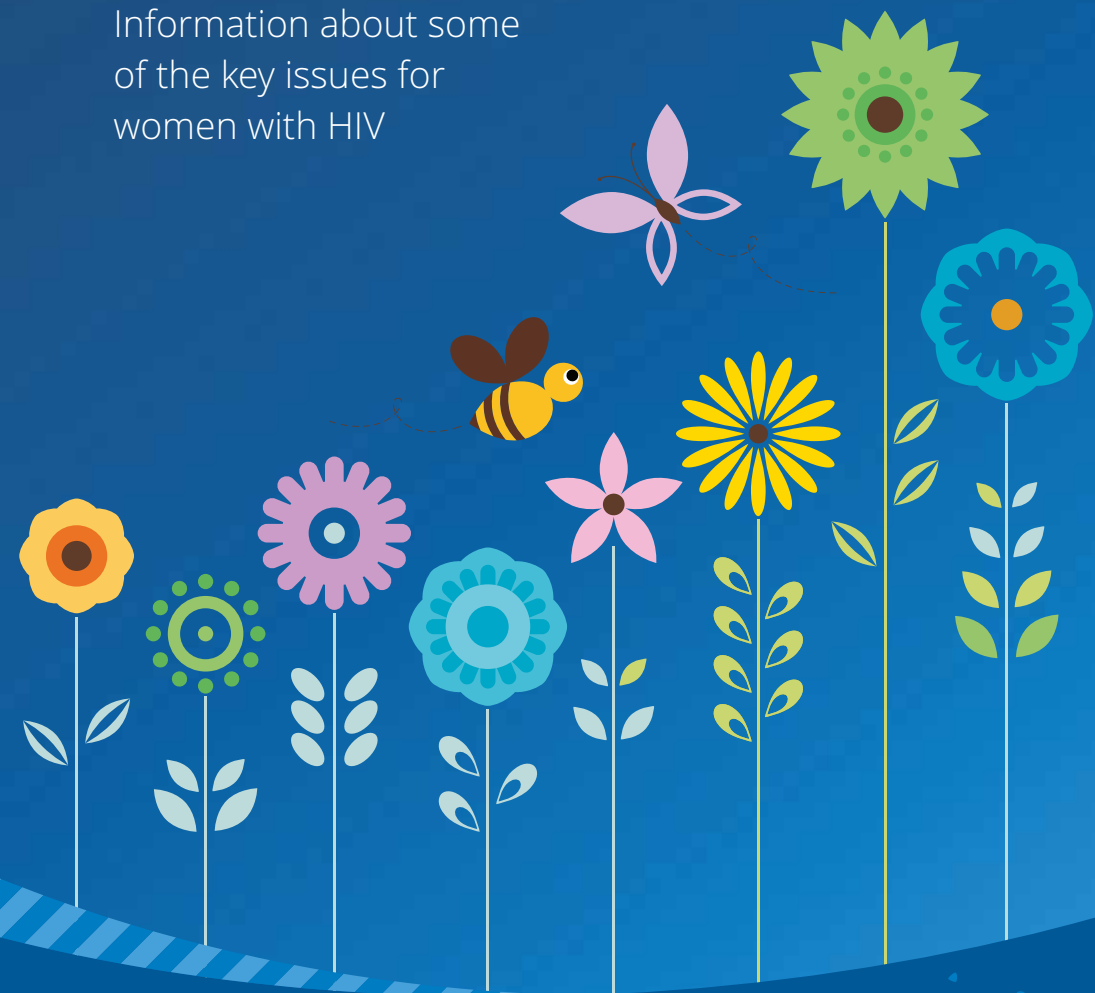


# LIVINGWELL

## Women with HIV

Information about some  
of the key issues for  
women with HIV



**Australian Federation  
of AIDS Organisations**

Leaders in the HIV community response

**napwha** national association of  
people with HIVAustralia



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LIVING WITH HIV:

# BEING HIV POSITIVE

LIVING WELL > LIVING WITH HIV > BEING HIV POSITIVE



**Women make up more than 2,000 of the almost 30,000 people living with HIV in Australia. While HIV affects everyone differently, women often face particular challenges.**

Women with HIV are diverse in terms of education, ethnicity, sexuality and where and how they choose to live their lives. There is no 'typical' woman with HIV because HIV is a virus that can infect anyone.

HIV antiretroviral treatments have radically improved and now offer most people with HIV a long and healthy life — working, studying, relationships, travel, having children, looking after your families, and doing all kinds of things you enjoy. While dealing with a chronic medical condition is not always easy, many women have found that staying optimistic and taking practical steps to stay physically and mentally healthy can produce great results.

## Remember:

**Taking some time** to sort out how you feel is important. Getting an HIV diagnosis can be overwhelming and people frequently experience a range of emotions — all of which are normal. Over time, your way of dealing with your HIV diagnosis will change so take the time and space you need to think through what is happening and how it affects your particular situation. If you are struggling, consider talking to a close friend or speaking to a counsellor or peer support worker at an *HIV community organisation* (see page 102).

**Being informed** about HIV will help you make choices and get greater control over your life. There is still no cure for HIV but you can do lots of things to keep your immune system healthy and to prevent illness. Your doctor can explain your treatment options and there are many other things you can do, like exercising, eating well and generally being kind to yourself. Taking an active role in your health care can help keep you well. For more information see *Keeping Well* (page 88).



**Getting support** from friends or family can make all the difference but it's useful to think carefully about who you want to tell and when you want to tell them. How are they likely to react? Will they be supportive? Will they keep your information private? If you're unsure who to tell or don't want to talk to your regular support network yet, consider a chat with a counsellor or peer support worker at one of the many well established *HIV community organisations* (see page 102). They can also put you in touch with positive women networks which can help you feel stronger and less isolated.

### **Remember, as a woman with HIV you have the right to:**

- \* choose when and if you tell people about your HIV status
- \* take control of your health and make your own decisions about how you live with HIV
- \* choose which antiretroviral treatments or therapies you use, including the right to decide when to start treatments
- \* a full and active sex life
- \* have children
- \* work and to make changes to the way you work
- \* high quality health care in an environment which is supportive, sensitive and free from discrimination

## You may also like to check out...

- \* **Next Steps** is a useful resource providing an overview of information for people who are recently diagnosed HIV positive. It's available at [www.hivnextsteps.org.au](http://www.hivnextsteps.org.au)
- \* **My Positive Journey** is a kit produced by **Positive Women Victoria**. Conceived and written by 32 women from around Australia, the kit explores diagnosis, disclosure, discrimination, new relationships, taking care of yourself and the future. By sharing their experiences, the authors hope to 'light the pathway' and help other positive women navigate the challenges and complexities of living with HIV. My Positive Journey is available on Positive Women Victoria's website at [www.positivewomen.org.au](http://www.positivewomen.org.au)
- \* **What would I tell the newly diagnosed me?** is a film which shares some great insights by positive people diagnosed some time ago. (Available online at [bit.ly/newlydiagnosedme](http://bit.ly/newlydiagnosedme)).
- \* **Songs in the blood** is a radio documentary telling the stories of ten diverse HIV-positive Australian women. (Available online at [bit.ly/songsintheblood](http://bit.ly/songsintheblood)).





# WHAT IS HIV?

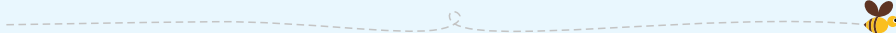
LIVING WELL > LIVING WITH HIV > WHAT IS HIV?



## What is HIV?

**HIV (Human Immunodeficiency Virus) is a virus that damages your immune system so your body becomes less effective at fighting off infection and other diseases.** Once you get HIV, you cannot get rid of it.

Fortunately, there are antiretroviral treatments which can minimise the amount of HIV in your body and limit damage to your immune system — keeping you in good health. These treatments can also greatly decrease the chances of passing HIV on to others during sex. Research for a cure is continuing but is expected to take many more years.



## What is AIDS?

**If you don't take HIV antiretroviral treatments, your immune system can become severely damaged so that you develop serious "opportunistic infections" and diseases that make you feel very ill and can be fatal. A person at this stage is described as having AIDS (Acquired Immune Deficiency Syndrome).**

As more people are diagnosed early in their illness and take modern, effective treatments, people rarely progress to having AIDS in Australia any more. Even people who are diagnosed late with an opportunistic infection or AIDS-related cancer are generally expected to recover from such illnesses if they are treated effectively.



## How HIV affects your body

HIV attacks your immune system by destroying cells which normally fight off infection. The main cells infected by HIV are CD4 cells — a type of white blood cell. Over time, HIV reproduces itself within CD4 cells, creating copies of itself and infecting other CD4 cells. If your immune system becomes immunocompromised, you will be at risk of developing 'opportunistic infections' or other more serious illnesses.

Some people have no symptoms when they are first infected with HIV but many people get a seroconversion illness which usually lasts a week or two. During seroconversion, HIV enters the body and begins to multiply rapidly. Seroconversion illness often includes flu-like symptoms like tiredness, headache, lethargy, aching joints, fevers, night sweats, a rash, diarrhoea, and swollen lymph glands. Because the seroconversion illness feels a lot like the flu or other illnesses, many people do not recognise it as the first sign of HIV infection.

After the first few weeks, HIV attacks the immune system more slowly so most people feel well for years. Even without treatment, the average time before clear symptoms emerge is around seven years, but it generally ranges from about two to 15 years. For more info on how HIV effects your body, check out UK charity, Body and Soul's [video](https://bit.ly/bodyasoul) (at [bit.ly/bodyasoul](https://bit.ly/bodyasoul)).



HIV antiretroviral treatments have dramatically changed the experiences of people living with HIV. A recently diagnosed person who is in the early stages of HIV infection and commences treatment shortly after diagnoses will usually have a life expectancy similar to their HIV-negative peers.

However, every person is different so your experience of living with HIV will be based on the interaction of factors including:



- \* how advanced your HIV infection is when you are diagnosed
- \* how well you look after yourself emotionally and physically
- \* decisions about HIV treatments
- \* how well treatments work for you
- \* factors based on your own physiology and genetics
- \* co-infection with other illnesses such as sexually transmissible infections and hepatitis



**It is important that you (and your doctor) regularly monitor your HIV to maximise your current and long-term health. For more information see *Monitoring HIV* (page 31).**



## How is HIV transmitted?

Just because you have HIV does not mean you will infect anyone. HIV is not passed on by hugging, kissing, coughing, touching, or sharing cups or cutlery.

HIV can be transmitted when the virus enters the blood stream of another person. This can happen when infected fluids are injected (e.g. when sharing needles) or when a significant amount of the virus comes in contact with a mucous membrane (e.g. the cervix through unprotected sex).



HIV is present in blood, semen (cum), pre-cum, vaginal fluid, rectal fluid and breast milk. For transmission to occur, HIV must be present in these fluids in relatively high quantities. The amount of HIV in body fluids varies, which is why HIV is not transmitted through tears, sweat or saliva. Modern HIV antiretroviral treatments also have a major impact. HIV treatments generally decrease a person's HIV viral load. That can have great benefits for a person's health, while also greatly decreasing their chances of infecting anyone else. See *Treatments* (page 37).



**Sex without a condom and sharing needles or syringes are the most common means of HIV transmission.**

Having anal sex without a condom is generally riskier than having vaginal sex without a condom. Oral sex has a very low risk of HIV transmission unless a person has cuts or sores in their mouth. Risk of transmission from a man to a woman during oral sex also increases if the woman has cuts or sores in her mouth and her male HIV-positive partner ejaculates. Risk of HIV transmission through sex increases if either partner has a *sexually transmissible infection (STI)* (see page 51).

There are a number of strategies you can use to prevent HIV transmission through sex, the most effective being using (male or female) condoms. For more information see *Safe Sex* (page 15). HIV cannot be transmitted if each person uses a clean needle and syringe to inject drugs.



**HIV can also be passed from mother to child through pregnancy, at delivery or through breastfeeding but there are a range of interventions to prevent transmission.**

Mother-to-child transmission in Australia is rare. When it has occurred, it has usually been because the mother was not diagnosed during pregnancy so interventions were not applied (For more information see *Having Children*, page 71).



## Telling Friends and Family

It is hard to know how people will react when you tell them you are HIV positive. Many people find that family and close friends are supportive and understanding although that is not always the case. Unfortunately, some people react very negatively, usually based on fear and ignorance about HIV infection and stigma about HIV.

Disclosure is a very personal process. You don't need to rush out and tell people. You may want to give yourself some time to adjust to your diagnosis. If you think an important person in your life may have a bad reaction, you may decide to wait until you are feeling more confident or you may decide not to tell them. It is usually very beneficial to tell at least **one** important person in your life to make sure you have some support.

### Ask yourself:

- \* Who can I trust with my information?
- \* Who will offer me the support that I need?
- \* Who will be able to accept the news without judging me?
- \* Who will respect my privacy and be able to keep this information confidential?
- \* What's best for me?

Being 'out' about your HIV status can be very empowering. Alternatively, you may want to keep your HIV status (and any other aspects of your personal life/health information) private.

Disclosure can be additionally fraught for women with children, as many women feel a pressing need to protect their children from possible discrimination.

Remember, once you have told someone, you cannot 'untell' them. If you don't want everyone knowing you have HIV, be careful not to tell people who gossip. When you do tell someone, you can ask them to keep your confidence although that can be stressful for them. You could ask them to be careful who they tell, let them know if you've told anyone else they can also talk with, or suggest other people they could turn to for support.

If you want to talk about having HIV with someone outside your circle of family and friends, it can be useful to talk with a counsellor or HIV peer support person. They can help you work through particular issues and can also help you decide who you want to tell, when you want to tell them and also how best to tell them.



## **Telling Your Partner**

If you are in a relationship but haven't told your partner about your HIV diagnosis, you will need to think carefully about how, where and when you can broach the subject.

Your HIV diagnosis may come as a shock to them and they may be scared or confused. They might also need to be tested for HIV. Your doctor or HIV community organisation staff can provide support to help you work through this process.

Telling your partner can be difficult but it is often important. You will probably need their support and understanding as you learn to live with HIV. For many women, their partner becomes a major source of support.

It is important not to delay telling your partner for too long as the longer you leave it, the more difficult and complex it may become. Some people react badly to the idea that their partner has been keeping their HIV diagnosis a secret from them or did not trust them.



**You will need to discuss sex as soon as you can so you can come to an ongoing agreement about safe sex.** Be reassured, there are many thousands of people with HIV in Australia who are leading active and satisfying sexual lives with HIV-negative partners by practising safe sex. Consider making an appointment to see your doctor together to discuss risk of HIV transmission in your specific circumstances.

In some states public health law says you must tell prospective sexual partners that you have HIV before you have sex unless you take reasonable precautions to prevent transmission, for example, using (male or female) condoms.

There have been a small number of criminal prosecutions for HIV exposure or transmission. It is difficult to generalise about these cases but it is important to note that all have relied on the fact that the person with HIV did not disclose their HIV-positive status before sex. There have been no criminal prosecutions where a (male or female) condom has been used during sex. If you are concerned about the possibility of prosecution you can contact an HIV-specialist legal service (see page 111) for free advice or referral.

**Not all women have partners who are respectful and supportive.** Some women, including women with HIV, experience domestic violence. Domestic violence is about power and control. It may include physical violence and/or social and emotional control.

No one has the right to be violent towards you but it can be hard to know what to do about it. Fortunately, there are people out there who can help. If you would like to speak to someone, call [the National Sexual Assault, Family & Domestic Violence Counselling Line](https://www.nsv.gov.au) on 1800 RESPECT (1800 737 732). It is a free telephone and online confidential service for anyone who is experiencing or has experienced domestic violence or sexual assault. It is available 24 hours a day, 7 days a week.



## Telling Your Children

When and how to tell children is one of the main issues that arises after diagnosis for women with children. Some women decide to talk to their children straight away while others wait until their children are much older. It very much depends on your family situation and your judgment. You know your children so you are in the best position to make this decision.

Although there is no definite time to tell kids about your HIV diagnoses, it is worth considering that older children may feel angry if they think that important information has been withheld for a long time. When you decide to tell your children, it can be a good idea to tell some other people who can provide them with support — maybe an aunt or a good friend whom your child trusts. Some women find it useful to reassure their children by talking about some of the more routine aspects of managing their health like it is no big deal, e.g. saying things like ‘I must remember to pick up that script at the doctor’s tomorrow’.



**Talking with other positive women, particularly those with children, can be helpful for exploring different approaches you might take.** There are a lot of issues to consider, including the repercussions of asking your children to keep the information about your HIV private or possible consequences for them if they tell other friends. [Disclosing to your Child](http://bit.ly/disclosingtyc), is a great booklet produced by Straight Arrows (available online at [bit.ly/disclosingtyc](http://bit.ly/disclosingtyc)). It provides more detailed information about issues to be considered and experiences of other parents deciding when to disclose their HIV status to their children. This is also an issue you can discuss with a counsellor or health care professional if you would like some guidance on what might be best in your particular family circumstances.



## Telling People at Work

You are not required to tell people about your HIV status in most work environments. Similarly, most employers are not allowed to ask whether or not you have HIV. There are a few exceptions. Doctors, nurses and dentists who perform exposure prone procedures are required to know and disclose their HIV status. Everyone who applies to join the Australian Defence Force is tested for HIV, and if found to be HIV positive, will not be allowed to join. The Australian Defence Force also regularly undertakes HIV testing of its personnel. In some states, it is illegal to work as a sex worker if infected with HIV (or other STIs) even if you only practise safe sex and/or have an undetectable viral load.



## Telling Your Doctor & Other Health Providers

It is important to have a doctor who is expert in treating your HIV (see *Choosing Your Health Care Provider*, page 26) but you may need to see other doctors or health professionals about other issues. You do not have to disclose your HIV status to your doctor, dentist or health care worker although it is often important to tell people providing medical treatment about your HIV infection as it gives them a clearer picture about your health. Seemingly unrelated conditions may be caused by your HIV infection. Any drugs prescribed for another condition may impact your HIV and/or interact with HIV antiretroviral treatment. It is a good idea to tell your dentist as HIV can affect your gums and teeth. Providing full health information to your healthcare providers may prompt them to give you more information which you can use to make your own decisions.



