




Having a Baby
a guide for HIV positive women, men and their partners





“A couple of years ago I attended a Pozhet event where people were talking about having kids. I was not in a relationship and had always thought I couldn’t have kids. Just hearing it was a possibility changed my whole feeling about the future.”

— Michael, *hiv positive*

This booklet was developed by Pozhet (Heterosexual HIV Service), a state-wide service hosted by Sydney Local Health District (SLHD) with input from the following partners:

Paediatric HIV Service Sydney Children's Hospital SESLHD
ACON Women and Families Project
Family Planning NSW
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Thinking about having a baby

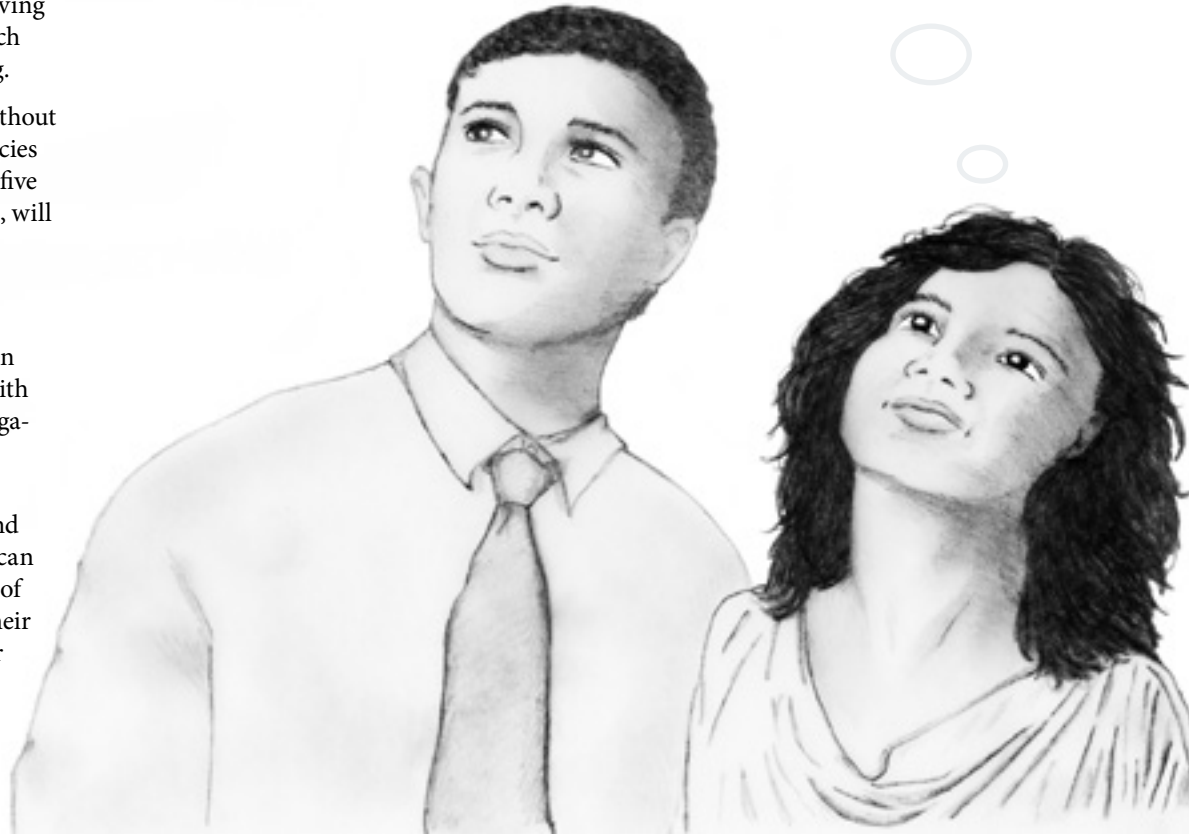
People with HIV have the same hopes and desires about having children as anyone.

Whether single or in a relationship everyone has the right to make their own informed decision about whether or not to have children.

