



napwa

A decorative graphic consisting of two overlapping, flowing purple lines that curve across the middle of the cover. Small blue dots are scattered along these lines.

treat yourself
right

Information for Women
with HIV and AIDS

3rd Edition

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introduction

This booklet contains health information for women living with HIV. You may be reading it because you have recently been diagnosed with HIV, have known about your diagnosis for some time, or you may be reading it to get an update on health issues specific to women with HIV.

This booklet aims to provide information in a manner that helps you to make the best decisions about your health at different life stages. It includes sections on treatments, disclosure, sex, contraception, pregnancy and menopause.

In this booklet the drugs that are used to treat HIV; antiretroviral drugs, are usually referred to as ARV for simplicity. Sometimes the terms 'anti-HIV drugs' or 'HIV treatment' are also used. In all cases the assumption is that a combination of these agents will be used together, as that is the key to controlling HIV infection.

While there is an emphasis on the way that ARV's work in the body in this booklet, we also acknowledge that there are many other components in a full and healthy life. Now that HIV is a treatable condition, the food you eat, the air you breathe and the decisions you make about smoking, exercise and getting adequate rest; all play a very important part of staying well.

Don't try to read this booklet from cover-to-cover like a novel. You will feel overloaded, and some information is repeated in different sections where it relates to different specific issues. Use the content page and the index to skip

straight to the sections that are relevant for you.

Information can change quickly in HIV. A booklet like this cannot cover all the relevant research in women, but there are some excellent websites that cover breaking news in HIV research, including women-specific news. (*See page 11 for recommended sites*)

Finally, this booklet does not replace your doctor. It is designed to give you an overview and help explain issues in HIV treatment for women, but it is essential that you see a skilled and experienced doctor to manage your health.

As a woman with HIV

- You have the right to take control over your own health and make your own decisions about how you live with HIV;
- You have the right to choose if and when you reveal your HIV status, or to keep your diagnosis confidential;
- You have the right to choose which treatments or therapies you use;
- You also have the right to refuse any treatments or therapies with which you do not feel comfortable;
- You have the right to a full and active sex life;
- You have the right to have children;
- You have the right to work, or make changes to the way you work;
- You have the right to high quality health care, support and counselling in an environment that is supportive, sensitive and free from discrimination.

•just diagnosed?

If you have only recently learned that you are HIV positive, you may be feeling shocked, frightened, angry or upset. It may help to know that there are women from all over Australia and from all walks of life who are HIV positive. Positive women are from many different cultural and religious backgrounds, of all ages, sexualities, with and without children.

HIV is not a death sentence.

Nowadays, more and more women with HIV are living longer, enjoying healthy and fulfilling lives, working, studying, having relationships and children, and making their own choices about treatment.

In addition, improved and inclusive research practices means that much more is now known about the effects of HIV treatments in women's bodies.

As a woman with HIV living in Australia now, it is likely that you will live a normal life span. You are able to have sex, and you are able to have children. If you choose to have a child, it is extremely unlikely that your child will have HIV if you follow specialist advice. (See pages 50-62 on pregnancy)

Talking to someone you trust is important. This may be a friend, a relative, a doctor or someone from an AIDS organisation or an organisation specifically for people living with HIV/AIDS (PLWHA): Someone who has some

knowledge of HIV is a good choice. You don't have to tell everyone in your life now, or ever. (See pages 3-5 of disclosure.)

Many women feel a strong need to speak to another positive woman, but are unsure how to get in contact with one. Positive women in Australia have a strong commitment to providing support for each other and good communication networks. If you are unsure how to contact a positive women's group, contact your local AIDS organisation or PLWHA (People living with HIV/AIDS organisation) and explain that you want to make contact with another positive woman. The worker should then put you in touch with your closest positive women's group who will find you a person to talk with.

You will need to take medicine at some point to control HIV. The drugs used to treat HIV are called antiretrovirals (ARV for short) and they are used in combinations of three or more together.

The treatment of HIV is evolving. The drugs do have side effects and some individuals find more difficulties with them than others. There may be some trial and error before you find the right drugs for you. New drugs and new combinations of drugs are being researched with the aim of reducing side effects and improving effectiveness.

Just diagnosed with no symptoms?

Your doctor will do some tests to see how your immune system is functioning and how active HIV is in your body.

HIV activity is measured as **viral load**, which is the number of copies of HIV in each ml of your blood. A key test for your immune system is the **CD4 cell count**, which looks at the numbers of specific immune cells in your blood.

If your viral load is low (below about 10,000 copies) and your CD4 count is high (500 or above) there will be no need for you to start treatment.

Take your time to adjust to your diagnosis and get some emotional support.

Just diagnosed and pregnant?

If you choose to go ahead with the pregnancy, you have a very good chance of having a baby who does not have HIV.

You will need to work out a treatment plan with your doctor. You will probably need to start taking anti-HIV treatment (antiretroviral drugs, or ARV for short) after week twelve of your pregnancy.

If your doctor has not had experience in working with HIV positive pregnant women, you may want to ask for a referral to someone who has. There is a doctors' group called the Australasian Society for HIV Medicine (ASHM) that can help you find the right person. (See pages 87-92 for contacts)

Just diagnosed with symptoms?

If you've been diagnosed with HIV and have an AIDS-related illness or symptoms, you will be advised to start treatment promptly both for the condition causing the symptoms and for the underlying HIV infection.

Often with women the symptoms will be gynaecological, such as persistent thrush or pre-cancerous changes in your cervix. Starting anti-HIV treatment (antiretroviral drugs, or ARV for short) promptly, along with appropriate treatment for the specific condition can help your immune system to improve, reducing the chances of a relapse.

This is a very stressful situation to be in and you may be angry and afraid. You may need to see a counsellor to help you work through your feelings.

You have a very good chance of your health improving dramatically with treatment.

Telling people you are HIV positive

It is important that you have people who you can talk with about being HIV positive, but it is a good idea to keep some control over where that information goes. Unfortunately, there is still ignorance about and stigma attached to HIV infection, so you may be concerned about how people will react. Many people find that family, close friends and partners are very supportive and understanding.

When you are thinking about whom to talk to, it may be helpful to consider the following questions.

- Can I trust this person with this information?
- Will they offer me support?
- Are they likely to judge me?
- Will they respect my privacy?

You may find it useful to discuss these issues with a counsellor or social worker. Some women decide to keep their HIV status fairly private but want to be able to discuss it with a few trusted friends. In this situation, it is a good idea to give anyone you tell permission to talk to another specific person. This is a practical way of keeping the information private, while recognising that the people you tell may also need some support.

Telling partner(s)

If you are in a relationship with a HIV-negative partner(s) who does not know you are positive, you will need to discuss and practice safe sex with them. The legal obligation to tell your HIV status to partners varies between states, but the outcome should be always to protect your partners from infection and yourself from STIs. It is up to each woman to weigh up the advantages and disadvantages of disclosure, and if or when she will tell her partner(s). It is difficult to disclose and the longer you leave it, the harder and more complex it may be. However, it is better if you have your partner's support and understanding to help you to live with HIV. You may be afraid that your partner(s) will be angry, accusing or judgmental. It may help to know that almost all of the women who took part in recent Australian research and were currently in relationships had disclosed to their partner. The majority of

these women reported that their partners were very supportive, or that their HIV positive status "didn't make a difference" to how their partner felt about them.

Your partner(s) may certainly be scared or confused. You might be scared that he or she will leave you. It can be as big a shock to your partner(s) as it was for you, to learn that you are HIV positive. It is often helpful to have a doctor or HIV counsellor available to support you and answer questions when you tell people close to you. Your partner(s) may need to consider having a HIV test. You will probably find that your partner(s) can come to terms with you being HIV positive and, in fact, it may strengthen your relationship.

Telling children

It's up to you when you want to tell children that you are HIV positive. This is one of the main issues that arise for women with children after diagnosis. Talking with other positive women, particularly those with children, can be really helpful for exploring different approaches you might take. This is also an issue that you can discuss with a counsellor or health care professional if you would like some guidance on what might be best for your particular family circumstances.

Some women decide to talk to their children straight away, whereas others decide to wait until the children are older. It very much depends on the family situation and your judgment. You know your children and are in the best position to make this hard decision.

When you decide to tell your children, it may be a good idea to tell some other people who can provide support for the child — maybe a relative or a good friend whom your child trusts. Older children may

feel angry, particularly if they feel that important information has been withheld. Some states have HIV family support services that can assist at this time.

There are people you do not have to tell

If you are HIV positive, you do not have to disclose your HIV status to:

- your friends;
- your employer;
- your work colleagues;
- doctors, dentists or other health care professionals.

Having said this, it may be wise to tell any doctor treating you — particularly over the long term or for serious conditions — that you have HIV. To help you make the best decisions about your health, your doctor will need as full a picture as possible. It is also a good idea to tell your dentist, since HIV can affect your gums. If you do tell a doctor, dentist or any other health care provider, they cannot refuse to treat you or manage your care; this would be discrimination and against the law.

Circumstances in which the law may require disclosure

Generally, you are not obliged to tell anyone you are HIV positive. However, in some circumstances, the law may require that you disclose.

- In some states¹, HIV positive people are legally obliged to tell any sexual partner, even if they intend to have safe sex;
- The Department of Immigration requires anyone applying for

permanent residency in Australia to be tested for HIV; and

- When applying for superannuation or life insurance, you will probably need to answer questions about your HIV status. These companies are legally allowed to refuse to insure you if you are HIV positive or you refuse to tell them your status. Your AIDS council or PLWHA group may be able to give you information about HIV-friendly superannuation and insurance companies.

Occupations that require HIV testing

HIV testing is mandatory in the Australian defence force. Health care workers who perform 'exposure-prone procedures' such as surgery (including dental surgery) are required to know their HIV status and must not perform such procedures if they are HIV positive (or hepatitis C PCR positive)².

If you are refused service

If you are refused any service or believe you have been treated unfairly because you are known or presumed to be HIV positive, this may be a case of discrimination. It is against the law to discriminate against people because of their HIV status. If you would like more information about how to deal with HIV-related discrimination, there are a number of services which can assist. The HIV/AIDS Legal Centre (in NSW) is one of these. The AIDS council in your state or territory will be able to provide more information or refer you to an appropriate person or service.

¹ NSW ² PCR stands for **polymerase chain reaction**. A PCR tests checks for the presence of the actual virus in the blood, rather than the *antibodies* to a virus.

living with HIV

Your Health

Your health, self-image and emotional well-being are affected by a variety of different factors, many of which intersect. Fitness, nutritional status, being in a healthy weight range for your height and having enough time for relaxation and getting adequate sleep are all very significant. Having positive, fulfilling relationships with other people and being able to express doubts, fears and aspirations to a trusted friend and/or partner are also part of a holistic picture of health.

Many women have caring responsibilities for children or significant others. Balancing the needs of others, the demands of paid work and your own needs is a major source of stress for women, and often this results in other people's needs taking priority. In the long term, always putting others first is not healthy. Having some time for yourself, to relax and unwind and put yourself first should be seen as a necessity, not a luxury – even though it might be very hard to organise. Taking time out for self-care will make you stronger and more able.

Money is also critical to health. Having to struggle to make ends meet and needing to budget carefully to pay for essential items really takes its toll and can exacerbate other tensions in life. There are no easy answers here, but acknowledging the problems and getting support for good budgeting, debt consolidation where necessary and seeking like-minded people and friends can help. For women who are not doing paid work, financial stress can be considerable. Being dependant upon a partner or upon social security also brings with it a set of demands and obligations. Finding out what concessions you are eligible for can prove helpful.

Living with HIV is another component in the overall picture of your health. Where it fits in relation to other things in your life depends upon when you were diagnosed, your current health status and whether HIV is impacting on your romantic or sexual relationships.

How HIV affects your body (the 'natural history' of HIV)

The human immunodeficiency virus (HIV) reproduces itself by invading cells, integrating with the cells and turning them into factories for producing more copies of HIV, then sending more HIV cells out to infect more of your cells.

The quantity of virus per unit of your blood (or other tissue) is called 'viral load'. The lower your viral load is, the better.

HIV invades cells of the immune system, the system that usually works to fight infection and keep you well. The cells are called CD4 cells (also called T-cells or T4 cells), dendritic cells and macrophages. Your 'CD4 count' is an important indicator of the health of your immune system - the higher your CD4 count, the better.

After infection with HIV, your body mounts a defence. It produces more and more CD4 cells to cope with the reproducing virus, and it also produces antibodies. It is these antibodies that HIV tests detect, which is why the term 'HIV positive', meaning testing positive to antibodies for HIV, has become synonymous with having HIV infection in your body. The process of changing from being HIV antibody negative to positive is called 'seroconversion'. The period from your initial exposure to HIV to the development of antibodies is called 'primary infection'. During this time, some people experience a 'flu-like' illness, which can be quite severe.

Initially any damage caused by HIV has no outward effect. This is called asymptomatic infection, which may last for many months or years. Sometimes if you have asymptomatic infection, you may have swollen lymph nodes, which is called PGL (Persistent Generalised Lymphadenopathy). But this is not a sign of damage itself.

If you have HIV and feel 100% well, you still may have signs of immune damage detectable by laboratory tests; for example, your CD4 count may be below normal levels. Viral load tests can also demonstrate that HIV is actively replicating inside the bodies of asymptomatic people from the moment of infection; at no time is the virus truly latent. The presence of HIV keeps the immune system in a state of over-activation, which eventually drains its resources.

Once your CD4 cell count falls to 200 or below, you are at risk of developing an AIDS-related illness. However, some AIDS-related illnesses such as invasive cervical cancer can occur at higher CD4 counts.

HIV treatment intervenes in this process of disease progression by suppressing viral replication and thus allowing CD4 cell levels to recover, so that the body can maintain its immune defence against serious illness.

HIV treatment is also called antiretroviral therapy, ARV, combination therapy or highly active antiretroviral therapy (HAART).

Stages of HIV infection in the absence of treatment

Stage 1	HIV invades cells, merges, and turns them into factories to produce HIV (primary infection).
Stage 2	Your immune system keeps HIV replication in a steady state for an average of 6-10 years (clinically asymptomatic stage—i.e. there is a steady decline in CD4 cell count, but the person usually remains quite healthy).
Stage 3	Your CD4 count drops lower, and you begin to experience AIDS-related conditions like thrush, skin conditions and minor but persistent infections (symptomatic HIV infection).
Stage 4	Your CD4 count is below 200 and you have had a serious illness caused by immune deficiency (an 'AIDS-defining illness')- AIDS. Invasive cervical cancer, which is considered an 'AIDS-defining illness' can occur with CD4 Counts higher than 200.

Other ways in which HIV can affect your well-being

Fatigue

One of the common effects of HIV which many women find hardest to deal with is fatigue or chronic tiredness. Feeling tired a lot of the time can make it more difficult to manage under the pressures of everyday life; work, family, partners etc. Fatigue may be caused by the chronic presence of HIV. It may also be caused by damage to your immune system, or by HIV antiviral or other treatments. Depression or anxiety may also cause you to feel tired.

Role of diet and exercise

Many women find improved diet and regular exercise can help reduce fatigue. Some complementary therapies may also help improve your energy levels and sleep.

Weight-bearing exercise (exercise which increases the weight stress on your

body) is very important for your health, because some ARV's are associated with muscle wasting and bone thinning (HIV itself can also cause wasting). Weight bearing exercise doesn't have to mean 'pumping iron' in a gym (though if you like doing this, go ahead!) the 'weight' you are working with can be your own body weight. Examples of weight bearing exercises include: yoga, walking, cycling or Pilates. Unfortunately swimming is not in this group, as the water supports your weight.

Weight loss

Because HIV can prevent your body from absorbing food and nutrients, you can easily find you are losing weight particularly if your CD4 count is low. You may also be more likely to get stomach infections, which can cause diarrhoea and weight loss. It is important, as far as possible, to maintain a healthy body weight to help sustain your body's defences against infection. Prevention is the best treatment. Talk to a doctor, and see a dietician, or talk to other positive women about ways to improve your diet and appetite.

Weight gain

While it is important not to be too thin, being overweight increases your risk of lipohypertrophy (abnormal weight gain in the trunk, associated with ARV, particularly some Protease Inhibitors). In addition, being seriously overweight increases your risk of diabetes and heart disease.

Your Body Mass Index (BMI)

Your body mass index (BMI) is a calculation of your body fat based on your height and weight. While it is deemed to be a generally reliable indicator of body fat, it may overestimate body fat in athletes and muscular people and underestimate it in elderly people. A waist measurement of over 35 inches in women, together with a BMI over 25, increases the likelihood of you experiencing diseases such as high blood pressure, cardiovascular disease, type 2 diabetes and some cancers. It is generally agreed that people of certain ethnic backgrounds, including those of Asian heritage, should aim for a BMI below 23. Indigenous Australians may well need to aim for a 'normal' BMI of 22-23.

- Underweight = <18.5
- Normal weight = 18.5-24.9
- Overweight = 25-29.9
- Obesity = BMI of 30 or greater

You can calculate your BMI yourself using one of the websites listed below, or have your doctor calculate it for you.

<http://nhlbisupport.com/bmi/>

<http://www.halls.md/body-mass-index/bmi.htm>

Decreasing your risk of cardiovascular disease

Cardiovascular disease is the leading cause of death in women in Australia, and medication taken to control HIV may increase your risk. Maintaining your fitness, keeping your BMI below 25 (or 24 for some people) and not smoking are ways that you can significantly reduce your risk of cardiovascular disease.

You and your doctor: the partnership

Finding a good doctor is going to make an enormous difference to your health.

A 'good doctor' is someone who:

- Listens to you and treats your views with respect;
- Is willing to work with you in a partnership;
- Explains treatment advice using language you understand;
- Is up-to-date on the latest research on HIV and HIV treatments;
- Is experienced in treating people with HIV;
- Makes an effort to find women-specific research;
- Understands that women's bodies are different to men's;
- Understands that your lifestyle must be a consideration in your health care;
- Respects the complexities of your carer responsibilities;
- Is accessible and responsive to you needs.

Listening

Being able to express your needs and concerns to your doctor is very important. A doctor who relates to you as a person, rather than as a collection of symptoms, is particularly important when you are living with HIV. Treatment strategies (including the strategy of deferring treatment) are long-term and their success depends upon incorporating them well into your life.

Social, economic and emotional factors can impact on your health, and a good doctor can be a really good reference point – not just to write prescriptions, but also to link you into other supports.

Explaining

Treating HIV involves making decisions, and to make the best decisions for your circumstances, your doctor needs to be able to explain different options and strategies to you and help to evaluate what will work best. In some circumstances, such as if you have become pregnant or if your health is deteriorating, both you and your doctor may feel under pressure to reach a decision quickly. Acknowledging this pressure on both sides and agreeing on a timeframe for decision-making may help prevent a feeling of being overwhelmed.

Up-to-date

Best practice changes swiftly in HIV medicine. Not only does the number of drugs expand, but also studies showing how different combinations work in different circumstances are constantly being published or presented and

discussed at conferences. In addition to how well various drug combinations suppress HIV, other research focuses on minimising side effects and comparing strategies on treatment initiation. It is fair enough to check that your doctor stays abreast of the developments of international conferences and key AIDS-focused medical journals.

Experienced in HIV

Treating HIV is complex and it requires a degree of commitment from a doctor to stay abreast of new developments. If a doctor is already treating many others with HIV, then economies of scale come into play – it makes sense that she or he will be doing the homework. Seeing other people with HIV also means that a doctor will understand how people in the 'real world' may have different needs, lifestyles and treatment histories to people in clinical trials.

In treating people with HIV there is an emphasis on evidence-based medicine. That means basing treatment decisions on evidence that has been provided as objectively as possible. Large-scale clinical trials provide the highest grade of evidence, but in addition to these there are observational studies.

Women are different

The differences between men and women mean that there can be a different response to HIV disease and its treatment. It's important that your doctor has this in perspective and keeps an eye on women-specific research.

Men outnumber women as participants in clinical research, and most major HIV trials involve groups of people who are predominantly male. However, there has been a concerted attempt to get more women into clinical trials to conduct sub-studies of the women in major trials where possible, in case women responded differently to men.

Lifestyle and family responsibilities

If you are a mother, or have other caring responsibilities, this is going to impact on the way you prioritise your health care. It's important that your doctor understands and respects this. Being the key or sole caregiver for dependents can greatly impact on your health options.

It's also important that you can be frank with your doctor about your sex life and about smoking, alcohol and any other recreational drugs you may use. Your doctor should not make you feel ashamed or judged when you discuss issues that impact upon your health.

Accessibility

You need a doctor who is going to be accessible, particularly if your health concerns are complex or if you are at risk of a serious decline in your health.

Getting information

Knowledge about HIV/AIDS and its management is increasing constantly. New treatments are being tested and there are now many drugs and therapies which have been shown to

prevent, reduce or delay illness. This means that there has been a vast reduction in the number of people who are HIV positive who progress to AIDS.

Now that relatively effective treatment is available, it's possible even after being diagnosed with an AIDS-defining illness, to become completely symptom-free and even for the immune system to improve its functioning. There is more information on treatments on pages 17-35. Because there are so many benefits to be gained by managing your health, it is important that you start getting the right kind of information and support as soon as possible.

Internet tools

The Internet can be a fantastic tool for getting up-to-date information, but it can also be a confusing minefield of information that is accurate, inaccurate, outdated and downright scary. Knowing where to look and who to trust in terms of timely, accurate and woman-sensitive information is extremely important.

Internet-based information is no substitute for seeing a good doctor, and web-based HIV information is intended to support, not replace, the relationship you have with your doctor. Always feel free to take material from the Internet in to your consultation with your doctor to inform your conversation if you think it could be helpful (for example, if you are making a treatment decision or worried about side effects).

Two international sites that regularly update their treatments sections and

that have women-specific sections are www.nam.org.uk (English) and www.thebody.com (American).

The NAM site is very comprehensive, updated regularly, and assumes a universal health care system, which is basically similar to Australia.

The Body website has very annoying pop-up advertisements that you have to grit your teeth and ignore, but its information is well researched and reviewed, although bear in mind that it is US based, so new treatments are available there sooner than here, and their healthcare system is very different to ours.

Another excellent site for women is WISE words at www.projectinform.org

The Australian NAPWA and AFAO sites are found at www.napwa.org.au and www.afao.org.au. These sites are authoritative, but they are significantly under-resourced compared with the top international sites listed. So you will not get the latest developments as quickly using an Australian site.

Getting support

There are many people who can help you make decisions about the way that you manage living with HIV and AIDS. There are doctors and health professionals who have experience with HIV and AIDS, and community organisations set up specifically to support HIV positive people, and organisations at state level that are specifically for positive women.

Other people living with HIV — especially other positive women — can be invaluable. It can help to hear

how other women have dealt with issues such as relationships, sexuality, work, making decisions about having children, telling people they are positive, treatment choices, and staying well.

There are many free services, pamphlets and newsletters available from AIDS organisations and community health centres throughout Australia. Your state or territory AIDS council, positive women's groups and PLWHA organisations can give you information about treating and managing HIV. Most states also have support groups and organisations specifically for HIV positive women. You'll find a list of services, resources and useful contacts at the end of this booklet.

Monitoring your HIV

How are you feeling?

When you had your HIV test, you should have had counselling before the test and when you received the test results. If you were not given any counselling, feel the counselling was inadequate, or need ongoing counselling, ask your AIDS council or positive women's group to suggest someone you could talk to.