**Your HIV doctor can discuss your health with other health care workers directly involved in your HIV care.** This is important because optimal care often relies on the expertise of different healthcare providers working in

partnership. Your healthcare provider cannot reveal your HIV status to anyone else except in extreme and unusual circumstances; for example, if you are unconscious and requiring emergency medical care and your HIV status is relevant to that care. Your HIV doctor must obtain your consent to discuss your health with other health care workers not directly involved in your HIV care.

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**Disclosing your HIV status to a healthcare professional may feel stressful but remember, for many doctors working in this field, HIV is 'normal'.**

Some healthcare professionals may not be as experienced in treating people with HIV and may be insensitive or actively discriminate. If this happens, remember two things. Firstly, they're the ones at fault, not you. Secondly, it is illegal to discriminate against a person with HIV, including in health care settings. If you have a bad experience or are refused service, you can make a complaint. You may want to contact your local HIV community organisation to talk through your complaint options, or contact your *state anti-discrimination agency* or the *Australian Human Rights Commission* (see page 111) to make a complaint.





SEX AND HIV:

# SEX AND SEXUALITY

LIVING WELL > SEX AND HIV > SEX AND SEXUALITY



**People with HIV want the same things as other people — love, affection and the pleasure you can get and give by having sex. Sex can be a really positive way to feel good about yourself and your partner. Having sex can make you feel desired and valued, happy and fulfilled. HIV-positive people can enjoy a healthy and fulfilling sex life. Most HIV-positive Australians do.**

Some people choose to be single or celibate, which is fine as long as it feels right for you. It's not unusual to feel less interested in sex during stressful times or periods when you feel unwell. An HIV diagnosis can make you feel differently about yourself. Some women also experience body image issues, feeling less than happy about how their body looks or feels. Many HIV-positive women lose interest in sex for the first year or so after diagnosis but the good news is that for most women, sexual desire does return. If you don't feel comfortable having sex, there are many other intimate sexual activities you can enjoy that involve little or no risk such as kissing, massaging, mutual masturbation and oral sex. Just remember, you are a woman with a right to your own sexuality.

It can be hard to feel relaxed about sex when you have HIV because you may be afraid of infecting your partner. It can also be a challenge to talk about HIV and negotiate safe sex with your partner. Talking to a counsellor or to other women living with HIV can be useful.

Sex between women is usually low risk for HIV (and STIs). Penetrative sex between men and women is higher risk. See below for a list of risk reduction strategies to prevent HIV transmission. Straight Arrows' booklet [Sex Matters](#) also offers useful information for heterosexual people living with HIV (available online at [bit.ly/sexmatters](http://bit.ly/sexmatters)). It includes a handy A-Z content list covering topics such as female condoms, safe sex, and women's sexual health.



## Safe Sex

**Condoms (Male Condoms).** Correct use of **condoms** during vaginal or anal sex prevents HIV transmission. Condoms also prevent transmission of most STIs, some of which can increase risk of HIV transmission and also compromise your health.

Most condoms are made from latex. They're best used with a water based lubricant such as Wet Stuff or KY because oil based lubricants like Vaseline or hand cream can damage condoms. Lube can also make sex with condoms more fun. If you are allergic to latex there are also condoms made of polyurethane. Polyurethane is stronger and thinner than latex and oil-based lubricants can be used with them.

If both you and your partner are HIV positive, you may be thinking about sex without condoms but it's good to discuss the potential risks of STIs with your partner and weigh these up against the pleasure many people get from sex without condoms. Even if you are in a monogamous relationship it is important you both have a full screening for STIs before deciding not to use condoms. Many STIs have no symptoms but they can do long term damage to your health.



**Condoms (Female Condoms).** Correct use of **female condoms** during vaginal or anal sex prevents HIV transmission. Female condoms also prevent transmission of most STIs, some of which can increase risk of HIV transmission and also compromise your health.

To be effective, female condoms must be inserted into the vagina before sex. Female condoms are made from polyurethane and are about 15cm long, with two flexible rings (one at each end). The ring at the end of the women's vagina is closed. The other ring, which is open, rests outside. Female condoms are self-lubricated, although other, additional lube can be used. Female condoms must not be used at the same time as male condoms. For more information on how

to use **female condoms** and explanation of their advantages and disadvantages, see Family Planning NSW's female condoms factsheet (available online at [bit.ly/femalecondo](http://bit.ly/femalecondo)).

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**Undetectable viral load.** Effective HIV antiretroviral treatment can significantly reduce a person's **viral load** until it is 'undetectable'. Having an undetectable HIV viral load greatly reduces the risk of HIV transmission. If you have had a stable undetectable viral load for at least 6 months, take your treatment consistently, and you and your partner have no other STIs, you can be confident you will not pass on HIV through sexual intercourse. Used in combination with (male or female) condoms, undetectable viral load means the risk of HIV transmission is virtually zero.

A *viral load test*, (see page 32) measures HIV in blood but your viral load can be higher in other body fluids such as vaginal fluid, particularly if you have a sexually transmissible infection. Talk to your doctor about your particular circumstances if you are thinking of relying on low viral load as a reason for not using condoms.

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**Oral sex.** There is only a very low risk of passing on HIV through oral sex because (as with semen) vaginal fluids contain low amounts of HIV and the mouth has very good protective immune mechanisms, including saliva. Risk of transmission increases if a person has cuts or ulcers in their mouth, has an STI or if the positive partner is menstruating.

To protect yourself, don't let anyone perform oral sex on you if they have a cold sore or ulcer because they may infect you with an STI, like herpes. Your infection with an STI would then increase the risk of your passing on HIV to your partner.

There is no risk of infecting your HIV-negative partner by performing oral sex on them.



**Hands.** It is safe for another person to use their hands or fingers to penetrate your vagina or anus providing the person has no cuts, sores or scratches on their hands. If they do have any cuts, sores or scratches, it is advisable to use latex gloves.

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**Sex toys.** Penetrative sex toys like vibrators or dildos should always be washed or used with (male or female) condoms to prevent the spread of a range of infections. Always change the condom between users/partners.

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**Menstrual fluid.** Having sex when you have your period can increase the risk of HIV transmission so it's a good idea to consider using (male or female) condoms during vaginal sex or dams during oral sex.

For women who have hepatitis C, it is important to prevent others having contact with your blood as the hepatitis C virus is easier to transmit than HIV, and is readily transmissible through blood. (It is also important not to share toothbrushes or razors to prevent Hep C infection.)

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**Pre-Exposure Prophylaxis (PrEP).** PrEP describes the use of HIV antiretroviral medication by people who are **HIV negative** to prevent HIV infection. If used effectively PrEP can dramatically reduce the risk of HIV infection. PrEP can also be combined with (male or female) condoms and other prevention methods to maximise protection. Understanding of PrEP effectiveness is growing. Your HIV-negative partner will need to speak to their doctor about their eligibility for PrEP and how it should be taken.



**Post-Exposure Prophylaxis (PEP).** PEP is a 4-week course of anti-HIV drugs that may prevent HIV infection after a sexual encounter during which HIV risk reduction strategies were not used or have failed (e.g. a condom broke). PEP is most likely to prevent HIV transmission when used as soon as possible after the potential exposure. If it is not started within 72 hours (3 days) it is not likely to work. Your HIV-negative partner can access PEP by speaking to their doctor. During the evening or on the weekend, you can access PEP at your hospital emergency department. For more information and details about where you can get PEP visit the [Get PEP](https://www.getpep.info) site at [getpep.info](https://www.getpep.info).



## **Sexually Transmissible Infections (STIs)**

It is important to avoid sexually transmissible infections (STIs) if you have HIV. STIs increase the risk of HIV transmission. They can also cause more severe symptoms and be more difficult to treat in people with HIV. Sexually transmissible infections include herpes, syphilis, gonorrhoea, chlamydia and genital warts, but they also include hepatitis B and C (see *STIs*, page 51).



# CONTRACEPTION

LIVING WELL > SEX AND HIV > CONTRACEPTION



Contraception lets you avoid pregnancy or plan a pregnancy when you're ready to have a child. There is a wide range of methods to choose from, each with their own advantages and disadvantages. Before choosing a method of contraception it is important to discuss all options with your doctor, with particular attention to the way contraception may aggravate issues associated with your HIV infection, and ways your HIV infection and any antiretroviral treatments you are taking may undermine the effectiveness of contraception.

A number of agencies have produced great resources about contraception:

- \* SHine SA provides detailed information about different forms of contraception on their website at [www.shinesa.org.au](http://www.shinesa.org.au)
- \* Family planning NSW has great factsheets about different forms of contraception at [www.fpnsw.org.au](http://www.fpnsw.org.au)
- \* NAM has an interactive tool, [HIV & Contraception](http://bit.ly/hivandcontraception), designed to give women with HIV personalised information about different contraception choices. It includes questions about any HIV treatments you may be taking. HIV & Contraception is available online at [bit.ly/hivandcontraception](http://bit.ly/hivandcontraception). (Just be aware, it is UK based, so you'll need to double check any information with your doctor.)



## Barrier contraception

Importantly, the only contraceptives that also prevent HIV transmission are male and female condoms.

**Male condoms** are highly effective at preventing pregnancy, as well as preventing the transmission of HIV and most sexually transmitted infections. However, condoms need to be used properly to be effective. Male condoms should not be used with female condoms (see below). Find out more about condoms from Family Planning NSW's male condom factsheet available online at [bit.ly/fpmalecondom](http://bit.ly/fpmalecondom).

**Female condoms (Femidom)** may be a good option for some women with HIV. They are not readily available in Australia but are available at some sexual health clinics, some family planning clinics, selected women's health clinics and pharmacies, and can also be ordered over the Internet. Female condoms may be slightly less effective at preventing pregnancy than male condoms (95% effective compared to 98%) but are comparable to the efficacy of a diaphragm or cap. Female condoms should not be used with male condoms. Find out more about female condoms from Family Planning NSW's female condoms factsheet available online at [bit.ly/femalecondo](http://bit.ly/femalecondo).

**Both diaphragms and caps** are rubber dome-shaped devices that fit over the cervix. They need to be expertly fitted by a doctor but from then on are self-inserted before sex.

The main disadvantage to diaphragms and caps is that to be effective, they need to be used and used correctly each time sexual intercourse occurs. The effectiveness of diaphragms and caps is hard to measure, partly because they must be positioned correctly (and you must remember to insert them). Australian sexual health services estimate that if 100 women used diaphragms and caps for a year, between four and twenty of them would get pregnant.

Previously diaphragms and caps were not recommended for women with HIV because it was thought that spermicide had to be used with them, and spermicide can irritate the vagina and increase the chances of transmitting HIV. However, there is no added contraceptive benefit to using spermicide with diaphragms or caps, and doing so is no longer recommended. Find out more from Family Planning NSW's [diaphragms and caps](#) factsheet available online at [bit.ly/fpdiaphragm](http://bit.ly/fpdiaphragm).



## Hormonal contraception

The main advantage of hormonal contraception is that you are in control of it and you don't need to remember to use it each time you have sex, although you may need to remember to take it every day depending on what hormonal method you choose.

A major problem with hormonal contraceptive products is that many antiretroviral treatments reduce their efficiency so they increase the likelihood of pregnancy. These drugs include non-nucleoside reverse transcriptase inhibitors, nevirapine (Viramune) and efavirenz (Sustiva) and protease inhibitor drugs. It is vital you ask your doctor to consider all possible drug interactions. Also, hormonal contraceptive methods do not reduce HIV transmission risk.



**The Pill** The most common form of hormonal contraception is the Pill. It is estimated to be more than 99% effective in preventing pregnancy, although this may be decreased if you take certain other medication or if you experience vomiting or diarrhoea. Some other medications, including some antibiotics, can make the Pill less effective.

Drugs in several HIV antiretroviral treatments may make some brands of the Pill less effective. Generally, women taking antiretroviral treatment that interacts with the Pill should avoid 'low dose' Pill formulations. If you want to use the Pill, it is important to discuss the interaction of antiviral therapies with different formulations of the Pill to find a combination that works for you. Find out more about the Pill from Family Planning NSW's [Combined Oral Contraceptive Pill](#) factsheet available online at [bit.ly/fporalcontraceptive](http://bit.ly/fporalcontraceptive).



**Depo-Provera** is a contraceptive injection that lasts for approximately 12 weeks. Depo-Provera is not affected by antiretroviral treatments except for the drug Atazanavir. To



find out more about Depo-Provera, see Family Planning NSW's [Contraceptive Injection](#) factsheet available online at [bit.ly/fpconinjection](http://bit.ly/fpconinjection).

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**Implant** Implanon is a small rod inserted under the skin of the upper arm (about the size of a match) that slowly releases the contraceptive hormone. The device is very effective. It provides protection for three years but is readily reversible if pregnancy is desired or if you have side-effects. Implanon effectiveness is impacted by many antiretroviral treatments so ask your doctor to consider all possible drug interactions. To find out more about Implanon, see Family Planning NSW's [Contraceptive Implant](#) factsheet available online at [bit.ly/fpconimplant](http://bit.ly/fpconimplant).

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**IUD (intra-uterine device)** An IUD is a small T-shaped contraceptive device made from plastic and copper that fits inside the womb (uterus). It is also sometimes called a coil. An IUD releases copper into the body causing changes that prevent sperm from fertilising eggs. It is a highly effective contraceptive and is not affected by antiretroviral treatments. An IUD needs to be fitted by a doctor or nurse. To find out more, see Family Planning NSW's [Copper IUD](#) factsheet available online at [bit.ly/fpcopper](http://bit.ly/fpcopper).

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**The Mirena (Intrauterine system)** The Mirena is a small plastic device fitted in the womb. It contains hormones that reduce the risk of heavy periods (sometimes stopping them altogether) and is also used by women with heavy, painful periods as an alternative to hysterectomy. It is highly effective as a contraceptive device and is not affected by antiretroviral treatments. However, it is not recommended for women with a history of pelvic inflammatory disease. A Mirena must be fitted by a doctor or nurse but once fitted, works for five years. For more detailed information see Family Planning NSW's [Mirena](#) factsheet available online at [bit.ly/fpmirena](http://bit.ly/fpmirena).



## Surgical options

Both men and women can have surgery as a permanent form of contraception. For men the procedure is called a vasectomy. A small incision in the scrotum cuts the tubes that carry sperm to the penis. Normal ejaculation still occurs after vasectomy but the semen does not contain sperm. The operation is usually done under local anaesthetic and takes about 15 minutes. Additional contraception needs to be used for two months after the operation as live sperm can persist for some time after a vasectomy. The vasectomy failure rate is very low: approximately 1 in 2000.

For women, sterilisation involves cutting, blocking or sealing off the fallopian tubes. There are several different methods of doing so. Depending on the procedure, anaesthetic may be either local or general, with a hospital stay of a day or more. Other contraception needs to be used until after the first period following the procedure. The failure rate is approximately 1 in 200.

For more information, see Family Planning NSW's [factsheet](https://www.familyplanningnsw.org.au/factsheet) on male and female sterilisation available online at [bit.ly/fpsterilisation](https://bit.ly/fpsterilisation).



## Making your choice

Female and male condoms offer protection from pregnancy, STIs and HIV but some people find them difficult to use every time they have sex. No single contraceptive option is going to suit every woman with HIV so it is important to discuss options, both with your sexual partner(s) and your doctor, to work out what will fit best with your life and your needs.

Longer-lasting options like implants and injectables offer superior efficacy and mean one less pill to take on a daily basis, hence less margin for human error. They are also cheaper. Caps and diaphragms can be inserted ahead of time and left in 'round the clock', so can be convenient but they have a high failure rate

based in part on women forgetting whether or not they are in place.

Family Planning NSW provides a useful summary of contraception options in their [contraception factsheet](#) available online at [bit.ly/fpcontraception](http://bit.ly/fpcontraception).



## **The Emergency Contraceptive Pill (sometimes called the 'Morning after Pill')**

If you are concerned about pregnancy because you had sex without using contraception or the contraception failed (for example, a condom broke or came off during sex), you may wish to access the emergency contraceptive pill. It consists of a high dose progesterone-only Pill (which is actually two pills taken together at the same time). For more information see Family Planning NSW's [Emergency Contraception](#) factsheet available online at [bit.ly/fpecontraception](http://bit.ly/fpecontraception).

You need to take the pill within 72 hours of unprotected intercourse although ideally sooner, as the chances of the emergency contraception working reduces with time. If taken within 24 hours, it prevents 95% of pregnancies, although its effectiveness may be undermined by certain antiretroviral drugs. It is available in pharmacies and some sexual health clinics.

It is important that you let the doctor or pharmacist know if you are on HIV treatment, as some anti-HIV drugs interfere with the way the emergency contraceptive pill works, and you may need to take twice the normal dose.

**Note: If your partner is HIV negative and you are concerned they may have been exposed to HIV, they should visit a doctor as soon as possible (definitely within 72 hours) to access post-exposure prophylaxis (PEP, see page 18), which is a short course of anti-HIV drugs that can prevent them from becoming infected with HIV. During the evening or on the weekend, you can access PEP at your hospital emergency department. For more information and details about where you can get PEP visit the [Get PEP](#) site at [getpep.info](http://getpep.info).**



## Sex between HIV-positive couples

Whether or not to use male or female condoms and lube if your partner is also HIV positive is a matter of personal choice. Condoms provide the most effective barrier against STIs, including the spectrum of warts viruses that can cause pre-cancerous and cancerous cells in the cervix and anus. Women with HIV are more susceptible to pre-cancerous changes so this is an important consideration, particularly if your male partner is or may be sexually active with others.



# TREATMENT AND CARE: CHOOSING YOUR HEALTHCARE PROVIDER

LIVING WELL > TREATMENT AND CARE > CHOOSING YOUR HEALTHCARE PROVIDER



**You may work with a range of health care providers to manage your HIV infection including general practitioners, infectious diseases specialists, sexual health specialists, complementary therapists, nurses, gynaecologists, physiotherapists, psychiatrists, counsellors, and social workers. Some you may use briefly. Others will become the backbone of your health care. Ideally, your health care providers will use a team approach to optimise your overall health and wellbeing.**

Choosing your health care providers is an important process because you need to feel comfortable and confident with those providing your care. Consider the following questions:



## **Am I comfortable with them?**

It is important that you trust your doctor's expertise and advice and that you feel comfortable in their care. Health care providers are expert in particular areas of medicine but ... this is your journey. It is important they give you the opportunity to have input on any suggestions they make and listen to any concerns you have. You will know best how HIV and any side-effects from antiretroviral treatment are affecting your quality of life and how you want to progress in the future. It's important that your health care providers have a personal and professional manner you are comfortable with.