Advances in medications and increased knowledge about HIV has meant people are living longer, healthier lives. Having children has become an option which more people with HIV are choosing.

Many people with HIV conceive without difficulty and have healthy pregnancies and babies, although at least one in five people, as in the general population, will have some issues around fertility.

- By taking appropriate HIV medications and with up to date medical advice and support women with HIV can become pregnant with no risk of transmission to their negative partner and with almost zero risk of transmission to their baby.
- With up to date advice, support and HIV medications, men with HIV can father children with minimal risk of transmission to their partner or their baby. (It is important to remember that men cannot directly transmit HIV to the baby in the womb).



Planning

If you are thinking about having a child start planning early. There are many things to consider when planning a family and having HIV will naturally play a major role in your decision making.

Try to make sure that

- you and your partner understand all your options so that you both agree on a plan of action
- you have some form of social support
- you have a doctor and medical team who are understanding and supportive

Making decisions with your partner

You may have different feelings and opinions than your partner about having a baby. The partner with HIV may be fearful of transmission to their partner or their child. Both of you may fear the effect of the HIV medications on the baby.

Whatever the situation, take the time to get on top of all the available information so that you don't feel rushed or confused.

Your doctor or social worker can help you both work through any fears you might have.

Support

Talking to your doctor about having a baby

Whether male or female, it is important to discuss your desire to have children with the doctor you see for your HIV care. Do this early on to make sure that you and your partner receive the best advice and information about your options. This will include how to reduce the risk of transmission to your baby and partner.

Your doctor will be able to help both you and your partner make an informed decision based on your particular situation.

Your doctor should

- assess your general health
- make sure you are using appropriate contraception methods to ensure you avoid unintended pregnancy
- discuss all the options
- provide information, advice and support
- talk to you about appropriate HIV medications
- make sure you and your partner are tested and treated for sexually transmitted infections

Women with HIV who are already on HIV treatment need to make sure that their current medications are safe for pregnancy. If you are not currently on HIV medications, your doctor will talk to you about commencing HIV medication before you try to conceive and during your pregnancy. This will reduce the risk of HIV transmission to your baby.

Even if the doctor you see for your HIV care is knowledgeable about HIV and reproduction they should refer you to the appropriate specialists so you can receive the best care and advice about fertility, conception, pregnancy and childbirth. This might include a gynaecologist/obstetrician (a doctor who specialises in pregnancy and childbirth) and a paediatrician (a children's doctor). Many clinics and hospitals will have teams which include doctors, nurses and social workers who will support you and your partner through the whole process, right up until after your baby is born.

There are individual situations where your doctor may advise against having a baby due to specific medical reasons. These reasons should be clearly explained to you. You also have the right to see another doctor to get another opinion.

Always ask lots of questions!

It is a good idea to write down the questions you would like to ask your doctor just in case you forget. You can also take a friend or your partner with you to appointments if that helps you feel more confident about discussing things which you don't understand or feel nervous talking about. Doctors and other healthcare workers should provide unbiased information, expert advice and counseling and should never be judgemental.

Support from family and friends

Although deciding to have a child is a very personal decision, support from family and friends can help to reduce stress and make the decision making process easier. This is particularly important if you are single and don't have the support of a partner.

Not everyone feels comfortable telling family and close friends that they or their partner have HIV. Some people are fearful about people being judgemental about their decision to have children. Others worry about people asking awkward questions about medications. Some positive people find that telling at least one trusted family member or friend can be a real help as they can provide support and help you answer any potentially awkward questions.

Talking to other people with HIV

Most people find it helpful to share experiences and talk to other people with HIV who have had or are planning to have a baby.

Going to peer support groups and using the internet to find websites, chat-groups or forums can help you make contacts and friends. At the end of this booklet there is a list of services which can help you contact other people with HIV.



What can I do to be well prepared?

When you are planning to get pregnant is the ideal time to make lifestyle changes. The following tips can help improve your fertility and make sure you have a healthy pregnancy and birth.

Eat healthy foods

There is no special diet that improves the odds of conception, but now is the time to start eating a healthier range of foods including fresh fruits, vegetables and lean meats.