How you are feeling at any given moment may be related to your HIV status, or to your general sense of physical and emotional well-being. If you are feeling unwell, it could be directly related to HIV or some other illness, or it may be that emotional or psychological stresses are playing a major role.

This section looks at the various ways in which HIV can be monitored and managed. Monitoring your HIV may involve a series of steps including regular

general check-ups, and tests which can look at how much HIV is in your body at any time, and how this is affecting your health and immune system.

Some people living with HIV have experienced very little illness, while others have had periods of illness and have spent time in hospital. Each person living with HIV is unique and no-one can know exactly how the virus will affect him or her.

In the past, most research about the effects of HIV did not look at the specific ways in which HIV and HIV treatments affect women's bodies. This is now being addressed, and more women are now taking part in research. Talk to your health practitioner about getting specific information about the effects of different HIV treatments on women.

There are HIV treatment officers attached to most AIDS councils or PLWHA organisations in each state and territory. They can provide you with up-to-date information and will spend time — face to face or by phone — discussing any matters that concern you.

Viral load tests and CD4 (T-cell) counts

Viral load tests

HIV multiplies — by 'copying' itself — within your body. Viral load refers to the amount of HIV in your blood at any given time. You can also measure viral load in other body fluids like vaginal fluids, but this is only available in a research setting. Routine viral load tests look at how much virus is in your blood.

The reason this is important is because the amount of virus in your blood is a direct indication of how much damage HIV may be doing. The higher the amount of HIV, the greater the risk of your immune system being damaged, and the greater the risk of serious HIV-related illness. Viral load test results are expressed in terms of the amount of HIV per millilitre of blood.

What does viral load test entail?

A viral load test is a simple blood test.

Interpreting viral load test results

Viral load tests may show a great range

How do you know what's happening to your body?

Even when you are feeling well, it is recommended that you keep a check on your immune system. The two tests that are most useful for finding out how your immune system is coping with HIV are **CD4 counts** and **viral load** tests.

These two tests are the most important tests in terms of ongoing health monitoring. They may be used as a guide so you can understand:

- how much HIV is in your body at any time;
- how this is affecting your immune system;
- whether you are at risk of opportunistic infection;
- whether you should start treatment; and
- whether your current treatments are working.

These tests will also have a role in terms of other decisions, for example, if you are considering pregnancy.

in the amount of virus the blood, varying wildly between individuals from millions of copies to as few as fifty. Your doctor will want to keep an eye on how your viral load is changing over time. This will be a pretty good indicator of how well you are doing on treatment, or if you are not on treatment, it may suggest whether your health is stable, or whether there is any risk you could get sick.

In general, the following understandings of viral load are used:

- More than 100,000 copies
– high viral load;
- 10,000 to 100,000 copies
– moderate viral load;
- 50 to 10,000 copies
– low viral load;
- Under 50 copies
– ‘undetectable’ viral load.

Currently, the T-cell or CD4 counts are more often used to make a decision regarding commencing ARV, but the viral load results may also be taken into account when making that decision.

Measurements of viral load

Sometimes you may hear the word ‘log’ used in relation to viral load. For example, your viral load after commencing treatment may drop from 100,000 copies to 10,000, which is called a ‘one log’ reduction. From 100,000 copies to 1,000 is a ‘two log’ reduction. An easy way to remember log is that they involve adding or subtracting a zero from a number.

An important note about ‘undetectable’ viral load

If your result comes back as ‘undetectable’ this does not mean that there is no HIV in your blood. Unfortunately, the term ‘undetectable’

can be very misleading. It means that the amount is less than 50 copies of HIV per ml of blood.

What factors affect viral load?

A number of factors can affect viral load. Viral load can go up and down in response to; your general health, antiviral drugs (and whether they are working), changes in treatment, the presence of other infections, vaccinations (e.g. hepatitis B), and the strength of your immune system.

Viral load and treatment decisions

You and your doctor need to decide if and when to start ARV treatment. You may want to use the results of your viral load tests over time to inform these decisions. This is discussed in more detail in the chapter *Making decisions about treatment* which begins on p17.

Viral load in blood and viral load in vaginal fluids

Research shows that there is usually a relationship between levels of HIV in the bloodstream and levels of virus in other body fluids like vaginal secretions. In other words, if your blood viral load is low, it is likely that the level of virus in vaginal fluids will also be low. However, this is not always the case and you are not able to have sexual fluids tested routinely for viral load. It is important to know that some studies have been unable to demonstrate a relationship between blood and vaginal fluids; finding low levels of virus in blood and higher levels of virus in vaginal secretions. The best that can be said is that if you have low levels of virus in your blood, you are most likely to also have low levels of virus in your vaginal fluids, but that a small number of cases will not reflect this pattern.

Viral load in the vaginal fluids is likely to be higher than as measured in the blood if you have a genital infection or sexually transmissible infection (STI) of some kind.

Viral load in breast milk

Viral load in breast milk may fluctuate and will not necessarily mirror blood viral load. Common infections such as mastitis in breastfeeding women can cause significant increases in breast milk viral load, regardless of blood levels.

CD4 (T-cell) counts

This is a blood test, which can tell how many CD4 cells (also called T- cells) you have. A person with a healthy immune system can have between 500 and over a thousand of these important white blood cells per millilitre of blood.

CD4, or T-cells, are important because they help make the immune system work efficiently to deal with, or get rid of, any unwanted bacteria, viruses or other harmful organisms. But unlike other viruses, HIV actually invades and destroys the CD4 cells. The immune system cannot function well without these cells. Eventually, if it goes unchecked, HIV will begin to destroy the CD4 cells at a faster rate than the body can produce them. When this begins to happen, the number of CD4 cells drops, and because the immune system cannot do its job, it is slowly overwhelmed.

Interpreting CD4 cell counts

If your CD4 count is 500 or less, you may be advised to consider starting antiviral treatment. If your CD4 count is 350 or less, treatment is clearly recommended.

If your CD4 count is 250 or less, this indicates that serious damage has occurred to your immune system. This places you at risk of serious illnesses related to HIV, called ‘opportunistic infections’. If you have 200 CD4 cells or less, antiretroviral therapy (to control HIV) is recommended, and you may also need to consider treatments called *prophylactic treatments*, which can minimise the likelihood of your becoming ill with particular infections. Discuss this with your doctor.

Other common tests

Pap smears

Women living with HIV and AIDS 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 unusual changes, which may suggest the risk or presence of cancer. It is not uncommon for women to have a condition that is called ‘cervical dysplasia’, regardless of HIV serostatus. This means that your Pap smear result shows some abnormal cells. In some women, these abnormal cells can lead to cervical cancer if they are not treated.

A Pap smear is a procedure where a speculum is inserted into your vagina to open it, and a swab is taken of cervical cells. The procedure is relatively quick and can easily be performed by your GP and by some nurses.

In general, HIV negative women are advised to have Pap smears every two years. The reason that HIV positive women are advised to have Pap smears every twelve months is that cervical dysplasia, or the presence of abnormal

cells, is more common in HIV positive women. Even if you have not had any abnormal cells, it is recommended that you have a Pap smear every 12 months.

If you have had abnormal cells found and treated in the past, it is recommended that you have Pap smears even more frequently, such as six monthly. The presence of abnormal cells does not mean you have, or will get cancer. However, in a small number of cases, they can suggest pre-cancerous conditions.

It is possible that progression from cervical dysplasia to cancer may be more rapid in positive women. If you have a Pap smear and cervical dysplasia is found, ask your doctor whether you should have a colposcopy.

A colposcopy is slightly different to a Pap smear. You have a speculum inserted in the same way as for a Pap smear, but your legs are supported in stirrups, as you are in this position for longer. The doctor then looks at your cervix using a special microscope called a colposcope (this does not touch your body). A further smear may be taken, and then your cervix is painted with a solution, which makes abnormalities easier to see – this can sting and be unpleasant. A small biopsy sample may be taken at this stage – again, this can cause discomfort. The procedure takes about 10 to 15 minutes.

Cervical cancer, which is described in more detail on page 72, can be difficult to treat. However, it can be prevented if abnormal cells are found early enough by routine testing.

Pap smears are available from any general practitioner or nurse practitioner, through Women's Clinics and Family Planning clinics, as well as through some sexual health and HIV clinics.

Other tests you may need

There are other tests which you may feel you need, or may be asked to consider, as part of managing HIV. These could include:

- Tests for Hepatitis B and C;
- Tests for any other sexually transmissible infections;
- Liver function tests (particularly if you are positive to hepatitis B or C);
- Tests to see if you have been exposed in the past to viruses (for example, cytomegalovirus or CMV), which can recur in people with lowered immune systems.

making decisions about treatment



Myths and facts about HIV treatment

Myth	Fact
You need to know everything about treatment to make good choices	You don't have to be the expert, that's your doctor's job. You just need to know enough to feel in control of your life and your health.
There is very little woman-specific research	The importance of women-specific research is well understood. There are long-term studies looking only at women with HIV, and most new drug trials aim to include women.
Side effects are unavoidable	People respond differently to different drugs. It might take some trial and error, but you and your doctor should be able to find a combination of drugs that is effective and that is tolerable for you.
Combination therapy involves lots of pills and difficult dosing	You can take an effective ARV regimen that involves once or twice daily dosing.
Taking treatments will change the way you look	Certain ARV drugs are associated with fat gain and fat loss in particular areas of the body and face, but other drugs are not. You have options.
Everyone with HIV should be on treatments	Whether you need to take treatments depends on your CD4 count and your viral load. For some people, deferring treatment is a good option.
Once you have started treatment you can never stop	Current research shows that people who stop and start ARV treatment increase their risks of HIV related disease, but there may be circumstances in which you can stop therapy for a period of time.
Every woman with HIV faces the same treatment issues	Treatment issues for women with HIV are very different depending on whether you are 'treatment experienced' or not. For women who have used lots of ARV drugs over many years, there are fewer options than for women who are just starting treatment. Whether or not you have hepatitis C or other illnesses also makes a difference.
There is no clear definite point at which you need to start ARV treatment	There is very clear evidence that taking ARV prevents HIV related disease and death in people whose immune systems are compromised. However, there is a 'grey area' where deferring treatment remains an option despite some immune damage.
Taking ARV during pregnancy will harm my baby	Taking effective ARV during the second and third trimester of pregnancy reduces the likelihood of HIV transmission to almost zero.

Women and antiretroviral drugs

Anti-HIV therapy means that many women with HIV can expect to live normal life-spans and, if they wish, to give birth to HIV-uninfected children. However, there is still no scientific consensus on when to start treatment, and no perfect regimen that is potent, easy to take and side effect free for all people.

Initially most of the research into HIV and its treatments was in men. Men significantly outnumber women as participants in medical research generally; partially due to concerns about experimental drugs and the possibility that women may become pregnant, and perhaps partly to do with women having complex roles and multiple responsibilities, making participation in trials harder. But there has now been enough research in women to know the following:

- Antiretroviral drugs work as well in women as they do in men, but the side effects can be different;
- Women are more likely to experience side effects than men (particularly changes to body shape through changes in fat distribution, especially fat gain);
- A woman with a lower viral load after seroconversion (becoming HIV positive) may progress to AIDS at the same rate as a man with a higher viral load.

What are antiretroviral treatments?

Antiretroviral (ARV) drugs stop HIV from replicating and infecting new cells in your body.

There are different classes (groups) of HIV antiretroviral drugs. These are:

- Nucleoside and nucleotide reverse transcriptase inhibitors (NRTIs, sometimes called nucleoside analogues, or nukes);
- Non-nucleoside reverse transcriptase inhibitors (NNRTIs, sometimes called non-nukes);
- Protease inhibitors (PIs);
- Fusion inhibitors and CCR5 entry inhibitors;
- Integrase inhibitors (A new class of drug which targets the Integrase enzyme that HIV uses to insert its genetic code into the DNA of the host cell).

Each of these classes of drugs works in a different way to interfere with the HIV life cycle and makes it difficult for the virus to reproduce. There is a range of different drugs in each of the classes and while drugs in the same class share some common characteristics, there are differences. Some are more effective at stopping HIV replication, and some are less likely to have certain side effects.

What is combination antiretroviral therapy?

Combination therapy is the use of two or more HIV antiretrovirals at the same time, as part of a treatment plan or strategy. Most commonly people take a combination of three drugs — sometimes more — from two or more of the classes listed above.

The reason for using antiretroviral drugs in combination is to prevent drug resistance. (See page 31 on resistance).

First line-therapy

Your first combination of antiretroviral drugs will usually include two drugs from the nucleoside/nucleotide analogue class, together with either an NNRTI or a protease inhibitor. The protease inhibitor may be 'boosted' by the addition of a small dose of another protease inhibitor, ritonavir.

The World Health Organisation HIV

treatment guidelines recommend using a drug from the NNRTI class as the third drug in the combination, as these are less likely to cause side effects. However, under Australian and US guidelines, the use of either an NNRTI drug or a protease inhibitor should be determined by an assessment of the individual.

The precise drugs chosen should be the ones least likely to cause you side effects in the short and long term, with

What are the different kinds of antiretroviral drugs?

Drug Class	What drugs are in this group?
Nucleoside/nucleotide analogues (reverse transcriptase inhibitors)	<ul style="list-style-type: none"> • AZT (zidovudine or Retrovir) • ddl (didanosine or Videx) • d4T (stavudine or Zerit) • 3TC (lamivudine or EpiVir) • abacavir (Ziagen) • tenofovir (Viread) • emtricitabine (FTC, Truvada)
Non-nucleoside reverse transcriptase inhibitors (NNRTIs or 'non-nukes')	<ul style="list-style-type: none"> • nevirapine (Viramune) • efavirenz (Stocrin)
Protease inhibitors	<ul style="list-style-type: none"> • indinavir (Crixivan) • ritonavir (Norvir) • saquinavir - Hard/Soft gel (Invirase, Fortovase) • nelfinavir (Viracept) • fosamprenavir (Telzir) • lopinavir/ritonavir (Kaletra) • atazanavir (Reyataz) • Darunavir (Prezista, TMC - 114) • tipranavir/ritonavir (Aptivus/r) licensed in Australia, but not yet reimbursed by the Govt - available on an access scheme.
CCR5 Entry & Fusion inhibitors	<ul style="list-style-type: none"> • Fuzeon (enfuvirtide or T-20), Maraviroc (Selzentry, Celsentri). Not yet licensed in Australia, but available under trial/access scheme.
Integrase Inhibitors	<ul style="list-style-type: none"> • Raltegravir, MK-0518 (Isentress). Not yet licensed in Australia, but available under compassionate access scheme.

a convenient dosing schedule for you. It is important that combination of drugs is potent enough to reduce your viral load to undetectable levels.

Co-formulations

Some drugs are formulated together in order to reduce the number of pills that you have to take. There is a marketing advantage in co-formulation for the manufacturers - the ease of use means that people are more likely to take drugs made by a particular company if the drugs can be combined into a single pill.

Co-formulated drugs include:

Combivir (AZT/3TC)

Trizivir (AZT/3TC and abacavir)

Kaletra (lopinavir/ritonavir)

Truvada (FTC and tenofovir)

Kivexa (abacavir/3TC)

Treatment options

Treatment options are different depending on whether or not you have taken ARV before, so this section will be split into information for women who have never taken treatments (called 'treatment naive' women) and women who have taken treatments ('treatment experienced' women).

These guidelines are based on available evidence to date and upon expert opinion, which balances the need to start treatment before irreversible damage to your health occurs (in the form of an opportunistic infection or cancer) with caution about exposure to unnecessary side effects.

If you've not taken ARV in the past

You may be thinking about starting HIV for a number of reasons, including:

- A new HIV diagnosis;
- Having had an increase in viral load and/or decrease in CD4 count;
- Having a diagnosis of an AIDS-related condition like CIN (cervical intraepithelial neoplasia - pre-cancerous changes in cells of your cervix);
- Becoming or wanting to become pregnant;
- Finding out more about ARV.

Current treatment guidelines recommend you begin antiretroviral therapy:

- Before your CD4 cell count falls to 200 (between 201 and 350);
- When your CD4 count is between 350 and 500, your doctor will present therapy as an option;
- If your viral load is above 100,000 copies per ml and your CD4 count is 500 or above, ARV is an option.

Whether or not you need to start treatment is determined by how healthy your immune system is (measured by your CD4 count) and how actively HIV is reproducing itself (measured by your viral load). As this chart below shows, in some instances there is a clear recommendation to either start taking therapy or to defer it. There is also a grey area where you and your doctor need to balance the relative risks and benefits of either starting or deferring ARV.

CD4 cell count	Viral load	Start therapy?
Below 200 cells	Any	Recommended
Between 200–350	Any	Offered*
Above 350	>100,000	Considered**
Above 350	<100,000	Deferred
Any	Any	Recommended with AIDS-defining illness or with severe symptoms of HIV infection

*The current Antiretroviral Guidelines in use in Australia state that all decisions regarding initiating therapy in an HIV-infected person should be made on the basis of prognosis, as determined by the CD4 T cell count and level of the HIV viral load, the potential benefits and risks of therapy, and the willingness of that person to accept therapy.

**Research data from observational cohort studies show that at any given CD4 cell count, those with HIV viral load greater than 100,000 have a higher risk of progression to AIDS and this risk also increases with increasing age. Hence, starting therapy could be considered at a CD4 count more than 350 when these factors and others (the tolerability and long-term toxicity of the antiretroviral regimen and the person's willingness to maintain a high level of adherence to lifelong therapy) are taken into account.

There are a few key things to keep in mind when you are making decisions about treatment:

- Treatment side effects and dosing schedules are not nearly as difficult as they were when ARV was first introduced. Your doctor should be able to find a combination of drugs that is easy to take without significant side effects for you.
- To protect your immune system and prevent the risk of opportunistic infections you need to keep your CD4 count above 200;
- There is likely to be an advantage in starting treatment when your CD4 count is around 350 rather than letting it drop closer to 200;
- For women with high viral loads – above 100,000 copies, it may be advisable to start treatment even if your CD4 count is 350 or above;
- The first few weeks on new ARV treatments can be the most difficult. Your doctor should tell you what to expect, and you may need childcare, help in the house or time off work.

If your health is such that you are considering treatment but you have the option to start or defer, consider your options in the light of the multiple responsibilities (like work, a family, a household) that you may have. Setting aside time to learn about your options, talking about different approaches with a trusted doctor, counsellor or positive woman and thinking about the timing of any change, depending on what is happening in your life, can help you to manage changes in a positive, timely manner.

If you are starting HIV treatment for the first time ask your doctor to help you choose:

- A combination that will suppress viral load (potent drugs);
- A combination that will not limit your future treatment choices;
- Drugs that work well together;
- Drugs with side effects you can cope with;
- A combination that suits your lifestyle.

If you are considering pregnancy in the future it's a good idea to discuss this with your doctor now, as it is likely to affect which drugs you choose.

The vast majority of women with HIV in developed countries who become pregnant on antiretroviral therapy have healthy babies, but there are specific HIV drugs recommended (and some to avoid) during pregnancy.

For more information of pregnancy and HIV, see page 50-62.

Preventive treatments (prophylaxis)

If you have a CD4 count below 200 you may be advised to start taking drugs that are designed to prevent specific diseases associated with AIDS. These drugs are often called 'prophylactic' treatments, and they are used to prevent conditions like *Pneumocystis carinii* pneumonia (PCP); an AIDS-related pneumonia. You may need to take these preventive treatments in addition to ARV until your CD4 cell count improves.

the new ARV that you are considering.

If your current combination has you taking a lot of pills at each dose, you could talk to your doctor about the option of co-formulations, where there are several different ARV in a single pill. See page 21 for co-formulations that are currently available, or expected to be available in the near future. Similarly, if you are finding it hard to remember doses, talk to your doctor about switching to a combination that allows once-daily dosing.

You may want to make a change to your treatments because you are experiencing side effects that emerge over time, such as changes in your body shape (Lipodystrophy) or changes in the way that your body processes fat and sugar (metabolic changes) which are measured in your blood tests. Talk to your doctor about whether you could benefit from switching to drugs that are not associated with metabolic and body shape changes. See pages 29-30 for more about lipodystrophy.

Treatment issues for women who have taken ARV before

('treatment experienced' women)

If you are currently taking ARV, the issues that you face in making changes to your therapy are:

- Finding an effective combination for you that will suppress your viral load;
- Having a good dosing schedule;
- Not causing unmanageable side effects.

Your treatment options may be limited if you have had detectable viral load results while taking ARV, as this sets up the conditions for developing drug resistance. Having resistance to one drug can often affect several drugs in a class, which is called 'cross-resistance'. Having resistance testing done before changing your drugs is an important step if there is any possibility of you having pre-existing resistance to

Managing your treatments

When ARV drugs first became available, many people were taking drug combinations that really did make life very complicated, but since then there has been considerable research into the ways of combining treatments to allow better dosing schedules, such as once or twice a day. If you find it hard to remember to take pills, talk to your doctor prioritising once-daily dosing when considering your treatment options. Current evidence suggests that once you start taking ARV you will need to keep taking them for life. Therefore, you need to be very committed to the decision before you start (although the drugs in your

combination may change, as different agents are developed).

Research shows that you cannot miss occasional doses and that skipping pills puts you at high risk of developing drug-resistant HIV.

You may need frequent medical appointments at first, to check how the treatment is working. Some women find this difficult to manage at work or within their family, if they have not disclosed their HIV status. Your doctor, a treatments officer from your local AIDS Council, or other positive women can suggest practical strategies for coping with all of this.

Your state of health, lifestyle and personal preference will be factors when choosing which drugs to take. Together with

your doctor, you should consider any symptoms you may have, and any other drugs you are taking.

If you are resuming HIV treatment after stopping therapy for any reason:

- Ask your doctor to conduct resistance testing to choose drugs that will work well for you;
- Discuss the reasons that you stopped therapy to help choose the agents that will best suit your lifestyle.

Treatments decisions are likely to be influenced by your general well-being; changes in your viral load or CD4-cell count, side effects, your lifestyle, whether you are planning pregnancy, the availability of new treatments and approaches, and finally your attitudes to medicine.

There is a lot of information around about treatment but you don't have to tackle it all at once. Don't be intimidated! Explain to your doctor that you need a reasonable timeframe for making decisions. Depending on circumstances, you may have several months or several weeks to make a decision about the way forward. You can also ask for referral to material that can help you make up your mind, such as plain-language written material to take away and consider.

You don't have to rush into any decision before you are ready for it. In the end, which drugs you do or don't take is up to you, but knowing your options will allow you to make an informed decision.

Side effects

A side effect is a reaction or condition that arises as a result of taking a

particular drug. The term usually refers to adverse effects (or problems), like nausea, diarrhoea, or nerve damage. You may find some side effects are relatively minor and can be dealt with fairly simply (for example, medications can be prescribed for diarrhoea and nausea). Some people have no side effects and continue on their first regimen of drugs for years. Other people, however, may have serious side effects.

There are three categories of side effects: Short term side effects, chronic or persistent side effects, and side effects that emerge over time.

Short-term side effects are problems that arise as soon as you start the drug but often subside over time — usually within days or weeks. Rashes, vomiting and jaundice are examples. Sometimes these are called 'induction' side effects, because they occur as your body adjusts to the new medication, and they can be intense, so speak to your doctor if you are experiencing them. The key to managing side effects is to be forewarned by your doctor about what to expect, so that you can then organise to be supported through them; taking time off from work or caring responsibilities if possible. In some cases there may be other medications you can take to reduce the severity of certain side effects.