## **Do they treat other women with HIV?**

HIV can impact women differently from men in terms of certain physical symptoms, specific treatments and managing family and other responsibilities. Many women prefer to see a health care provider who sees other women with HIV. You can contact a *positive women community organisation* (see page 102) to ask if they are able to suggest health care providers living in your area who are experienced working with women with HIV.

Many women prefer to see a woman doctor or other health care provider, particularly for gynaecological or sexual health matters, as they think a woman practitioner is more likely to be sensitive to specific issues affecting women, such as menstrual irregularities, cervical screening or pregnancy. Whether you choose a male or a female health care provider, it is important to find a practitioner who is sensitive to gender and family and lifestyle issues.



## **If they don't treat many people with HIV, are they willing to learn about HIV and its treatment so I get the best care?**

HIV antiretroviral treatments are very complex and innovations in treatment are frequent, so in Australia they can only be prescribed by doctors who have qualified as an 'S100 prescriber'. You will need to be monitored by an S100 prescriber but may also rely on a local GP who will need to have a basic understanding of HIV medicine. Clear lines of communication between your S100 prescriber and your GP will be important for you to get the best care.



## **Will they explain the benefits and possible side-effects of any treatment?**

Starting antiretroviral treatments early can deliver great benefits in the long term. HIV treatments now generally produce far less debilitating side-effects than they used to.

However side-effects vary and it is important for your doctor to explain all possible risks and benefits of any treatment, including what you can expect when you start, to help you decide which treatments you want to take (see *Treatments*, page 40). You need as much information as possible to make your own treatment decisions.



## **Will they help me manage side-effects?**

Your doctor should clearly explain the potential side-effects of any treatments and how best to deal with them. If you are worried about possible side-effects, you could ask your doctor about whether it would be useful to make specific

plans (like having a few days at home for short term side-effects) or have some simple remedies on hand (like Imodium for diarrhoea) when you start taking new drugs.



## **Will they respect my decisions?**

Some women with HIV have experienced pressure from their doctors regarding particular HIV antiretroviral treatments. Remember, the doctor is a medical expert but the decision whether or not to take particular treatments is

yours alone. A good doctor will appreciate that most people don't make HIV treatment decisions lightly, and that most woman will have carefully considered their reasons for starting or changing treatment.



## Will they consider complementary therapies and alternative ways of managing symptoms and side-effects?

Some women avoid telling their doctor they are using any complementary therapies because they are worried their doctor will be judgemental and won't support them. Some doctors may be less supportive than others but most are prepared to work with complementary therapists to ensure their patient is getting the best quality care available. If you are interested in complementary therapies, it may be a good idea to be upfront about it and establish whether your doctor is prepared to work co-operatively with other therapists. (See *Complementary Therapies*, page 41).

### A note on complementary therapists

Many women with HIV use complementary therapies, however, this area is largely unregulated so it can be confusing or difficult to work out whether an alternative therapist is appropriately qualified and whether the treatments they are prescribing are safe (particularly if you are using any antiretroviral treatments). Some complementary therapies have professional bodies which can be a guide to the qualifications of the therapist although it's not a guarantee of their work. Your local PLHIV support organisation should be able to refer you to qualified practitioners who are experienced in working with people with HIV. Avoid any therapist who claims to be able to 'cure' HIV. (See *Complementary Therapies*, page 41).



### Are they happy to refer to other practitioners?

Good health practitioners will support you in seeking a second opinion if you are making a difficult decision. They will understand that it can be useful to have another view or to seek confirmation of their assessment. Your doctor should also have a list of healthcare providers to whom they can refer for assistance in other areas, such as emotional or psychological support.





## What are their fees?

It's important to consider whether you can afford the treatment options you choose. Most HIV services are offered free or are heavily subsidised. Private specialists (such as gynaecologists) will charge so it's important to ask about the cost prior to a consultation. Complementary therapies can be expensive. HIV support groups may offer cheaper access to alternative therapies such as massage. You may also be able to negotiate a discount with a regular therapist if you are on a pension or a low income earner.



## Will they keep my information private?

All doctors and other health care practitioners are bound by strict laws regarding privacy. Your doctor is not allowed to disclose information about your health, including your HIV status, to other people unless they are directly involved in your HIV care or they have your consent.



## What if I want to change doctor?

If you are unhappy about the service you are getting or your doctor leaves the practice, you might want to change doctor or try more than one doctor. You can arrange to have your medical records transferred to your new doctor.

If you wish to make a complaint, talk to your local *HIV service organisation* (see page 102) about how to go about it.

AFAO's factsheet [Working with Your Doctor](#) contains some other useful tips on how to get the most out of working with your healthcare providers. It's available online at [bit.ly/withyourdoctor](http://bit.ly/withyourdoctor).



# MONITORING HIV

LIVING WELL > TREATMENT & CARE > MONITORING HIV



**It is important to regularly check the effect HIV and any antiretroviral treatments are having on your body, even if you are feeling well. Each person with HIV is unique so you will need regular check-ups.**

There are a number of important pieces of information that can help you make decisions about treatment and other things you might do to improve your health.

The two most common tests involve measuring your viral load and your CD4 count. They show:

- \* how much HIV is currently in your body
- \* how HIV is affecting your immune system
- \* whether you are at risk of opportunistic infection
- \* the urgency of beginning HIV treatment or how well your current treatment is working

Before your regular check-up, it can be useful to think about how you have been feeling, what is working well for you and what is not working so well. Make a note of any concerns or questions to ask at your next appointment and bring a list of all current medications.



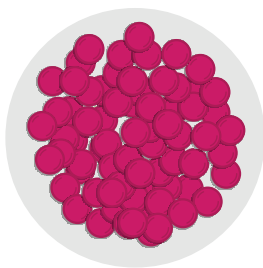
## Viral load

**HIV multiplies by copying itself within your body.** Your viral load indicates how active your HIV infection is, the risk of damage to your immune system and the risk of serious HIV-related infection. Your viral load also indicates whether you are taking your antiretroviral treatment as prescribed, how well your treatments are working or the urgency of starting treatment.

A viral load test is a simple blood test that measures the amount of HIV in your bloodstream. The lower your viral load, the better.

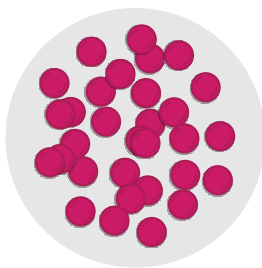
HIV treatments aim to suppress your viral load so it becomes and stays undetectable. You will still have HIV in your body but an undetectable viral load greatly increases the likelihood of staying healthy and decreases the likelihood of infecting anyone.

Research has shown a relationship between levels of HIV in the bloodstream and levels of HIV in other body fluids like vaginal secretions, so if your viral load is low in your blood it is likely the level of viral load in your vaginal fluids will also be low. However, this may not always be the case. Importantly, viral load in vaginal fluids is likely to be higher than in blood if you have a genital infection or other STI, which will increase HIV transmission risk (see *Sexually Transmissible Infections*, page 51). Viral load may also be higher in breast milk than in the blood used for your viral load test.



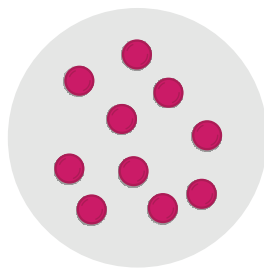
**High**  
(Greater than 100,000  
copies/mL)

There is a lot of HIV in your blood. This can do a lot of damage, make you sick and make it easier to pass on HIV to someone else.



**Low**  
(Fewer than 10,000 to  
30,000 copies/mL)

HIV is being controlled and is unlikely to make you very sick. It is not as easy to pass on HIV.



**Undetectable**  
(Less than 20-50  
copies/mL)

Only a very small amount of HIV is in your blood. This should keep you well and makes it unlikely you can infect someone else.

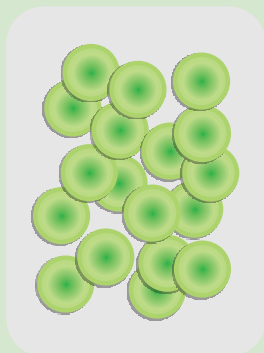


## CD4 count

**CD4 cells are a critical part of your immune system.** A person with a healthy immune system usually has between 500 and 1400 CD4 cells per cubic millimetre of blood. HIV infects and destroys CD4 cells until they are so depleted that your immune system does not work properly. This can occur without you looking or feeling any different.

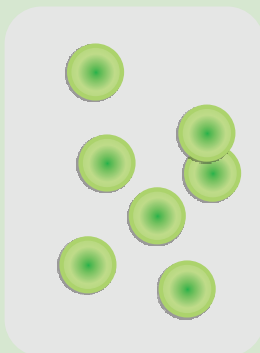
The CD4 test is a blood test that identifies how many CD4 cells you have and how strong your immune system is. If your CD4 count is low, you are more likely to get sick. If you go on treatment, your CD4 count is likely to go up considerably.

Your CD4 cell count may go up or down with your menstrual cycle or during times you feel 'run down' or have any other illness, like the flu. Pregnancy can lower CD4 cell count due to the effect of the larger blood volume in a woman's body while pregnant, but it should not affect the immune system's health. After the baby is born, CD4 count usually goes back to the same level as before pregnancy.



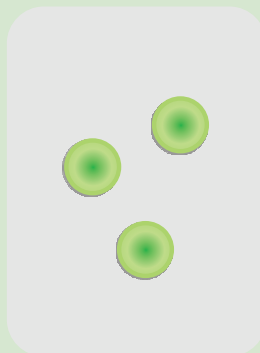
**More than 500  
cells/mm<sup>3</sup>**

Your immune system is still relatively healthy but recent research suggests there may be real benefits in starting treatment now to keep your immune system healthy over the long term. Talk to your doctor about how starting treatment now can benefit your health.



**350 to 500 cells/mm<sup>3</sup>**

Your immune system appears weakened. Think seriously about starting treatment as soon as possible. Delaying treatment can have serious repercussions.



**Less than 350  
cells/mm<sup>3</sup>**

Your immune system is very weak. Start treatment immediately.



## Pap smears

Women living with HIV are advised to have a Pap smear every twelve months. A Pap smear is a simple procedure in which a sample of cells is swabbed from the cervix (at the top of the vagina) to test for any changes which may suggest the risk or presence of cancer.

The presence of abnormal cells is more common in HIV-positive women although just having abnormal cells does not mean a person has or will get cancer. In a small number of cases, they can suggest pre-cancerous conditions which can progress to cancer more rapidly than in women without HIV. This is more common among women who are not on HIV treatments.



## Breast Screen (Mammogram)

Breast cancer is the most common cancer in Australian women. One in nine women will develop breast cancer by the age of 85 years. HIV does not appear to increase breast cancer risk.

Breast screening (through a mammogram) is the best method for detecting breast cancer. A mammogram is a low dose x-ray of your breasts. Two-yearly mammography screening is recommended for women aged 50 to 69 years, although free mammograms are available from the time a woman turns 40.

Early detection of abnormalities offers the best chance of successful treatment and recovery. Most women who have abnormal mammogram results don't have cancer.



## Other tests

There are other tests you may need including:

- \* tests for any other sexually transmissible infections (STIs)
- \* blood tests to see if you also have hepatitis B or have no protection against this virus and will need to have a vaccination
- \* blood tests to see if you have hepatitis C
- \* tests to see if you have been exposed in the past to other viruses (for example, cytomegalovirus — known as CMV) which can recur in people with very low immune systems
- \* other general blood tests including full blood count, liver and kidney function tests
- \* other tests that may be indicated including a chest x-ray, skin test (Mantoux test) or a blood test to check if you may have been exposed to tuberculosis (TB) lung infection in the past

Many women with HIV juggle more than one chronic illness, for example, diabetes, hepatitis, heart conditions or osteoporosis. If this is the case, you will need to have other tests from time to time. Your doctor will work with you to monitor your health and schedule tests when required.



# TREATMENTS

LIVING WELL > TREATMENT & CARE > TREATMENTS



**HIV treatments are made up of combinations of (usually three) HIV antiretroviral drugs. These treatments are very effective at stopping HIV from reproducing, which keeps the immune system strong so it can fight infection. Treatments reduce and often prevent long term health issues related to HIV. Treatments today are much easier to take, with far fewer side-effects than in the past.**

HIV treatments come in different ‘classes’, each of which works in a different way to make it difficult for HIV to multiply. There is a range of different drugs in each class. While drugs in the same class share characteristics, there are also differences. For example, some are more effective at stopping HIV replication, some may inhibit HIV entering cells, while others are less likely to trigger certain side-effects.

HIV treatments used to involve multiple doses of different drugs taken at specific times each day (some before and some with food), which often meant complicated medication schedules. For most people, such complex drug routines are a thing of the past. Although most people now take a combination of three drugs from at least two drug classes, separate treatments are often co-formulated and combined into a single pill to reduce the number of pills people need to take. Many people with HIV now take their HIV antiretroviral treatment in a single pill each day. Your doctor may also prescribe other prophylactics: drugs or precautionary measures to prevent you developing opportunistic infections or other medical complications.

HIV antiretroviral treatments are subsidised by the government under the PBS (Pharmaceutical Benefits Scheme), although most states and territories include a ‘co-payment’ where you pay a small portion of the full cost. If you find yourself



under financial stress, there are financial assistance programs for people with HIV. Contact your local *AIDS Council* or *PLHIV organisation* for information (see page 102). If you do not have a Medicare card you will still be able to access ongoing HIV health care. Your HIV doctor will be able to assist you to get access to HIV treatments. For general information on accessing treatment without Medicare, check out AFAO's *Next Steps* website at [bit.ly/gettingmed](http://bit.ly/gettingmed).

HIV treatments may also be available through clinical drug trials which aim to assess the effectiveness and safety of new drugs or new ways of using currently available drugs. Ask your health care provider if you are interested in this aspect of care.



## Starting Treatment

HIV treatment recommendations used to be based firmly on a person's CD4 count but that is no longer the case. HIV treatment is now recommended for all people living with HIV, irrespective of CD4 count, as research has shown that starting treatments sooner rather than later is beneficial to your health. Treatment also reduces the likelihood of onwards transmission of HIV. The question of 'when to start' treatment now really depends on your own readiness.



**Starting antiretroviral therapy is a serious commitment** because once you start, you will need to take treatments for the rest of your life (treatment breaks are not recommended). You may also experience side-effects, although these are usually mild and short term.

If you haven't started treatment, it's important you take whatever time you need to decide when and how you want to start. Some people start treatment as soon as they are diagnosed. Others wait a little longer but be aware, if your CD4 count drops below 500, starting treatment may become a matter of considerable urgency.

**If you are worried about possible side-effects**, you could ask your doctor whether it would be useful to make specific plans (like having a few days at home for short term side-effects) or have some simple remedies on hand (like anti-nausea or anti-diarrhoea medication) when you start treatment.

**If you are worried about remembering to take your treatment** at the right time each day you might like to talk to your doctor or your PLHIV organisation about when and how you would need to take it, and then work out how to fit it into your life so it becomes routine, e.g. with breakfast each day, just before bed, etc. If you don't think you can manage a regular schedule of treatment right now, you can talk to you doctor about what you might need to change or organise so you'll be able to take treatment in the future.

To work through some of the main issues people consider when thinking about starting treatment, check out Living Positive Victoria's [HIV Treatment Myths and Misconceptions](https://bit.ly/treatmentmyths) resource at [bit.ly/treatmentmyths](https://bit.ly/treatmentmyths).



## Deciding what to take

Sometimes deciding which treatments to take can be a little complicated and confusing. If you're on treatment, it remains important to review your treatment regularly to ensure you are taking the combination of antiretroviral treatments that work best for you. Treatments are likely to change over time influenced by factors like:

- \* your general well-being
- \* changes in your viral load or CD4 count
- \* any other illnesses
- \* side-effects
- \* age
- \* lifestyle
- \* the availability of new treatments and new approaches
- \* your attitudes to medicine.



**Treatments aim to get your viral load to an undetectable level**, however that is not always possible. If you are one of those people struggling to get an undetectable viral load — do not blame yourself! You are certainly not alone.

Deciding on the best type of treatment may seem overwhelming. Doctors may say one thing while other positive women, friends or family may say something else. This really is a decision for you based on how you think you can best manage the scheduling and any possible side-effects of specific treatments. Everyone is affected by HIV differently, so your HIV specialist should work with you to tailor and monitor a treatment program specific to your needs.



**Some treatments can affect a future pregnancy** so if you are thinking about getting pregnant, you should talk through your HIV treatment options with your doctor so your treatment can be planned with pregnancy in mind (see *Pregnancy*, page 76).

Remember, you do not need to ‘master’ the science of HIV: that is the job of your doctor. But if you want to know more, check out NAPWHA’s [Treatment Database](https://bit.ly/treatmentdatabase) (online at [bit.ly/treatmentdatabase](https://bit.ly/treatmentdatabase)) or the [Antiretroviral Agents Adult Dosage Chart](https://bit.ly/afaodosagechart) on the AFAO website (online at [bit.ly/afaodosagechart](https://bit.ly/afaodosagechart)). It can also be useful to talk to people at your local PLWHA organisation or AIDS Council.



## Side-Effects

Any drug can cause side-effects but not everyone gets side-effects from their HIV treatments and not everyone experiences the same side-effects. It’s hard to estimate how often people have specific side-effects, but headaches,

nausea and diarrhoea are not uncommon. In the vast majority of cases, these side-effects are manageable and often decrease after the first month or so. Adverse reactions can also occur if your immune system reacts badly to a drug. These symptoms are usually a rash and/or fever. Such symptoms will usually resolve themselves but if you develop a rash when beginning a new drug, seek medical advice. Some people develop side-effects over time, like abnormalities in liver function or (rarely these days) abnormal redistribution of fat throughout your body. Importantly, most people living with HIV are side-effect free.



## Complementary Therapies

If you experience any side-effects, your doctor may prescribe other medicines (like anti-diarrhoea or nausea medications) to help you deal with them. Many people report complementary therapies or dietary changes are also useful in controlling side-effects. Just be aware, some complementary medicines interact negatively with HIV treatments so let your doctor know if you are taking any herbs, vitamins, traditional Chinese medicines or other complementary medicines. Your doctor can refer you to an HIV-experienced dietician if you think it may be beneficial. Of course, if you are struggling with side-effects, your doctor will consider changing your treatments, aiming to identify a treatment plan that produces no side-effects at all.