Take a folic supplement

This is the most widely recommended vitamin to take before conception and in the first few months of pregnancy to reduce the chance of infant neural tube defects. Talk to your doctor about any supplements and vitamins you may need to take.

Stop smoking tobacco

Smoking can reduce fertility in both men and women. By quitting smoking you can improve your chances of getting pregnant. Ask your doctor for info about Quit Smoking programs.

Limit alcohol

A woman who is trying to conceive should strictly limit her consumption of alcohol and avoid binge drinking completely. Alcohol can also affect a man's sperm count. The ideal is not to drink at all. Alcohol can affect the health of an unborn baby.

Avoid non prescribed/illicit drugs

Drugs can affect fertility and the health of the baby. Talk to your doctor if you have any questions or need support. There is some evidence that marijuana can affect male fertility.

Frequently asked questions

How will having HIV affect my chances of getting pregnant?

HIV does not appear to have a significant impact on conceiving. There is some evidence that either the medications or HIV itself can affect the thickness of semen and the movement of sperm. It is not clear to what extent this affects overall male fertility. Women with HIV sometimes report irregular periods. Previous pelvic infections and irregular periods can affect fertility. Lifestyle and age can also affect fertility for both men and women. Talk to your doctor early so that you and your partner can be checked and treated for any fertility issues.

Will becoming pregnant affect my HIV?

There is currently no evidence that pregnancy affects the course of HIV. A woman's immune system can weaken a little when pregnant but will return to pre-pregnancy levels after the birth.

How do I conceive without putting my partner at risk?

There are many ways to conceive which reduce the risk of transmission of HIV. These options depend on your situation and are discussed in the following section on conception.

Will my baby get HIV?

The good news is that the risk of transmitting HIV to your baby can be reduced to less than one percent if

- the woman (if HIV positive) remains on or commences HIV treatment medications during her pregnancy
- the baby is given a short course of HIV treatment after birth
- the mother does not breastfeed

Women with an undetectable viral load throughout their pregnancy are able to deliver their baby vaginally. In some situations, a caesarian delivery will be recommended.

If these guidelines are not followed then there is about a 25 percent chance of passing HIV to the baby.

If a woman does not have HIV, as long as she remains HIV negative during her pregnancy, her baby will not become positive.

Conceiving while reducing the risk of transmission to your partner

If you are a positive man or a positive woman and you are considering having a child, talk to your doctor as early as possible. The doctor will help you choose the safest way to conceive while reducing any potential risk of HIV transmission.

Even if you are well informed and prepared, worrying about HIV being passed to or from your partner while trying to conceive can cause anxiety.

There is a growing body of information and research about reducing the risk of transmission which can help you make the decision which is right for you. This includes the Swiss Statement.

The option you choose will depend on your situation and should always be discussed with your HIV doctor.

In 2008, a group of Swiss scientists produced a statement known as the *Swiss Statement*. It concluded that an HIV positive person who is taking effective HIV medication, has an undetectable viral load and who does not have any other sexually transmitted infections, has only a negligible risk of passing the virus on to others. Since that time a number of studies have produced similar results. A 2011 international study involving nearly 2,000 serodiscordant heterosexual couples found a 96% reduction in the risk of transmission through sex where HIV treatment was being taken as prescribed and without missing doses.

This means that having sex without a condom in order to conceive is an option which you can discuss with your doctor.



When the female partner has HIV and the male doesn't

For people in this situation the do-it-yourself method of self-insemination carries no risk of exposure to the male partner.

Self-insemination

Women living with HIV can attempt to conceive by inseminating themselves with their negative partner's sperm. The male partner should test for HIV and other sexually transmitted infections before beginning this process.

The safest way of insemination in this situation involves passing semen into the vagina without having vaginal sex. This eliminates the risk of HIV transmission. This is quite a simple process which can be made more intimate and enjoyable with a bit of imagination. It can also be done in your own home. The male partner ejaculates into a container and either of you can then insert the sperm into the vagina with a syringe.