Persistent side effects are those that are ongoing while taking a particular drug or drugs. They either need to be controlled by other medications or, if the side effects are unendurable, you need to change your antiretrovirals. Diarrhoea is a common example of a persistent side effect that is treatable, and another is changes in your central nervous system (disturbed thinking, feeling 'nervy' and

How much do I need to know?

Different people have different attitudes to medicine. Some women want to be partners in their care, and feel empowered by understanding what is going on with their treatment. Other women just want to be able to trust that their doctor will make the right decisions about treatment without having to think about it at all. Some women switch between these two extremes depending on what is going on with their health and what is going on in other aspects of their lives.

The list for minimalists

- You need to be having your CD4 cell count and viral load monitored every three to six months if you are not on treatment;
- You need to have your CD4 cell count and viral load monitored regularly if you are on treatment;
- You need to have Pap smears every 12 months (or six monthly if you've previously had abnormal cells detected);
- You need to take antiretroviral drugs exactly as directed;
- You need to consult your doctor if you are having trouble with your treatment – experiencing unacceptable side effects or having real trouble taking the pills as directed;
- Tell your doctor about any medicines, vitamins or herbs that you take regularly or occasionally;
- Do not take any preparation containing St John's Wort if you are taking antiretroviral drugs;
- You need to see your doctor if you are planning pregnancy to discuss the best way forward for you;
- You need to see your doctor immediately if you become pregnant and have not got a pregnancy management plan in place;
- Wear sunscreen. Recent research shows that people with HIV have a higher risk of skin cancer;
- Stop smoking;
- Eat well, exercise and maintain a healthy body mass index.

Short-term	Persistent	Emerging over time	Management
Jaundice (with atazanavir)			<ul style="list-style-type: none"> Stay well-hydrated Talk to your doctor about medication options
Rash			<ul style="list-style-type: none"> Report all rashes to your doctor: Some are mild but others may be serious and require medication cessation Use non-soap, non-scented cleansers Avoid very hot showers or baths Protect rashes from sun exposure
Diarrhoea	Diarrhoea		<ul style="list-style-type: none"> Replenish fluids to avoid dehydration Consider anti-diarrhoea medications like lmodium Eat food high in soluble fibre (fibre that absorbs liquid) Avoid milk products, greasy or sugary foods and foods with insoluble fibre (like skins of fruit and vegetables) Codeine-containing painkillers can help
		Anemia	<ul style="list-style-type: none"> Have red blood cell count checked every three months Diet can help: Animal sources of iron are meat, fish and poultry, non-animal sources are dark leafy greens, asparagus and lima beans Stop taking drugs associated with anaemia and switch to something else Moderate anaemia responds to medication while severe requires a blood transfusion

Short-term	Persistent	Emerging over time	Management
Headache	Headache		<ul style="list-style-type: none"> Over-the-counter pain killers like aspirin, paracetamol, ibuprofen, codeine For relief - Rest in a dark, cool room; placing something cold over the eyes; massaging the base of the skull and temples Avoid headache triggers like caffeine, chocolate, red wine, lots of citrus fruit, food additives like MSG, cheese
Nausea/vomiting	Nausea/vomiting		<ul style="list-style-type: none"> Eating simple foods like bananas, rice, cooked apple and dry toast Herbal teas, particularly peppermint, chamomile and ginger Maintaining hydration if you are vomiting Avoiding hot, spicy or greasy foods Avoiding a completely empty stomach (nibbling dry crackers before getting out of bed and having them during the day as necessary) Anti-nausea medication
		Changes in body fat distribution (lipodystrophy) and blood fats	<ul style="list-style-type: none"> Fish oils can help control blood fats Medications can help control abnormal fats Treatment breaks have had limited success in reversing body fat changes, and may expose you to the risk of disease progression and death Switching drugs have limited success in reversing changes.

nightmares), which usually is not treatable.

Long-term side effects (sometimes called long-term toxicities) are those conditions that develop over a long period of time using a particular drug or drugs. Examples of this are peripheral neuropathy (a kind of nerve damage) and lipodystrophy (a fat distribution problem which can lead to changes in your body shape).

There are some side effects which are short term in some people (or with some drugs), and persistent in others. You may not know until you have been on a drug for about a month whether the side effects will subside or persist. If side effects persist and you and your doctor can't come up with effective ways of managing them, you will need to switch to different drugs.

Vomiting

If you vomit within an hour of taking your medication, take another dose as your body will not have absorbed the ARV (make sure you include all relevant medications). If you vomit more than an hour after taking your medication you don't need to take another dose.

Before going onto any antiretrovirals, you should make sure your doctor is clear with you about potential side effects. Ask your doctor for written information if possible. If you are concerned, ask whether you can also be given something to have on hand in case you experience one of the more common side effects (like diarrhoea).

The question of long-term side effects is more difficult. Some of the recent research in women has shown that

women who are overweight before commencing ARV are more likely to experience changes to body shape caused by fat accumulation, this long term side effect is associated with using some HIV treatments, especially protease inhibitors. Being in a healthy weight range for your height is a useful health goal for any woman, but it is not certain that it will protect you from unwanted fat accumulation.

Side effects you may experience

When you are on antiretroviral treatment you may experience:

- no side effects;
- mild or unpleasant side effects;
- difficult but manageable side effects;
- side effects you are unable to tolerate;
- serious side effects (rarely).

Two out of three women will experience some side effects.

The most common side effects experienced by women

- tiredness
- nausea
- vomiting
- diarrhoea
- muscle pains
- headaches
- changes in menstrual patterns
- skin rashes
- nightmares
- peripheral neuropathy (tingling and numbness in hands and feet)
- changes in body shape (lipodystrophy)
- changes in blood sugar and cholesterol levels

Coping in the first few weeks

Side effects may be difficult to manage at first but some of them are really time-limited and disappear after a period of several weeks or up to two months. Because the first two weeks on a new treatment are the most difficult, you might consider planning to take time off work or organising childcare. Talk to your doctor in detail about what to expect and which side effects are known to settle, and which side effects tend to be ongoing.

Some side effects may occur because your combination therapy is interacting with other drugs you are taking. Make sure that you have told your HIV doctor about all the other drugs you use, including vitamin and herbal supplements and recreational drugs.

Lipodystrophy (changes in body shape)

A significant side effect linked to antiretroviral treatments is a condition known as lipodystrophy. The term refers to the unusual or abnormal distribution of fat throughout your body and is linked to particular classes of drugs – protease inhibitors are associated with fat accumulation (lipohypertrophy, where fat accumulates around the trunk of the body, the breasts and sometimes the upper back) and nucleoside reverse transcriptase inhibitors are linked with lipoatrophy (fat loss from limbs, face and buttocks).

Increasingly the two patterns of fat changes (loss in some areas and gains in others) are seen as distinct. Not everyone taking drugs from these classes will get the conditions (the estimation is

that about 20% of people with HIV will experience this, and women are more likely to than men), and certain drugs are more closely associated with the conditions than others. Fat accumulation tends to appear more quickly than fat loss, but both syndromes tend to emerge relatively slowly.

The strongest associations with specific drugs are d4T with lipoatrophy and ritonavir with lipohypertrophy. The drug d4T is very rarely prescribed now in Australia because of this association and because there are other drugs available that can give the same antiviral control without this side effect. Ritonavir, however, is very widely used in small doses as a 'booster' of other drugs in the protease inhibitor class and fat accumulation is likely to occur over time, particularly if the drug that ritonavir is boosting, is also associated with changes in fat distribution.

Older protease inhibitors such as indinavir, nelfinavir and saquinavir are also associated with fat accumulation, while the older nucleoside analogues including AZT and ddI are related to fat loss. If you are taking any of the drugs in this list you may want to be monitored for signs or symptoms of body fat changes. The NNRTI drug efavirenz has also been associated with lipodystrophy, particularly with breast enlargement.

Recent research shows that lipodystrophy appears to be more prevalent in women than in men and arguably the negative effects of changes in body and face shape are experienced more acutely, because such societal emphasis is placed on women's appearance. The fat accumulation associated with protease

inhibitors may increase fat deposits around your trunk and sometimes on the back of the neck, and breasts can become enlarged. At the same time you may lose fat from your arms, legs, bottom and face. This can be distressing. The physical appearance of lipodystrophy may be mild, moderate or severe.

While the exact mechanisms that cause lipodystrophy are imperfectly understood, the changes are not simply cosmetic, but are accompanied by underlying metabolic changes in the way that the body processes fats and sugars. There is evidence that this increases women's risk of cardiovascular disease (heart attack and stroke). Women who are taking anti-HIV drugs associated with fat accumulation and higher levels of fats in the blood (lipids) need to be monitored and a change of HIV drugs or specific lipid-lowering agents may be required. If you are taking protease inhibitors, ask your doctor to regularly monitor your blood fats, glucose and cholesterol levels for any changes.

Regarding the processing of sugar, the evidence is less clear. Women with HIV taking treatments have high rates of blood sugar abnormalities (such as insulin resistance and diabetes mellitus) but recent studies show this to be linked with body shape and traditional risk factors like being overweight or obese and having a family history of abnormalities rather than HIV treatments themselves.

Managing lipodystrophy

The first step in managing lipodystrophy is to consider changing your HIV drugs. Which drugs you change to will be determined by your past HIV drug history and any resistance or

intolerance that you might have. However, there are some agents that have significantly better profiles in terms of avoiding lipodystrophy than others.

There is evidence that switching to a protease inhibitor-sparing regimen or switching to the newer protease inhibitor atazanavir, can reverse some of the metabolic disorders associated with lipohypertrophy (fats in the blood). For fat loss, switching from d4T to abacavir and/or tenofovir may be effective. AZT causes fat loss to a lesser extent than d4T, but both AZT and ddI are nevertheless associated with the fat loss syndrome to a degree. In the NNRTI class, nevirapine is not associated with either lipodystrophy or lipohypertrophy, while efavirenz is associated with increasing lipids, though to a lesser extent than the protease inhibitors.

Taking medication to reduce lipids can be very effective in reducing harmful levels of fats in the blood, even while you continue taking the protease inhibitors that increase lipid levels. There is some evidence that fish oils too can be helpful for blood fats. However, neither fish oils nor additional medications have been shown to reverse the physical appearance of body fat accumulation to date.

Research in this area is ongoing, so if you have experienced changes in your body shape you should talk to your doctor about the most up to date research and put a treatment plan together. However, long-term avoidance of ARV is not a good option, as not treating HIV when you need to can be life-threatening.

Lifestyle factors are also really important

in reducing cardiovascular risks. So being physically active, not smoking and reducing dietary intake of 'bad' cholesterol (LDLs or low density lipoproteins) and increasing 'good' cholesterol (HDL or high density lipoproteins) all have important roles to play – this means eating more olive oil and omega-3 fish oils, and less animal fat.

Diet and exercise alone, however, have not been shown to significantly improve body shape changes associated with lipodystrophy in clinical studies. Although common sense suggests that increasing lean muscle mass and decreasing fat might mask some of the changes (we all also know that doing this is a lot easier said than done.) Being overweight or obese appears to increase the likelihood of experiencing lipodystrophy for women.

Drug resistance

When HIV reproduces, it makes thousands of copies of itself. Some of these copies can have mistakes or 'mutations', and these changed copies will go on to reproduce further copies of themselves. Sometimes, HIV changes in such a way that it can escape the control of antiretroviral drugs. These copies can then go on multiplying, unchecked by the drugs, leading to a whole new population of virus which is resistant to one or more of the drugs in your combination.

You may be able to change to another combination that can work against these resistant copies of HIV. In some cases the HIV in your body can develop resistance to other drugs belonging to the same group. This is called cross-resistance.

Avoiding resistance

It is more difficult for HIV to become resistant to drugs if they are taken at the right time and in the right amounts every day. This is because the drugs need to get into the body at optimal levels to fight the virus effectively. Most importantly, do not miss doses of your drugs.

Certain types of foods can also affect drug levels or eating patterns, so if your drugs have specific requirements related to diet or meal times, it's important to observe them.

Missing doses or sporadically stopping and starting therapy can seriously increase the risk of resistance. It is important that you do not stop taking any antiretroviral drugs without discussing it with your doctor because there is a danger that your body will develop resistance to drugs that you have been using.

Stopping therapy

There has been considerable research into the effects of stopping anti-HIV treatment for periods of time, often called 'structured treatment interruptions'.

When treatment is stopped, viral load begins to rise and CD4 cell counts fall. Recent research has shown that if your CD4 cell count is in the vicinity of 250-350 stopping therapy significantly increases the risk of having an AIDS-defining illness or dying. In addition, taking treatment breaks may in fact increase, rather than decrease the risk of side effects, including serious side effects such as heart attack and stroke (cardiovascular disease).

There is also a risk of developing drug resistance if you stop taking drugs in an unplanned way, as HIV drugs stay in the body for varying periods of time (nevirapine and tenofovir, for example, stay in your body for a long time after dosing with levels dropping very gradually). If you have only one drug in your system, you are applying selective pressure to HIV that quickly results in resistant strains emerging that can affect your response to drugs in the future.

If you are experiencing side effects

If you are finding treatment side effects very unpleasant, you may be considering stopping or changing therapy. Research now indicates that stopping treatment should be a last resort that might further damage your health.

Some side effects are most pronounced for the first weeks of taking a particular treatment, some are persistent, and some emerge over time (abnormal fat metabolism), so it is important to determine where your particular side effect fits into this scheme, to work out how best to deal with it.

Stopping therapy and then re-starting with the same agents is unlikely to be an effective strategy with any side effect, and if it is the kind of symptom that tends to disappear over time, it will worsen the problem.

For side effects that emerge in the long term, such as changes in fat metabolism and body shape, taking a short pause in therapy is not going to reverse the conditions and taking a longer treatment break could be very

dangerous for your health. Substituting other ARV drugs is the best approach. If drug resistance or drug intolerance limits your anti-HIV drug options there are other drugs that can reduce side effects like high levels of fats in the blood.

Financial reasons

If you are under financial stress, as women with HIV frequently are, it can be hard to find the co-payment for combination ARV. If this is happening to you, you are not alone, but it is an indicator that you might need some help organising your budget so that your health needs are not last on the list. For example, you may be able to pay off utility bills slowly to find the cash for your ARV. There are also financial assistance programs for which you might be eligible, such as the Bobby Goldsmith Foundation (NSW) or the David Williams Fund (Victoria). Call your local AIDS Council, PLWHA organisation or positive women's group for information.

Changing therapy

No-one should have to live with unbearable side effects.

When changing drugs, it is important that you switch to a regimen that still maintains antiviral potency.

While there are broad classes of antiretroviral drugs, each agent is slightly different to the others, and certain drugs are more likely to cause particular side effects than others. Some people are more sensitive to drugs that place particular stresses on the body, such as people with pre-existing liver or kidney complaints.

There is now evidence that changing drugs can make a significant difference to side effects, including long-term ones like lipodystrophy.

Salvage therapy

Salvage therapy is the term used for treatment regimens designed for people who have experienced detectable viral load on different treatment combinations due to drug resistant HIV. This is an area where creative combinations of new and old drugs can be tailored for individual requirements, and where research is ongoing. Every major HIV conference announces new strategies to help people who are highly treatment experienced, and you or your doctor can keep abreast of new developments through the excellent websites listed on page 11.

Joining a clinical trial can be a good way of getting access to new drugs for salvage therapy if you are in this position.

Women and clinical research

Clinical research is the study of medicines in the human body. Men outnumber women overwhelmingly as participants in clinical research, and this is to women's disadvantage — there are significant differences in men's bodies and women's, so women need to be involved in research to ensure that there is good, unbiased information about how drugs work in our bodies.

A lot is known about the ways to reduce viral load in the human body to prevent the immune deficiency, opportunistic infections and death. However, there are still some grey areas: It is still not known when the best time is to start treatment, what the best drug combination is, and how best to reduce side effects for all people. In instances where there is no direct evidence as to what would be the best possible treatment for your individual situation, your doctor may suggest that you could participate in a clinical trial. It is very important that the research is explained very clearly to you, and that you have the opportunity to discuss it with other people such as a treatment officer at an AIDS Council or PLWHA group.

A clinical trial is used to test the safety and effects of new drugs, combinations of drugs, and/or drug dosing strategies.

The point of a trial is that the outcome is uncertain — it is hoped that the new agent will offer an improvement, or that a new strategy will offer benefit, but no-one knows for sure.

Access to experimental drugs

Participating in clinical trials can give you access to experimental drugs that look better – more potent, less inclined to cause side effects – than currently available drugs. On the other hand, there is a gamble involved, and experimental treatments can turn out to have unexpected problems associated with them, or to suppress HIV less effectively than established treatments.

Participation

It's important if you are considering participating in a clinical trial that you understand what it will mean for you. The trial may involve extra medical appointments, and you may be eligible to be reimbursed for travel expenses and childcare. There may be a greater number of blood tests than you would usually have. You always have the right to have any procedures fully explained and you do not have to consent to anything that makes you uncomfortable.

Barriers to participation in clinical research for women can include time, commitment and location. Mostly trials are conducted in most major capital cities, and participation may involve more frequent visits to the doctor than usual. Issues like childcare are increasingly considered, as carer responsibilities are recognised more by researchers and advocates for positive women.

Women, and people of diverse races and ethnicity living with HIV, need to be represented in HIV research to get a true picture of the way that treatments work in different bodies and different lives.

Women's participation in clinical research helps other women worldwide with their treatment decisions.

Women, and people of diverse races and ethnicity living with HIV, need to be represented in HIV research to get a true picture of the way that treatments work in different bodies and different lives.

Sex

You have the right to pursue a happy, safe and fulfilling sex life. That means being free to enjoy a range of sexual activities, and being free to not have sex, with the partner or partners of your choice.

Protecting your sex partners from HIV acquisition, means using condoms and water-based lubricant when you have vaginal or anal sex with men.

Using condoms and lubricant also protects you from sexually transmissible infections (STIs) that can compromise your health and fertility. Men transmit most STIs more efficiently to women than women do to men, and many STIs like Chlamydia can be asymptomatic, so a person may have it and pass it on without knowing. If either you or your partner has an STI the risk of HIV transmission is increased. If you have an STI it is likely to increase the levels of HIV in your vaginal fluids. If your partner has an STI, his or her body's inflammatory response to an infection increases the range of target cells for HIV entry.

Safe sex also means thinking about hepatitis C (HCV) transmission. Having HIV and HCV together makes it more likely that you can transmit HCV to your partner through sex. If you don't have HCV but your partner does, your HIV status makes you more vulnerable to acquiring HCV. See the section on hepatitis C for more information.

Common infections increase transmission risks

Any infection that you have in the genital tract such as thrush (candida), herpes, chlamydia, gonorrhoea or syphilis can increase your viral load in your sexual fluids, making HIV transmission more likely. Similarly, if your HIV-negative partner, whether male or female, has a genital infection it makes them more vulnerable to HIV infection. Sexual health screening and prompt treatment for any sexually transmissible infection is important for your sexual health, and for your partner.

Lubricant and condoms

It's important to use water-based lubricant with condoms, as without it, they are more prone to breaking. Using lubricant when you have sex can also facilitate your pleasure. If you are having sex with a man, using water-based lubricant helps reduce friction and make the condom work optimally. If you are using a dental dam or other barrier for oral sex, the lubricant goes on the genital side, and the mouth on the non-lubricated side.

NEVER use oil-based lubricants like Vaseline, papaw cream, hand cream or other substances as these can weaken the latex. In addition, they are not good for the vaginal mucosa, as they can clog its self-cleansing mechanisms.

NEVER use two condoms at once – this can cause friction and make condom failure (splitting, tearing or falling off) more likely.

Oral sex

Oral sex (where you partner uses his or her mouth on your clitoris and genital area) is considered safe regarding transmission of HIV. Vaginal fluids are relatively low in HIV concentration, and the mouth has very good protective immune mechanisms, including saliva. Sexually transmissible infections such as herpes and gonorrhoea, however, can be transmitted through oral sex.

There have been no documented cases of transmission of HIV from

vaginal fluid in the mouth, but there may be some risk in exceptional circumstances, such as when you have your period and your partner has an open mouth wound, or an open ulcer or lesion in or around the mouth. As a general rule, don't let someone go down on you with a cold sore or ulcer unless they use a barrier, as they may transmit something to you – such as herpes, and the risk of you transmitting HIV to him or her also increases.

Latex sheets known as dental dams or condoms slit length ways have sometimes been advocated for 'safe' oral sex, but these are considered unnecessary in terms of HIV prevention (the exception here is in the occupational context for sex workers, who often seek to minimise any microbial contact by using barriers as much as possible).

There is no risk of HIV acquisition for your partner/s if you perform oral sex on them.

Menstruation and sex

Menstrual fluid is made up of blood, uterine tissue and other substances, and it does contain HIV, although there has been little research about the levels of virus present. It is possible that there are increased risks of HIV transmission during menstruation, so barrier protection such as condoms and lubricant are particularly important.

- Using a diaphragm prevents menstrual blood entering the vagina;
- Using a tampon or a sea sponge can be helpful if you want to have

oral sex during your period, but bear in mind that there may be traces of blood present;

- For women who have hepatitis C, it is particularly important to prevent others having contact with your blood as HCV is more readily transmissible than HIV. HCV is readily transmissible through blood.

Circumcision

Male circumcision is a surgical procedure that involves the removal of all or part of the foreskin from the head of the penis.

It has been known for many years that men who have a foreskin (i.e. they have not been circumcised) are at greater risk of acquiring HIV from women via vaginal (and anal) intercourse. **Recent studies in Africa** have shown that circumcising men reduces their risk of contracting HIV from women by about 60%. As a result, circumcision is now being advocated in those countries with a high prevalence of HIV, and predominantly heterosexually spread.

However, **circumcision is not currently being promoted at a population level, in countries such as Australia, because HIV is predominantly spread amongst men who have sex with men.**

However, circumcision is something an HIV positive woman and her HIV negative partner may wish to consider, in which case it is recommended that you discuss this with your doctor.

Fingers

In the absence of open wounds or cuts, sexual play using fingers on the clitoris or in and around the vaginal and anal

areas is safe for HIV. However, fingers that have been in or around the anal area should be washed before going into the vagina to prevent the development of a urinary tract infection (UTI). Bacteria from the rectum can easily travel up the urethra, because it is located near the rectum in women, and can cause infections in the bladder.

Sex toys

Sex toys swapped between people without thorough cleaning can transmit a range of infections (vaginal fluids, blood or faeces could be present). There has been one case of an HIV transmission reported in 2003 through this route (blood was on a sex toy that was shared between female lovers). Alternatives to cleaning between partners are covering the toys with condoms and changing them with each person, or each having your own toys and ensuring they don't get mixed up.

S&M

Any play that involves the contact of a vulnerable surface (vagina, anus or broken skin) with someone else's blood or semen or vaginal fluids poses a risk of HIV infection. Never re-use any equipment without careful cleaning.