NAPWHA has produced a small booklet, iPlanPLUS, to help you keep track of any possible side-effects so you can talk to your doctor and ensure you're on the best treatment combination available. iPlanPLUS is available online at [bit.ly/iplanplus](http://bit.ly/iplanplus).



## Drug Interactions

**Other prescription medicine** may interact with your HIV antiretroviral treatment. Your doctor will be able to manage those interactions and tailor a specific treatment plan for you. Just make sure that your doctor is aware of all

prescription medicines you are taking, whether or not that particular practitioner prescribed them. It can be useful to have a list of all drugs with you to act as a check list whenever you see your doctor.



**Natural or alternative medicines**, including herbs, can interact with HIV drugs (e.g. St John's Wort). Some can also be toxic to the liver. Different people react differently to certain natural therapies, so not all natural therapies are safe for everyone or free of side-effects. Talk to your doctor about any alternative medicines you are using and talk to your complementary therapist about any HIV antiretroviral drugs you may be taking.



**Hormonal Contraception** (like the pill) can be undermined by some HIV antiretroviral treatment, so it can increase the likelihood of pregnancy. These drugs include non-nucleoside reverse transcriptase inhibitors — nevirapine (Viramune) and efavirenz (Sustiva), protease inhibitor drugs, and the booster drug Cobicistat. It is important to talk to your doctor to consider all possible drug interactions so they can work out the best treatment plan for you.



**Methadone and other opiate substitute therapies** may interact with HIV antiretroviral treatment. Treatments may reduce the effects of methadone (leading to symptoms of withdrawal) or increase the effects of methadone (causing increased sleepiness). Conversely, methadone may work the same as usual but it may increase or decrease the effects of HIV treatments and cause unnecessary side-effects. HIV treatments that may interact include nevirapine, efavirenz, ritonavir, nelfinavir and lopinavir/ritonavir.

Fortunately, negative effects of any drug interactions can be managed by adjusting the dosage of methadone and/or HIV medications. If you are

concerned about drug interaction, talk to your doctor as soon as possible so they can work out the optimal therapy for you. Do not stop taking HIV treatment without talking to your doctor.



## Adherence – Taking the drugs

Taking your treatment as prescribed (adherence) is very important. If you do not, the virus may develop resistance to your treatments which allows HIV to become stronger and also reduces future treatment options. Missing doses regularly means the virus could escape the control of the drugs and it may also affect your health.

Every time HIV reproduces there is a chance it may ‘mutate’ or change slightly. The more the virus reproduces, the more chance of mutations occurring. In theory, these mutations can make the HIV more resistant to individual drugs or sometimes to a class of drugs but this does not happen commonly unless a person misses pills or doesn’t take their treatment regularly.



**It is important to take the full dose of each drug as prescribed.** This allows the drugs to be maintained at a consistent level so they can work against the virus at

maximum capacity. If you are having difficulties taking a certain drug because of side-effects or dose requirements, talk to your doctor about changing to a combination that suits you better and is easier to remember. It is better to change treatments than to stay on a combination that doesn’t suit.

**There are many ways to remember to take your drugs on time. You could experiment with some of these:**

- \* Take your drugs at the same time each day.
- \* Establish a routine which associates pill-taking with meals where appropriate.

- ✱ Use a medication sorting box which lets you set out your pills for the week in labelled sections so you can easily see what you have taken and what you need to take next. These are available from chemists. Camping supply shops also sell small plastic jars that can be useful for storing backup doses.
- ✱ Use your phone or calendar to set an alarm or reminder notice.
- ✱ Use a calendar or diary in a prominent place at home or work on which you can tick off each time you take your pills.
- ✱ Keep a backup dose in a portable pill container in your bag for when you are not going to be home. (Just be aware that medications expire so swap over your spares from time to time.)
- ✱ In case you're not at home, have extra supplies of your drugs at other places where you know you'll be, e.g. partner's house, work, etc. (Again, keep an eye on expiry dates.)
- ✱ Prepare for travel or holidays by getting a stock of drugs in advance. Always take extra in case you experience travel delays. If flying, always pack your medicine in your carry-on hand luggage. Plan ahead to adjust your treatment schedule for different time zones. For more information on travelling with HIV, see *Should I Travel?* (page 96).
- ✱ Get tips from other people with HIV about how they remember to take their pills.
- ✱ Do not keep treatments at home if you are no longer taking them. Return them to your usual pharmacy where they can be disposed of appropriately.
- ✱ The National Prescribing Service has a handy phone App which can record the names of your medications. It will also answer questions (by email) about drug interactions. This can be particularly useful if you have been prescribed something by a doctor who is not aware of your HIV and any HIV treatments you are taking. The App is available at [bit.ly/medsap](http://bit.ly/medsap).

For a list of tips about treatment adherence, check out AFAO's [HIV Treatment Adherence](http://bit.ly/afaoadherence) factsheet (online at [bit.ly/afaoadherence](http://bit.ly/afaoadherence)) or [NAPWHA's Adherence Tips](http://bit.ly/napwhaadherence) (online at [bit.ly/napwhaadherence](http://bit.ly/napwhaadherence)).

For more information about HIV Treatments, see AFAO's [HIV Test and Treatments](http://www.hivtnt.org.au) website at [www.hivtnt.org.au](http://www.hivtnt.org.au).



## YOUR BODY: REPRODUCTIVE AND SEXUAL HEALTH

LIVING WELL > YOUR BODY > REPRODUCTIVE AND SEXUAL HEALTH



### Menstrual Irregularities

Menstrual changes are not uncommon in women regardless of HIV status. Often, changes are caused by hormonal variations that occur naturally in most women over time.

Menstrual changes can, however, be caused by HIV, particularly if you have a low *CD4 cell count* (see page 33) and/or a high *viral load* (see page 32). They can also be caused by some antiretroviral drugs. You may experience:

- \* heavier than usual bleeding
- \* lighter than usual bleeding
- \* long breaks between periods
- \* periods which are more painful than usual
- \* a worsening of premenstrual symptoms
- \* irregular or 'breakthrough' bleeding
- \* no bleeding at all
- \* the onset of menopause at a slightly younger age

Many women report changes in their menstrual cycle when they start HIV treatment although research on this issue is inconclusive. Periods may stop when women have a chronic illness or experience severe weight loss. Women who miss their periods may experience pelvic pain, swollen breasts or hot flushes. The absence of periods can also be caused by other things (not the least of which is pregnancy). Heavy bleeding can occur, which can lead to anaemia.





**It's important to report any changes in your menstrual cycle to your doctor. Menstrual problems can affect your physical and psychological well-being but they are usually readily diagnosed and treatable.**



**Menstruation and pregnancy** It may be difficult for you to become pregnant if you are having irregular periods. It will be harder to monitor your menstrual cycle and to predict when ovulation (egg release) will occur. If you are trying to get pregnant, talk to your doctor about how you might manage irregular periods and your aim to get pregnant.



## **Vaginal thrush (candida)**

Vaginal thrush is common in all women but occurs more frequently and with greater severity among HIV-positive women. Symptoms include an itchy crotch, stinging when urinating, a dry or sore vagina during sex and a thick white (usually odourless) discharge. Thrush can also occur in other parts of the body (the mouth and the oesophagus), although that is more common when the immune system is weaker.

Thrush is caused by a naturally occurring yeast (candida) which usually lives in harmony with its human host in the gut, the folds of the skin, the mouth, the vagina and the anus. Thrush occurs when the balance of this yeast is disturbed and the candida multiplies out of control. If the immune system is not working well, candida can start to behave like an infection. Thrush is less common when women are on HIV treatment and the immune system becomes stronger.



**How is it treated?** A range of topical antifungal agents is available. Broad-spectrum anti-fungal creams or tablets (such as Canesten) are available from the chemist. You won't need a prescription. Some people suggest live yoghurt

containing lactobacillus acidophilus works although many health practitioners maintain the bacteria in commercial acidophilus yoghurt is ineffective.

For more serious thrush, antifungal drugs may be used. Fluconazole is often used to treat severe or recurring thrush but it (and other medications) can cause liver problems in people who have hepatitis C, although this is rare. If you have hepatitis C, it is extremely important to discuss treatment options thoroughly with your GP, and if possible, find an alternative treatment.

### **To help prevent vaginal thrush:**

- \* Wipe your bottom from front to back after going to the toilet.
- \* Avoid using soap to wash the genital area.
- \* Avoid using antiseptics, douches or perfumed sprays in the genital area.
- \* Avoid using perfumed toilet papers and menstrual products.
- \* Avoid wearing tight-fitting pants and synthetic underwear.
- \* Consider changing your clothes-washing detergent and don't use fabric softeners.

Note: Thrush is not considered a sexually transmissible infection, however, women can be re-infected by male partners during unprotected sex because thrush can be found under a man's foreskin. This is not common but if you think this may be happening, speak to your doctor. For further information about thrush, see Melbourne's Sexual Health Centre's [factsheet](https://bit.ly/mshcthrush) at [bit.ly/mshcthrush](https://bit.ly/mshcthrush).



### **Human Papillomavirus (HPV – genital warts)**

The human papillomavirus (HPV) is a very common sexually transmissible infection. Most people will have it at some point in their life. It's possible for your body to clear HPV infection by itself but women with HIV are much less likely than HIV-negative women to clear the infection.

Some strains of HPV can cause abnormal cervical cells to develop. If not treated, they can lead to cervical cancer, particularly in women who also smoke. Women living with HIV, especially those aged over 40, have a higher chance of developing abnormal cervical cells caused by HPV than women without HIV. Treatment for abnormal cervical cells is highly effective provided they are detected early.

HPV can also cause anal cancer. The association between HIV and anal cancer is an emerging area of knowledge. If you have any concerns, talk to your doctor.

A vaccine against HPV is available. It is free to young men and women, however, it is only effective if given before a person is infected. Given most adults are infected with HPV, it is unclear whether the vaccine would be effective for most adult women with HIV. Speak to your doctor. Melbourne's Sexual Health Centre provides more information in their [factsheet](https://www.mshc.org.au/factsheet) about HPV (online at [bit.ly/mshchpv](https://bit.ly/mshchpv)).



## Pelvic Inflammatory Disease (PID)

Pelvic inflammatory disease (PID) is an inflammation of the pelvic area usually caused by untreated sexually transmissible infections like gonorrhoea or chlamydia.

Some women have PID without knowing or without noticing any symptoms. Untreated PID becomes increasingly painful and can cause infertility. PID seems to be more common and more severe among HIV-positive women. The symptoms can be mild, moderate or severe:

- \* pain or cramps in the lower back and abdomen
- \* pain during intercourse
- \* deep pelvic pain
- \* pain going down to the top of the legs
- \* bleeding between periods
- \* vaginal discharge that is smelly and itchy
- \* high temperature
- \* fatigue



**If you notice any of these symptoms or have any concerns about PID, talk with your doctor. PID must be treated by antibiotics. In severe cases women may need to be admitted to hospital.**



## **Cervical cancer**

The main message about cervical cancer for HIV-positive women is that early detection is critical. Cervical cancer is a preventable condition, and if diagnosed at an early stage, it can be cured.

Regular Pap smear tests are a very effective way to identify or prevent cervical cancer because cervical cancer usually develops slowly. Before cancer appears, the cells of the cervix go through changes known as dysplasia. Not all dysplasia mean you have cancer or are likely to get it, but sometimes it does.

The National Cervical Screening Program recommends all women aged between 18 and 70 who have ever been sexually active have regular Pap tests. Women with HIV should have Pap tests every six or twelve months because the kinds of cervical cell abnormalities that can lead to cancer are more common in HIV positive women. Research also suggests that some treatments may be less effective in women with HIV. Early detection is key!



## **Osteoporosis**

Osteoporosis describes weakening of the bones through loss of bone density. It is very common — more than a million Australians have it. Osteoporosis is more common in women who have gone through menopause than younger women because of the lowering of female hormone levels (oestrogen) in the body which occurs during menopause.

People with HIV tend to have lower-than-normal bone density. It's not entirely clear why this is, but it seems likely it is caused both by HIV and some HIV treatments. Women with HIV and hepatitis B or C co-infection may have an increased risk of reduced bone density. Bone density can be painlessly measured with a special scan. If you are aged over 50 and haven't had a bone density scan, or if you are worried about your bone density, you could ask to have one done.



**There are a number of things you can do to reduce loss of bone density and its effects.** These include doing regular weight-bearing exercise (such as walking, running, or climbing stairs) and having a healthy diet, with plenty of calcium and vitamin D. Oily fish, liver, fortified spreads and cereals, and egg yolks are a good source of vitamin D, as is sunlight. Calcium can be found in milk and other dairy products, leafy green vegetables such as kale and broccoli, beans such as soy and baked beans, nuts, sesame seeds and many types of fish, such as salmon and sardines.

**Some women with HIV may be advised to take vitamin D supplements.**

Some may also be advised to take calcium supplement tablets, particularly if your diet does not include many of the foods containing this nutrient. Taking too much of a supplement can be harmful so it is a good idea to talk to your GP or someone at your HIV clinic before you start. There is no clear evidence that vitamin D supplements help reduce the risk of bone loss in people with HIV but it does help your bones absorb calcium.

**Remember — smoking and heavy drinking can increase your risk of osteoporosis. For more general information about osteoporosis, visit the [Osteoporosis Australia](http://www.osteoporosis.org.au) website at [www.osteoporosis.org.au](http://www.osteoporosis.org.au). For information about HIV and bone health, see [Your Body Blueprint](http://www.yourbodyblueprint.org.au) at [www.yourbodyblueprint.org.au](http://www.yourbodyblueprint.org.au).**





# SEXUALLY TRANSMISSIBLE INFECTIONS

LIVING WELL > YOUR BODY > SEXUALLY TRANSMISSIBLE INFECTIONS



**Sexually transmissible infections (STIs) like chlamydia, gonorrhoea, herpes or syphilis can affect any woman but they can have a more significant effect on women with HIV. HIV can cause more severe symptoms and can make an STI more difficult to treat. STIs can also place an additional burden on your immune system.**

If your partner is HIV-negative and either you or your partner has an STI, the risk of HIV transmission is increased. You or your partner could have an STI even if you have no symptoms.

Using condoms for sex is a practical preventative measure although it won't completely remove all risk of infection with some STIs. Many STIs do not have obvious symptoms so a regular check-up is recommended. Basically, the more sex you have with different people, the more regularly you should be tested for STIs. Many STIs can be quickly and easily dealt with if they are picked up early. NAPWHA's treatment page [Women & STIs](#) also offers some useful information at [bit.ly/womenstis](http://bit.ly/womenstis).



## Herpes

Herpes infections are caused by the herpes simplex virus, which can also cause cold sores on the mouth.

**Symptoms** are not always immediate but may include:

- \* Blisters or a small split or cut in the skin
- \* Itching and tingling
- \* Burning/pain when urinating
- \* Feeling generally unwell (muscular aches, headaches and fever)

**Transmission** occurs most easily when there are sores or blisters present but herpes can also be passed on when there are no obvious symptoms. Herpes is transmitted both sexually and non-sexually during skin-to-skin contact.

**Herpes and HIV** The frequency and severity of outbreaks of genital herpes may increase if your immune system is weakened by HIV. It is also possible for undiagnosed herpes infection (which has not caused symptoms in the past) to be 'reactivated' and cause symptomatic illness.

Herpes may increase the replication of HIV and therefore raise viral load. Symptomatic herpes in an HIV-negative person increases their risk of HIV infection.

**Treatment** Medical educators urge the aggressive treatment of herpes infections in people with HIV. Recurrent outbreaks may be treated with the antiviral drugs acyclovir (Zovirax), famciclovir (Famvir) or valaciclovir (Valtrex). Reducing stress, having a healthy diet and taking care of yourself can all help reduce the recurrence of herpes.

**Prevention** Male or female condoms for vaginal or anal sex, and the use of barrier protection like dams, can help prevent infection but herpes can still be transmitted if condoms do not completely cover the infected area. Antiviral treatment may help prevent spread to sexual partners. Talk to your doctor.



## Chlamydia

Chlamydia is one of the most common STIs in Australia. It is caused by a bacterium and, if left untreated, can cause pelvic inflammatory disease (*PID*, see page 48).

**Symptoms** Most people don't have any symptoms, so don't know they have chlamydia, which is why it is transmitted so frequently. When there are symptoms, they may include:

- \* a change in vaginal discharge
- \* irregular bleeding (especially after sex)
- \* pelvic pain, including during sex
- \* stinging or burning when passing urine

**Transmission** Chlamydia is spread through vaginal or anal sex without a condom. It can also be spread through oral sex.

**Chlamydia and HIV** Chlamydia greatly increases the viral load in semen, which makes it is easier to pass HIV on to other people.

**Treatment.** Testing for chlamydia is easy — done by your doctor checking a urine sample. Chlamydia responds effectively and quickly to a short course of antibiotics. All sexual partners from the last six months should be tested and if they test positive, should be treated. It is important that you return to your doctor for a check-up once the treatment is completed to make sure you have no recurring infection. You should not have penetrative sex until you have received a negative test result following the check-up. If chlamydia is left untreated, it can cause serious health problems.

**Prevention** Chlamydia is prevented by using barrier protection like male or female condoms or dams every time you have sex. A chlamydia test is recommended whenever you change sexual partners and at least once a year if you are under 25 and sexually active.





## Syphilis

Syphilis is caused by a bacterium. In Australia it is more common among gay men or in remote Aboriginal communities. There may be no symptoms for many years but syphilis can eventually cause serious health problems.

**Symptoms** Not all people with syphilis have symptoms so you may not know you have it unless you have a blood test for it. There are three stages of infection: primary, secondary and late syphilis. During the primary stage, a person may or may not notice a single or multiple sores that are usually firm, round and painless. These typically last 3 to 6 weeks. During the second stage, a person may notice a (usually non-itchy) rash on one or more areas of the body. Rashes may appear on the palms of the hands and the bottoms of the feet, however they can appear elsewhere. Symptoms may also include fever, swollen lymph glands, sore throat, patchy hair loss, headaches, weight loss, muscle aches, and fatigue. During the late stage, people may experience no symptoms for years but may then develop severe symptoms including damage to the brain, nerves, eyes, heart, blood vessels, liver, bones, and joints. Symptoms of late stage syphilis include difficulty coordinating muscle movements, paralysis, numbness, gradual blindness, and dementia. This damage may be serious enough to cause death.

