby a bath. Then the baby stays with you in your room. Sometimes newborn babies can experience unexpected problems that are not related to HIV and these babies may require a period of nursing in the special care unit.

The 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 the baby. 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. For example, they might suggest 3TC syrup and a single dose of nevirapine. You will be taught how to give your baby the medicine before you go home as the baby will require the medication for 4-6 weeks.

You will be formula feeding your baby therefore you will need to have prepared for this prior to delivery. You will need to have a supply of formula, bottles, teats and a steriliser available for use both once the baby goes home and also for when you are in hospital.

### **Are there other treatments that my baby requires?**

Babies who are HIV positive are prone to pneumonia called *Pneumocystis jiroveci* pneumonia (referred to as "PCP"). This is a type of pneumonia that can be life threatening in babies with HIV infection. It is difficult to tell if your baby has HIV in the first few weeks so as a result, we may recommend an antibiotic called co-trimoxazole (Septrin, Bactrim). If this is recommended, it starts at six weeks of age and will stop when the team is sure that the PCR test for HIV infection in the baby is negative.

This medicine helps to protect the baby from PCP.

### **HOW DO I KNOW IF MY BABY IS HIV POSITIVE OR NEGATIVE?**

All mothers pass antibodies on to their baby. If you are HIV positive you will pass HIV antibodies on to your 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.

The baby is tested regularly in the first six months of life. Babies are considered uninfected at 3 months of age if all of the PCR tests have been negative and the baby has not been breast fed. Testing becomes less frequent after the first 3 months, but it is important to continue testing until your baby is 18 months old, or until the 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 whilst you are pregnant, and talking through the 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 the blood is usually taken from a vein in the baby's arm. The frequency of the tests may be a little different from hospital to hospital but the first test is usually done when your baby is one week old or before you leave the hospital.

Before you go home from hospital you will be given an appointment to come back and see the paediatrician when your baby is 4-6 weeks old. The doctor will examine your baby, the anti-viral medicine will be stopped and another blood test will be taken. Your baby may be commenced on co-trimoxazole (Septrin, Bactrim) to take until the next visit to the doctor at 3 months of age. This is the medicine that protects your baby from getting PCP.

If the 3 month test on the baby is PCR negative (ie HIV is not found) you will be asked to stop all the medications on the baby. Your baby will have one final PCR test at 6 months as added reassurance that the early HIV PCR tests were negative. If a result is PCR positive (ie HIV is found) at any of the times tested, your doctor will need to advise you on the next step.

There will be another medical visit at 12 months of age. This is usually only a check up visit and no blood tests will be done. One last test in the baby whose PCR tests are negative in the first 6 months is done at 18 months. This is the HIV antibody test to make sure that all of the mother's antibodies have cleared. This can take up to 18 months.

## **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 might save another trip to the doctor.

## **IF MY BABY IS HIV POSITIVE, WHAT SHOULD I EXPECT?**

If your baby is HIV positive then your child will be seen by a paediatrician (children's doctor). Your baby's health will be monitored regularly and you will be provided with lots of support. We suggest you read the booklet from our Service called "Your Child and HIV" for some guidance on what happens next.

## **MY BABY IS HIV NEGATIVE. WHAT HAPPENS IF I GET SICK DUE TO MY HIV INFECTION?**

It is really important to think about this, difficult though it may be. If you have a partner then perhaps they can help out. If you don't have a supportive partner you will probably want to tell a close friend or relative, so that they can help out when you are sick. You might also want to make arrangements in advance for someone to look after your child if you are no longer able to do so. These are difficult things to think about, but you can talk to your social worker about assistance that is available to you. The social worker of the Paediatric HIV Service at Sydney Children's Hospital Randwick can also help.

## **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. You don't have to do it alone. There are many supports out there and many positive women who have pioneered the way.**

### **Speak to another positive woman**

To get the support from family and friends means that you may need to tell them that you are HIV positive. However, not everyone is comfortable with this. Positive women's support networks provide you with the opportunity to meet and develop a

circle of friends who not only live with HIV they 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 a Support Worker**

After you have 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 limited support within your network of family and friends, speak to your social worker who will be able to arrange referrals to other support service providers in your local 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, Baby Bonus, Maternity Immunisation Allowance, Family Tax Benefit and Childcare Benefit.