Fisting

Fisting is where the whole hand is inserted into a vagina or anus. Fisting cannot transmit HIV unless there is an open wound on the hand of the fister. However, vigorous fisting may cause abrasions or tears in the vaginal or anal walls which may increase the risk of transmission in subsequent unprotected

Cleaning of sex toys and sex-related equipment

- Firstly, clean using detergent, water and scrubbing or wiping all surfaces.
- To disinfect after cleaning, rinse and immerse either in a mixture of one part bleach to two parts water or 70% alcohol, then rinse and allow to dry before reuse.
- For toys like vibrators that can't be immersed, wipe with detergent and water, rinse, then disinfect by wiping either with a solution of one part bleach to two parts water or 70% alcohol.

sex. For example, if the vagina is bleeding and you subsequently have unprotected sex with a man, it increases his risk of becoming HIV positive. Using plenty of water-based lubricant helps prevent injury and to make the experience smoother, some people opt to use latex gloves for fisting.

If you think your male partner has been exposed

If you have had unprotected sex (penetrative sex without a condom) with a man, he is at risk of HIV acquisition. There is a course of treatment that he can take that will minimise the likelihood of acquiring HIV. This is called post-exposure prophylaxis (PEP).

How do you get PEP (post-exposure prophylaxis)?

Your partner needs to go a medical centre or emergency department of

a hospital and ask for PEP. Treatment is more effective the sooner that it is begun. It must be commenced within 72 hours. (There is a national list of services where PEP is available at www.getpep.info. Alternatively, phone the freecall hotline in your State or Territory: NSW 1800 737 669; Victoria 1800 889 887; South Australia 1800 888 559; Tasmania 1800 005 900; and Western Australia 1300 767 161).

Your partner will be assessed for risk and then prescribed a regimen of antiretroviral drugs for a period of four weeks. You may be asked to provide information about your CD4 count, viral load and details of your past and current antiretroviral use, if any. You may also be asked about any current sexually transmissible infections and results of any HIV resistance tests you have had. These details are used both to calculate the risk of transmission to your partner, and to ensure that he gets the optimal antiretroviral drugs for his individual situation.

If you think your female partner has been exposed

While transmission between female sex partners is rare it is not impossible. If you have had sexual contact where your blood or sexual fluids is likely to have entered her bloodstream, then she may wish to access treatment that will minimise the likelihood of acquiring HIV. This is called post-exposure prophylaxis (PEP). See above for details.

Low libido (sex drive)

Sex drive varies from individual to individual, and can fluctuate according to daily stresses, tiredness, health, hormonal changes and relationship status (the first flush of new love, for example, has a way of firing up the libido considerably!). Some women describe the shock of an HIV diagnosis as having a severe impact on libido, but adjusting to the diagnosis and gaining confidence about how to have sex without risk of transmission can improve this.

A range of medication commonly taken by women with HIV can also reduce libido – many people taking ARV have reported changes in sexual feelings, but there is not clear evidence showing that the drugs cause it. Antidepressants, however, are commonly used by people with HIV and are linked with reduction in sexual desire, difficulty getting an erection in men, and difficulty having an orgasm in women. Not all antidepressants cause this to the same degree, so chatting frankly to your doctors about the pros and cons of different drugs is worthwhile. Of course depression itself can cause low libido, and antidepressant treatment may actually then lead to an improvement in libido.

Hormonal contraceptives can also impact on libido, so getting advice on switching brands or changing to barrier contraception also may be a good idea, if you are bothered by low libido.

Low testosterone (a male hormone that women also have in smaller quantities) can be a cause of low libido and women can be treated successfully with testosterone in very low doses, however the concern is that too much can have 'masculinising' side effects.

- HIV can only be transmitted when there is a way for the virus to enter into your partner's bloodstream or lymphatic system, where HIV is present in a high enough quantity for infection to occur.
- The risks of HIV transmission increase when either of the sexual partners has any kind of sexually transmissible infection.
- The risks of transmission also increase when a person has very recently been infected with HIV (primary infection).
- Using condoms and lubricant for sexual intercourse (whether vaginal or anal) protects your partner from acquiring HIV. Sexual intercourse without condoms and lubricant is the most likely route of sexual transmission from a woman to a man, whereas other forms of sex are relatively safe.
- If your partner has open wounds, cold sores (herpes simplex) or has had very recent dental surgery, or if you have genital ulcers or lesions, you need to consider using barriers for oral sex, or not having oral sex until your partner's wounds have healed.
- If you practice S&M activities that might draw blood you need to ensure that all equipment is properly cleaned and disinfected after use, and not shared.

Contraception and ARV

Using condoms with water-based lubricant when you have sex with a man prevents HIV transmission, protects you from unwanted pregnancy and from most sexually transmissible infections.

But what if your partner is positive? What if you forget to use one, or if it slips off or breaks?

Women with HIV, like other women who are sexually active with men, benefit from being able to choose from a range of contraceptive options.

Condoms and lubricant provide an effective barrier against HIV transmission and against other sexually transmissible infections that can affect your sexual health, but in some instances you may need other options either for emergency contraception, or as an alternative to condoms.

Contraceptives prevent pregnancy in a variety of different ways, and these can be divided into four broad groups: Barrier methods, devices that are inserted into the womb (intrauterine), hormonal contraceptives and surgical interventions.

Barrier methods

Barrier contraceptives use a physical shield to prevent the male sperm meeting the female egg: this group comprises standard condoms that fit onto the penis, female condoms that fit into the vagina, and diaphragms and cervical caps which are inserted through the vagina and fitted over the opening of the cervix.

Standard condoms are widely available through supermarkets, chemists, vending machines and sexual health services, and they are often given out for free at gay community events. They are estimated to have a 5-10% failure rate for pregnancy, according to the Australian FPA Health website: www.fpahealth.org.au/sex-matters/factsheets/23.html, but are very effective if used properly with water-based lubricant.

Diaphragms and caps

Diaphragms and caps need to be expertly fitted by a doctor initially, and from then on are self-inserted. Both diaphragms and caps are rubber devices that fit over the cervix, and there are two different versions of each. For detailed information about how these devices are different and how they are inserted, see www.fpahealth.org.au/sex-matters/factsheets/53.html

The effectiveness of diaphragms and caps as contraceptives is hard to measure, as it depends on many factors such as remembering to use the device, and positioning it correctly. 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.

There is no added contraceptive benefit in using spermicide with diaphragms or caps.

Female condoms

'Female' condoms (Femidom) might be a good option for women with HIV, but they are not readily available in Australia as they are not popular and have a use-by date. They can be ordered over the Internet, however, and are available at some sexual health clinics. Female condoms are slightly less effective at preventing pregnancy than male condoms: 95% effective compared with 98%. This is comparable to the efficacy of the diaphragm or cap.

The main disadvantage to barrier contraception is that to be effective it needs to be used, and used correctly, each time sexual intercourse occurs. Many find this onerous. In instances where barrier contraception fails, or when it is not used, emergency hormonal contraception (the 'morning after' pill) or an IUD can be used as a back up. (Although the old-fashioned IUD may not be such a good option for women with HIV because of the menstrual and other pelvic problems it can cause.)

Sex between HIV-positive couples

Whether or not to use condoms and lube if your partner is also HIV positive is a matter of personal choice.

Condoms provide the only really effective barrier against HIV and against sexually transmissible infections including the spectrum of warts viruses that can cause pre-cancerous and cancerous cells in the cervix. Women with HIV are more susceptible to pre-cancerous changes, so this is an important consideration, especially if a male partner is or may be sexually active with others.

In instances where both partners are HIV positive and neither of you is having sex outside your relationship, you may prefer not to use condoms at all for contraception. This does involve some risks.

There have been some documented cases of 'super-infection', where a person already HIV positive gets infected again, with a new strain of HIV by his or her sexual partner, which might hasten disease progression. There are a handful of cases in the scientific literature where superinfection is proven to have occurred, and as detection of superinfection is quite complex, some experts believe it happens more frequently although there are no data to support this. Superinfection has not been documented when couples are taking treatment, but there is a concern that if it did occur, people could transmit drug-resistant strains of HIV that could have serious health consequences. It has been theorised that superinfection is most likely to occur shortly after seroconversion, but again, this has not been proven.

In a nutshell, it is possible that condomless sex between people with HIV carries some risk (which can't be

quantified), but it's likely that if both are on HIV treatments that suppress viral load to undetectable levels that the risk is minimal.

Hormonal contraception

Hormonal contraceptives work by altering your body chemistry to prevent ovulation (the release of eggs that can be fertilised by sperm) and/or to thin the lining of the uterus to prevent the implanting of a fertilised egg and thicken the cervical mucus to provide a barrier to sperm (some progesterone-only preparations do not prevent ovulation). Major advantages of hormonal contraception are that it is woman-controlled and that it requires no administration at the time of having sex. Hormonal contraceptives can be taken as daily tablets (the Pill), as patches, as implants under the skin, as periodic injections or as emergency contraception - the 'morning after' pill. A hormone-releasing contraceptive device can also be inserted into the womb.

There is some evidence that hormonal contraception can increase HIV 'shedding' in your genital tract (vaginal region), so if your partner does not have HIV, you may want to discuss how this may affect his or her risk of acquiring HIV with your doctor.

The convenience of hormonal contraceptives is unparalleled for women who don't experience side effects. There are some potentially serious associations to consider, however, and smoking increases these risks considerably.

Risks with hormonal contraception

Hormonal contraceptives increase your risk of cardiovascular disease (heart disease and stroke) that may be of particular concern for women who have high levels of lipids (fats in the blood) caused by anti-HIV medications.

The combined Pill is formally classed as carcinogenic as the incidence of liver, breast cancer and cervical cancer is increased in women taking it. The risk of getting breast cancer increases by 24 % in women taking the Pill. This may be a matter of concern particularly for women who have other risk factors as well, such as having a strong family history of the disease or having identified that you carry one of the genes associated with breast cancer. On the positive side, women taking the combined Pill are less likely to get ovarian or endometrial cancer as there is a protective effect. Weighing up the risks of these serious medical conditions is something that needs to be discussed in detail with your doctor when you are planning your contraception.

Side effects with hormonal contraception

Side effects include weight changes, breast tenderness, mood changes and an increased risk of blood-clot formation. Obesity, a family history of blood clots, long-term immobilisation and varicose veins are associated

with a greater risk of side effects, and if more than one of these factors applies, the combined Pill should not be used (see page 46-47 for the different types and delivery systems of hormonal contraception).

Some women experience quite pronounced side effects with longer-lasting contraceptives like the implants and injectable forms. These side effects may include changes to menstrual patterns.

ARV interactions with hormonal contraception

A major problem for most hormonal contraceptive products is that many anti-HIV medications interact with them, reducing their efficacy (see table 1). This includes the non-nucleoside reverse transcriptase inhibitors, nevirapine (Viramune) and efavirenz (Sustiva) and the class of protease inhibitor drugs with the exception of indinavir (Crixivan).

There are two ARV that increase blood levels of contraceptives: indinavir and delavirdine, however delavirdine is not licensed in Australia and indinavir is an increasingly unpopular drug owing to the complexities of its dosing requirements and its side effects.

The only hormonal device that states it is not affected by medicines taken at the same time is the hormone-release device that is inserted into the womb, known as the intrauterine system (IUS) or Mirena.

ARV that reduce levels of hormonal contraceptives

Drug	Affect on hormonal contraception	Advice
Nelfinavir (Viracept)	Reduces oestrogen and progesterone content ⁴	Do not use with hormonal contraceptives - significant association with contraceptive failure
Ritonavir (Norvir)	Reduces oestrogen blood levels ⁵	Dosage increase or alternative contraception used
Efavirenz (Stocrin)	Not fully studied	Do not use with hormonal contraceptives. ⁶
Nevirapine (Viramune)	Significant decrease in blood levels of both oestrogens and progesterones ⁷	Use barrier contraception in addition or as an alternative to hormonal contraception
Saquinavir (Invirase, Fortovase)	Reduces oestrogens ⁸	Do not use with oestrogen-based contraceptives (combined Pill or patch)
Kaletra (lopinavir/ritonavir)	Both lopinavir reduces both oestrogens and progesterones; ritonavir reduces oestrogens	Use barrier contraception in addition or as an alternative to hormonal contraception
Atazanavir (Reyataz)	Increases progesterone and oestrogen concentrations; "May affect safety and effectiveness" of oral contraception or patch.	If used in combination with ritonavir, may decrease concentrations of contraceptive hormones - alternative contraception preferred.

³ Clark et al J Acquir Immune Defic Syndr 37, 1, September 2004 pp 1219-1220.

⁴ Reduces norethindrone (progesterone) levels by 18% and ethynyl estradiol (oestrogen) levels by 47%.

⁵ Reduces ethinyl estradiol (oestrogen) levels by 32-40%.

⁶ In a retrospective study of 2053 women there were two apparent contraceptive failures for women taking efavirenz. As efavirenz is also associated with birth defects, contraceptive failure is particularly important to avoid.

⁷ Based on evidence examining a single dose of an oral contraceptive containing ethinyl estradiol (0.035 mg) and norethindrone (1.0 mg).

⁸ One of the 11 women in a retrospective study who conceived while on hormonal contraception was taking saquinavir (Clark 2204).

ARV, hormonal contraception and the risk of unplanned pregnancy

It is difficult to say how great the risk of unplanned pregnancy is when taking ARV that interacts with hormonal contraception. One retrospective study³ (a study that looks back at medical records) found that 10 women out of 2053 fell pregnant while taking hormonal contraception. Ten of these were taking the Pill (brands not recorded), and one was taking Depo-Provera (ARV not recorded). Of the failures on the Pill, eight women were taking nelfinavir, one saquinavir and two efavirenz. Nelfinavir was found to significantly increase the risk of contraceptive failure, so this agent should be avoided if taking oral contraception.

Types of hormonal contraception

The Pill

The Pill is the most common form of hormonal contraception. It comprises two active synthetic hormones, oestrogen and progesterone, so it is sometimes called the 'combined Pill'. The Pill is estimated to be over 99% effective in preventing pregnancy, although this may be decreased by other medicines or by gastro-intestinal symptoms like vomiting or diarrhoea. Risks of side effects are increased for smokers.

For women who are taking ARV that interacts with the combined Pill, lower dose formulations should be avoided.

The progesterone-only Pill (mini Pill)

The progesterone-only pill (the mini-Pill) contains progesterone only and is a less effective contraceptive being between 96 and 99% effective. The mini-Pill is not a good option for a woman taking ARV unless you are using one of the combinations that does not interact or unless you are doubling up with a barrier method, as it is less effective than the combined Pill to begin with, so any further dilution of potency is more likely to result in unwanted pregnancy.

The Patch

The contraceptive patch is a small (5cm by 5 cm) beige patch that is stuck onto smooth, hair-free skin that delivers a combination of synthetic hormones oestrogen and progesterone into the blood stream, like the combined Pill. If used correctly, it is 99% effective. The patch needs to be changed weekly for three weeks, then for the fourth week of the cycle no patch is worn and break-through bleeding occurs, which mimics a period. As the stomach does not absorb the hormones delivered by the patch, its efficacy is not affected by vomiting/diarrhoea. Unfortunately medications like antiretrovirals will affect blood levels, however.

** At the time of writing the patch has not yet been licensed for use in Australia though the application has been made to the TGA*

The injections

There are two available forms of injected hormonal contraception that provide longer-lasting protection. Injections are required only every twelve weeks for medroxyprogesterone acetate (Depo-Provera) and every eight weeks for norethisterone enanthate (Noristerat) (the latter is not available in Australia). Each product uses progesterone only. The side effects associated with the injectable form are the same as for the progesterone-only Pill, including vomiting, nausea, headache, dizziness, breast discomfort and weight changes, in addition to local reactions like bruising and itching. Women who have had severe depression are cautioned against these products. Becoming pregnant after having an injectable contraceptive may take longer (up to several months after Depo-Provera, although fertility may also return immediately), so it is not a good option for women who wish to conceive in the relatively near future. Injected contraceptives are more than 99% effective as long as injections are given at the prescribed intervals and so long as no medicines are taken that decrease blood levels of the active ingredients. For a woman taking ARV that causes an interaction with the contraceptive, the advice is to have the injections 10 weeks apart rather than 12 weekly. This is not a proven strategy, however, and the risks of contraceptive failure and/or increased side effects from the contraceptive from more frequent injections are possible.

The implant

The contraceptive implant Implanon (etonogestrel) is another progesterone-only product. This is a small rod inserted under the skin of the upper arm (about the size of a match) that slowly releases the hormone. This device provides protection for three years, but is readily reversible if pregnancy is desired or if the side effects are not tolerated. (If you do have the implant removed, you are advised to practice barrier contraception for seven days beforehand, as sperm can live inside your body for seven days).

Intrauterine system

The IUS (Mirena) is a small T-shaped device that is inserted into the womb by a doctor or trained nurse. It slowly releases the hormone progesterone. Unlike all of the other hormonal methods, this one is not affected by other medicines so it should be effective regardless of ARV regimen.

The IUS has the advantage of a local mechanism of action (within the womb) so it is unlikely to be affected by other medicines but, like other hormonal contraceptives, it has side effects. Insertion into the uterus is not going to be appropriate or acceptable to all women especially if you have a history of pelvic inflammatory disease, and some women get an infection within the first 20 days of use. However the IUS is not associated with pain and heavy bleeding for which other forms of IUD are notorious. Significant advantages of the IUS are improvement of menstrual symptoms, ease of reversibility and long lasting protection.

The IUS is also very cost effective compared with oral contraception (the Pill and mini-Pill).

Unlike other intrauterine devices (IUD – formerly called coils) that can cause heavy bleeding and particularly painful periods, the IUS can improve difficult menstrual symptoms, often making periods lighter and less painful. Fertility quickly returns upon removal.

Side effects include some irregular bleeding, spotty skin and headaches for the first few months. Harmless cysts may also form on the ovaries.

Emergency contraception

The ‘morning after Pill’ can be used after a barrier contraceptive fails (a condom comes off, or a diaphragm or cap was incorrectly placed) or if no contraception was used. It consists of a high dose progesterone-only Pill – actually two pills taken together at the same time within 72 hours of unprotected intercourse. If taken within 24 hours it prevents 95% of pregnancies. It is available in pharmacies and some sexual health clinics.

The ‘morning after Pill’ is affected by ARV drugs in the same way that other oral contraceptives are, so for women taking combinations including agents that lower the blood levels contraceptives (in table 1), it is likely to be less effective. In addition, the longer after intercourse that the pills are taken, the less protection is given. Emergency contraception may stop ovulation or fertilisation of an egg, or stop a fertilised egg from implanting. It does not cause an abortion.

For women needing emergency contraception who are taking ARV that interacts with hormonal contraception, getting some individual medical advice about whether the dosage should be increased is worthwhile. However, taking the pills as soon as possible is also advisable, so taking the standard dose immediately while waiting for further advice would be better than waiting, if it is impossible to speak to a doctor without delay.

If you need emergency contraception and you are outside the 72-hour window (or if you want to use the most effective option) you can have a copper IUD inserted up to five days after the unprotected sex, or five days after the earliest day upon which you may have ovulated. This is a good option if you think that you might like to use the IUD for ongoing contraception, however copper IUDs are associated with unpleasant menstrual side effects like very heavy and/or painful periods.

Intrauterine device (IUD)

An IUD is a small plastic and copper device that is put into your womb. It has one or two soft threads on the end. These thin threads hang through the opening at the entrance of your womb (cervix) into the top of your vagina.

An IUD can stay in for three to ten years, depending on type. It should only be fitted by a trained doctor or nurse. An IUD used to be called a ‘coil’.

The IUD is estimated to be about 98-99% effective in preventing pregnancy, but it provides no protection from STIs or HIV, and disadvantages include the fact that it is likely to cause heavier, more painful periods. If the device fails and

you become pregnant, there is also an increased risk of an ectopic pregnancy.

Surgical options

Both men and women can have surgery as a permanent form of contraception. For men the procedure is called a vasectomy, where 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 (‘shooting blanks’). The operation is usually done under local anaesthetic and takes about 15 minutes. However, additional contraception needs to be used for two months after the operation as live sperm can persist for some time after vasectomy. The failure rate is 1 in 2000.

For women, sterilisation involves cutting, blocking or sealing off the fallopian tubes. There are several different methods of doing this, and depending on how it is done the 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 1 in 200.

Making your choice

Only condoms offer protection from STIs including HIV and protection from pregnancy in one package, but despite these advantages, some find them difficult to use every time.

Progesterone-only contraceptives interact with a smaller number of ARV than combined products, and the 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. Again, longer lasting products are also cheaper. Caps and diaphragms can be inserted ahead of time and left in ‘round the clock’ and so can be convenient, but they have a high failure rate based in part on women forgetting whether or not they are in place.

No one contraceptive option is going to suit every woman with HIV and discussion both with your sexual partner(s) and your doctor is important to work out what will fit best with your life and your needs.

Pregnancy

Many women with HIV both in Australia and worldwide are choosing to become mothers. You are able to reduce the chances of your baby acquiring HIV to below 2% by taking ARV, considering an elective caesarean delivery, and by not breastfeeding. Without these interventions, the rate of HIV infection from mother to infant is between 24-30%.

HIV can be transmitted from mother to infant in the womb, during delivery or after delivery through breast milk. Without any treatment or other intervention, about one in four women with HIV will transmit HIV to her infant.

There are several key factors affecting the likelihood of transmission:

Your health (your viral load and your immune status), the way your baby is delivered, and the way you feed your baby. Generally speaking, the lower your viral load the less likely you are to transmit HIV to your baby. Caesarean delivery performed before you go into labour also decreases the likelihood of transmission if you have a detectable viral load.

Planned pregnancy

A planned pregnancy gives you the greatest range of options and can minimise stress, leaving you time to discuss issues with your doctor,

switch drugs if necessary or to take a treatment break prior to conceiving. It also gives you a chance to sort out your maternity leave entitlements and financial arrangements if you're in the paid workforce.

But life doesn't always go to plan, and you may find yourself accidentally pregnant.

Unplanned pregnancy

An unplanned pregnancy can range from being an unpleasant shock or a welcome surprise, with many other emotions, some of them conflicting, in between. You have every right to consider all your options.

You may want to have a baby. You may definitely not want a baby. You may want a baby some time in the future, but the timing might not be right – your 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 to continue with the pregnancy or to have a termination. You may wish to seek expert advice about HIV and pregnancy before you decide, or your decision may have nothing to do with your HIV status. Pregnancy counselling is available in all states and territories through abortion clinics, women's hospitals and GPs.

Most terminations are performed at a clinic or hospital between seven and twelve weeks after the first day of your last period. Non-surgical termination is now available in a few centres in Australia using a combination of two medications. This can be performed up to nine weeks after the first day of your last period. The abortion pill RU486 (mifepristone) is not yet widely available in Australia, though may be in the future.

If you decide to continue with the pregnancy, talk to your doctor as soon as possible about how to reduce the risk of transmitting HIV to your baby.

Pregnancy check list

- Get screened for any genital infections and, if necessary, treated. Repeat at 28 weeks if you are sexually active and your partner/s haven't been treated.
- Learn about your treatment options and make a plan, with different options in it according 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, and an obstetrician.
- Make a delivery plan with options according to how well your viral load is controlled during pregnancy.
- Have a baby shower and get lots of presents.

* Another useful resource is: "Common Threads"; *Women's stories of pregnancy, parenting and living with HIV*, by Karolyn McDonald, published 2006.

¹⁰ While monotherapy (treatment with one drug only) is generally considered a bad move as it can lead to drug resistance, this option is worth considering for women with low viral load to begin with who wish to limit both their own and their babies' ARV. This option has been well-studied in the UK and the use of AZT in this manner, in women without pre-existing AZT resistance, does not lead to high level drug resistance, though there was a 3% low level resistance reported at delivery.