Given how easy it can be to miss the symptoms of syphilis and the significant consequences of infection, testing for syphilis is important if you have any concerns. The diagnostic tests for syphilis may fail more frequently (producing false positives and negatives) in people with depleted immune systems. However, these failures are still believed to occur only rarely.

**Transmission** Syphilis is spread through unprotected vaginal, anal or oral sex. It can also be spread during pregnancy from an infected woman to the developing foetus.

**Syphilis and HIV** Genital sores caused by syphilis make it easier to transmit and acquire HIV. Syphilis can also progress to severe symptoms more quickly in people with HIV. There can be rapid progression from early syphilis to nervous

system involvement in a matter of months, rather than the years or decades it takes in HIV-negative people. Complications to the nervous system may also occur in the early stage of infection, not just in the later stages.

Co-infection with HIV and syphilis may also result in more rapid onset of HIV disease and AIDS. It can decrease CD4 count (thereby damaging the immune system) and increase HIV viral load.

Syphilis can be more difficult to treat in people with HIV. There have also been cases of treatment failure in patients with secondary syphilis, all of whom were HIV positive. People with HIV can also progress to neurosyphilis despite standard treatment. If you have syphilis (early or latent), careful monitoring is advised so that any abnormality is treated immediately.

**Treatment** If treated early and appropriately, syphilis can easily be cured by penicillin injections or tablets. If you are allergic to penicillin there are alternative treatments. The duration and intensity of treatment depends on the stage of infection. Although the treatment is straightforward, it is important to have repeat blood tests to check that the treatment has worked. After treatment with penicillin some people (particularly those who have early syphilis) have a flu-like illness for 24 hours. This includes fevers, aches and pains and generally feeling unwell. It will go away and doesn't require any specific treatment except plenty of rest and fluids.

**Prevention** Always use male or female condoms for vaginal, anal and oral sex. Condoms are not 100 per cent effective because they will only stop infection from the skin covered by the condom – they may not cover all sores or rashes in the affected area. Use dams for oral sex. Avoid contact with any sores. Avoid sex if either partner has infectious syphilis. You should not have sex until your rash or sore clears up. Regular testing is important as it is the only way to truly diagnose syphilis. Once tested, you and/or your partner can be treated. Wait at least a week after treatment before having sex.



## Gonorrhoea

Gonorrhoea is an infection caused by the bacteria *Neisseria gonorrhoeae*.

**Symptoms** Infection with gonorrhoea may have no symptoms. If symptoms do occur they may include:

- \* an unusual discharge from the vagina
- \* pain when urinating
- \* deep abdominal pain during vaginal sex
- \* sore, dry throat

Men may experience a discharge (pus) from the penis and/or a burning sensation when urinating. Gonorrhoea can also infect the anus and the throat, usually without any symptoms at all.

**Transmission** Gonorrhoea is spread through unprotected vaginal, anal and oral sex.

**Gonorrhoea and HIV** HIV infection may exacerbate some of the symptoms and complications of gonorrhoea. Also, some research has shown a link between gonorrhoea and faster HIV disease progression. Cases of severe arthritis related to gonorrhoea have been reported in people with HIV. There are also reports of keratoconjunctivitis, a severe inflammation of the membrane which covers the eye.

**Treatment** Women are tested using a urine test or a swab from the cervix, anus or throat. Gonorrhoea is treated with antibiotics. A follow-up swab is taken to make sure the infection is gone. Men are tested by a urine test or swab from the penis or a swab from the anus or throat.

**Prevention** Always use male or female condoms for vaginal, anal and oral sex. Use dams for oral sex to cover the vagina or anus. Make sure your current partners have been tested. You should not have any sexual contact for one week after completion of treatment (not even sex with a condom).





# OPPORTUNISTIC INFECTIONS

LIVING WELL > YOUR BODY > OPPORTUNISTIC INFECTIONS



**The term opportunistic infections refers to a number of illnesses, infections and conditions which occur when the immune system has been damaged by HIV. They are called ‘opportunistic’ because the things that cause them (e.g. viruses, bacteria) are often present in the body and the environment but they don’t cause serious illness in a person with an intact immune system. When the immune system is significantly damaged (for example, by HIV) these common bugs may use the ‘opportunity’ to cause disease. Opportunistic infections can be serious, causing debilitating illness or death. Generally, the risk of developing an opportunistic infection increases as a person’s CD4 count decreases.**

Opportunistic infections were very common in the early days of Australia’s HIV epidemic but the effectiveness of HIV antiretroviral treatments means most opportunistic infections are not common any more. If your HIV doctor thinks you are at risk of opportunistic infections (depending on your CD4 count) they may recommend specific antibiotic treatments that act to prevent them. Opportunistic infections include a number of conditions described elsewhere on this site, including *thrush / candidia* (see page 46) and *herpes* (see page 52).



## Opportunistic infections also include:

**Shingles** is one of the more common opportunistic infections people may experience. It is caused by reactivation of the varicella zoster virus. Anyone who has had chicken pox has been exposed to this virus. Shingles symptoms can include skin rash, pain along nerves (usually face, chest or abdomen) and painful, fluid-filled blisters.



**Pneumocystis pneumonia (PCP)** is a serious infection that causes inflammation and fluid buildup in the lungs. It is caused by a common fungus. Most people have been exposed to PCP but it is easily controlled by a healthy immune system. PCP causes a type of pneumonia in people with weakened immune systems, including people with HIV who have a low CD4 count. Before HIV antiretroviral treatments, PCP was very common among people with HIV but is now far less common.



**Cytomegalovirus (CMV)** is an extremely common virus which can be transmitted by saliva, blood, semen and other bodily fluids. It can cause mild illnesses when first contracted although many people may never have symptoms. Once a person is infected, it does not leave the body. In patients with HIV and an extremely low CD4 count CMV can cause infections in the eye leading to blindness. It can also cause severe diarrhoea and ulcers.



**Tuberculosis (TB)** is a bacterial infection that attacks the lungs and can invade other organs. TB can be in your body without making you sick. If your immune system becomes damaged, the TB may become 'active' again, making you ill.

TB usually affects the lungs, but it can also affect the brain, kidneys, spine or other organ systems. TB can cause serious health problems. Your doctor will check to see if you have ever been in contact with this infection in the past and are therefore at risk.

**If your CD4 count is 200 or below, you will need to pay careful attention to any symptoms that indicate the presence of an infection. Such symptoms include persistent diarrhoea, fever, night sweats, vision loss or change, abdominal pain, enlarged lymph nodes, unexplained weight loss, shortness of breath and/or chest pain. You should report such symptoms to your doctor as soon as possible to discuss treatment options.**





# HEPATITIS B AND C

LIVING WELL > TREATMENT > HEPATITIS B AND C



## Hepatitis B

Hepatitis B is caused by a virus in blood and body fluids. Hepatitis B causes inflammation of the liver and can cause liver fibrosis (scarring), cirrhosis, and liver cancer. Hepatitis B is more infectious than HIV.

**Symptoms** Hepatitis B symptoms may include a mild flu-like illness, loss of appetite, abdominal pain and discomfort, vomiting and nausea, pale faeces, aching joints and jaundice (recognised by yellowing of the eyes). People with Hep B virus can suffer recurring symptoms, including serious liver damage. A blood test is used to determine a diagnosis. This may show up as 'positive' between one and six months after exposure to the virus. The majority of adults, 95%, will clear the virus from their body after infection. A small number will become chronic carriers of hepatitis B.

**Transmission** Hepatitis B can be passed on through infected blood or body fluids through sex (including oral sex) or by sharing injecting equipment, toothbrushes or razors, and tattooing and body piercing with un-sterile equipment. Hepatitis B can be passed on to a baby during pregnancy or childbirth. Like HIV, hepatitis B is present in breast milk and can be passed on to a baby when breastfeeding.

**Hepatitis B and HIV** Hepatitis affects the liver, so your ability to tolerate some HIV treatments (which are metabolised through the liver) may be reduced. Studies have failed to find a link between hepatitis B and more rapid HIV disease progression, although some have suggested a link may exist.

**Treatment** People who have HIV and hepatitis B are usually advised to commence treatment for hepatitis B. In practice, two commonly used HIV antiretroviral drugs also treat hepatitis B infection. Your doctor would usually include these drugs in your HIV treatment combination when you start HIV treatment, thus treating both viruses at the same time. Sometimes when HIV treatments are first commenced they can cause a “flare” of inflammation of the liver. Your doctor will monitor this situation.

Treatment does not cure hepatitis B but it can change an aggressive infection into a mild one, helping stop damage to the liver.

**Prevention** Male or female condoms should be worn during anal or vaginal sex or other genital contact. Clean injecting equipment must be used when injecting drugs. Sharing razors or toothbrushes is not recommended. The only guaranteed preventative measure if you do not have hepatitis B, is vaccination, which can be safely used if you're HIV positive. A good response to vaccination is more likely if your immune system is strong. All sexual partners of people with hepatitis B and all household members should also be vaccinated if they do not already have immunity.

For more information see Hepatitis Australia's pages on [Hepatitis B](https://www.hepaustriab.com.au/hepatitis-b) (online at [bit.ly/hepaustriab](https://www.hepaustriab.com.au/hepatitis-b)).



## Hepatitis C

Hepatitis C (Hep C) is a viral infection that affects the liver. The Hep C virus lives in the blood and liver cells where it can cause inflammation and scarring (called fibrosis) or cirrhosis, which is more serious. Hep C can potentially cause long-term, serious health problems, including liver failure and cancer. However, recent treatment advances mean more and more people will now be cured of their Hep C infection.



Some women with HIV in Australia have both HIV and Hep C. When people have both HIV and hepatitis C, they are described as having a co-infection.

The emotional and physical effect of an HIV and Hep C diagnosis should not be underestimated. It can be particularly stressful because there are not always clear-cut answers about how to manage both conditions together. It is important to allow yourself the psychological and emotional space to deal with these issues and to get expert advice. There are numerous support groups and organisations for people with Hep C, including [Hepatitis Australia](http://www.hepatitisaustralia.com) ([www.hepatitisaustralia.com](http://www.hepatitisaustralia.com)). Your doctor can also provide advice and refer you for more information about treatments or counselling.

**Symptoms** Hepatitis C infection does not mean the same thing for everybody. Research suggests that approximately 25% of people who are infected with Hep C clear the virus completely within two to six months of infection although they continue to have Hep C antibodies in their blood. The other 75% of people are at risk of developing ongoing (or chronic) infection and cirrhosis of the liver. Of those people who develop chronic hepatitis, about 20% will not experience any noticeable illness or symptoms, however, they can still transmit the virus to others.

After a period of 15 years, most people with chronic Hep C infection will experience some symptoms and develop some liver damage. After 20 years, some will develop cirrhosis. A small number will experience liver failure or develop a form of liver cancer known as hepatocellular carcinoma.

**Transmission** Hep C is much more infectious than HIV. It is usually transmitted via blood exposure. Research suggests that Hep C is also sexually transmissible, although this occurs much less frequently than with HIV or hepatitis B. The hepatitis C virus can be found in menstrual blood, suggesting the importance of safe sex (using condoms). Hepatitis Australia's [Need-To-Know News on Hepatitis C Treatment](http://bit.ly/hepaaustralianews) details the latest information online at [bit.ly/hepaaustralianews](http://bit.ly/hepaaustralianews).

**Hep C and HIV** There is evidence that HIV may cause a more rapid progression to liver damage in people with Hep C. This is because HIV appears to increase

Hep C viral load. It is less clear what effect Hep C has on HIV infection. Studies have produced conflicting results, including some that indicate having Hep C does not necessarily increase the impact or disease progression associated with HIV.

One area where Hep C can have a serious impact, however, is in the area of HIV treatments. There are a number of anti-HIV drugs which are toxic to the liver, and these are used with care in people who have abnormal liver function or evidence of inflammation. It is important you see an HIV doctor experienced in treating HIV and Hep C co-infection. Regular liver function tests and other tests including scans relating to the liver are particularly important if you also have Hep C.

Straight Arrows, Victoria's lead agency for heterosexual people living with HIV, provides more detailed information on [HIV and HEP C co-infection](http://bit.ly/hivandhepc) online at [bit.ly/hivandhepc](http://bit.ly/hivandhepc).

**Treatment** Hepatitis C treatments are currently developing at a rapid pace. Recent research suggests that soon most people with Hep C will be able to be cured by much shorter term treatment than ever before. For up-to-date information check out Hepatitis Australia's Hep C [treatment page](http://bit.ly/treathepc) (online at [bit.ly/treathepc](http://bit.ly/treathepc)) and talk to your doctor.

**Note: Use of the current Hep C drugs Ribavirin or Rebetron are definitely not recommended if you are pregnant or are considering pregnancy. For more specific information relating to Women and Hepatitis visit Hepatitis Australia online at [bit.ly/womenandhepc](http://bit.ly/womenandhepc).**

**Alternative therapies** may be a useful way of assisting your body, particularly your liver, to cope with both the physical and psychological impacts of HIV and Hep C. It is also useful to pay attention to your diet, reduce alcohol consumption, avoiding binge-drinking and do some exercise.

Herbal formulations may be beneficial but be aware, some can actually cause damage. While it is often thought that herbs are 'safe' and 'natural', there are

documented cases of some herbal medications causing liver damage. As with alternative therapies for HIV, make sure you find a qualified, reliable practitioner for any alternative therapy you may wish to use. See Hepatitis Australia's Complementary Therapies page or contact your local Hepatitis support organisation for more useful tips.

**Prevention** Hepatitis C is primarily transmitted through blood to blood contact. The highest risk activity is the sharing of needles, syringes, or other drug injecting equipment like tourniquets. Hep C can also be transmitted through tattooing equipment or body piercing equipment which is not sterile. Some people have been infected with Hep C through blood transfusions but all blood is now screened before transfusion. People with hepatitis C should not share tooth brushes or razors.



**Technically, menopause means stopping having monthly periods (menstruation). It marks the end of your fertility and is accompanied by significant hormonal changes. Most women begin to experience menopause somewhere between the ages of 38 and 58, with 51 being the average age for Australian women. Remember, menopause is a transition, not a disease.**

Different women experience menopause very differently. Although menopause is not an illness, it does have 'symptoms'. Hot flushes, mood changes, night sweats and fatigue are normal. You may become more prone to accidental urination. Sexual changes also accompany the end of menstruation including vaginal dryness, thinning of the vaginal walls and reduced libido. Some women experience loss of concentration, memory loss, anxiety or fatigue. Your risk of heart disease increases as does your risk of bone loss (*osteoporosis*, see page 49) after menopause.

Menopause is usually a gradual process rather than an abrupt change. The first phase is called 'peri-menopause': periods become less frequent and other menopausal signs can appear.

If you are uncertain whether changes in your body are caused by the onset of menopause or something else, your doctor can do blood tests that check your hormone levels and can provide a clear answer.

For more general information about menopause (although not specific to women with HIV), check out [About Menopause](#) from Women's Health Queensland (online at [bit.ly/aboutmenopause](http://bit.ly/aboutmenopause)). For information about HIV and menopause, see [Your Body Blueprint](#) (online at [bit.ly/ybbmenopause](http://bit.ly/ybbmenopause)).

## Tips for living with menopausal symptoms

- \* Dress lightly and in layers
- \* Avoid caffeine, alcohol, and spicy foods
- \* When a hot flush starts to come on, practice slow, deep breathing (about 6 breaths per minute)
- \* Consider seeing an acupuncturist for treatment
- \* Use relaxation techniques like yoga, tai chi, or meditation
- \* Consider soy-based foods
- \* Perform daily pelvic floor exercises to strengthen the muscles of your vagina and pelvis
- \* Use water-based lubricants during sexual intercourse
- \* Talk to other women, particularly positive women, about their experiences and strategies they have found useful
- \* Always check with your doctor about the safety of any natural products you may want to take to relieve the symptoms of menopause. Some can be harmful.



### Menopause and HIV

Some studies have shown that women with HIV undergo menopause at an earlier age but it is unclear if this is due to HIV or other lifestyle factors. Since successful HIV treatments have been used more widely, research suggests the experience of women with HIV does not differ much from that of uninfected women. Women with HIV do more commonly have irregularities in their menstrual cycle that may be mistaken for menopause.

Although the impacts of menopause on women with HIV are not fully understood, two key areas should be considered:

**Bone density** Some health care providers suggest menopause can occur earlier in women with HIV. Early menopause can accelerate the loss of bone density, which increases the risk of early osteoporosis. HIV antiretroviral drugs such as Tenofovir may also contribute to loss of bone density.

Regular weight-bearing exercise and a calcium-rich (but not high fat) diet protect bone health. It is also important not to smoke. If you are concerned about your bone density, see your doctor. (For more information, see *Osteoporosis*, page 49).

**Heart disease** Menopause does not cause heart disease, however, certain risk factors increase around the time of menopause. A decline in the natural hormone oestrogen may be one such factor. HIV treatments can increase fats in the blood, which may also increase risk of heart disease. The link between HIV treatments and menopausal factors increasing heart disease risk is not well understood.

Changing habits to decrease cardiovascular risk is an important way to increase your heart health: stopping smoking, improving your diet by reducing fat, and doing regular moderate exercise are the key factors here.

For more information on menopause and HIV, check out **Your Body Blueprint** online at [bit.ly/ybbmenopause](http://bit.ly/ybbmenopause).



## Menopause: Improving Your Health

- \* Protect bone health (diet, weight bearing exercise)
- \* Maintain and improve fitness
- \* Don't smoke
- \* Reduce alcohol consumption (more than a glass a day speeds bone loss)
- \* Adopt a healthy heart diet
- \* Supplement calcium
- \* Practice pelvic floor exercises regularly
- \* Check herbal/alternative supplements with your doctor for interactions with HIV drugs
- \* Use lubricants for sex

To learn more about HIV and menopause, check out this great video from Positively UK *I'm Taking Care of Me — Menopause* at [bit.ly/takecaremenopause](https://bit.ly/takecaremenopause). Although filmed in the UK, it provides insight into what a conversation about menopause between an HIV-positive woman and her doctor might look like.