Formula 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 regular childhood problems.**

The Tresillian and Karitane hotlines provide valuable 24-hour advice on issues such as feeding, settling and routines. They offer day stay 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 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. Should you wish to disclose, you might want to do this with the assistance of the specialist doctor, nurse or social worker caring for you and your child.

### **Camp Goodtime**

Camp Goodtime is a national camp for children and 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 event. It is a time for families to come together to support each other and be supported through workshops, support groups and having fun. Childcare is provided by a dedicated group of trained volunteers. There are nurses who attend this camp and provide first aid if required.

### **Support groups**

Support groups separate to camp are run throughout the year for families in NSW living with HIV. The Paediatric HIV Service at Sydney Children's Hospital Randwick will inform you of when they are.

### **Summary by Amelia**

Since writing about my experience for this booklet, I have given birth to my second beautiful healthy daughter. It definitely was a much better experience, with all the

services I accessed having a greater understanding about the needs of a positive woman. Good luck in all of your endeavours and don't hesitate to call any of the services listed at the end of this booklet for assistance.

### **Further Resources**

#### **Paediatric HIV Service, Sydney Children's Hospital, Randwick, NSW**

Clinical Nurse Consultant Ph: (02) 9382 1654

Social Worker Ph: (02) 9382 1851

<http://www.sch.edu.au/departments/hiv/>

#### **National Association of People Living With HIV/AIDS (NAPWA)**

Suite G5, 1 Erskineville Road, Newtown, NSW 2042

Ph: (02) 8568 0300 free call 1800 259 666

<http://napwa.org.au>

#### **Pozhets (The Heterosexual HIV/AIDS Services)**

Ph: 1800 812404

<http://www.pozhet.org.au/>

#### **AIDS Council of NSW (ACON)**

Ph: Freecall 1800 063 060 or email [acon@acon.org.au](mailto:acon@acon.org.au)

<http://www.acon.org.au>

#### **Positive Women (NSW)**

AIDS Council of NSW PO Box 350 Darlinghurst NSW 1300. Ph: (02) 9206 2000

<http://www.acon.org.au>

#### **Positive Women Victoria (Inc)**

PO Box 222, Prahran VIC 3181

Alfred Hospital Commercial Road, Prahran, VIC 3181

Ph: (03) 90766918 or contact via <http://www.positivewomen.org.au>

### **Positive Women (South Australia)**

HIV Women's Project, 64 Pennington Tce, North Adelaide, SA 5006

Ph: (08) 8239 9600.

### **Positive Women (Western Australia)**

664 Murray Street, West Perth WA 6005

Ph: (08) 9482 0000

### **Positive Women (Auckland)**

2 Poynton Tce, Newtown, Auckland, New Zealand

Ph: 649 309 2693.

### **Family Planning Association (FPA Health)**

328 - 336 Liverpool Road, Ashfield NSW 2131

Ph: (02) 8752 4364

<http://www.fpahealth.org.au>

### **Further Reading**

#### **Your Child and HIV - Be Positive About Being Positive**

Written by M. Goode, L Maurice, Sarah and David, C Romberg and A Stewart.

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HIV Service, Sydney Children's Hospital. Revised 2008.

### **Baby Resources**

Karitane – Caring for families

Ph: 1300 227 464 or 9794 1848

<http://www.karitane.com.au/newframe.htm>

Tresillian Family Care Centres

Ph: 1800 637 357 or 9787 0855

<http://www.cs.nsw.gov.au/tresillian/helpline.htm>

**Other useful websites**

[www.womanchildrenhiv.org](http://www.womanchildrenhiv.org)

[www.aidsinfo.nih.gov](http://www.aidsinfo.nih.gov)

[www.chiva.org.uk](http://www.chiva.org.uk)