Do I need to take antiretrovirals?

Taking antiretroviral drugs (ARV) reduces the likelihood of your baby becoming HIV positive, but you have some options. Many women take combination ARV throughout their pregnancies; others opt to delay ARV until after week 12. For some women, taking AZT alone after week 12 may be a fair option¹⁰. This option is not recommended as highly as combination therapy, but some women may want it after considering the risks and benefits of AZT alone compared with combination therapy. Studies have shown that AZT monotherapy for a short period in drug naïve asymptomatic women, with low viral loads and good CD4 cell numbers such as this does not lead to drug resistance, however, you should be aware that this option is not generally recommended.

It is recommended that you take combination ARV, plus AZT as an intravenous infusion during delivery and that your baby is treated with AZT for four weeks after birth.

You do not have to take medication against your will. If you choose not to take any ARV during your pregnancy or delivery however, this does increase the likelihood of your baby acquiring HIV even if your viral load is undetectable.

Whether or not you have taken any ARV during your pregnancy or during

delivery, you will be required to have your baby treated with ARV for a period of four weeks to improve his or her chance of being HIV negative (this treatment is called PEP, or post-exposure prophylaxis, and it can prevent infection by 'mopping up' infectious HIV particles to which your baby might have been exposed. It is not fail-safe, but it increases the likelihood of avoiding infection). The treatment prescribed for your baby may be AZT alone, or if you have AZT resistance, a combination of ARV.

What are the benefits of taking combination ARV during pregnancy?

The benefits of ARV during pregnancy are twofold. By reducing your viral load to the lowest possible levels you dramatically increase the likelihood of your baby being HIV negative. Combination therapy that suppresses viral load also improves or keeps stable your own immune status while minimising the opportunities for drug resistance to develop.

What are the risks and benefits of taking a treatment break for the first trimester?

Whether or not a treatment break is a good idea depends very much on your individual circumstances. The risk of a treatment break is that you might get a viral rebound (increased viral load) at a critical stage in your pregnancy, that might increase the chances of HIV transmission to your baby. This is an issue that you need to explore in depth with your doctor, weighing up the risks and benefits.

If your pregnancy is planned and you are on ARV, you can discuss the timing of a treatment break and all the available research; to assess whether the benefits of limiting ARV exposure outweigh the risks in your circumstances, with your doctor. You should then have resistance testing performed on your virus to ensure that when you resume therapy after week 12 that it is optimally suppressive.

If you discover you are pregnant while on ARV do NOT stop taking treatment (see your doctor immediately to change therapy if you are taking efavirenz).

What are the risks of taking ARV during pregnancy for my baby?

There are some theoretical risks associated with taking ARV in pregnancy, particularly in the first 12 weeks when the foetus is developing all its organs.

Throughout pregnancy both mother and baby can experience side effects from ARV like anaemia, nausea, 'laboratory abnormalities' (low-level alterations in the function of organs such as liver and kidneys that do not cause symptoms but can be measured in blood tests), or more serious physical symptoms or symptomatic changes in organ function.

Women are advised not to take efavirenz at any stage of pregnancy due to an association with birth defects.

There has been some debate about the value of interrupting ARV treatment during the first trimester of pregnancy to limit foetal exposure to drugs: Some women opt to do this, but current treatment guidelines warn that it can be counterproductive, as it can cause a viral load rebound in the second trimester of pregnancy that can increase the chances of HIV transmission. Where pregnancy is unplanned and you are taking ARV, by the time you have confirmed that you are pregnant the risks of interrupting your treatment probably outweigh any benefits, but if you are worried discuss your individual situation with your doctor.

Despite the risks, the medical consensus is that the benefits of taking drugs to prevent HIV infection outweigh the risks if therapy is warranted for you at any stage of pregnancy.

Your ARV options

Having the lowest possible viral load is the most certain way of preventing HIV transmission to your infant, so the ARV combination that is best for you also gives your baby the best chance. However, there are a couple of extra factors to be aware of.

The way that your body processes medications can be altered by pregnancy so if you are pregnant or planning pregnancy, your doctor should check the latest research to see whether there is any specific information pertaining to pregnancy (for example, might dose alteration be needed?). Therapeutic drug monitoring could be useful to ensure that you are getting maximum antiviral potency.

The ARV drug AZT (zidovudine, Retrovir) is the most thoroughly studied ARV in pregnancy, followed by nevirapine (Viramune). Women are often advised to use an ARV combination that includes AZT, unless you have a particular reason for avoiding the drug (such as pre-existing resistance to it or a history of experiencing difficult side effects with it).

Efavirenz (Stocrin) is cautioned against in pregnancy, as it is associated with birth defects. It should only be used in pregnancy where you and your doctor are informed of the risks and where you accept that there are no other options and its benefits to you outweigh the risks.

Nevirapine (Viramune) has been well-studied in pregnancy; however, there are some cautions about its use. There

have been nevirapine-associated hepatitis-related deaths in pregnant women, and the drug contains a product warning that women with CD4 counts above 250 may be at higher risk of liver-associated side effects than other people with HIV. Because of its potential impact on the liver, it is a drug to avoid if possible for women co-infected with HCV if there are other good options. Nevirapine in pregnancy should be part of a three-drug combination, never used as a monotherapy because of the risks of resistance developing.

Ritonavir (Norvir) taken at full dosing strength can also be a problematic drug in terms of side effects, including for the liver. However, this drug is now commonly taken in small doses to 'boost' the activity of other protease inhibitors and it is far more tolerable when used in this way. It is co-formulated as Kaletra with lopinavir.

Genetic testing of foetus

Various pre-natal genetic tests are available to screen for abnormalities such as Down 's syndrome. Tests include ultrasound screening, chorionic villus sampling and amniocentesis. The aim of these tests is to diagnose abnormalities in the womb so that in some instances the foetus/mother can be treated, or so the mother has the option of termination, or so the mother can prepare herself. You should receive special genetic counselling to help you make decisions about which tests you'd like performed, as each has a rate of 'false positives' (suggesting abnormalities where none

exist), and there is a risk to your foetus with the invasive tests – both the risk of miscarriage, which all women face with these tests, plus an increased risk of HIV transmission. Genetic testing can increase stress and anxiety for some women, and reduce it for others so it needs careful consideration.

Do I need to have a caesarean delivery?

There used to be a blanket recommendation that all women with HIV have a caesarean delivery to minimise transmission risks. The evidence that opting for an elective caesarean before you go into labour (called a pre-labour elective caesarean, or PLEC) reduces transmission is strong. As women with HIV are more likely to go into labour slightly prematurely, it will be recommended that your caesarean be scheduled at 38 weeks rather than the standard 39.

Opting to have an emergency caesarean after your labour has started is not associated with the same reduction in transmission, so if complications are likely, scheduling the delivery prior to your due date is preferable.

It is likely, however, that there is a low level of viral load (a viral load 'nadir') below which a pre-labour caesarean doesn't offer any extra protection from transmission. In other words, if your viral load is undetectable throughout pregnancy and prior to delivery, it is unclear whether there is any additional protective benefit in having a caesarean.

Women who have caesarean deliveries are recommended to take intravenous antibiotics to avoid post-operative infection.

Caesarean delivery is recommended if:

- You have detectable viral load before delivery
- You have detectable HCV levels in the blood
- You are taking no ARV, or AZT monotherapy
- Delivery complications are anticipated (multiple births, breech position, other gynaecological issues)

Disadvantages of caesarean delivery

A caesarean section delivery is major surgery and it can be at least six to eight weeks before your body recovers enough for you to do basic things like drive a car—this can be particularly hard while having a tiny infant to look after! The recovery time is a particular disadvantage for women who have other dependent children, or other additional caring responsibilities.

There is also the risk of post-operative infection, a reaction to the anaesthetic, and surgery itself is a risk.

Some women get a sense of achievement from vaginal delivery, and some have a pronounced dislike of surgery.

Advantages of a pre-labour elective caesarean

- It reduces transmission risks;
- You know when the baby will be born
- You will avoid episiotomies or tearing that can occur with vaginal birth, and subsequent incontinence problems.

Other issues in delivery

In theory, any intervention during delivery that exposes your baby to your blood or vaginal fluids increases the risks of transmission, so any monitoring of your baby that breaks the skin (like scalp electrodes) should be avoided, and forceps or suction caps for delivery should be avoided (there is no actual evidence of these interventions increasing transmission, but it makes sense that they could).

What if I go into labour or my waters break before my scheduled caesarean?

If this occurs, you should go immediately to hospital where you will be given intravenous AZT immediately. Once you are in labour, there is no HIV prevention benefit in having a caesarean so you may either opt to deliver vaginally, or to proceed to have an emergency caesarean.

Why is AZT during delivery recommended?

Regardless of your viral load and the treatment options you take during

pregnancy, you will be advised to have intravenous AZT during delivery. Most HIV transmission to infants takes place during delivery (rather than in the uterus or after delivery). Research has established that AZT during pregnancy, during delivery and after delivery to the infant (sometimes called three part chemoprophylaxis) has a significant protective effect, but the precise mechanism of action is not understood. Your infant may be more vulnerable to infection if you omit the AZT during delivery.

Does my baby have to take ARV?

Your baby will be prescribed ARV for four weeks after delivery, either as single drug or combination therapy. The precise drugs may change according to individual circumstances (i.e. the ARV used by the mother and her treatment history) or according to new research.

Infant treatment is called PEP, or post-exposure prophylaxis, and it can prevent infection by 'mopping up' infectious HIV particles to which your baby might have been exposed. It increases the likelihood of avoiding infection.

Your baby may experience side effects like anaemia and neutropaenia, but many babies do not experience any side effects. If side effects are severe, your baby may require blood transfusions or may need to stop therapy.

Why can't I breastfeed?

Breastfeeding places your baby at

high risk of HIV infection, so where infant formula is available and the water supply is clean, formula feeding is advised for all women with HIV.

There is ongoing research in Africa looking for ways of reducing mother-to-infant transmission through breastfeeding because in many African countries infant formula is either not affordable, available or there are serious issues about quality of water supply. Interventions have included exclusive breastfeeding followed by immediate weaning and the prolonged use of ARV to treat infants. In 2003 a third of the infants infected with HIV worldwide were infected through breast milk. No studies so far have shown infection rates as low as can be achieved by no breastfeeding at all.

If my viral load is undetectable, can I transmit HIV through breast milk?

The lower the viral load the lower the likelihood of transmission, but there are still significant risks in breastfeeding your child regardless of the number of HIV copies circulating in your blood.

Unfortunately viral levels in breast milk do not always correspond to levels of virus measured in the blood. Research has shown that levels of virus in breast milk fluctuate unpredictably, even varying from left breast to right breast on the same woman (the speculated cause of this is that small infections or inflammations of the breast tissue and milk ducts, 'sub-clinical mastitis', are very common and this then increases HIV replication and shedding).

What about heat-treating breast milk?

Two different forms of heat-treating expressed breast milk have been tested with promising results: 'Pretoria pasteurisation' and flash heating. Flash heating is where a container of breast milk is placed into water and the water and milk are heated together until the water reaches a rolling boil, after which the milk is removed from the water and allowed to cool. Pretoria pasteurisation is where a container of water is heated to boiling and removed from heat, and a container of breast milk is immediately placed in the hot water for 20 minutes, after which it is allowed to cool to 37 degrees centigrade.

Recent experiments showed flash heating to be the more effective option for removing HIV, but it must be emphasised that these techniques are being developed for women who do not have good access to infant formula or clean water¹¹. Heat-treating milk may affect nutritional and immunological components of breast milk.

Infant formula is nutritionally as close to breast milk as possible. There is no need to 'graduate' to special formula after six months. These 'follow-on' formulas have added iron, but your baby should be able to get iron from food at this stage, and iron-enriched formula is very constipating and largely a marketing ploy.

Does bottle-feeding mark me as being HIV positive?

Many women in developed countries struggle with breastfeeding and opt

to bottle-feed. Difficult deliveries, prior breast surgery (especially breast reduction), post-natal stress, low milk supply, breast and nipple pain, needing to take some certain medications and smoking are all common reasons for not breastfeeding. You do not have to disclose that you are HIV positive to justify not breastfeeding, and no-one has the right to make you feel bad about this.

Feelings about not breastfeeding

You may feel a sense of grief or loss from not breastfeeding your baby. Talking to a counsellor or to other positive women may help.

Might advice about breastfeeding change?

Research into ways of reducing HIV transmission through breast milk will continue because it is incredibly important for infant welfare where breast milk substitutes are not viable. In some contexts treating an HIV-uninfected baby with ARV for relatively long periods while breastfeeding may be a good alternative, but in the Australian context, the risks of the extended ARV exposure would outweigh the benefits because of the ready availability of infant formula and a safe water supply.

What is 'best practice' if I have hepatitis C as well as HIV?

Treating your HIV with combination ARV is definitely recommended if you have

¹¹ J. Acquir Immun Defic Syndr 2005;40:175-181

hepatitis C (HCV), as HIV replication makes it more likely that you could transmit (HCV) to your baby. Treating your HIV lessens the chance of HCV transmission (otherwise the chance of HCV transmission is estimated as up to 18%). The goal of therapy would be to keep HIV viral load below 50 copies/ml if possible.

However, **do not treat your HCV during, or up to six months before pregnancy.** One of the drugs used to treat HCV, ribavirin, is associated with birth defects and foetal death.

Pregnancy does not affect HCV progression unless you have cirrhosis (scarring of the liver).

During pregnancy, avoid invasive procedures like amniocentesis because this procedure could enable infection of your baby to occur.

Risk of HCV 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 having a pre-labour elective caesarean is often recommended, although there is no research actually showing that this decreases transmission (the studies have not been done). Any invasive monitoring procedures such as foetal scalp monitoring are also advised against.

Infant HCV

Hepatitis C antibodies will pass from the mother to the baby. These antibodies don't clear from your child's system until about 18 months of age. He or she can be tested for hepatitis C at that time, but if it is important to know before that time; a hepatitis C PCR test can be carried out at 1-2 months, and then repeated. If both of these are negative, your child does not have hepatitis C infection, even though antibodies will remain for some time. If your child does have HCV don't be alarmed. Children are usually symptom free, and they have a better response to HCV treatment than adults, often experiencing few or no side effects. Disease progression is usually minimal for the first 20 years. Children cannot undergo treatment for HCV until they are 18 years old.

Children are usually symptom free, and they have a better response to HCV treatment than adults...

Summary of treatment options according to your treatment history and immune status

Woman's situation at beginning of pregnancy	ARV options	Delivery options	ARV during delivery	Treatment of new born
Pregnant on fully suppressive therapy	Continue therapy (seek doctor's advice to substitute another drug if taking efavirenz)	If viral load remains undetectable, vaginal delivery is an option for women where no complications are anticipated; otherwise pre-labour caesarean. (If HCV is detectable in your blood a pre-labour elective caesarean is recommended)	Intravenous AZT during delivery	AZT for 6 weeks after delivery
Pregnant on no therapy, with viral load below 10,000 copies	Highly recommended: Commence combination ARV after 1st trimester (week 12) that includes AZT if feasible - if HCV+ this option is recommended OR (less highly recommended) commence AZT monotherapy after week 12 OR no therapy (not recommended but an option some might take).	A If viral load is undetectable, vaginal delivery is an option for women where no complications are anticipated; B If monotherapy is taken or if HCV+, pre-labour caesarean is advised; OR C Caesarean is definitely advised if no ARV is taken in pregnancy	Intravenous AZT during delivery	A and B AZT for 6 weeks after delivery C newborn must be treated with combination ARV

continued ...

Woman's situation at beginning of pregnancy	ARV options	Delivery options	ARV during delivery	Treatment of new born
Pregnant on ARV with detectable viral load	Determine best possible ARV options with reference to possible drug resistance, tolerance and avoiding drugs that are contra-indicated in pregnancy, then switch drugs to optimal regimen. Include AZT if that drug is feasible (i.e. not pre-existing resistance or history of tolerance problems).	If viral load becomes undetectable, vaginal delivery is an option for women where no complications are anticipated; If viral load is detectable or if HCV+, pre-labour caesarean is advised	Intravenous AZT during delivery.	AZT for 6 weeks after delivery; If viral load is detectable during delivery combination therapy for newborn may be advised .
Pregnant on no therapy with viral load above 10,000 copies	Determine best possible ARV options with reference to possible pre-existing resistance, tolerance of agents and avoiding any ARV contra-indicated in pregnancy, then commence combination ARV (Highly recommended)	If viral load becomes undetectable, vaginal delivery is an option for women where no complications are anticipated; If viral load is detectable or if HCV+, pre-labour caesarean is advised	Intravenous AZT during delivery.	AZT for 6 weeks after delivery; If viral load is detectable during delivery combination therapy for newborn may be advised

How do I know if my baby is HIV positive?

Your baby will be given a simple blood test after birth called a PCR test. This test looks for the presence of HIV in your baby's blood, and if HIV is not detected this is a good indication that your baby does not have HIV.

PCR tests are scheduled within 24-48 hours after birth, then at ages; one week, six weeks, three months, six months, 12 months and finally 18 months. (Some hospitals may vary this slightly, such as testing at week four rather than week one.) If all tests in the first three months are negative, it is extremely unlikely that your baby is infected.

What if my baby has HIV?

This will be very difficult for you. You (and your partner if you are partnered) will need a lot of support and it is important that you are provided with referrals to professional services (counsellors, mental health professionals, support groups and other positive women) to help you cope.

You will need to make a decision about treatment together with the paediatrician. There is some debate about the best time to begin ARV 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, but on the matter of

whether to treat all babies from birth, expert opinion is divided. If you feel very uncertain about the best way to proceed, your paediatrician and your HIV doctor should talk with you both about all the available evidence and about how this applies to your baby.

If your baby doesn't commence ARV immediately, your baby will need to take drugs to prevent common infections like PCP.

Looking after yourself

Your mental health post-partum

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 be accompanied by self-doubt, exhaustion, and guilt for having any negative feelings.

The constant demands of an infant, together with recovery from childbirth, are very hard to imagine for anyone who has not been responsible for one full-time. If your delivery did not go as planned you may also feel some anger, pain or disappointment about that.

You may also have nagging fears that your child has HIV despite evidence otherwise. This anxiety is very understandable, especially as your baby keeps undergoing testing until 18 months of age. Your paediatrician and HIV doctor need to take time to talk with you about your fears.

Asking for extra help and support from family, friends and from the community sector (both the HIV related support services and those set up for new mothers) does not mean you are 'not coping' - it means you are trying to be the best mother you can be.

If your baby does have HIV you are facing some difficult decisions that place you under extreme stress. You have the right to be upset and to take time to make decisions.

Giving birth changes your life. Many new mothers need to see a mental health professional to help with the adjustment.

You need not experience this alone or feel that something is wrong with you if you are struggling. The ongoing 'burden of secrecy' can be huge and knowing that support is available is important for you, your baby and your family.

One in seven women experience post-natal depression. If post-natal depression occurs, psychotherapy, psychosocial support (support groups) and cognitive-behavioural therapy can all play a role in helping you regain equilibrium. Many women also find antidepressant medication useful.

The joy of giving birth might also be accompanied by self-doubt, exhaustion, and guilt for having any negative feelings.

Menopause

Menopause usually begins somewhere between the ages of 38 and 58, with 51 being the average age. Technically menopause means stopping having monthly bleeding (periods or menstruation). It marks the end of your fertility and is accompanied by significant hormonal changes.

Except where menopause occurs due to surgery, (hysterectomy or removal of the ovaries) it is a gradual process rather than an abrupt change. The beginning phase is called 'peri-menopause', where periods become less frequent and some other menopausal signs can appear.

If you are uncertain as to 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.

Sex

- Experiment with lubricants until you find one that suits you; and
- Practice pelvic floor exercises regularly (squeezing the pelvic floor, as if to stop the flow of urine, and holding for several seconds before release).

Key issues

- 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.
- Check all herbal/alternative supplements with your doctor for interactions with HIV drugs.
- Use lubricants for sex.

Different women experience the changes of menopause very differently. Menopause is not an illness, but it does have 'symptoms'; hot flushes, mood changes, night sweats and fatigue are par for the course. 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. Your risk of heart disease increases, as does your risk of bone loss (osteoporosis). Some women experience changes in their thinking and understanding (cognitive changes). A good general site (not specific to women with HIV) is www.womhealth.org.au/factsheets/aboutmenopause.htm

The impacts on how having HIV affects the experience of menopause is not really known yet. There is a suggestion that menopause may occur slightly earlier on average in women with HIV. The effects of HIV treatments, such as increased fats in the blood, suggest that the increased risk of heart disease may be higher. Changing any habits that further increase cardiovascular risks is a really important positive change to make in your life. Stopping smoking, improving your diet and doing regular moderate exercise are the key factors here.

Earlier menopause can accelerate the loss of bone density, which increases the risk of early osteoporosis. ARV drugs such as tenofovir may contribute to bone loss. Regular weight-bearing exercise and a calcium-rich (but not high fat) diet protect bone health. A bone density test can be arranged, if appropriate, through your doctor.

Hormone replacement therapy (HRT)

Hormone replacement therapy (HRT) is a major issue for women experiencing really unpleasant menopausal symptoms. HRT was touted as the solution for a swathe of menopausal problems until a major study identified that it increased the risk of breast cancer and heart disease. More recent studies, however, have thrown doubt on these findings. The current advice is, if the individual benefits of the therapy are assessed to outweigh the risks, use HRT for short-term relief of symptoms in low doses if possible. Decisions about taking HRT need to be made in consultation with your doctor who can discuss the risks and benefits for you.

Does having HIV or taking HIV treatment increase the risks of HRT? HIV treatment increases the risk of heart disease, and it is possible that HRT may further increase this. Regarding breast cancer, it is not clear whether there is an increased risk. One recent study showed that people with HIV have a greater risk of non-AIDS-related cancers than HIV negative people, particularly skin cancers¹². It is possible that women with HIV are at increased risk of breast cancer, but there is no evidence of this.

Alternatives to HRT

Non-hormonal methods of treating menopausal problems include increasing consumption of soy products and using herbal preparations. There is no hard 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.

Many positive women report that nutrition can play a key role in reducing menopausal problems.

If you have had breast cancer or have a higher than average risk (assessed through family history) you should avoid high-dose supplements of soy products, where the active ingredients may be processed in such a way that they may fuel oestrogen-receptor positive breast cancer (it is thought that consuming soy food products as part of a normal diet does not constitute a risk). For more information on this see www.breastcancer.org and www.project-aware.org (these sites have good sections on menopause, but be aware that it does not consider HIV in¹²

menopause, so you should check any recommendations with your doctor).

Antidepressant medications in the SSRI class (selective serotonin re-uptake inhibitors, the class from which Prozac comes) used in doses lower than those to treat depression can be used to treat hot flushes. However, antidepressants can reduce your sex drive or ability to orgasm.

In addition to soy products (phytoestrogens), there are a wide range of herbal preparations that are reputed to be helpful with symptoms and general enhancement of well-being. There is a lack of research in this area, but it makes sense to explore the possibilities keeping a few key things in mind:

- Herbs can interact with HIV drugs - check with your doctor (St John's Wort and garlic, for example, have proven interactions);
- See 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.