Self-inseminating when the female is ovulating will increase the chance of falling pregnant. Your doctor can explain the specific details of these processes.

HIV treatments and sex without a condom

There is a decreased risk of transmitting HIV if the person with HIV is on HIV treatment and has an undetectable viral load. If you and your partner are thinking about trying to conceive by having sex without a condom, you both need to talk to your doctor so that you understand all the issues and any risks which may be involved.

To reduce the risk of transmission

The female partner with HIV should

- take appropriate HIV medications as prescribed and without missing any doses
- have regular viral load checks to ensure that HIV is undetectable and has been undetectable for at least six months

Both partners should

- be checked and treated for sexually transmitted infections
- limit conception attempts to when the woman is ovulating (see 'Timing is important!' on page 16)

When the male partner has HIV and the female doesn't

When the male partner has HIV and the female partner is negative the situation is more complex. There are a variety of options but none are completely risk free.

Assisted reproduction — sperm washing with assisted insemination

Assisted reproduction is primarily used for couples with fertility problems but can also be used for couples with HIV to reduce the risk of transmission.

Sperm washing coupled with assisted insemination of the sperm using intrauterine insemination or in vitro fertilisation is the safest technique to reduce the risk of transmitting HIV to the female partner. It involves separating the sperm from the seminal fluid as only the seminal fluid contains HIV.

There is an extremely low risk of HIV transmission through sperm washing; however, there is still a potential risk. There have been no reported cases of HIV transmission using this process.

Although this method has a low risk of HIV transmission, it has a lower success rate than having sex. It is not available for all couples trying to conceive, is expensive and can be stressful. It is currently not available in NSW but is available in Victoria. Talk to your doctor about whether this process is suitable for you and your partner.

HIV treatments and sex without a condom

New information about the benefits of HIV treatments has meant that trying to conceive by having sex without a condom is a potential option when the male partner has HIV. If the male is on HIV medications and has an undetectable viral load, there is a greatly reduced risk of transmission. Both partners also need to be tested and treated for sexually transmitted infections. It is important to talk to your doctor before making a decision about trying to conceive this way.

To reduce the risk of transmission

The positive male partner should

- take HIV medications as prescribed and without missing any doses
- have regular viral load checks to ensure that HIV is undetectable and has been undetectable for at least 6 months

Both partners should

- be checked and treated for all sexually transmitted infections
- limit conception attempts to when the woman is ovulating
(see *'Timing is important!'* on page 16)

When both partners are living with HIV

When both partners have HIV there is a potential risk of re-infection. This occurs when someone who has HIV becomes infected with another strain or a resistant strain of HIV. The risk of re-infection is unlikely if you are both on treatment.

Pregnancy via natural conception is increasingly accepted as a strategy for couples who both have HIV and are on treatment.

If you are worried about re-infection, you may want to limit sex to the fertile period (See *'Timing is important!'* on page 16).

You can also follow the advice already given for couples who are serodiscordant, such as sperm washing.

Using donor sperm

Some couples may choose to use donor sperm. This option is also used by single women and women in same sex relationships. Laws regarding anonymous donor sperm came into force in NSW in 2010 which means that assisted reproduction clinics can no longer use anonymous donor sperm. This has reduced the number of donors and made it more difficult to access sperm through clinics.

You can choose to use a friend as a sperm donor and either go through a clinic or embark on the process of self insemination. If you do this it is important to make sure the donor has been tested for HIV and sexually transmitted infections. In NSW sperm donors are required by law to be tested for HIV before donating. It is important that you know and understand the legal implications of using a donor.

Go to health.nsw.gov.au and search for "donor sperm" for more information.

Timing is important!

A woman is only fertile for a limited time during her menstrual cycle. This is known as ovulation – when the egg is released from the ovaries. Having sex or self-inseminating just before and during ovulation increases the chance of pregnancy. Your doctor or clinic can give you advice so you will know when the time is right.

For couples with no fertility problems it can take an average of five months to conceive. If after six months you are not pregnant, talk to your doctor.