## Hormone replacement therapy (HRT)

Whether or not to take hormone replacement therapy (HRT) can be a major decision for women experiencing unpleasant menopausal symptoms.

Until 2002, HRT was touted as the solution for many menopausal problems until a major study found that it increased the risk of breast cancer and heart disease. More recent studies suggest the 2002 study was flawed because of the age of the women who participated in it.

Current evidence suggests hormone replacement therapy is relatively safe for women in their 50s, and is also safe for women to continue into their 60s. It is less safe if women initiate HRT in their 60s. It is currently recommended that HRT is safest if taken as a relatively short-term treatment, for example, for a few years. Your doctor can provide more specific advice.

HRT can be taken with HIV treatments but you should ask your doctor if there are any interactions between HRT and any specific antiretroviral drugs you are taking. For example, the HIV drug Ritonavir can affect the dosage of HRT required.

HRT is certainly not necessary for many women but is definitely worth discussing with your doctor based on your specific circumstances and symptoms of menopause. Your doctor can discuss any risks or benefits. The decision whether or not to start HRT remains yours.



## Alternatives to HRT

**Many positive women report good nutrition** plays a key role in reducing menopausal problems.

**Low dose antidepressant medications** (lower than the doses used to treat depression) can be used to treat hot flushes. However, in some people, antidepressants can reduce sex drive or ability to orgasm.



**Some women increase their consumption of soy products** to treat menopausal problems. There is no research evidence proving the usefulness of these remedies, but in cultures where soy products are eaten in large quantities, menopausal problems are reported to be less severe.

**Importantly, if you have had breast cancer or have a higher than average risk of breast cancer (assessed through family history), educators suggest you should avoid high-dose supplements of soy products where the active ingredients may be processed in a way that fuels oestrogen-receptor positive breast cancer. This is an issue to discuss with your doctor. Cancer Australia provides more detailed information about **breast cancer** online at [bit.ly/austbreastcancer](http://bit.ly/austbreastcancer).**

**There is a lack of research regarding the effectiveness of herbal preparations** to help with menopausal symptoms and general enhancement of wellbeing but there are many preparations that have been reputed to be helpful, including black cohosh, dong qui, wild yam, evening primrose, ginseng, ginger, red clover and valerian for sleeping problems. Some of these products may be associated with other significant health problems, so check with your doctor before commencing.



## When considering natural therapies, bear in mind:

- \* Herbs can interact with HIV drugs — check with your doctor (St John's Wort and garlic, for example, have proven negative interactions).
- \* Discuss your circumstances, including use of any prescription drugs, with a good herbal practitioner.
- \* Contact your local AIDS Council or PLWHA group if you would like to see a complementary medicine practitioner but you are unsure who to see or need financial assistance.
- \* Set a budget and don't exceed it.



### Future research

Work is continuing to better understand the impact of menopause on HIV-positive women (and the impact of **HIV on menopausal women**). For example, an HIV Menopause Clinic has been established at St Miriam's Hospital in the U.S. (see [bit.ly/hivmenopauseclinic](http://bit.ly/hivmenopauseclinic)). Ongoing research will provide more knowledge about how women with HIV manage menopause and particular issues that arise.





**Many women with HIV are choosing to have children. Although you have HIV, it's possible for you to have a healthy pregnancy and it is likely your baby will be born healthy and HIV negative. Without antiretroviral treatment or other interventions, about one in four women with HIV transmit HIV to their infants. With effective interventions, the risk of transmission is very low.**

There are four recommended steps to reduce the risk of passing on HIV to your baby:

- \* Take HIV antiretroviral treatments during pregnancy
- \* Don't breastfeed
- \* Consider a caesarean delivery
- \* Treat your baby with HIV medications (usually for 4 to 6 weeks)

Generally speaking, the lower your viral load the less likely you are to transmit HIV to your baby. The aim of HIV treatment in pregnancy is to achieve an undetectable viral load. If this is not achieved, a Caesarean delivery will be offered and will usually be performed before you go into labour.

Notes on treatments:

- \* You must avoid becoming pregnant if you or your partner are taking the Hep C treatment Ribavirin or Rebetron, or if you have taken it during the previous six months.
- \* All women are advised to take folic acid when planning to conceive and early during pregnancy. If you are taking a drug called Cotrimoxazole (Septrin or Bactrim) because of an opportunistic infection or as prophylaxis, you may need to take an increased dose of folic acid.

## Planned pregnancy

A planned pregnancy can minimise stress, leaving you time to discuss issues with your partner and your doctor to optimise your health and to switch HIV drugs if necessary. It gives you the opportunity to commence health strategies before pregnancy e.g. taking folic acid. It also gives you a chance to sort out any maternity leave entitlements and to make financial arrangements.



## Unintended pregnancy

Life doesn't always go to plan and you may find yourself unexpectedly pregnant. Unplanned pregnancies can range from being an unpleasant shock to a welcome surprise. You have every right to consider all your options.

You may want a baby. You may definitely not want a baby. You may want a baby at some point in the future, but your current health, your work situation or your relationship status might make having a baby just too hard right now. It is your right to decide whether or not to continue with the pregnancy. Pregnancy counselling is available in all states and territories through abortion clinics, women's hospitals and GPs. If your concerns are related to HIV, it is important to talk to your doctor before making any decisions.



### Pregnancy check list

- \* Get screened for any genital infections and, if necessary, get treated. If you are sexually active, repeat the STI screening at 28 weeks.
- \* Learn about your treatment options and make a plan, including different options related to how well your viral load is controlled during your pregnancy.
- \* Learn about your delivery options and get a referral to a doctor with experience in HIV and pregnancy.
- \* Make a delivery plan with options related to how well your viral load is controlled during pregnancy.



## Conception for sero-discordant couples

In the past, getting pregnant through unprotected sex with an HIV-negative partner was not recommended but there is now clear evidence that being on HIV antiretroviral treatment and having an undetectable viral load can prevent the transmission of HIV. In certain situations, the risk of HIV transmission is low enough that it's considered safe for a couple to have unprotected sex in order for the woman to become pregnant. This is the case when:

- \* you are on antiretroviral treatment and have been taking treatment as prescribed and
- \* you have had an undetectable viral load for more than six months and
- \* neither you nor your partner has any sexually transmitted infections (STIs) and
- \* you only have unprotected sex on the days when you are ovulating (see *Knowing your fertile period*, page 73)

You can further decrease the risk of transmission if your HIV-negative partner takes specifically prescribed anti-HIV drugs around the days you have unprotected sex (pre-exposure prophylaxis or *PreP*, see page 17), or if required within 72 hours after unprotected sex (post-exposure prophylaxis (*PEP*), see page 18). You and your partner will need to discuss the options with your doctor to find the best course of action in your particular circumstances.



## Knowing your fertile period

You decrease HIV transmission risk and greatly increase your chances of conceiving if you have any unprotected sex on the days when you are most fertile. This is when you are ovulating and an egg is released from one of your ovaries.

Getting to know your body and your menstrual cycle will allow you to estimate and recognise when ovulation happens and increase your chances of getting pregnant.

If you note down the dates of the beginning of each period, you will work out the length of your menstrual cycle. The average length is 28 days, but many women have a cycle that is longer or shorter.

### **To get a rough idea of when you are ovulating:**

- \* Work out the date you are expecting your next period to begin
- \* Count backwards 16 days
- \* Your fertile time begins around that date, and should last for about five or six days

Alternatively, you may be able to identify your fertile time by noting the changes in your vaginal secretions. At the beginning and end of your cycle vaginal secretions are creamy, sticky and thick. As your body prepares for ovulation, they become wetter, thinner, clearer and stretchy like raw egg white. Your breasts may feel tender. You may also experience mild stomach pain and feel bloated. An ovulation kit (like a pregnancy home test) or an ovulation thermometer can be obtained from your pharmacy to help identify when you may be ovulating.



### **Other options**

There are other options if you want to avoid unprotected sex. These include self-insemination where the male partner ejaculates into a container and his sperm is then inserted into the vagina using a syringe. It remains important to use this process while you are ovulating.

If your partner is also HIV positive, you may wish to consider 'sperm washing'. Sperm washing requires the male partner to give a semen sample to a clinic. The sperm (which does not contain HIV) is then separated from the seminal fluid (which does contain HIV), before the sperm is injected into the woman's uterus. Sperm washing is expensive as it requires the involvement of a fertility clinic, and is only available through the public health system in Victoria. Sperm

washing is usually not necessary to prevent HIV infection during conception given the great advances in antiretroviral treatment effectiveness and the availability of *PrEP* (see page 17) and *PEP* (see page 18).

Many couples face problems conceiving regardless of issues associated with HIV infection. If you are concerned about you or your partner's fertility, you can be referred for specialist fertility advice and assistance. The first step is to talk to your GP.

**Having a Baby: A guide for HIV-positive women, men and their partners** is a practical resource developed by Pozhet, an organisation for heterosexual people living with HIV in New South Wales (available online at [bit.ly/hivhavingababy](http://bit.ly/hivhavingababy)). It explores many of the issues people with HIV consider when planning to have a baby. The resource was produced in 2013. It includes technical information on conception that remains correct, but be aware that recent trial results have increased confidence in the unlikelihood of HIV being transmitted to a negative partner if you have a stable undetectable viral load and your partner uses PrEP and/or PEP (see above). Talk to your doctor.





**Many women with HIV now experience pregnancy and have a child (or children) who does not have HIV.** Expert understanding of strategies to prevent transmission of HIV means the great majority of babies born to HIV-positive women in Australia are born without HIV infection.



## Antenatal care and HIV treatment

HIV generally does not affect pregnancy and pregnancy does not make HIV progress any faster. Being pregnant will not affect your *viral load* (see page 32). Your CD4 count may drop, however, this drop is usually temporary. Your *CD4 count*, (see page 33) will generally return to pre-pregnancy level soon after the baby is born. A drop in CD4 will become a concern if your CD4 count falls below 200 because you will be at risk of opportunistic infections, so additional medications may be needed.

Use of antiretroviral drugs is recommended for all HIV-positive pregnant women regardless of viral load. The decision whether to take antiretroviral treatments remains yours but it is important to know that reducing your viral load to the lowest possible level (ideally to an undetectable level) dramatically reduces the likelihood of your baby getting HIV. In fact, an HIV-positive woman's viral load is the single most important factor determining her baby's risk of HIV infection. Having a low viral load will also improve your immune status throughout your pregnancy.

Be aware that whether or not you take HIV antiretroviral treatments during your pregnancy and delivery, you will be required to have your baby treated with

antiretroviral therapies for a period of six weeks after delivery to improve his or her chance of being HIV negative (see *PEP*, page 18). In addition, it is still recommended that all women with HIV in Australia do not breast feed.

Your doctor should follow Australian Guidelines and closely monitor you for any treatment side-effects during pregnancy, particularly because some side-effects are more common in pregnant women.



**Your doctor should also regularly check for opportunistic infections** as part of your ongoing HIV care if you have a very low CD4 count. Treatment and prevention for most opportunistic infections during pregnancy is similar to that for non-pregnant adults. Only a few drugs are not recommended.



**Many women with HIV also have genital herpes.** HIV-positive mothers are far more likely to experience an outbreak of herpes during labour than negative mothers.

To reduce this risk, preventative treatment for herpes with Acyclovir is often recommended during pregnancy. Prevention and treatment of tuberculosis (TB) infections is also recommended if necessary during pregnancy. There are specific guidelines about treating HIV during pregnancy that your doctor will follow.



**Various pre-natal genetic tests are available to screen for abnormalities.** Tests include ultrasound screening, chorionic villus sampling and amniocentesis. Some of these tests (e.g. amniocentesis) are invasive so they increase risk

of HIV transmission from you to your baby, and therefore are not performed on women with HIV. You can discuss this issue in more detail with your Obstetrician.





## HIV & Hepatitis

**Hepatitis B:** Hepatitis B infection can impact your pregnancy so it is important to be tested. It is possible to pass on hepatitis B to your baby, however, whether or not you have hepatitis B, the National Immunisation Program provides free hepatitis B vaccine to all infants shortly after birth. If you choose to have your baby immunised the birth dose will be given as soon as the baby is stable, preferably within 24 hours of birth and up to seven days of age.

Your baby will need three more doses of the hepatitis B vaccine to be fully immunised. These will be given at two, four and six months of age in combination with your baby's other routine childhood immunisation so your baby will not receive any additional needles.

The hepatitis B vaccines used in Australia contain a genetically engineered part of the virus. It is not a live virus, so it is not possible to get hepatitis B from the vaccine.



**Hepatitis C:** Pregnancy does not affect *hepatitis C progression* (see page 61) unless you have cirrhosis of the liver.

Some Hep C treatments are not recommended during pregnancy as particular drugs (like Ribavirin) are associated with birth defects and foetal death. Talk through your Hep C treatment options with your doctor.

Conversely, if you have hepatitis C and are pregnant, HIV antiretroviral treatments are definitely recommended because HIV replication makes it more likely that you could transmit Hep C to your baby. Treating your HIV lessens the chance of both HIV and Hep C transmission. See [Women and Hepatitis](#) on the Hepatitis Australia website for more information at [bit.ly/womenandhepc](http://bit.ly/womenandhepc).

Risk of Hep C transmission is increased during delivery if your waters break more than six hours before delivery ('prolonged rupture of membranes'), which also increases the chance of HIV transmission. For this reason, pre-labour elective caesarean is often recommended. Any invasive monitoring procedures such as foetal scalp monitoring are also advised against.





# DELIVERY

LIVING WELL > HAVING CHILDREN > DELIVERY



**You and your doctor should discuss your options for delivery in the early stages of pregnancy and also review your viral load when you are around 36 weeks pregnant to discuss your best options for delivery at that time.**

There used to be a blanket recommendation that all women with HIV should have a caesarean delivery to minimise transmission risks. This is no longer the case, and caesarean delivery is usually only offered to women with a detectable viral load prior to delivery, so many women are now choosing to have vaginal deliveries. As women with HIV are more likely to go into labour slightly prematurely, if a caesarean (called a pre-labour elective caesarean) is needed it would be scheduled at 38 weeks rather than the standard 39 weeks. Having an emergency caesarean after your labour has started is not associated with the same reduction in transmission risk, so if complications are likely, scheduling the delivery prior to your due date is preferable.



## Caesarean delivery is recommended if

- \* You have a detectable viral load before delivery, especially if it is above 1,000
- \* You have detectable Hep C levels in your blood
- \* You are not taking antiretroviral therapy
- \* Delivery complications are anticipated, for example, multiple births, breech position, other obstetric issues of concern.





**Recent research has shown that caesareans may not add additional protective benefit** if you have maintained a low or undetectable viral load throughout pregnancy. A caesarean is major surgery and it can be at least six weeks

before your body recovers enough for you to do basic things (like drive a car). This can be particularly hard while looking after a tiny infant. Recovery time is a particular disadvantage for women who have other dependent children or other caring responsibilities. There is also the risk of post-operative infection and other standard risks associated with surgery. It is important to talk to your doctor and make plans before your delivery date.

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**It can be useful to have a small bag packed in advance** including things like pyjamas, toothbrush and importantly, your HIV antiretroviral treatments. Even as you begin the important process of having your baby, it is important to

remember to take your treatments on time. Make sure your partner or health care team understand your treatment schedule.

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**If you have not been on HIV antiretroviral treatment during your pregnancy** you will be advised to have

intravenous antiretroviral drugs during delivery. Most HIV transmission to infants takes place during the time of labour and delivery (rather than in the uterus in the early part of pregnancy).



# BREASTFEEDING

LIVING WELL > HAVING CHILDREN > BREASTFEEDING



**Recent research has found that if the mother is on HIV antiretroviral treatment and has an undetectable viral load, the risk of HIV transmission through breastmilk is low.** That means in developing countries without a safe water supply, the World Health Organization recommends that HIV-positive women breastfeed if they can access antiretroviral treatments.



## **Women with HIV in Australia are still strongly advised against breastfeeding**

because HIV is present in breastmilk and our clean water supply allows for bottle feeding. Research has shown that levels of the virus in breast milk fluctuate unpredictably, even varying from left breast to right breast. The speculated cause is that small infections or inflammations of the breast tissue and milk ducts are very common and these increase HIV replication and shedding. Also, some HIV treatments have a small amount of ingredients that may also pass into your breastmilk.



## **You do not have to disclose that you are HIV positive to justify not breastfeeding.**

Many women do not (or cannot) breastfeed, for a whole range of reasons. However not breastfeeding can cause some women considerable stress within their family and/or community. If you feel a sense of distress, grief or loss about not breastfeeding your baby, talking to a counsellor or to other positive women may help. If you are looking for a way to explain your actions and don't want to disclose your HIV

status to those who question your choices, you could consider offering the following explanations:

- \* My baby didn't latch well.
- \* I decided to bottle feed because it allows other people to take part in feeding and bonding with my baby.
- \* My doctor advised me to formula feed because the baby wasn't gaining weight.
- \* I wasn't making enough milk for my baby's needs.
- \* I decided not to breastfeed.
- \* I prefer bottle feeding.
- \* My baby doesn't breastfeed well.
- \* I needed to take a medication after delivery that made it not safe for my baby to breastfeed.

*This list is drawn from the Canadian CATIE website. For more information go to [bit.ly/hivbreastfeeding](http://bit.ly/hivbreastfeeding)*





# LOOKING AFTER YOURSELF POST-PARTUM

LIVING WELL > HAVING CHILDREN > LOOKING AFTER YOURSELF POST-PARTUM



**For a range of reasons, even the most resilient woman can become emotionally vulnerable after childbirth. For women with HIV, the overwhelming life changes brought about by a new baby can be compounded by anxiety about the future.** The joy of giving birth may also bring self-doubt, exhaustion, and guilt about any negative feelings you may have. If your delivery did not go as planned, you may feel some disappointment, pain or anger. The constant demands of an infant combined with your recovery from childbirth can be exhausting. You may have nagging fears that your child has HIV despite evidence to the contrary. That anxiety is very understandable, especially as your baby will need to continue to be tested for HIV until 18 months of age. Make sure you get your paediatrician and HIV doctor to make time to talk with you about your fears.