Herbal products include black cohosh (there is some research supporting this as a treatment for hot flushes and night sweats), dong qui, wild yam, evening primrose, ginseng, ginger, red clover and valerian for sleeping problems. The project aware website www.project-aware.org has a comprehensive list of menopausal symptoms and herbal remedies.

Future of research

An HIV Menopause Clinic has been established at St Miriam's Hospital, Providence, USA, which is very encouraging and should result in more being known about how women with HIV manage menopause and if there are any particular issues that arise.

Living with menopausal symptoms

- Dress lightly and in layers.
- Avoid caffeine, alcohol, and spicy foods.
- Practice slow, deep breathing whenever a hot flush starts to come on. (Try taking 6 breaths per minute).
- Consider seeing an acupuncturist.
- Use relaxation techniques like yoga, tai chi, or meditation.
- Eat soy foods.
- Perform pelvic floor exercises daily to strengthen the muscles of your vagina and pelvis.
- Use water-based lubricants during sexual intercourse.
- Talk to other positive women about their experience and about the strategies they found useful.

¹²Burgi A et al. Incidence and risk factors for the occurrence of non-AIDS-defining cancers among human immunodeficiency virus-infected individuals. *Cancer* (online edition), 2005.

Female parts

Taking care of your genital and reproductive health is an important part of staying well. Our immune systems are most active in the areas where the outside world permeates our bodies – our mouths and in our female parts. That is why immune suppression increases the risk of gynaecological conditions and diseases.

Ask your male sex partner/s to either:

- Use condoms and lubricant (even if he also has HIV); and/or
- Have comprehensive sexual health check-ups and to treat any infections promptly as this is important for your sexual health.

Female sex partners can also transmit some infections such as the wart virus (human papillomavirus or HPV which can lead to cervical cancer), thrush, bacterial vaginosis and herpes. Therefore sexual health screening, prompt treatment and always cleaning and covering sex toys is important.

Key points

- You need to have a Pap smear every 12 months to screen for pre-cancerous changes in your cervix.
- If you have previously had an abnormal Pap smear, you need to have Pap smears every six months.
- Put a reliable system in place to remind you of when you are due for a Pap smear.
- You need to maintain your CD4 cell count above 200.
- Sexually transmissible infections (STIs) are a threat to your reproductive health and can lead to serious consequences such as infertility and increase the transmissibility of HIV.
- Being tested and treated for STIs is an important way of staying well.
- Take charge of whether you want to use condoms and lubricant or other barriers to decrease the chances of getting a sexually transmissible infection.

Vaginal thrush (candidiasis)

Candida albicans is a naturally-occurring yeast, which generally lives in harmony with its human host in the gut, the folds of the skin, the anus, the mouth and the vagina. Thrush occurs when the balance of this yeast is disturbed and it multiplies out of control.

Are you at risk?

There is often some *Candida albicans* living in the vagina, but it can multiply to above normal levels when there is a change in the vaginal environment (for example, in sugar or pH levels). Generally, the yeast co-habits happily, but if the immune system is not working well, the *Candida* can start to behave like an infection. Vaginal thrush is a very common infection in women, regardless of HIV status. However, chronic or very frequently recurring vaginal thrush is the most common gynaecological disorder in women with HIV.

Thrush can also occur in other parts of the body (the mouth and the oesophagus). This is more common when the immune system is weaker (usually when the CD4 count is less than 100).

What are the symptoms?

Symptoms include an itchy and inflamed vulva and vaginal area, and a curdy, white, usually odourless vaginal discharge.

Prevention

Although there is no good evidence for any of these methods, some women

find that avoiding hot, damp conditions can help prevent thrush: having a good airflow to the affected area (wearing cotton undies or no undies for a while), avoiding lots of sex, avoiding perfumed products that can irritate the skin and ensuring that you always wipe from the front to the back with toilet paper, are also said to help to reduce the occurrence of symptoms.

How is it treated?

Topical antifungal agents

Topical antifungal agents are treatments that are applied to the affected area. There is a range of topical treatments, some of them natural therapies, which may be helpful. These include:

- Broad-spectrum anti-fungal creams or powders such as Canesten. These are available from your chemist. You won't need a prescription, but you will have to pay for these products;
- Some women find that baths with lavender oil drops can be soothing;
- The use of lactobacillus acidophilus has been shown to be ineffective.

Systemic treatment for recurrent thrush

For more serious thrush, antifungal drugs may be used. These include: fluconazole; ketoconazole; itraconazole; posaconazole; amphotericin B. If you are prone to recurrent thrush, getting a spare script from your doctor so you can readily access effective treatment when you need it is a good strategy. Increasing your CD4 count by using antiretroviral drugs may help to prevent recurrent thrush.

Anti-Candida diets

You may have heard that Candida can be managed by special diets, which eliminate foods supposed to cause Candida. However, many doctors believe there is no evidence that these diets have any impact on candidiasis, and warn they can be dangerous in positive women because they are very restrictive and can cause excessive weight loss. However, avoiding excessive sugar intake is good general dietary practice.

Sexually transmissible infections (STIs)

Sexually transmissible infections like Chlamydia, gonorrhoea or syphilis may affect any woman. HIV can affect the severity and course of some infections, and ongoing infection can be a burden on the immune system, so it is important to be tested and treated if necessary, then re-tested if you change sexual partner.

This section will not cover every possible STI in detail, but will address the STIs that are of particular concern in Australia for women with HIV due to their prevalence (the frequency with which people in Australia have the infections) and/or the way these infections interact with HIV.

Symptoms

Not everyone who has an STI has any signs or symptoms, but if you have any of the following you should have an STI check-up:

- Unusual discharge from the vagina;
- Pain or burning when you pass urine;
- Itches, rashes, lumps or blisters around the genitals or anus;

- Pain and/or bleeding during sex;
- Bleeding between periods (including women who are using hormonal contraception);
- Bleeding after sex.

Sometimes symptoms can disappear, or appear and disappear sporadically but this does not mean that the infection is gone if you have not had it treated.

Prevention

Using condoms and lubricant when you have sex is an excellent preventive measure, although condoms don't provide complete protection from every transmissible infection. Women who have sex with other women can also transmit STIs to each other, so STI screening has a role regardless of sexuality for any women who are, or have been, sexually active regardless of sexual orientation.

Chlamydia

Chlamydia is an STI caused by bacteria that infects the cervix in women and can travel upwards through the reproductive organs to the fallopian tubes. It is particularly important to screen for and to treat. It is readily transmissible, highly prevalent in the general Australian population particularly in people under 25 and if left untreated, it can give rise to serious illness like pelvic inflammatory disease (PID) and can compromise your fertility. Because it is often asymptomatic in both men and women, people often don't know that they have it.

The only way to know for sure if you have Chlamydia is to have a test.

This involves either a urine test or taking a cell specimen from the vagina using a swab. This can be done on its own, as part of other testing for STIs, or as an extra test when you have a Pap smear.

Treatment is simple – a course of antibiotics which can either be taken as a single dose or as a longer course. Your doctor will advise you on the best treatment approach for your situation. If you are prescribed the longer course, it is important that you take every tablet and that your partner is treated too if he or she is infected. You and your partner should avoid vaginal, oral and/or anal sex until you have both completed the course of treatment.

Herpes

Herpes infections are caused by a virus, either herpes simplex virus type I or II. Herpes simplex I is the virus that causes cold sores. This virus can also cause genital herpes, and is now the most common cause of new genital herpes infections in young adults. Genital herpes is also caused by the herpes simplex II virus, and this is the most common cause of recurring lesions.

Are you at risk?

Genital herpes is a sexually transmissible infection. Transmission occurs via intercourse, even when no herpes lesions are visible. Condom use for vaginal or anal sex, and the use of barrier protection like dams, can help prevent this although protection is significantly less than 100%.

A number of effective anti-herpes drugs are available by prescription, and there are national guidelines outlining their use. If your regular

partner (regardless of HIV status) has genital herpes, he or she should get preventive (sometimes called suppressive) herpes treatment prescribed to stop outbreaks and to lower your risk of infection. Herpes treatment used preventively does not reduce the infection risk to zero.

If your partner has oral herpes (cold sores on the face or around the mouth) it is very important that he or she does not perform oral sex on you from the time that he or she gets the warning 'tingle' to the time that the infection has completely cleared up. People who already have antibodies to HSV-1 (regardless of whether they can recall having cold sores in the past) will not contract it again from their partner(s). If you do not have this protection from antibodies however, it is possible for you to get herpes in the genital region from a partner's oral infection, whether or not he or she has any visible lesions.

Symptoms

May include:

- Itching and tingling in the genitals;
- Painful sores or blisters around the vagina/anus;
- Burning/pain when urinating;
- Recurring vulvovaginal thrush may also sometimes be caused initially by outbreaks of genital herpes.

Herpes and HIV

Outbreaks of genital herpes may occur more often, and be more severe, if your immune system is weakened by HIV. Some women also report herpes lesions that take a very long time to heal.

It is also possible for undiagnosed herpes infections, which have not

caused symptoms in the past, to be 'reactivated', and cause symptoms. This can happen if your CD4 count gets very low (below 200) and then is subsequently improved by ARV treatment.

Treatment

Medical educators urge the aggressive treatment of herpes infections in people with HIV. It can be treated with drugs named aciclovir (Zovirax), valaciclovir (Valtrex) or famciclovir (Famvir). These drugs are very safe and have almost no side effects. However, they do need to be prescribed by a doctor.

Improving your immune system with ARV can greatly reduce your susceptibility to herpes outbreaks. In addition, avoiding triggering factors can all help reduce the recurrence of herpes.

Syphilis

Although Syphilis rates have been recently rising among gay men in Australia, syphilis is not particularly common among women. However, it is worth being screened for, as the disease progresses more quickly in the context of immune impairment, and can also become more difficult to treat if you have HIV. It is also easily cured.

Syphilis is caused by bacteria and is passed from person to person through sexual contact, skin-to-skin contact with a syphilis sore, or from a mother to her baby. Women who have sex with men can acquire and transmit syphilis. It is only very rarely transmitted from woman to woman.

Testing for syphilis involves either a blood test, or taking a swab from

any sores present on the skin, mouth, vagina, or anus.

Untreated syphilis can develop in three stages:

- The first stage, called primary syphilis; sores appear on the body where the bacteria have entered – such as on the vulva, vagina or cervix. These sores are highly infectious and take two to six weeks to heal;
- The second stage, called secondary syphilis; a painless rash can appear, often covering the palms of hands and soles of feet; flat wart-like growths can appear around the genitals and patchy hair loss may occur. In addition, fever, tiredness, and swollen lymph glands can all occur at this stage;
- The third or latent stage, called tertiary syphilis; after many years untreated syphilis may start to cause very serious damage to the heart, brain, eyes, other internal organs, bones and nervous system. At this stage syphilis could be fatal.

In people with HIV, the disease can progress far quicker, with some cases reported of progression to the tertiary stage occurring within months of infection, so prompt diagnosis and treatment is essential.

Syphilis is treated with antibiotics, usually penicillin, and sexual partners also need to be tested and treated.

Gonorrhoea

Gonorrhoea is caused by bacteria that can be passed from one person to another during sex. The bacteria usually live inside the cells of the cervix (entrance to the womb), the urethra

(tube where urine comes out), the rectum (back passage), the throat and occasionally the eyes.

The infection can spread if you have vaginal, anal or oral sex, or share sex toys. Using a condom correctly will reduce your chance of getting or passing on gonorrhoea.

It is also possible to transfer the infection from the genital area to the eyes by fingers, and for a pregnant woman to pass the infection to her baby's eyes at birth.

About 50% of women, but very few men, will have no symptoms. If you do have symptoms, which might show up from 1 to 14 days after infection, they include:

- An unusual vaginal discharge which may be thin or watery, or yellow or green;
- Pain when passing urine;
- Lower abdominal pain or tenderness.

A gonorrhoea test involves a sample of cells being taken from the potentially infected area using a swab (a soft, rounded cotton implement similar to a cotton bud), although a urine test can also diagnose it if the infection is in the urethra or cervix.

Treatment consists of antibiotics, frequently a single dose.

In women, gonorrhoea can spread to other reproductive organs causing pelvic inflammatory disease (PID). This can lead to long-term pelvic pain, blocked fallopian tubes, ectopic pregnancy (pregnancy that occurs outside the womb) and infertility. It is estimated that there is a 15% risk of PID with each episode if the gonorrhoea is

not treated.

HPV Human Papilloma virus (Genital warts)

Genital warts are an extremely common STI. Warts are caused by the HPV (human papillomavirus), which has over 200 different strains, but many people who are infected with HPV do not have any symptoms (i.e., actual warts).

Many women who are or who have been sexually active have been infected with one or more strains of HPV (human papillomavirus). Some strains of this virus have been shown to cause pre-cancerous changes in the cervix.

The most common manifestation of HPV is genital warts, but most people who have HPV have no symptoms. An estimated 80% of all sexually active men and women have been exposed to HPV.

Wart virus infection can occur in three ways:

1. Visible warts (warts which are easy to see); these may have either a hard, smooth surface, or a 'cauliflower-like' appearance;
2. Sub-clinical infection; where you cannot see warts on your skin, but the wart virus can be found inside the skin cell using a microscope, and it may still be able to infect other people;
3. Latent infection; where the wart virus can only be found with special tests that look for wart virus DNA.

If you do have visible warts, treatment is:

- Putting cream or a liquid onto the

warts. This can be done at home or in the clinic;

- Freezing (cryotherapy);
- Heat (electrocautery);
- Surgery;
- Laser treatment.

There are now vaccines (Gardasil, Cervarix) for HPV that have been proven effective in clinical trials of adolescents and women up to the age of 45. However, it is thought that these products would have less utility in people already exposed to the virus, as most positive women have been. The place of these vaccines for women with HIV is still to be determined.

Cervical cancer

Cervical cancer is preventable and if diagnosed early, curable. Abnormalities in cervical cells and cervical cancer affect many women regardless of HIV status. They are more common in women with HIV, and HIV-related immune suppression appears to make cancers more invasive and more likely to recur after treatment.

Early detection and treatment is the key.

Not all abnormalities in cervical cells (a condition called cervical dysplasia) mean that you have cancer or are likely to get it. The pre-cancerous cell abnormalities have been broadly categorised into two groups according to severity: LSIL (Low-grade squamous intra-epithelial lesions), and HSIL (High-grade squamous intra-epithelial lesions). LSIL tends to spontaneously resolve on its own without treatment, though can sometimes progress to HSIL.

If you have a Pap smear that shows

high-grade lesions (HSIL), your doctor should immediately refer you for further tests. Pap smears showing LSIL in women with HIV would also be a reason for further testing, unlike LSIL in women without HIV, who would usually have the Pap smear repeated in twelve months, instead of the usual 24 months (for women without HIV).

An examination of the cervix called a colposcopy may be recommended. The cervix is closely examined under a microscope and cells may be taken for testing. Some people argue that this test should be routine in all HIV positive women, but others disagree, saying it is unnecessary unless Pap smear results are abnormal. If you would feel reassured by having regular colposcopies, speak to your doctor. Some women can find colposcopy invasive and painful.

Some research has suggested that progression to cervical cancer may be faster in HIV positive women. In addition, recent research has showed that you are at higher risk of a recurrence of cervical dysplasia after surgery when you are HIV positive, especially if your immune system is significantly impaired (CD4 cell count below 200).

Other risk factors

- HPV is the main risk factor, and is present in close to 100% of cervical cancers. The vast majority of women who contract HPV, however, do not go on to have HSIL, let alone cervical cancer.
- Smoking appears to be a risk factor for cervical cancer.
- The risk of developing cervical cancer also increases with age;

women may be at increasing risk from their mid-30s.

Effectiveness of treatment

The main reason it is important to detect cervical cancer or pre-cancer early is that it appears current treatments may be more likely to fail in HIV positive women, especially women who have a low CD4 count. Abnormal cells that have been treated (e.g. through laser surgery) may also be more likely to recur.

Vaccines are currently being tested for HPV and initial results have been promising. Even if you have been infected with a strain of HPV, a vaccine to protect you from another may be helpful, though at this stage there is not much evidence to guide decision-making.

Importance of testing

The main message for HIV positive women in terms of cervical cancer is that early detection is critical. This should include:

- Annual Pap smears;
- Further referral if your Pap smear shows abnormal cells;
- Aggressive treatment in the case of severe dysplasia;
- Maintaining your CD4 count above 200 with ARV to keep your immune system strong.

Pelvic Inflammatory Disease

PID is an inflammation of the pelvic area usually caused by untreated sexually transmitted diseases like gonorrhoea or Chlamydia. Many, if not most, women have PID without knowing it and without noticing any significant symptoms. Untreated PID may become increasingly painful and can cause infertility. An episode of untreated PID may lead to infertility in 10% of women. PID seems to be more common and more severe amongst 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;
- Bleeding between periods;
- Vaginal discharge;
- Fever (high temperature);
- Fatigue.

If you notice any of these symptoms or have any concerns about PID, talk with your doctor. PID must be treated with antibiotics, as early as possible.

You may need to have a scan to see if there are any cysts or abscesses present. If you have complications, you may need to have a laparoscopy – this is a procedure (a type of ‘keyhole surgery’) where a tiny camera is inserted through a very small incision under your navel into your pelvic cavity to view the area. In complex cases you may need to be admitted to hospital to be treated with a combination of intravenous antibiotics.

Hepatitis B

Hepatitis refers to inflammation of the liver. This section is about hepatitis that is caused by the hepatitis B virus.

Hepatitis B is a sexually transmissible disease, and it is also vaccine-preventable, so people who are sexually active can protect themselves by having the vaccination.

Are you at risk?

Hepatitis B is transmitted in similar ways to HIV so risk factors include unprotected anal or vaginal sex, injecting drugs where equipment is shared between users, and genital contact. Unprotected oral sex where ejaculation occurs can also, though more rarely, result in transmission of hepatitis B.

Symptoms

Symptoms of hepatitis B infection usually show up between one and six months after exposure to the virus. They may include; a mild, flu-like illness, loss of appetite, abdominal pain and discomfort, vomiting and nausea, pale faeces, aching joints, and jaundice (can be recognised by yellowing of the eyes). People with hep B virus can develop chronic infection which can result in serious liver damage. A blood test will determine a diagnosis.

Prevention

Using condoms and dental dams during sex, and avoiding risk behaviours like needle sharing can minimise the risk. But the only truly effective preventative measure is vaccination. The vaccination can be safely used even if you're HIV positive.

Hepatitis B and HIV

Hepatitis affects the liver. So the ability to tolerate HIV treatments, which also affect the liver, may be reduced. Treatment is available for people with chronic hepatitis B, though a cure is difficult to achieve.

Other infections and HIV

- Having two infections at once is often called 'concurrent infection' or 'co-infection';
- Being screened and treated for other infections that you may have in addition to HIV is very important for your health;
- Other infections, such as sexually transmissible infections, can be harder to diagnose and treat when you have HIV;
- Some infections, such as syphilis, have a different and far more aggressive disease course in the presence of HIV;
- The presence of other infections can activate your immune system in a manner that increases your viral load, placing you at risk of faster disease progression.

Other infections in your genital tract can increase HIV activity there, making you potentially more infectious to your partner/s.

Menstrual irregularities

Menstrual irregularities are not uncommon in women, regardless of HIV status. If you experience menstrual irregularities, it is important to remember that HIV or HIV treatment may not be to blame.

Often, the problems are caused by hormonal changes that occur naturally in most women over time. They may also be due to conditions not related to HIV. However, HIV and antiviral drugs can have some effects on your menstrual cycle. You are more likely to experience HIV-related menstrual irregularities if your CD4 count is low and/or your viral load is high.

Although the effect of HIV on female hormone function has not been extensively studied, it is thought that changes in the immune system could cause hormonal changes and lead to menstrual irregularities.

Any abnormal bleeding, such as bleeding after sex or very heavy periods, should be reported to your doctor.

Menstrual problems sometimes experienced by positive women

A number of menstrual problems are reported by some positive women. These can include:

- Heavier than usual bleeding (called hypermenorrhoea);
- Lighter than usual bleeding (called oligomenorrhoea);
- Periods which are more painful than usual (dysmenorrhoea);
- A worsening of premenstrual symptoms;
- Irregular or 'breakthrough' bleeding;
- No bleeding at all (amenorrhoea).

Amenorrhoea is common in women who have been diagnosed with a chronic illness, or who have had severe weight

loss or anaemia. Women with serious illness such as AIDS may experience amenorrhoea. Women who miss their periods may have pelvic pain, swollen breasts or hot flushes.

It is possible that there may be other causes (for example, if you do not have a period, you could be pregnant). It's important to report any changes in your menstrual cycle to your doctor or women's health specialist. Your health practitioner should take a full gynaecological history, a pelvic examination, and some blood tests may be necessary. Menstrual problems can affect your physical and psychological well-being, but they are usually readily diagnosed and treated.

What causes menstrual problems?

Many women with HIV report changes in their menstrual cycle.

Causes of menstrual changes can include:

- Weight loss (particularly if the body mass index falls below 20);
- Poor nutrition;
- Chronic disease;
- Liver disease (related to HCV infection);
- Significant use of illegal drugs, especially heroin and marijuana;
- Plausibly the protease inhibitor ritonavir (a small study has shown a connection, but it is not proven).

Inadequate research has been done on the effects of treatment on a woman's menstrual cycle to date, and much of the information available is inconclusive. This can make it difficult to assess

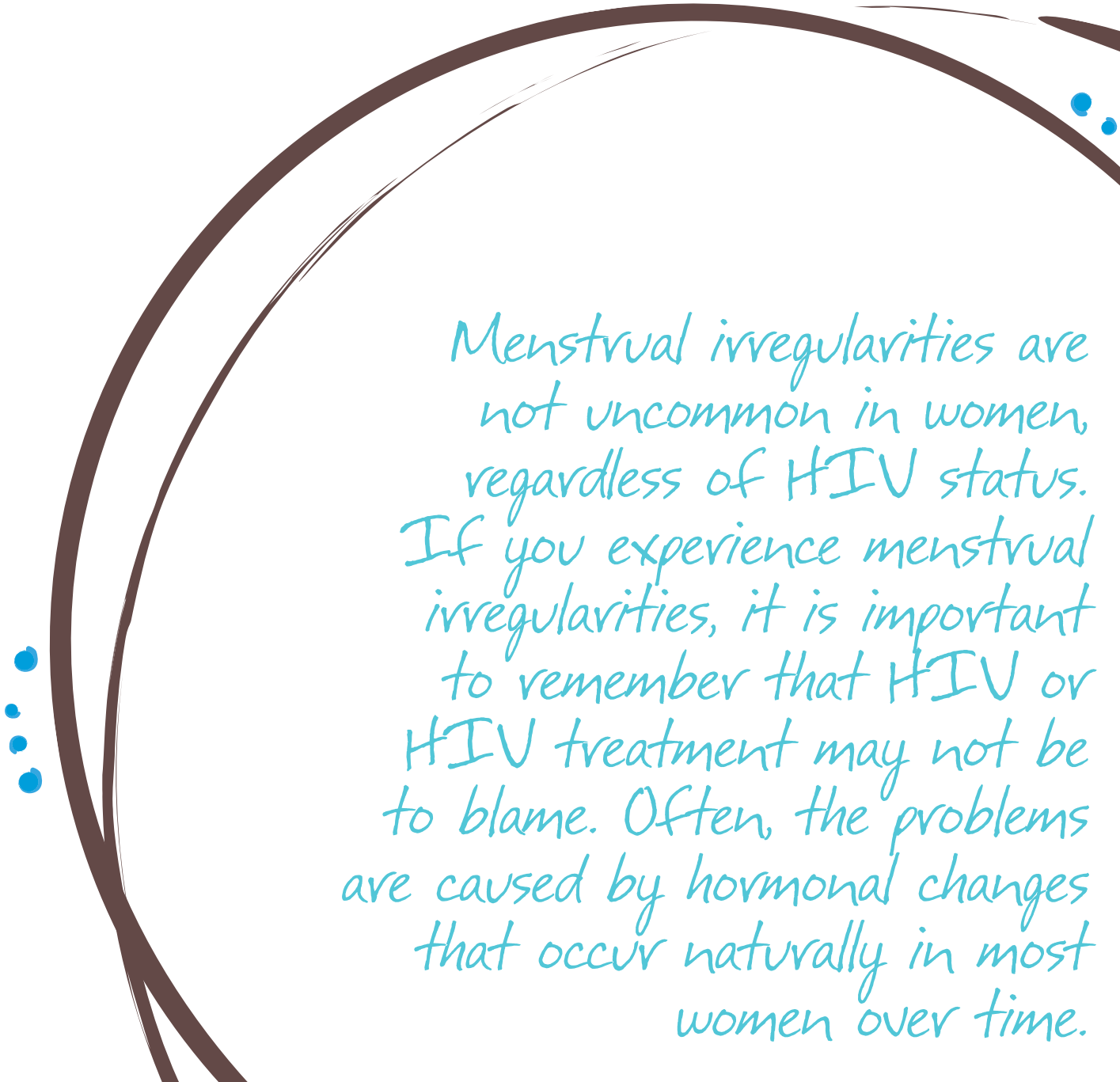
whether the problem is directly related to HIV, to treatments, or has some other cause.