It is recommended to use condoms when having sex outside the female partner's fertile period. This will protect the negative partner from any potential exposure to HIV by reducing the number of times you have unprotected sex to when the woman is most likely to get pregnant.



Fertility issues

Many couples experience difficulty conceiving. Unless you have been diagnosed with fertility problems, you won't usually be suspected of having problems until you have tried, and failed, to conceive for one year. Approximately 20% of all couples experience difficulty.

Because of community attitudes, discrimination and lack of support around having children, some people with HIV have left having children until they were older.

Stress and environmental issues as well as age can affect fertility. In some cases, assisted reproductive processes can help.

Assisted reproduction

Assisted conception is when a doctor or clinic assists the process of fertilising the egg with sperm.

As stated earlier these techniques, including sperm washing and assisted insemination, can be invasive and stressful and some procedures are not available in all Australian states.

There are strict screening processes for couples wanting to access assisted conception; however, treatment should not be denied to you just because you have HIV. You will need to tell the clinic if one of you has HIV so that the clinic will be able to assess your situation and discuss your options.

Although couples affected by HIV have the right to assisted reproduction, some clinics may not be supportive and some may not have the technologies required. Consult your local HIV service, doctor or social worker to find an HIV friendly clinic.

What other options do you have?

Adoption and foster care

Although adoption is legally possible it may not be a realistic or practical option. It is difficult to adopt a child in Australia and the process can take many years.

Fostering may be an easier option. Every potential foster carer or adoptive parent is assessed and applicants have to allow the agency involved to access their health records. Having HIV does not mean you or your partner will not be eligible to become foster carers or adoptive parents. You are able to apply to foster if you are single, in a de facto or a same sex relationship.

For more information about adoption and fostering go to the NSW Department of Family and Community Services website, www.facs.nsw.gov.au

Surrogacy

Surrogacy is when a woman agrees to become pregnant and give birth to a baby for a couple or single person with the intention of giving that baby to them once the child is born.

Surrogacy laws are different in all Australian states and can be confusing. In NSW this is an option available to heterosexual couples, single women or women in same sex relationships. In each of these situations, the women must have fertility or medical issues which require a surrogacy arrangement.

Surrogacy is also an option for single men and to men in same sex relationships . It must be done on an altruistic, not commercial, basis. You can talk to the HIV AIDS Legal Centre (HALC) for legal support regarding adoption, fostering or surrogacy.

Information about surrogacy can be accessed on the Surrogacy Australia website, www.surrogacyaustralia.org



The future

Whether single or in a relationship, male or female and whatever your sexuality, you have a right to make informed decisions about whether or not you have children and how you attempt to conceive.

Talk to as many people as you can for support and advice. And remember, improved HIV medications and knowledge means that in Australia having a baby with almost zero risk of transmission to the baby or your partner is a very real option.

At the end of this resource, there is a list of relevant services and websites which can help you access support and advice. Good luck and have fun!!

My kids are my everything and I am so grateful to have them. When I was first diagnosed in the nineties I thought I would never have children. I now have two kids and am so grateful for the fact that both are negative. I know with all the measures in place that mother to child transmission is very uncommon, but I am still thankful.
— (Ella, *hiv positive*)

Glossary

Terms you may read and hear about when making decisions about HIV and conception

Antiretroviral Therapy

Standard antiretroviral therapy (ART) consists of the combination of at least three antiretroviral (ARV) drugs to suppress the HIV virus and stop the progression of HIV disease. Also known as HAART (highly active antiretroviral treatments).

Assisted Reproduction Techniques

This is where a doctor or clinic assists the process of fertilising an egg with sperm.

They include:

Sperm washing

This process separates the semen from the seminal fluid. The woman is inseminated using one of the following processes:

- **intrauterine insemination (IUI):** the washed sperm is placed into the woman's uterus
- **in vitro fertilization (IVF):** the egg is removed and fertilized by washed sperm outside the body and then replaced
- **intracytoplasmic sperm injection (ICSI):** a form of IVF where the egg is removed and injected with a single sperm before being replaced

PrEP (Pre-Exposure Prophylaxis)

Treating the partner who doesn't have HIV with HIV medications is a potential option.