**Do not hesitate to ask for additional help from family and friends** but also from community agencies (both HIV support services and those set up for new mothers). Those agencies are there because it is common to need help at this time. Asking for help doesn't mean you are 'not coping' — it means you are trying to be the best mother you can be.



**One in seven women experience post-natal depression.** Research suggests that women who have previously been depressed are more likely to experience post-natal depression (although it is not always the case). If you have previously experienced depression it may be useful to let

your health care provider know so they can make sure you get support if necessary. Early identification and interventions to address post-natal depression can be very effective.

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**If you experience post-natal depression,** you may find that psychotherapy, cognitive-behavioural therapy or discussions with a support group help you regain your sense of balance. **PANDA (Post and Antenatal Depression Association)** has some very helpful factsheets at [www.panda.org.au](http://www.panda.org.au), and runs a phone Helpline on

1300 726 306. PANDA is keen to support any new parent struggling during pregnancy or after the birth of their baby, as well as their partner, family and friends. Some women also find antidepressant medication useful.

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**If your baby does have HIV, you will face some difficult decisions.** You have the right to be upset and to take your time. You also have the right to professional support. There are many agencies and support groups who are happy to work with you as you make decisions and plans for the future. See *Keeping Well* (page 88) for some more tips on staying healthy and happy.





## **Does my baby have to take HIV treatments?**

Whether or not you have taken any antiretroviral treatments during pregnancy, your baby will be treated with HIV antiretroviral treatments for a period of 4 to 6 weeks to improve his or her chance of being HIV negative.

This treatment is called post-exposure prophylaxis (commonly known as PEP). PEP can prevent HIV infection by 'mopping up' infectious HIV particles to which your baby may have been exposed. It is not fail-safe but it increases the likelihood of avoiding infection. Your baby may experience side-effects but many babies do not.



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

Your baby will be given a simple blood test after birth (a PCR test) to look for the presence of HIV in their blood. Your baby will then be tested regularly for the virus over the next six months. Babies are generally considered HIV negative at three months of age if all of the tests have been negative and the baby has not been breastfed. Testing continues until your baby is about 18 months old to be sure the baby is not infected.



## What if my baby has HIV?

It can be very difficult to learn that your child has HIV. You (and your partner if you have one) will probably need a lot of support and may benefit from referral to professional services such as a counsellor or other support groups to help you cope.

Although it can be distressing, early diagnosis means you can begin to provide your child treatment and care to help them live a long healthy life. HIV antiretroviral treatment is very effective in children, making HIV a long-term manageable condition.



### **Medical care for children with HIV is very specialised.**

You will be referred to a clinic that specialises in paediatric HIV care. You can expect staff to be friendly, welcoming and non-judgemental. They will make sure you have a team of people to support you and your child as they grow, including doctors, nurses, pharmacists and also psychologists and social workers if that is useful. If you do not live near a specialist clinic, they will arrange to 'share care' with a doctor who lives closer to home.



### **You will need to make decisions about your child's treatment after discussions with your paediatrician.**

There is some debate about the best time to begin antiretroviral treatment for babies – whether to start straight away or to wait until your baby shows immune decline or symptoms or markers that suggest he or she is at risk of HIV progression. Children under one are at risk of progression to AIDS without treatment. Your paediatrician and your HIV doctor should talk with you about all available evidence and how this applies to your baby. If your baby doesn't commence HIV treatment immediately, they will need to take drugs to prevent common infections.



**HIV can be a lot to deal with. It is not uncommon for people to experience unhappiness, distress, anxiety or depression at some point. Sometimes medication can be useful or necessary, but fortunately there are a lot of other things you can do to look after your mental health and wellbeing.**

You may experience periods of fatigue or constant tiredness. The cause could be psychological or physical. Stress and depression are common causes of fatigue, however, constant tiredness may be related to your HIV or other illnesses, diet, or lack of sleep or exercise. If you are feeling more than usually fatigued or the onset of tiredness is sudden or extreme, talk to your doctor.

It's important to be proactive. Keep doing things you enjoy — things which make you feel good about yourself. Take some time to really look after yourself.



## **THINK:** **Am I eating well?**

It is important to eat well and enjoy food to help your immune system stay healthy. This means eating a balanced diet that includes fresh fruit, vegetables, grains and protein. Avoid low calorie diets or 'fad' diets that are excessively restrictive.

Women with HIV may need to eat a diet higher in protein than HIV-negative women in order to conserve lean muscle mass. Some women need specific help to maintain normal blood lipids and sugar. You may want to talk with a dietitian to help manage your specific nutritional needs. A dietitian may be able

to recommend ways to manage stress, fatigue, diarrhoea, nausea, or changes in body shape or weight loss.

**If you are thinking about taking extra vitamins** or nutritional supplements, talk to your doctor or HIV specialist to ensure they won't interact with any other medication or medical conditions.

Nutrition is really important to both your physical and mental health but food can play a more important role than that. You might need to eat on the go now and then but taking some time to sit down and enjoy a meal can give you a moment to catch your breath. Sitting down and eating a meal with someone you like can also feel really good.



### **Am I sleeping enough?**

Sleep is fundamental to both physical and mental health. Not getting enough sleep can trigger emotional and mental health issues. Conversely, too much sleep can make you feel tired and reduce motivation to do things. Talk to your

GP about different options to address sleeping issues. There are many possibilities aside from medication, including specific breathing and relaxation techniques.



### **Am I doing enough exercise?**

Regular physical exercise will keep you fit and it can also help you manage stress, improve your mood, increase your energy levels, decrease symptoms of anxiety and mild depression, maintain your lean muscle mass and can help

you sleep soundly at night. A daily walk in the fresh air can help you feel and sleep better. Exercising with someone else can make it more enjoyable as well as increasing your social contact. Exercise is good but enjoyable exercise is really good! And if you enjoy it, you're more likely to keep doing it.



## Am I dealing with work?

Work has the potential to affect your health and wellbeing in both positive and negative ways. Work can be boring, stressful or just an economic necessity. If you're lucky, it can also be interesting, fulfilling, and a great reason to get up in the morning. If you have a choice whether to work or not (or whether to work full-time or part-time) it is a good idea to think about the role of work in your life before you make any decisions.



### **Your ability to work may be compromised by your**

**health**, and it can be difficult to balance the demands of work and family/personal life. Perhaps you are experiencing periods in which you are unwell or need

regular time off for medical care. Taking antiretroviral treatments can also be an issue impacting work, particularly if you are experiencing side-effects (such as diarrhoea). Take some time to make sense of your options. You may want to talk it through with your partner, your doctor, a counsellor or peer support worker.



### **If you feel you need to have time off, think about how you will talk to your employer**

before you ask to see them. Remember, you do not have to tell them you have HIV. You may want to tell them or you may prefer to explain

that you have a medical condition. You may find it easier just to discuss the symptoms you are managing.

It is useful to remember that the nature of the workforce is changing all the time. You may find there are opportunities for part-time work or work with flexible working hours.

Some women with HIV who are not working find it rewarding to get involved in activities such as volunteer work or study in order to keep busy and to develop or maintain skills and social networks.



## **Am I drinking too much or taking drugs that are doing me no good?**

Drinking too much alcohol and excessive use of recreational drugs increase emotional and mental health issues, as well as damaging your physical health and interfering with your HIV antiretroviral treatment. Think about your alcohol and drug use and whether they're really helpful (beyond the moment).

A little alcohol can help you relax, feel good and increase your appetite. A glass of wine or beer or a single measure of spirits should do you no harm (unless you are pregnant). Heavy drinking increases your body's requirements for certain nutrients, such as vitamin B6, and places a strain on your liver. A healthy liver is needed to process HIV antiretroviral treatments. Some women on treatments find they become increasingly likely to experience a 'hung over' feeling following even small amounts of alcohol.



## **Some recreational drugs also interact with HIV antiretroviral treatments**

so it's important to talk honestly to your doctor about any drugs that you use, whether regularly or occasionally. Using recreational drugs while you are on antiretroviral treatment can be harmful because:

- \* each person's body has a different reaction
- \* your immune system may be damaged through long-term use of some drugs
- \* some recreational drugs lower the levels of HIV treatments in your blood so less of the dose is absorbed

- \* some HIV treatments raise the blood levels of amphetamine-based drugs to possibly dangerous levels.

If you do inject recreational drugs, do not share needles or injecting equipment — even with other HIV-positive people. Use your own injecting equipment or use a new fit every time. This is important to reduce the risk of infection with HIV, hepatitis C or other blood borne viruses.

If you use drugs, you may want to reduce your use or stop altogether. You can seek advice and support through your doctor, community health service, or HIV support group.



**Methadone and other opiate substitute therapies may interact with HIV antiretroviral treatment.**

Negative drug interactions can be managed by adjusting the dosage of methadone and/or HIV medications. Talk to your doctor as soon as possible so they can work out optimal therapy for you. Do not stop taking HIV treatment without talking to your doctor.

For information about interactions between HIV antiretroviral drugs and recreational drugs, see VAC's **Touchbase** site at [touchbase.org.au](http://touchbase.org.au). It lists more than 20 drug types and their interaction with HIV and HIV treatments (under the 'Living with HIV' section heading). Alternatively, check out ACON's **Stimcheck** site at [www.stimcheck.org.au](http://www.stimcheck.org.au) or NAPWA's **Get Smart with Substances** webpage at [bit.ly/napwhasubstances](http://bit.ly/napwhasubstances).



**Should I be smoking?**

If you are HIV positive, stopping smoking is one of the most important steps you can take to improve your health. Smoking affects blood supply to your heart and other parts of your body. It reduces the amount of oxygen in your

blood and damages blood vessel walls. Smoking increases your risk of heart attack, stroke and peripheral artery disease (which can lead to gangrene and limb amputation) as well as lung disease (emphysema). It also increases the risk of many types of cancer and of osteoporosis.



**Smoking is particularly damaging for people with HIV because it will further weaken your immune system.**

Stopping smoking improves your health within hours, with significant improvement in the following weeks and months. Your risk of cardiovascular disease will decrease rapidly within a year, and within two to six years it will be similar to that of a non-smoker. The risk of having a stroke begins to fall soon after quitting smoking, with most benefit experienced within two to five years.

**Giving up smoking is challenging. Remember:**

- \* Not everyone is successful the first time. It may take several attempts before you are smoke free. Each attempt brings you closer to your goal.
- \* There are many strategies (including acupuncture and hypnosis) to help you quit and you may decide to use more than one. Get advice and support from **Quitline** (Tel: 13 78 48).
- \* The more support and help you receive the more likely you will succeed.
- \* Talk to your GP and your friends for emotional support. Having good people around you can only increase your chances of giving up.
- \* There are now medications available to help you stop smoking (NRT — nicotine replacement therapy). Talk to your doctor about whether these are suitable for you.
- \* Most people will need to try to quit smoking a number of times. It is important you don't stop trying. If you are determined, you will eventually succeed.

For more information, see AFAO's **Giving Up Smoking** factsheet (online at [bit.ly/afaosmoking](http://bit.ly/afaosmoking)).





## Is my relationship doing me harm?

Healthy relationships with friends and family are a major source of support for many women living with HIV.

Unfortunately, not all women have partners who are respectful and supportive. Some women, including women with HIV, experience domestic violence. Domestic violence is about power and control. There are many ways it can be expressed: physical violence or social and emotional control.

Whether or not you have HIV, no one has the right to be violent or abusive towards you. It can be hard to know what to do about abuse while you are caught up in the many complexities of a relationship. Fortunately, there are people out there who can help. If you would like to speak to someone, call the National Sexual Assault, Family & Domestic Violence Counselling Line on 1800 RESPECT (1800 737 732). It is a free telephone and online confidential service for anyone who is experiencing or has experienced domestic violence or sexual assault. It is available 24 hours a day, 7 days a week.



## Is HIV affecting me more as I get older?

Thanks to improvements in HIV antiretroviral treatments, people with HIV can now generally expect to live long lives. Consequently, the number of people with HIV who are entering their 50s, 60s and 70s is growing. With longer life expectancy, older women with HIV are beginning to experience many of the illnesses and conditions that come with ageing including changes in physical and cognitive abilities and managing more than one chronic disease.

There is evidence that living long term with HIV can accelerate the aging process in some people. As a person living with HIV it can be very difficult to untangle whether symptoms are related to HIV or not. Regardless, it is important to talk to your healthcare practitioner if you are concerned about any aspects of your physical or mental health.



**While HIV treatments have greatly decreased the likelihood of women with HIV developing AIDS-defining illnesses, there are a number of non-AIDS conditions that are more common in older women with HIV than their HIV-negative counterparts.** These conditions include cardiovascular disease, lung disease, certain cancers, and hepatitis B and C.

AIDS-related dementia (once common) is now rare, however some people with HIV develop HIV-Associated Neurocognitive Disorder (HAND). HAND may include reduction in attention, language, motor skills, memory, and other aspects of cognitive function. People may also experience depression or psychological distress.



**Some people in the general community become more isolated as they age, including people with HIV.** It is important to stay connected and seek support if you are experiencing any loneliness or depression. Given the 'greying' of the HIV-positive population, some people have begun looking into retirement plans, including nursing homes or aged care facilities. This is an area the HIV sector is currently working on to ensure facilities are able to offer appropriate care, free from any discrimination. If you would like to speak to someone about your options, contact your local PLHIV organisation.

With or without HIV, your long term health is strongly influenced by how well you look after yourself in daily life. Staying active and socially connected, eating well, not smoking, and moderating consumption of alcohol can significantly improve your long term health.



## Should I travel?

Many people with HIV travel whether for work, study or pleasure. To avoid problems, it is often best not to disclose your HIV status unnecessarily while travelling to other travellers, work colleagues, immigration or customs. HIV continues to be heavily stigmatised in many places, and frankly, your HIV status is none of their business.

If you're planning on travelling overseas, be aware that some countries continue to restrict entry and residence to people with HIV, although many do not. The [Global Database on HIV-specific Travel and Residence Restrictions](http://www.hivtravel.org) provides up to date information for all countries in the world at [www.hivtravel.org](http://www.hivtravel.org). If you're planning a holiday, refer to the section on 'Countries with restrictions for short term stays (<90 days)'. If you're hoping to stay longer, refer to the section on 'Countries with restrictions for long term stays (>90days)'. If you remain uncertain about your legal rights, you can contact the country's embassy to ask them directly.



Usually, bringing (importing) HIV antiretroviral treatments for your personal use will not pose a problem but if you are worried you may want to check each country's specific customs regulations by ringing their embassy before you go. If you are using a drug substitution treatment (such as methadone or buprenorphine) you should definitely check country regulations as some countries consider substitution treatment to be illicit drug use.

When travelling, keep your medication in its original packaging (labelled with your name) and also your doctor's prescription or a letter (to show the medication was prescribed) but make sure the prescription does not mention HIV. It is usually best to carry your medication in your hand luggage as checked luggage can be lost or delayed. It is also useful to take some extra medication with you in case your return is delayed for some reason. Looking for prescription medicine in another country can be time consuming and

expensive, and your medication may not be available. Your doctor can also provide a letter (not mentioning HIV) to say you are carrying prescribed medication for personal use.

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Many people take their antiretroviral treatment at the same time every day which can be tricky when crossing time zones. If you are on a complicated schedule or if you are concerned about managing the time change, ask for advice from your doctor. If you are concerned about how your health will be while travelling, you may want to find out where the local HIV clinic is or get the address of a specialist physician before you travel.

It is very important to have health insurance when travelling, particularly if you are travelling with an existing medical condition. For advice on finding a travel insurance company that offers affordable insurance for people with HIV, contact your local *PLHIV organisation* (see page 102).

Last word of advice .... Have a great trip!



## **Do I need some help?**

Are things starting to pile up? It is important to deal with issues as soon as you can. Whether it's about work, relationships, family, money, housing, etc., avoiding them can increase your levels of stress while things linger 'in the back of your mind'. Also, many issues don't resolve themselves and not addressing the problem early on can actually make things worse.

Sometimes life can seem overwhelming, or perhaps just one issue has got the better of you. Asking for help is not a sign of weakness. Asking for help means you're taking action to think things through and sort things out. Asking for some expert help is increasingly common. There are a lot of agencies that are set up specifically for this purpose.

Remember:

- \* Be kind to yourself
- \* Don't judge yourself harshly
- \* Don't bottle up worries or concerns
- \* Don't isolate yourself
- \* Join in with activities
- \* Try something new
- \* Ask for help when you need it

For more tips on keeping well, check out the [Top Tips](http://www.hivtips.org.au) website (online at [www.hivtips.org.au](http://www.hivtips.org.au)), Your Body Blueprint's [Staying Social](http://www.yourbodyblueprint.org.au) page at [www.yourbodyblueprint.org.au](http://www.yourbodyblueprint.org.au), or visit Pozhet's [Living Well](http://bit.ly/pozhetslivingwell) page (online at [bit.ly/pozhetslivingwell](http://bit.ly/pozhetslivingwell)).



## What is normal?

There are many things you can do to increase or maintain your mental health, including many of the things listed in *Enjoying Life* section: staying active and socially connected, eating well, not smoking, and moderating consumption of alcohol or other drugs (see page 88).

Life has lots of ups and downs and it is normal to feel sad or worried when things don't go well but if you are experiencing negative or damaging feelings that are intense or last for a long time or if you are having trouble getting things done, it may be useful to talk to someone. There is nothing weak or overly dramatic about seeking support. Remember, many people who experience depression, anxiety or other mental health issues find appropriate treatment either greatly reduces their symptoms or they completely recover.

**If at any time you feel you are in crisis, contact **Lifeline** on their 24 hour crisis and support line 13 11 14. You do not need to feel unsure or embarrassed to access their service, which answers almost 2000 calls a day.**



## Depression

There are many and multiple causes of depression including major stress, drug and alcohol use, and concurrent medical conditions. Women are more likely to experience depression than men. Often a combination of

factors contribute to a person developing depression. Living with HIV infection may or may not be one of them.

While you may not be able to identify the cause of depression, it is important to recognise the **signs and symptoms** and **seek help**. There are many effective treatments including medical and psychological treatments. There are also many things you can do to work towards recovery and staying well. It's important to find something that works for you. Remember depression is very common and for many people who seek help, it is a short term problem.

For more information on depression and its treatment see **Beyond Blue's** website at [www.beyondblue.org.au](http://www.beyondblue.org.au) or contact **Beyond Blue** or your local *PLHIV organisation* (see page 102).