It is important to do something about abnormally heavy bleeding, since it can lead to anaemia. Anaemia means that your blood cannot transport enough oxygen to the body's tissues. It can be caused by an abnormally low level of red blood cells. Unusually or extremely heavy bleeding can deplete the numbers of these crucial cells. There have also been reports of the ARV drugs AZT, d4T and ddI changing menstrual patterns.

Anaemia can cause serious complications, especially for HIV positive women. If you experience excessively heavy menstrual periods, tell your doctor as soon as possible, get a full blood count taken, and have your iron levels checked as well.

Menstruation and pregnancy

If you are having irregular or problem periods, it may be difficult for you to become pregnant. If bleeding occurs at irregular times 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 check with your doctor that the irregularities you are having are normal, and will not interfere with a pregnancy.



Menstrual irregularities are not uncommon in women, regardless of HIV status. If you experience menstrual irregularities, it is important to remember that HIV or HIV treatment may not be to blame. Often, the problems are caused by hormonal changes that occur naturally in most women over time.

co-infection with hepatitis C

About one in every five women with HIV in Australia has both HIV and hepatitis C (HCV). This section of Treat Yourself Right is specifically about having both viruses and will contain information about how HCV affects the body, how the two viruses interact, treatment of HCV, and how HIV and HCV treatments work together. However, because so many Australian women have both viruses, HCV is also mentioned specifically in other areas of this booklet, such as in the sections of antiretroviral drug side effects, sex and pregnancy.

What is hepatitis C?

Hepatitis is a general medical term that describes the inflammation of the liver. It is commonly caused by the hepatitis viruses, (including hepatitis A, B and C), but it can also be caused by other factors such as alcohol use or drugs (prescribed or alternative medicines).

- Avoiding or reducing alcohol consumption is a key lifestyle factor for limiting liver damage.

HCV replicates in liver cells, eventually killing cells. The liver protects itself by replacing killed cells with fibrous tissue that does not operate as normal liver tissue, decreasing the function of the liver. This is called fibrosis. When extensive fibrous tissue is present the condition is called cirrhosis, or scarring of the liver. A diagnosis of cirrhosis means that the liver is at risk in the future of not functioning properly. When this happens, it is known as 'decompensated' cirrhosis. There may be symptoms such as swelling of the stomach, weight loss or bleeding. The only treatment at this stage would be a liver transplant. In addition, once cirrhosis has developed there is also a small risk each year of developing liver cancer. However, it is important to remember that in most cases of HCV infection, cirrhosis does not develop and even if it does, this usually takes many years to happen.

Prevention and transmission

Like HIV, HCV is a blood-borne virus. Unlike HIV, it is mostly transmitted by blood-to-blood contact rather than sex; however, there is evidence that it is more readily sexually transmissible if you have HIV.

HCV is a far more robust virus than HIV and can survive for longer periods outside the body. This makes it possible to transmit HCV through sharing intimate household items that might contain traces of blood, such as toothbrushes and razors, or through unsanitary body piercing or tattooing. Evidence now shows that HCV can also be transmitted through the sharing of body jewellery. The primary mode of transmission is through sharing of injecting equipment (needles, syringes and/or tourniquets) but sexual transmission is also possible in certain situations. Circumstances that may make sexual transmission of HCV more likely include; having HIV, having another sexually transmitted infection such as syphilis, and having sex when there may be some bleeding involved. Sexual transmission of HCV may be a significant issue for couples with HIV, where one person has HCV and the other doesn't.

What does a hepatitis C diagnosis mean?

Testing positive for HCV does not necessarily mean you are going to become seriously ill. In many cases, people live well with hepatitis C infection for a long time, and a small but significant percentage of people even go on to eliminate the virus from the body. Many people, though, will have chronic (ongoing) hepatitis C infection, and this can cause liver damage over a long period of time.

It is currently thought that for every 100 people who have HCV::

- Around 1 in 4 (25%) will clear the virus altogether (though continue to have antibodies);
- Around 3 in 4 (75%) will have the virus long-term;
- Of these people with chronic infection, just over half (55%) are at risk of developing some long-term liver damage. Over a period of many years of infection around 1 in 5 will develop cirrhosis and 1 in 20 may develop liver failure or cancer.

In other words, in a small number of cases, there is a very real risk of HCV infection making you quite ill. This generally happens over several decades. However, if you have HIV infection, particularly if your CD4 count is low, you may be less likely to clear HCV infection and you may be more likely to develop cirrhosis at an earlier stage. For this reason it is a good idea to treat both your HCV and your HIV as actively as possible. As research into the field continues, new treatments are being developed.

- HCV can be sexually transmissible when people also have HIV.
- If your partner has HCV and you don't, you may want to take particular care to avoid any contact with his or her blood or sexual fluids.
- If you have HCV and your partner doesn't, take care to avoid him or her coming into contact with your blood or sexual fluids.
- Diaphragms are an effective way of keeping menstrual blood out of the vagina during oral sex.

Is there a cure?

Treatment with a combination of pegylated alfa- interferon and ribavirin can result in a cure – complete clearance of the virus. The goal of HCV treatment is to get the virus to undetectable levels and sustain the viral suppression. The treatment period is usually around one year. Pegylated interferon is injected weekly and the ribavirin is taken twice-daily in tablet form.

If your HCV viral load is undetectable six months after finishing treatment, this is called a sustained virologic response (SVR). Studies in people with hepatitis C alone, show that the vast majority of people who experience a SVR remain undetectable when followed-up for many years. However, in rare cases, people who achieve an undetectable viral load during treatment may get a viral rebound in the first six months after treatment stops. Even if this is the case and the undetectable viral load is not sustained, there can be benefits of treatment such as improvement in the condition of their liver.

There are several key issues to be aware of with HCV treatment:

- If you have a past history of depression, you may want to consider taking antidepressants before starting HCV treatment, to avoid depressive symptoms from interferon. It is a good idea to discuss this with your specialist;
- Interferon lowers the CD4 count during treatment, so your doctor will concentrate on monitoring other markers of your HIV infection, such as HIV viral load and CD4 percentages instead of absolute numbers;
- Ribavirin can cause anaemia. Some HIV drugs, such as AZT, can also cause anaemia so ideally you should not take these drugs together;
- Ribavirin interacts with ddI (didanosine, Videx) and d4T (Zerit), and cannot be taken with these;
- Ribavirin must not be taken during pregnancy, or up to six months before, as it can cause birth defects.

This is particularly important in people who have significant liver disease or cirrhosis.

The response rate to treatment largely depends upon the strain or genotype of HCV. There are at least six major genotypes of HCV, and genotypes one to three are the most common in Australia. Genotype 1 is the hardest to clear, with between 25 and 40% of people with HIV/HCV having an SVR. Genotypes 2 and 3 can be treated successfully in around 60% of people with HIV/HCV. Most people with HCV who were born in Australia have either genotype 1 or 3. For those born in Asia or elsewhere other genotypes are more common. Your doctor can test to see which genotype you have and you can factor this into your decision-making about treatment.

If HCV disease has progressed to the point where the liver can no longer function, a liver transplant is the only treatment.

Issues in HCV treatment

HCV treatment can cause very difficult side effects. Depression, difficulty sleeping, moodiness, aches and pains, fatigue, weakness, nausea, hair thinning, weight loss, muscle wasting, changes in taste, loss of appetite, diarrhoea, low red or white blood cell count, changes in concentration and respiratory problems can all occur. (Of course, some people may not get any side effects – and some may get all!) Treating HCV before you need treatment for HIV is often best, so that you and your liver have a chance to recover from the therapy before you start taking ARV, which can cause liver side effects. Of course this is not always possible, and sometimes it may be more important to treat your HIV first, especially if your CD4 count is particularly low.

When to treat

Treatment can be quite a commitment, and may take some planning for women with HIV who have children or other caring responsibilities. It's probably better to assume that you will have side effects and plan accordingly than to hope that you won't (a nice surprise is better than a nasty one).

Whether or not to treat will be determined in part by your HCV viral load and liver function tests – blood tests that look at liver enzymes. The only way to determine the extent of liver damage, however, is a liver biopsy (a long needle inserted into the liver to take a tissue sample). However, this is not performed often these days.

Treatment is always recommended for people with moderate to severe fibrosis or liver scarring, where the liver still maintains some functionality (compensated cirrhosis). However, some people with HIV/HCV co-infection may choose to treat HCV earlier before there is significant liver damage.

If your doctor has told you that you will require treatment, but have a choice as to whether to do so immediately or to wait, you may want to consider:

- How well you are set up to cope with side effects;
- Any plans you have for getting pregnant (HCV treatment cannot be taken while pregnant or for six months before hand).

If your HIV viral load is low and your CD4 count is high, immediate treatment gives you the opportunity to possibly clear HCV before you start treating HIV. That also leaves you in a good position if you are planning pregnancy in the next few years.

If you have any active HIV opportunistic infections or if your HIV viral load is high and your CD4 count low, HCV treatment is not advisable immediately. One of the HCV drugs (the interferon component) lowers your CD4 count, so treating your HIV first and giving your immune system a boost is better before starting HCV treatment in that instance.

HCV treatment while on methadone

You can undertake HCV treatment while you are taking methadone maintenance. However, you may be at heightened risk of experiencing HCV

treatment-related depression, so it is worth discussing the potential benefits and risks of taking an antidepressant preventatively with your doctor.

HCV treatment while taking heroin

Some HCV advocates suggest that a heroin 'relapse' should not be cause to discontinue HCV treatment. Many (although not all) doctors will not see heroin 'relapse' as a reason to stop therapy unless you are having trouble committing to, or tolerating, the treatment. However, it is important to remember that it is possible to get reinfected with HCV either during, or following, successful treatment.

The Australian Injecting and Illicit Drug User's League (AIVL) will be able to offer you support and advice on this issue. On the Internet, the Organization to Achieve Solutions in Substance-Abuse (OASIS) from the USA has some data on treatment for people on methadone and who sometimes take heroin that might be of help. Try www.hepcassoc.org, or do a Google search with the key words methadone, HCV treatment, and heroin.

Liver-friendly living

Many people with HCV manage their symptoms with a range of lifestyle alterations and complementary therapies. Avoiding or reducing alcohol consumption is key in limiting liver damage.

A balanced diet, high in protein and carbohydrates and low in salt can be an important part of managing active

liver disease; vitamin and mineral supplements may also be of use. Fresh fruits and vegetables are rich sources of antioxidants which are important for cell regeneration. Try to eat at least three different coloured fruits or vegetables at each meal. A number of people with liver disease tolerate fats poorly. If you are experiencing a loss of appetite, try eating smaller more frequent meals throughout the day.

High protein foods are essential to keep up kilojoules and avoid muscle wasting. Try to include these in every meal. This is easier by varying your sources of protein between lean meat, chicken, fish, low fat dairy products, eggs, nuts, seeds, pulses and legumes (e.g. peas, beans, lentils, etc). Textured vegetable protein products and calcium supplemented soy products, such as milk, yoghurt and cheese are also good choices especially for vegetarians.

With complementary therapies and diets like the liver-cleansing diet it is important to keep your doctor in the information loop. Some alternative medicines can lead to serious liver damage. You and your doctor need to discuss the big-picture issues of your health, your weight and whether any herbs or vitamins might impact on HIV treatment, if you are taking ARV.

opportunistic infections

What are opportunistic infections?

The term opportunistic infections (OIs) refers to a number of illnesses, infections and conditions which occur in people whose immune systems have been damaged due to HIV and AIDS.

They are called 'opportunistic' because the things that cause them (e.g. organisms such as viruses, bacteria, or fungi) are often commonly present in the body and in the environment. If you have an intact immune system, these agents will not cause serious infection or illness; the immune system will 'deal with' them. But when the immune system is significantly damaged, by HIV for example, these common bugs may use this 'opportunity' to cause disease.

Opportunistic infections can cause death and debilitating illness. Generally, the risk of developing an OI increases as a person's CD4 count decreases. The use of combination antiretroviral therapy has meant that many people with HIV in Australia, over the last eight to ten years, have not

sustained the serious immune damage responsible for AIDS. The number of people reporting OIs has dramatically decreased.

If you have or have ever had a CD4 count of 200 or below (particularly if it has been under 100) you need to pay careful attention to symptoms that may indicate the presence of an infection.

Persistent diarrhoea, fever, night sweats, vision loss or change, abdominal pain, enlarged lymph nodes, unexplained weight loss, shortness of breath and/or chest pain all need to be reported to your doctor. In addition, if you experience neurological disturbances including headaches, changes in your thinking, confusion, memory loss, paralysis down one side of the body, speech and comprehension problems can all be symptoms of serious AIDS-defining illnesses. It is important that you report any such symptoms to your doctor so that you can get an accurate diagnosis and commence treatment as soon as possible if needed.

complementary therapies

Many women with HIV/AIDS use complementary or alternative therapies. Most complementary therapies operate from the perspective of seeing the body as a whole – taking a ‘holistic’ view. This means the practitioner takes into account the inter-relationship of all body’s systems, as well the influence of mind, emotions and environment, when looking at an individual’s health concerns.

Many kinds of therapies come under the heading of ‘complementary’ or ‘alternative’ therapies, including:

- Acupuncture;
- Western herbal medicine;
- Homoeopathy;
- Traditional Chinese medicine;
- Massage;
- Bodywork or re-alignment techniques such as osteopathy or chiropractic.

A recent survey of HIV positive women in Australia found the most commonly used alternative therapies included massage, herbal medicines, meditation and visualisation, and vitamin supplementation.

Women use these therapies for a range of reasons, including:

- Health maintenance;
- To strengthen the immune system;
- To improve energy, tiredness or sleep difficulties;
- To help deal with the side effects of ARV treatments such as nausea and sleep difficulties;
- To help manage stress and anxiety;
- To assist with the relief of some HIV-related conditions such as pain in hands and feet or changes in menstrual patterns; and
- As an alternative to conventional medical treatments.

Many women will use both conventional (or ‘allopathic’) and complementary treatments at some point, sometimes alone or in combination with each other.

Are they effective in dealing with HIV?

There is an ongoing debate among positive people, community advocates and health practitioners about the usefulness, even the safety, of some complementary therapies. There are people strongly opposed to complementary health approaches, and others who will not use anything but these kinds of holistic approaches.

It is important, when considering complementary therapies, to seek as much information as possible about any approach you may try. This information may come from practitioners themselves, or other positive people. You may want to seek out clinical research or trials. It is important to establish that any information about a particular therapy is reliable, since some complementary therapies may be potentially harmful or dangerous.

To date, there is no evidence that any complementary therapies, like herbs, have proven anti-HIV effects, and you should be wary of anyone who makes this claim.

Anecdotal reports

Many women, both HIV positive and HIV negative, report that acupuncture is a useful therapy for menstrual irregularities. In addition, it is reported to have a role in treating mild chronic symptoms like headache or nerve pain. Seeing an experienced, reputable practitioner is very important, and avoid anyone who offers unqualified advice on prescribed treatments that you are taking, such as ARV.

Trials and research

It can be hard to find reliable information about complementary therapies. Often, they have not been the subject of formal clinical investigation in the same way as pharmaceutical drugs. If studies have been conducted overseas, the information may not always be accessible or translated.

Studies of complementary therapies are often disputed. Formal clinical trials such as those conducted on new drugs need to follow strict guidelines. It is argued that this approach may not suit the evaluation of some alternative therapies. For instance, preparations of Chinese herbs are individually mixed by the practitioner, according to the practitioner’s individual assessment. This contrasts with ARV drugs, where a specified dose is prescribed and recommended as standard for all. These differences in the approach can make it difficult to formally say whether alternative approaches are effective.

Nonetheless, as long as a therapy remains untested in formal clinical trials it cannot be labelled as useful, nor dismissed as ineffective.

Often positive women rely on the anecdotal stories of others living with HIV, or advocate a particular therapy based on their own personal experience. An up-to-date, HIV-experienced practitioner should also be able to inform you of approaches known to be useful in the treatment of HIV conditions or showing promise in trials.

Are there side effects or drug interactions?

Not all natural therapies are safe for everyone or free of side effects. Some substances can be quite potent, so you should be sure to notice any changes that happen to your body and discuss these with your health practitioner(s). For example, some herbal mixtures can be quite toxic on the liver, and could potentially interact with anti-HIV drugs or cause other problems.

In addition, the monitoring of natural therapies can be substandard, as an audit on manufacturing in Australia found; products produced by Pan Pharmaceuticals not containing the active ingredients claimed.

You should tell your GP about any alternative medicines you are using (like herbs), and talk to your complementary therapist about any ARV or other drugs you may be taking. Keeping a full list of all the treatment you take is useful to assist all of the practitioners involved in your care.

It is important, when considering complementary therapies, to seek as much information as possible about any approach you may try.

contacts

Key to Symbols

- ⌚ Limited hours
- (M) Membership organisation
- (V) Volunteer opportunities

National

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

02 8568 0300
Suite G5, 1 Erskineville Road
NEWTOWN NSW 2042
PO Box 917
NEWTOWN NSW 2042
www.napwa.org.au

Women@OZPOZ

Is an email discussion list for HIV positive women, auspiced by NAPWA. This informal electronic support network provides a safe, confidential environment where women can share their stories and questions, network and connect with other women and exchange information on the ups and downs of living with HIV. The Network is a closed list and members are required to sign up. For further information go to <http://lists.ozpoz.org/listinfo.cgi/women-ozpoz.org>

Australian Federation of AIDS Organisations (AFAO)

Level 1, 222 King Street
NEWTOWN NSW 2042
PO Box 51 NEWTOWN NSW 2042
Ph: 02 9557 9399
Email: afao@afao.org.au
www.afao.org.au

Australasian Society for HIV Medicine (ASHM)

Locked Mail Bag 5057
DARLINGHURST NSW 1300
Ph: 02 8204 0700
Email: ashm@ashm.org.au
www.ashm.org.au

Australian Hepatitis Council

PO Box 716 Woden ACT 2606
Ph: 02 6232 4257
Email: admin@hepatitisaustralia.com
www.hepatitisaustralia.com

New South Wales Area code (02)

PLWHA (NSW) (M) (V)

Advocacy, services, publications, speakers' bureau, events, social marketing, education & peer support.
Suite 5, 94 Oxford St DARLINGHURST.
9361 6011 or 1800 245 677
www.plwha.org.au

ACON (M) (V)

HIV prevention, health promotion, advocacy, care and support services for PLWHA, gay men, lesbians, Aboriginal and Torres Strait Islander, Injecting drug users and, sex workers.
9 Commonwealth St SURRY HILLS
9206 2000 or 1800 063 060 TTY 9283 2088
acon@acon.org.au
www.acon.org.au

- Positive Living Centre Sydney - 9699 8756 (Women & Family Project)

- Western Sydney – 9204 2400
- Hunter Newcastle – 4927 6808
- Illawarra Wollongong – 4226 1163
- Mid North Coast Port Macquarie – 6584 0943
- Northern Rivers Lismore – 6622 1555

Community Support Network (CSN) (V)

Transport & practical home help for PLWHA.

- Sydney – 9206 2031
- West Syd – 9206 2000
- Hunter/Newcastle – 4927 6808
- Illawarra/Wollongong – 4226 1163
- Mid North Coast Port Macquarie – 6584 0943
- Northern Rivers Lismore – 6622 1555
- CSN volunteers (training provided) 9206 2038

Ankali (V) Volunteers provide one-to-one emotional support for people living with HIV, their partners, family and friends. Referrals, counselling, professional support.

9332 9742

Positive Living Centre Sydney (PLC)

(M) (V) Regular programs, social events, meals, service info, referrals, care coordination, complementary therapies, internet access, re-skilling, art classes.

Mon (appointment), Tue-Fri 10am - 4pm (drop in) 6pm - 8pm (appointment)
703 Bourke St Surry Hills 9699 8756

Luncheon Club (V) Free lunch (Mon 12–4) for people living with and affected by HIV/AIDS. Women and children welcome. Luncheon Club Larder (Mon/Wed 12–4) Free food & essentials for people with HIV struggling on the DSP (bring pension card).

77 Kellick St WATERLOO
8399 3220 or 0416 040 074
www.luncheonclub.org.au

Bobby Goldsmith Foundation (BGF) (V)

Financial help, supported housing, financial counselling, help with essential bills, loans of essential appliances.

9283 8666 or 1800 651 011 (Freecall)
www.bgf.org.au

Positive Futures Assistance with returning to work or study, volunteering and alternatives to paid work.

9283 8666 or 1800 651 011 (Freecall)
www.bgf.org.au

HIV/AIDS Legal Centre Free HIV-related legal services. Wills, superannuation, immigration, discrimination

9206 2060 or 1800 063 060
www.halc.org.au

Multicultural HIV/AIDS & Hepatitis C

Service Bilingual/bicultural support, advocacy for people from non-English-speaking backgrounds.

9515 5030 or 1800 108 098
www.multiculturalhivhepc.net

Positive Central Individual Client Assessment & Treatment including:- Social Work, counselling, dietetics, occupational therapy, physiotherapy. Individual and group sessions, home visits.

9am and 11am Monday to Friday
9395 0444

Switched On Living Monthly information sessions about healthy lifestyle for PLWHAs, friends, family, carers.

8382 2072

HIV Positive Heterosexuals (PozHeits) (M)

Statewide Heterosexual HIV/AIDS Service providing education and support for Heterosexuals with HIV/AIDS and their families. Peer education and support

groups, Free-call telephone support, Outreach education and support, Western area group development programs, Positive Women specific programs, Social Outings, Treatment Updates, Workforce Development initiatives, Annual Workshop, Positive Weekend Retreat, Health promotion and resource development.