The negative partner takes a small dose of HIV medication, prior to sex, to help reduce the risk of transmitting HIV. This is known as PrEP or Pre-Exposure Prophylaxis.

PrEP is currently being trialed in Australia. Talk to your doctor if you want to know more.

Resistance

The ability of HIV to mutate and reproduce itself in the presence of HIV medications is called HIV drug resistance. One of the possible consequences of not taking your HIV treatment properly is that your HIV will develop resistance to HIV medications.

Undetectable viral load (UVL)

Viral load is the term used to describe the amount of HIV in your blood. Having an undetectable viral load doesn't mean that HIV has been completely removed from the body, but that the amount of virus remaining is very low.

Support and health services

The following list of services, websites and resources may be useful.

Planning a family

Paediatric HIV Service at the Sydney Children's Hospital, Randwick Medical services and support for pregnant women and children

Phone: (02) 9382 1851

Family Planning NSW Expert reproductive and sexual health services

Phone: 1300 658 886

Royal Hospital for Women Sydney

Phone: (02) 9382 6111

Royal Women's Hospital Melbourne

Phone: (03) 8345 2000

RPA Fertility Unit
Phone: (02) 9515 8824

Email: fertility.enquiries@sswahs.nsw.gov.au

Website: sswahs.nsw.gov.au/rpa/fertility

Adoption and Fostering

Family and Community Services (NSW)

Adoption and Permanent Care Services

Phone: (02) 9716 3000

Fax: (02) 9716 3001

Website: community.nsw.gov.au/adoption

HIV related health care

Finding an HIV Doctor

A list by state and suburb/town

Website: ashm.org.au/images/prescriber/ashmprescribers.pdf

NSW Specialist Sexual Health Clinics

HIV and sexual health testing, treatment and counselling. For your nearest location call the NSW Sexual Health Infoline

Freecall: 1800 451 624

PEP (Post Exposure Prophylaxis) Hotline (24 hrs, NSW)

Call immediately if you think you might have been at risk of exposure to HIV transmission. Trained staff will advise you what to do next
Freecall: 1800 737 669 (1800 PEP NOW)

Translation service

If you want to speak to a service in your own language, call the Translating and Interpreting Service on 131 450 for the cost of a local call. Ask for the interpreter and wait on the line. They will call the service phone number for you. You will then be able to speak to the service in your own language via an interpreter.

HIV support services

Pozhet (Heterosexual HIV Service)

Support, information, referrals and events for heterosexuals with HIV

Freecall: 1800 812 404

Website: pozhet.org.au

Email: pozhet@pozhet.org.au

Multicultural HIV and Hepatitis Service

Information and support for individuals and communities from culturally diverse backgrounds

Phone: (02) 9515 1234

Freecall: 1800 108 098

Website: mhahs.org.au

Positive Life NSW

A community-based organisation for people with HIV

Phone: (02) 9206 2177

Freecall: 1800 245 677

Website: positivelife.org.au

HIV/AIDS Legal Centre Inc (HALC)

HIV related legal matters

Phone: (02) 9206 2060

Freecall: 1800 063 060

Website: halc.org.au

Bobby Goldsmith Foundation

Practical, emotional, financial support

Phone: (02) 9283 8666

Freecall: 1800 651 011

Services in other states

Positive Women Victoria

Phone: (03) 9863 8747

Website: positivewomen.org.au

HIV Women's Project, Women's Health Statewide, South Australia

Positive women and families

Phone: (08) 8239 9600

Straight Arrows (Victoria)

For heterosexual people living with HIV

Phone: (03) 9863 9414

Website: straightarrows.org.au

Finding information on the internet

It is important to make sure that you get factual and up to date information.

Always check when a site was last updated and check to see who produced the site.

The Pozhet website has links to relevant and recommended websites.

pozhet.org.au

Booklets

Paediatric HIV/AIDS Service - Positive Pregnancy booklet

sch.edu.au/departments/hiv

Guide to HIV, Pregnancy and Women's Health

i-base.info/guides/pregnancy