## Anxiety

A combination of factors can lead to a person developing anxiety, including experiencing difficult emotional events, physical illness or long term substance use. People who tend to be 'perfectionists' are more likely to develop anxiety. Women are more likely to experience anxiety than men.

Anxiety is a normal emotion that affects most people from to time. However, if your anxiety is out of proportion to your situation or if it persists, it may be useful to seek professional help. For more information on anxiety and its treatment see **Beyond Blue's** website at [www.beyondblue.org.au](http://www.beyondblue.org.au) or contact **Beyond Blue** or your local *PLHIV organisation* (see page 102).



## Grief and Loss

Grief is a natural response to loss, including loss of a loved one or relationship, loss of a career or loss of a way of life. Some people experience a sense of grief and loss after being diagnosed with HIV or dealing with the impact of HIV on their lives.

Although HIV antiretroviral treatments now offer most people a long healthy life, there may be things you can no longer do for a whole range of reasons including physical or psychological reasons, because you are time-poor managing medical appointments, etc. Different people react differently to the idea their lives have changed, and of course the amount of change will be different for everyone.

Everyone experiences grief differently. It may make you feel sad, angry, anxious, regretful, relieved, overwhelmed, irritable or numb. It may also affect your behaviour, sense of identity and your relationships with others.

Grief can take some time to work through. If you feel you are struggling, it is important to ask for help. Contact **Beyond Blue** or your local *PLHIV organisation* (see page 102).







# GETTING SUPPORT

LIVING WELL > GETTING SUPPORT



## HIV AND POSITIVE ORGANISATIONS

### Australian Capital Territory

#### AIDS Action Council of the ACT (AACACT)

Advice, mental health and social support services, financial assistance, legal advocacy. Tel: (02) 6257 2855

[aidsaction.org.au](http://aidsaction.org.au)

#### Positive Living ACT

Social events for people with HIV, drop-in centre, support, counselling, dietician's clinic, financial assistance, referral. **Tel:** (02) 6257 2855

<http://napwha.org.au/organisation/positive-living-act>

### New South Wales

#### ACON

HIV prevention, health promotion, advocacy, care and support.

**Tel:** (02) 9206 2000 **Free call:** 1800 063 060 [www.acon.org.au](http://www.acon.org.au)

**ACON Hunter Office** Newcastle Tel: (02) 4962 7700

**ACON Mid-North Coast Office** Port Macquarie Tel: (02) 6584 0943

**ACON Coffs Harbour** Tel: (02) 6651 6017

**ACON Northern Rivers Office** Lismore Tel: (02) 6622 1555

#### Positive Life NSW

Advocacy, publications, services, speakers' bureau, social marketing, education and peer support. **Tel:** (02) 9206 2177 **Free call:** 1800 245 677

[www.positivelife.org.au](http://www.positivelife.org.au)

### **HIV Positive Heterosexuals (PozHets)**

Statewide service providing education and support for heterosexuals living with HIV and their families. **Tel:** (02) 9395 0444 **Free call: 1800 812 404**  
[pozhet.org.au](http://pozhet.org.au)

### **Multicultural HIV and Hepatitis Service**

Bilingual/bicultural support and advocacy for people from non-English speaking backgrounds. **Tel:** (02) 9515 1234 **Free call: 1800 108 098 (Rural NSW callers)**  
[www.mhahs.org.au](http://www.mhahs.org.au)

### **Ankali**

Volunteers provide one-to-one emotional support for people living with HIV, their partners, families and friends. Referrals into counselling and professional support. **Tel:** (02) 9332 9742 [thealbioncentre.org.au](http://thealbioncentre.org.au)

### **Bobby Goldsmith Foundation (BGF)**

Financial help, supported housing, financial counselling, help with essential bills, loans of essential appliances. **Tel:** (02) 9283 8666 **Free call: 1800 651 010**  
[www.bgf.org.au](http://www.bgf.org.au)

## **Northern Territory**

### **Northern Territory AIDS and Hepatitis Council (NTAHC)**

Education, advocacy & support. **Tel:** (08) 8944 7777 [www.ntahc.org.au](http://www.ntahc.org.au)  
**NTAHC Alice Springs** Tel: (08) 8953 3172

### **People Living with HIV/AIDS NT**

**Tel:** (08) 8944 7777

## **Queensland**

### **Queensland AIDS Council (QuAC)**

HIV education, advocacy & support.

**Tel:** (07) 3017 1777 **Free call: 1800 177 434** [www.quac.org.au](http://www.quac.org.au)

**QuAC Cairns** Tel: (07) 4041 5451 Free call: 1800 884 401

## Queensland Positive People (QPP)

Peer support, advocacy, treatments and health promotion information.

**Tel:** (07) 3013 5555 **Free call: 1800 636 241** [www.qpp.net.au](http://www.qpp.net.au)

**QPP Cairns** Tel: (07) 3013 5526

## Ethnic Communities Council of Qld

HIV education and support services. **Tel:** (07) 3844 9166 [www.eccq.com.au](http://www.eccq.com.au)

## South Australia

### SA Mobilisation + Empowerment for Sexual Health (SAMESH)

Support, education and counselling. **Tel:** (08) 7099 5300 [www.samesh.org.au](http://www.samesh.org.au)

### Positive Life SA

Advocacy and referrals. **Tel:** (08) 8293 3700 [www.positivelifesa.org.au](http://www.positivelifesa.org.au)

### Cheltenham Place/Centacare

Individualised support program for PLHIV, including home based respite support. **Tel:** (08) 8272 8799 [www.rasa.org.au](http://www.rasa.org.au)

### Personal Education and Community Empowerment (PEACE) Multicultural Services

HIV support, information and referrals. **Tel:** (08) 8245 8100

## Tasmania

### Tasmanian Council on AIDS Hepatitis & Related Diseases (TasCAHRD)

Care and support, advocacy, financial support, housing assistance, education.

**Tel:** (03) 6234 1242 **Free call: 1800 675 589** [www.tascahrd.org.au](http://www.tascahrd.org.au)

## Victoria

### Victorian AIDS Council (VAC)

Care and support, counselling, medical services, education, advocacy.

**Tel:** (03) 9865 6700 [www.vac.org.au](http://www.vac.org.au)

### **Living Positive Victoria (LPV)**

Support, advocacy, treatments. **Tel:** (03) 9863 8733

[www.livingpositivevictoria.org.au](http://www.livingpositivevictoria.org.au)

### **Positive Living Centre (PLC)**

Community centre, massage, naturopathy, relaxation, yoga, food pantry, peer support, financial assistance, legal centre, self-development and other activities.

**Tel:** (03) 9863 0444 **Free call: 1800 622 795 (Rural Victorian callers)**

### **The Centre Clinic**

Community health service for positive people. **Tel:** (03) 9525 5866

### **Positive Women – Victoria**

Support and information for positive women and their families and friends.

**Tel:** (03) 9863 8747 [www.positivewomen.org.au](http://www.positivewomen.org.au)

### **Straight Arrows**

Support, services for HIV-positive heterosexual men and women and their families. **Tel:** (03) 9863 9414 [www.straightarrows.org.au](http://www.straightarrows.org.au)

### **Multicultural Health and Support Service**

HIV education, advocacy & support. **Tel:** (03) 9342 9711 [www.ceh.org.au](http://www.ceh.org.au)

### **Alfred Hospital – HIV CALD Service**

HIV education & support to PLHIV. **Tel:** (03) 9076 3942

[www.alfredhealth.org.au/hivaidsservice](http://www.alfredhealth.org.au/hivaidsservice)

### **AIDS Housing Action Group**

State-wide confidential housing service. Free call: 1800 674 311

## **Western Australia**

### **Western Australian AIDS Council (WAAC)**

Education, advocacy and support. **Tel:** (08) 9482 0000 [www.waaid.com](http://www.waaid.com)



## **NATIONAL HIV ORGANISATIONS**

### **Australian Federation of AIDS Organisations (AFAO)**

National federation for the HIV community response.

AFAO's members are the AIDS Councils in each state and territory; the National Association of People with HIV

Australia (NAPWHA); the Australian Injecting & Illicit Drug Users League (AIVL); the Anwernekenhe National HIV Alliance (ANA); and Scarlet Alliance, Australian Sex Workers Association. **Tel:** (02) 9557 9399 [www.afao.org.au](http://www.afao.org.au)

### **National Association of People with HIV Australia (NAPWHA)**

National peak organisation representing people living with HIV, providing leadership in advocacy, policy, education and prevention.

**Tel:** (02) 8568 0300 **Freecall 1800 259 666** [www.napwha.org.au](http://www.napwha.org.au)

### **Anwernekenhe National HIV Alliance (ANA)**

Aboriginal and Torres Strait Islander community-based organisation providing national leadership in promoting and advocating for culturally appropriate services in HIV education, prevention, treatments, care and support for Aboriginal and Torres Strait Islander people. [info@ana.org.au](mailto:info@ana.org.au)  
[www.ana.org.au](http://www.ana.org.au)

### **The Institute of Many (TIM)**

Peer-run group for HIV-positive people offering online membership through which people can make friends, talk, share knowledge and skills through a confidential group on Facebook. TIM also brings positive people and their allies together at casual events in Sydney and Melbourne. For further information go to [www.theinstituteofmany.org](http://www.theinstituteofmany.org)

TIM Women is a confidential digital gathering space for HIV-positive women on Facebook. Women can ask each other questions, share stories, build resilience,

and help build and maintain community. For further information go to [www.theinstituteofmany.org](http://www.theinstituteofmany.org).

### **National Network of Women Living with HIV**

National peak organisation representing women living with HIV, providing leadership in advocacy, policy and education. For further information contact NAPWHA. **Tel:** (02) 8568 0300 [admin@napwha.org.au](mailto:admin@napwha.org.au)

### **Australian Injecting & Illicit Drug Users League (AIVL)**

National organisation representing people who use or have used illicit drugs, and the peak body for state and territory peer-based drug user organisations. **Tel:** (02) 6279 1600 [www.aivl.org.au](http://www.aivl.org.au)

### **Scarlet Alliance, Australian Sex Workers Association**

National organisation representing current and former sex workers, and the peak body for state and territory peer-based sex worker organisations. **Tel:** (02) 9690 0551 [www.scarletalliance.org.au](http://www.scarletalliance.org.au)



## **DRUG USERS**

### **Canberra Alliance for Harm Minimisation and Advocacy (CAHMA)**

Education, practical support, information and advocacy for users of illicit drugs. **Tel:** (02) 6279 1670 [www.cahma.org.au](http://www.cahma.org.au)

### **New South Wales Users & AIDS Association (NUAA)**

Education, practical support, information and advocacy to users of illicit drugs. **Tel:** (02) 8354 7300 **Free call: 1800 644 413 (Rural NSW callers)** [www.nuaa.org.au](http://www.nuaa.org.au)

### **Queensland Injectors Health Network (QIHN)**

Education, practical support, information and advocacy for users of illicit drugs.

**QuiHN Brisbane** Tel: (07) 3620 8111

**Free call: 1800 172 076 (Outside Brisbane)**

**QuiHN Gold Coast** Tel: (07) 5520 7900

**QuiHN Sunshine Coast** Tel: (07) 5443 9576

**QuiHN Cairns** Tel: (07) 4032 1463

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

### **Harm Reduction Victoria (HRVic)**

Education, practical support, information and advocacy for users of illicit drugs.

**Tel:** (03) 9329 1500 [hrvic.org.au](http://hrvic.org.au)

### **Western Australia Substance Users Association (WASUA)**

Education, practical support, information and advocacy for users of illicit drugs.

**Tel:** (08) 9321 2877 [www.wasua.com.au](http://www.wasua.com.au)



## **SEX WORKERS**

### **Sex Worker Outreach Project (SWOP) ACT**

Information and support for people who engage in sex work. **Tel:** (02) 6247 3443

[aidsaction.org.au/services-programs/swop](http://aidsaction.org.au/services-programs/swop)

### **Sex Worker Outreach Project (SWOP)**

Information and support for people who engage in sex work.

**Tel:** (02) 9206 2166 **Free call: 1800 622 902** [www.swop.org.au](http://www.swop.org.au)

### **Respect**

Information and support for people who engage in sex work.

**Tel:** (07) 3835 1111 [www.respectqld.org.au](http://www.respectqld.org.au)

### **South Australian Sex Industry Network (SIN)**

Information and support for people who engage in sex work.

**Tel:** (08) 8351 7626 [www.sin.org.au](http://www.sin.org.au)

### **Resourcing Health & Education (RhED)**

Information and support for people who engage in sex work.

**Freecall: 1800 458 752 (Ext. 3)** [sexworker.org.au](http://sexworker.org.au)

### **Magenta Sex Worker Support Project WA**

Information and support for people who engage in sex work.

**Tel:** (08) 9328 1387 [www.magenta.org.au](http://www.magenta.org.au)



## **FAMILY PLANNING ORGANISATIONS**

### **Australian Capital Territory**

**Sexual Health and Family Planning ACT (SHFPACT)**

**Tel:** (02) 6247 3077 [www.shfpact.org.au](http://www.shfpact.org.au)

## **New South Wales**

### **Family Planning NSW**

**Tel:** (02) 8752 4300 [www.fpnsw.org.au](http://www.fpnsw.org.au)

## **Northern Territory**

### **Family Planning NT**

**Tel:** (08) 8948 0144 [www.fpwnt.com.au](http://www.fpwnt.com.au)

## **Queensland**

### **True: Relationships & Reproductive Health**

**Tel:** (07) 3250 0240 [www.true.org.au](http://www.true.org.au)

## **South Australia**

### **SHine SA**

**Tel:** 1300 794 584 [www.shinesa.org.au](http://www.shinesa.org.au)



## Tasmania

### Family Planning Tasmania

**Glenorchy** Tel: (03) 6273 9117

**Launceston** Tel: (03) 6343 4566

**Upper Burnie** Tel: (03) 6431 7692

[www.fpt.asn.au](http://www.fpt.asn.au)

## Victoria

### Family Planning Victoria

**Tel:** (03) 9257 0100 **Free call:** 1800 013 952 [www.fpv.org.au](http://www.fpv.org.au)

### Family Planning Victoria Action Centre (for people under 25)

**Tel:** (03) 9660 4700 **Free call:** 1800 013 952

[www.fpv.org.au/health-care/action-centre](http://www.fpv.org.au/health-care/action-centre)

## Western Australia

### Sexual and Reproductive Health Western Australia (SRHWA)

**Tel:** (08) 9227 6177 [www.srhwa.com.au](http://www.srhwa.com.au)

### Quarry Health Centre for Under 25's

**Tel:** (08) 9227 1444 [www.quarryhealthcentre.org.au](http://www.quarryhealthcentre.org.au)



## LEGAL ADVICE

### HIV/AIDS Legal Centre (HALC)

**Tel:** (02) 9206 2060 **Free call:** 1800 063 060 [halc.org.au](http://halc.org.au)

### National Association of Community Legal Centres

*\* can refer to community legal centre services* **Tel:** (02) 9264 9595  
[www.nacclc.org.au](http://www.nacclc.org.au)

### **Australian Human Rights Commission**

**Tel:** (02) 9284 9600 National Information Service: 1300 656 419

[www.humanrights.gov.au](http://www.humanrights.gov.au)

### **ACT Human Rights Commission**

**Tel:** (02) 6205 2222 [hrc.act.gov.au](http://hrc.act.gov.au)

### **Anti-Discrimination Board of New South Wales**

**Free call: 1800 670 812** [www.antidiscrimination.justice.nsw.gov.au](http://www.antidiscrimination.justice.nsw.gov.au)

### **Northern Territory Anti-Discrimination Commission**

**Tel:** (08) 8999 1444 **Free call: 1800 813 846** [www.nt.gov.au/justice/adcc](http://www.nt.gov.au/justice/adcc)

### **Anti-Discrimination Commission of Queensland**

**Tel:** (07) 3247 0900 **Free call: 1300 130 670** [www.adcq.qld.gov.au](http://www.adcq.qld.gov.au)

### **South Australia Equal Opportunity Commission**

**Tel:** (08) 8207 1977 **Toll free: 1800 188 163 (Rural SA callers)**

[www.eoc.sa.gov.au](http://www.eoc.sa.gov.au)

### **Equal Opportunity Tasmania**

**Tel:** (03) 6165 7515 **Statewide Local Call: 1300 305 062**

[www.equalopportunity.tas.gov.au](http://www.equalopportunity.tas.gov.au)

### **Victorian Equal Opportunity and Human Rights Commission**

**Tel:** 1300 891 848 [www.humanrightscommission.vic.gov.au](http://www.humanrightscommission.vic.gov.au)

### **Equal Opportunity Commission Western Australia**

**Tel:** (08) 9216 3900 **Free call: 1800 198 149** [www.eoc.wa.gov.au](http://www.eoc.wa.gov.au)



## HEALTH SERVICES & SUPPORT

### Beyondblue

Mental health support and advice. **Tel: 1300 22 4636**

[www.beyondblue.org.au](http://www.beyondblue.org.au)

### Hepatitis Australia

Leadership and advocacy on hepatitis. **Tel: (02) 6232 4257**

**Hep info Line: 1300 437 222 (1300 HEP ABC)** [www.hepatitisaustralia.com](http://www.hepatitisaustralia.com)

### Lifeline

Crisis support and suicide prevention. Available 24 hours a day, 7 days a week.

**Tel: 13 11 14** [www.lifeline.org.au](http://www.lifeline.org.au)

### The National Sexual Assault, Family & Domestic Violence Counselling Line

Free telephone and online confidential service for anyone experiencing or who has experienced domestic violence or sexual assault. Available 24 hours a day, 7 days a week. **Tel: 1800 RESPECT (1800 737 732)** [www.1800respect.org.au](http://www.1800respect.org.au)

### Osteoporosis Australia

Osteoporosis information and services.

**Tel: (02) 9518 8140 Toll Free: 1800 242 141** [www.osteoporosis.org.au](http://www.osteoporosis.org.au)

### Perinatal Anxiety and Depression Australia (PANDA)

Information, support and referral on post-natal depression.

**National Helpline: 1300 726 306** [www.panda.org.au](http://www.panda.org.au)

### Quitline

Information, advice and assistance for people who want to quit smoking.

**Quitline: 13 78 48** [www.quitnow.gov.au](http://www.quitnow.gov.au)



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