9395 0444 or 1800 812 404
www.pozhet.org.au

The Sanctuary (V) Health Education & support, Complimentary Therapy (massage) Service, Peripheral Neuropathy Clinic (research), Multi-disciplinary/allied health clinics and Primary Care service development, Groups- Movie Afternoon.

6 Mary St, Newtown, 2042
9519 6142 or 9395 0444 (Positive Central)
9am and 11am Monday to Friday 6

The Haven (Western Sydney) Social support, convalescent and respite care. Meals, massage, classes, cheap groceries & frozen goods, workshops, Internet access.

9672 3600
thehaven1@optushome.com.au

Blue Mountains PLWHA Drop-in Centre

Peer support, meals.
Relocating in 2008 to
10 Station St, Katoomba.
4782 2119 6

Karumah (Newcastle) Social & peer support for PLWHA, carers, friends, and family. Lunch Tue & Thu, monthly BBQ.
4940 8393 6

Positive Support Network (Central Coast) Support and referral services
Mon–Fri 10am–3.30pm

4323 2905
posnet@telstra.easymail.com.au

Hepatitis C Council of NSW – Hep C Helpline

9332 1599 (NSW country 1800 803 990)
www.hepatitisc.org.au

Victoria Area code (03)

People Living with HIV/AIDS Victoria (PLWHA Vic) (M) (V) Advocacy, support, representation. Speakers' bureau, treatments officer, newsletter, events, social groups.

6 Claremont St South Yarra 3141
9865 6772 www.plwhavictoria.org.au

Victorian AIDS Council/Gay Men's Health Centre (VAC/GMHC) (M) (V)

The VAC/GMHC aims to improve the health and social and emotional well-being of the Victorian HIV positive and gay, lesbian, bisexual and transgender communities.

6 Claremont Street, South Yarra 3141
9865 6700 Freecall 1800 134 840
www.vicaids.asn.au
enquiries@vicaids.asn.au

Positive Living Centre Community centre and one-stop shop for services & activities for people living with HIV. Free tea/coffee/brunch, complementary therapies info/advice, massage, naturopathy, relaxation, yoga, low cost meals, food pantry, peer support, emergency financial relief, youth program, legal centre, community support, outreach social work, computer/internet/training, fitness classes, social/educational/self development courses and activities.

*Mon (appointment),
Tue-Fri 10am - 4pm (drop in)
6pm - 8pm (appointment)*
51 Commercial Road Prahran.
9863 0444 or 1800 622 795
enquiries@vicaids.asn.au

HIV/Sexual Health Connect

Counselling, information & referral on a variety of STI's and blood borne viruses
1800 038 125

The Centre Clinic Community health service for positive people and the LGBT community but open to all.

Rear 77 Fitzroy Street St Kilda 9525 5866
or 42 Separation Street, Northcote
9481 7155

AIDS Housing Action Group State-wide confidential housing service.

9417 4311 or 1800 674 311
ahag@infoexchange.net.au

Positive Women Victoria (M) Offers confidential support & information to women who have been diagnosed as HIV positive, as well as their family, friends & colleagues who want to know more about HIV & how it affects women. Publications also available on request.

9076 6918 www.positivewomen.org.au
info@positivewomen.org.au

Straight Arrows (M) Support, services for HIV positive heterosexuals (men and women) and their families.

Fairfield House, The Alfred Hospital (Moubray St entrance) Prahran 3181
9276 3792

www.straightarrows.org.au
information@straightarrows.org.au

Positive Counselling - HIV/Hep C (based at William Road Family Therapy)
Free counselling for individuals, couples, friends or family infected or affected by HIV.

3 Williams Rd, Windsor
9530 2311 *Friday only*
info@positivecounselling.org.au

HIV, Hepatitis and STIs Education and Resource Centre Community resources on HIV, hepatitis and STIs, health research on the internet.

Fairfield House
The Alfred Hospital, Moubray Street, Prahran
9076 6993

www.hivhepsti.info
erc@alfred.org.au

Country AIDS Network Victoria

Advocacy, resources and services for rural & remote PLWHA and/or Hepatitis, and/or blood borne viruses.

5443 8355
www.can.org.au
can@can.org.au

Hepatitis C Council of Victoria

9380 4644 (Vic country 1800 703 003)
www.hepcvic.org.au

Queensland Area code (07)

Queensland Positive People (QPP) (M) (V) A community-based organisation offering regular peer support & self-help activities; advocacy; treatments and health promotion information; referrals and the quarterly "QPP Alive" magazine to PLWHA and their partners, family and significant others affected by HIV/AIDS.

QPP State Resource Centre
21 Manilla St, East Brisbane, QLD 4169
PO Box 7403, East Brisbane, QLD 4169
3013 5555

1800 636 241 (within QLD)
www.qpp.org.au
info@qpp.org.au

Positive Directions (Spiritus)

- Brisbane - 101a Watson Street
CAMP HILL QLD 4152
PO Box 3387 Norman Park Qld 4170
3900 8000
- Cairns - 4051 1028
- Townsville - 4721 1384
- Sunshine Coast - 5441 1222
- Gold Coast - 5576 8366

www.positivedirections.org.au

Queensland Association for Healthy Communities (QaHC) (M) (V) Education, advocacy, support.

30 Helen Street Newstead QLD 4006
PO Box 1372 Eagle Farm QLD 4009
Brisbane and South East Qld - 3017 1777
or 1800 177 434 (Freecall outside Brisbane)

- North Qld - 4041 5451
- Central Qld - 5451 1118
- Men's Line Freecall - 1800 155 141

www.qahc.org.au
info@qahc.org.au

Hepatitis C Council of Qld (HCCQ) (M)

Education, support, info, advocacy, counselling.

3236 0610 or
1300 437 222 (Qld country)
www.hepqld.asn.au
reception@hepqld.asn.au

South Australia Area code (08)

PLWHA (SA) and Positive Living Centre (M) (V) Social drop-in and health centre for PLWHA. Massage, meals, treatments info, Positive Speakers' Bureau, transport service, social groups. M-F 9-5,

16 Malwa St Glandore 5037
8293 3700
www.hivsa.org.au

AIDS Council of South Australia (ACSA) (M) (V) Education, information and referral. Face-to-face and phone counselling, financial and practical assistance, individual advocacy.

64 Fullarton Rd Norwood 5067
8334 1611 or 1800 888 559
TTY 8362 0306

www.acsa.org.au
information@acsa.org.au

Adelaide Diocesan AIDS Centre (ADAC)

Home care, counselling, referral, intermediate accommodation, pastoral care, PAWS, lunches fortnightly

ADAC/Centacare
33 Wakefield Street, Adelaide 5000
8241 7022
manager@adac.centacare.org.au

HIV Women's Project Peer support group, info, advocacy and referral.

64 Pennington Tce, North Adelaide 5006
8239 9600 (Attn: Pam Price)
1800 182 098 (outside Adelaide metro)
www.whs.sa.gov.au
info@whs.sa.gov.au

Mosaic Counselling A confidential and free service for people affected by HIV or hepatitis C.

8223 4566 - 1300 364 277
www.relationships.com.au

Hepatitis C Council of SA Free and confidential service providing information, support, education, support groups and support phone line

3 Hackney Road, Hackney 5069
8362 8443 (SA country 1800 021 133)
www.hepccouncilsa.asn.au
admin@hepccouncilsa.asn.au

Western Australia

Area code (08)

HIV/AIDS Peer Advisory Network (HAPAN) (M) PLWHA group, meets once a month.

HIV Positive Peer Educator 9482 0000
hapan@waids.com

WA AIDS Council (WAAC) (M) (V)

Support services, counselling, treatments info, complementary therapies, retreats, forums, workshops, one-to-one peer support, education, women's project, newly diagnosed program.

664 Murray St West Perth 6005.
9482 0000 www.waids.com
waac@waids.com

The Living Centre (HIV/AIDS Pastoral Care) (M)

Drop in centre for people with or affected by HIV/AIDS. Peer, social and outreach support

9470 4931 pastoral_care@bigpond.com

Hepatitis Council of WA

9227 9800 (general enquiries)
9328 8538 (support, info)
1800 800 070 (WA country)
www.hepatitiswa.com.au
info@hepatitiswa.com.au

Tasmania

Area code (03)

Tasmanian Council on AIDS, Hepatitis and Related Diseases (TasCAHRD) (M) (V)

319 Liverpool St Hobart 7000
6234 1242 or 1800 005 900
www.tascahrd.org.au

Sexual Health Service Tasmania

60 Collins St Hobart
6233 3557 or 1800 675 859 (Tasmania Only)

ACT

Area code (02)

PLWHA/ACT (M) (V) Social events for positive people, drop-in centre, free internet, holistic bodywork, positive speaker's bureau, women's group, financial assistance, social networks, advocacy, referral, support, counselling, information, dietician's clinic and workshops. Please call the office for further details.

16 Gordon St Acton 2601 – 6257 4985
<http://aidsaction.org.au/plwha>
plwha.act@aidsaction.org.au

AIDS Action Council of the ACT (M) (V)

Information, referral and support.
Westlund House
16 Gordon Street Acton – 6257 2855
www.aidsaction.org.au

Positive Support Network Weekly social and educational night for positive people. Free dinner. Tue from 6pm.
6257 2855 – 6257 4985

ACT Hepatitis C Council

6257 2911 or HepLine 1300 301 383
www.acthepc.org info@acthepc.org

Northern Territory

Area code (08)

PLWHA/NT (M)

PO Box 2826 Darwin 0801. 8941 1711

Northern Territory AIDS and Hepatitis Council (NTAHC)

14 Railway Terrace Alice Springs 0870
8953 3172
46 Woods Street, Darwin 0800
8941 1711
Freecall 1800 880 899
www.ntahc.org.au info@ntahc.org.au

Glossary

Generic name	Abbreviation	Brand name	Drug class
abacavir	ABC	Ziagen	Nucleoside analogue
atazanavir	-	Reyataz	Protease inhibitor
darunivir (TMC 114)	-	Prezista	Protease Inhibitor
didanosine	ddl	Videx	Nucleoside analogue
efavirenz	EFV	Stocrin	NNRTI
emfuvirtide	T-20	Fuzeon	Fusion inhibitor
emtricitabine	FTC	Emtriva	Nucleoside analogue
fosamprenavir	FPV	Telzir	Protease inhibitor
indinavir	IDV	Crixivan	Protease inhibitor
lamivudine	3TC	Epivir	Nucleoside analogue
nelfinavir	NVF	Viracept	Protease inhibitor
nevirapine	NVP	Viramune	NNRTI
maraviroc	-	Selsentry/Celsentri (US & Europe)	Chemokine receptor antagonist (CCR5)
ritonavir	RTV (or /r when used as a booster)	Norvir	Protease inhibitor/ used to boost potency of other PIs
saquinavir (Hard/soft gel)	SQV	Invirase/ Fortovase	Protease inhibitor
stavudine	d4T	Zerit	Nucleoside analogue
tenofovir	TDF	Viread	Nucleotide analogue
Raltegravir (MK- 0518)	-	Isentress	Integrase Inhibitor
zidovudine	AZT	Retrovir	Nucleoside analogue
zidovudine/ lamivudine	AZT/3TC	Combivir	Dual nucleoside analogue
tipranavir/ritonavir	TPV/r	Aptivus	Dual protease inhibitor
lopinavir/ritonavir	LPV/r	Kaletra	Dual protease inhibitor
emtricitabine/ tenofovir	TDF/FTC	Truvada	Nucleoside/ nucleotide analogue
abacavir/zidovudine/ lamivudine	AZT/3TC/ABC	Trizivir	Triple nucleoside analogue
abacavir/lamivudine	ABC/3TC	Kivexa	Dual nucleoside analogue

* see page 19-20 for more information on drug classes.

A

Adherence

Taking medicine as prescribed. Sometimes also called 'compliance' in medical literature.

Adverse event

An unwanted side effect of a treatment.

AIDS

Acquired Immune Deficiency Syndrome. A collection of specific illnesses and conditions that occur because the body's immune system has been damaged by HIV.

AIDS-defining illness

Serious illnesses caused by HIV-related immune deficiency. A particular set of these serious illnesses were used by the US Centers for Disease Control (CDC) to define 'AIDS'.

AIDS-related illness

Illnesses, ranging from mild to serious, caused by HIV-related immune deficiency.

Anaemia

A shortage or change in the size or function of red blood cells. These cells carry oxygen to cells of the body.

Antenatal

Before birth.

Antibodies

A component of the immune system that recognises and eliminates certain infections and disease-causing agent.

Antigen

Something the immune system can recognise as 'foreign' and attack.

Antiretroviral (ARV)

A medication or other substance that is active against retroviruses such as HIV. See also HAART.

Asymptomatic

Having no symptoms.

B

B cell

A type of immune cell, responsible for making antibodies.

Bacteria

Single-celled micro-organisms.

Biopsy

A small sample of tissue that can be examined for signs of disease.

Breech

When a baby is in the bottom or feet first position, rather than the head first position, in the uterus.

C

Caesarean delivery

Surgical delivery of a baby through an abdominal incision.

Candida Albicans

A common fungal infection that exists naturally in the body but can over-grow and cause either localised or systemic disease in people who are immune suppressed. Often known as thrush.

Cardiovascular

The heart and other blood-circulating parts of the body.

Cardiovascular disease

Includes coronary heart disease (about 50%), stroke (about 25%), and other circulatory system diseases.

CD4 cell

A type of cell in the immune system that fights infection. HIV targets CD4 cell receptors, invades them, and uses the cell as a vehicle for HIV replication. The CD4 cell count roughly reflects the state of the immune system.

CD8

A molecule on the surface of some white blood cells. Some of these cells can kill other cells that are infected with foreign organisms.

Cell turnover

The rate at which old cells die and new cells are made.

Central nervous system

The brain and spinal cord, which is responsible for the integration of all nervous activities.

Cervix

The 'neck' of the uterus (womb), which separates the vagina from the uterus.

Cervical dysplasia

Growth of abnormal cells in the cervix, which may be pre-cancerous.

Cervical intraepithelial neoplasia (CIN)

Cancerous growth within the cells lining the cervix. Untreated, it can lead to cervical cancer.

Cholesterol

An essential component of cell membranes and nerve fibre insulation; cholesterol is important for the metabolism and transport of fatty acids and the production of hormones and Vitamin D. Cholesterol is manufactured by the liver, and is also present in certain foods. High blood cholesterol levels have been linked to heart disease and may be a side effect of some anti-HIV medications. See also: HDL, LDL.

Clinical

A term referring to the nursing or medical care of patients.

Clinical trial

Testing medical interventions in people. For example, experimental drugs which have shown promise in laboratory studies proceed through several stages of clinical trials: phase I trials establish that a drug is safe for humans to take; phase II trials examine whether the drug is effective against HIV; phase III trials are the final step before approval,

looking at effectiveness, safety and side effects in large numbers of people.

Chronic

A long-term condition.

Coinfection

Having more than one infection at the same time. For example, when a person with HIV has hepatitis B or C. This can make disease worse and treatment more difficult.

Colposcopy

Examination of the surface of the cervix under magnification to identify the location and extent of abnormal lesions.

Combination therapy

Using more than one drug at a time.

Complementary therapy

Different systems of healing, other than orthodox (also called allopathic or Western) medicine. These include acupuncture, massage, osteopathy, traditional medicines and so on. In the context of HIV treatment it is important that your prescribing doctor knows about all treatments you are taking, including herbs and vitamins, as substances can interact with anti-HIV treatment.

Contraindication

A reason why a drug should not be used.

D

Diabetes

A disorder in which sugars in the diet cannot be metabolised into energy due to a lack of the enzyme insulin. Late-onset diabetes mellitus may be a long-term side effect of some anti-HIV drugs. See also: insulin resistance.

Diarrhoea

Abnormal bowel movements, characterised by watery or frequent stools.

Diagnosis

The process of determining the nature of a disorder through symptoms, medical history and/or medical tests.

Disease progression

The worsening of a disease, for example when HIV-related symptoms or AIDS-related illnesses appear.

Dental dams

Flat pieces of latex that can be used as barriers for oral-clitoral-vaginal or oral-anal sex.

Drug class

A group of anti-HIV drugs with the same target of action. Anti-HIV drug classes include nucleoside analogue reverse transcriptase inhibitors, protease inhibitors and non-nucleoside analogue reverse transcriptase inhibitors, as well as several others. Combining drugs from three or more classes is the basis of Highly Active Antiretroviral Therapy (HAART). See also: HAART, nucleoside analogue, protease inhibitor, reverse transcriptase inhibitor.

Dysplasia

Abnormal growth of cells.

E**Epidemiology**

The study of diseases within a population.

F**Faeces**

Poo.

Foetus

An unborn baby.

Fusion inhibitor

Anti-HIV drug targeting the point where

HIV locks on to an immune cell.

Gastrointestinal

Relating to or affecting the stomach, gut or bowel.

Gynaecological conditions

Conditions affecting female genitals or reproductive organs.

H**HAART**

Highly Active AntiRetroviral Therapy; treatment of HIV infection using several different drugs together.

HBV

Hepatitis B virus.

HCV

Hepatitis C virus.

Hepatitis

Any inflammation of the liver. It is usually caused by viral infection, toxic agents or drugs but may be an autoimmune response. It is characterised by jaundice, abdominal pain, liver enlargement and sometimes fever. The different types of viral hepatitis include hepatitis A (formerly called infectious hepatitis), hep B (serum hepatitis), hep C (formerly called non-A, non-B hepatitis), and hepatitis D, E, F and G.

Herpes viruses

Family of viruses which can cause disease in HIV infection, e.g. cytomegalovirus and herpes zoster.

Hormone

A chemical which stimulates or suppresses cell and tissue activity. Some hormones are specifically associated with masculine or feminine secondary sex characteristics.

High density lipoproteins (HDL)

HDL is 'good' cholesterol – LDL is 'bad' cholesterol).

Human papillomavirus (HPV)

A group of wart-causing viruses which are also responsible for cancer of the cervix and some anal cancers.

Hyper

Prefix meaning higher than usual.

Hypo

Prefix meaning lower than usual.

I**Insulin resistance**

A diabetes-like condition in which, while adequate amounts of insulin are produced by the pancreas, the body does not respond normally to the action of insulin. In the wider community, insulin is related to obesity, while in HIV it may be related to lipodystrophy. See also: diabetes, lipodystrophy.

Immune cells

Cells that fight infection and disease in the body, such as CD4 cells and CD8 cells.

Immune suppression

A reduction in the ability of the immune system to fight infections or tumours.

Immune system

The body's natural defences against infection and disease.

Intolerance

Being unable to tolerate a particular medication due to adverse effects.

J**Jaundice**

A yellowing of the skin and whites of the eyes associated with liver or gall bladder problems.

L**Libido**

Another word for sexual drive.

Lipid

A fat. See also: cholesterol.

Lipoatrophy

Loss of body fat. This may occur as a result of a metabolic disorder linked either to HIV itself or drugs used to treat it.

Lipodystrophy

A metabolic disorder in which fat in the face, arms, legs and buttocks is lost and/or fatty deposits appear in the abdomen, breasts and neck.

Liver

A large organ, located in the upper right abdomen, which assists in digestion by metabolising carbohydrates, fats and proteins, stores vitamins and minerals, produces amino acids, bile and cholesterol, and removes toxins from the blood.

Low density lipoproteins (LDL)

LDL is 'bad' cholesterol – HDL is 'good' cholesterol.

Lubricant

A gel-like water-based substance used with condoms and/or used in sex to keep things wet and prevent abrasion.

M**Malignant**

Tumours which may grow rapidly, infiltrate surrounding tissues and spread around the body.

Macrophage

A white blood cell that roams the body tissues engulfing foreign organisms.

Monitoring

Regular observation, including blood tests, to check for signs of illness or immune system decline.

Monotherapy

Taking a drug on its own, as opposed to in combination with other drugs.

Mutation

A single change in gene sequence.

N**Naïve**

Never having taken anti-HIV treatments before.

Nausea

Feeling sick.

Neuropathy

Damage to the nerves.

Nucleoside analogue (NRTI)

Nucleoside analogue reverse transcriptase inhibitor, the family of antiretrovirals which includes AZT, ddI, 3TC, d4T, and abacavir.

A type of anti-HIV drug that works by inhibiting a stage of the HIV life cycle called reverse transcription. Non-nucleosides (NNRTIs) work in a similar way, but are chemically different.

NNRTI

Non-nucleoside reverse transcriptase inhibitor, the family of antiretrovirals which includes efavirenz, nevirapine and delavirdine.

Nucleotide analogue

Chemical which resembles a nucleotide. Family of antiretrovirals which includes tenofovir.

O**Oestrogen**

A hormone that controls female sexual development, promoting the growth and function of female sex organs and secondary sex characteristics. A synthesised form is used in combined Pill for contraception.

Opportunistic infection (OI)

Specific infections which cause disease in someone with a damaged immune system.

P**Pancreatitis**

A condition of the pancreas causing severe abdominal pain, shock and collapse, which can be fatal.

Pasteurisation ('Pretoria pasteurisation')

Heat treatment of milk to destroy disease-causing agents.

Pap smear

Process that involves taking a specimen of cells from the cervix using a swab and analysing them in the laboratory for pre-cancerous changes to the cells or the presence of cancer.

Pathogen

Any micro-organism which can cause disease. There are four main types: bacteria, fungi, protozoa, viruses.

Peripheral neuropathy

Damage to the nerves of the hands and/or feet, causing symptoms ranging from numbness to excruciating pain.

PID: pelvic inflammatory disease

This is a serious condition that can be caused by several different sexually transmissible infections, such as gonorrhoea and chlamydia or other bacterial infections, which travel from the vagina into the uterus and fallopian tubes. It causes pain and discomfort and can lead to infertility.

PLWHA

Person (or People) Living with HIV/AIDS.

Pre-cancerous cells

Abnormal cells that are not malignant, but which may become malignant if untreated.

Prophylaxis

A preventive measure, such as a treatment taken to prevent an illness.

Protease inhibitor

Family of antiretrovirals which target the protease enzyme. Includes amprenavir, indinavir, lopinavir, ritonavir, saquinavir, nelfinavir, and atazanavir.

Post-exposure prophylaxis (PEP)

A preventive measure that is used after exposure to an infectious agent has occurred. In HIV this is taking a course of antiretroviral medication within 72 hours of contact with the virus, which may reduce the chances of the person acquiring HIV.

Primary infection

The period immediately after infection, prior to the production of HIV antibodies (see also seroconversion).

Progesterone/progestogen

The hormone responsible for preparing the inner lining of the uterus for pregnancy. The synthetic form is used in hormonal contraceptives.

R**Recreational drugs**

Drugs taken for pleasure rather than to treat an illness. These may include illegal drugs.

Regimen

A drug or treatment combination and the way it is taken.

Replication

The process of viral reproduction.

Retrovirus

Family of viruses to which HIV belongs, that are distinguished by their use of RNA.

Resistance

HIV which has mutated and is less susceptible to the effects of one or more anti-HIV drugs is said to be resistant.

Reverse transcriptase inhibitor

A type of anti-HIV drug which works by interfering with an enzyme, reverse transcriptase, that HIV needs to reproduce.

Ribavirin

An antiviral drug which is effective against a range of viruses including herpes, the hepatitis C virus and several strains of influenza.

Rupture of membranes

When the membrane that seals the amniotic fluid in the uterus breaks prior to childbirth. Also called the breaking of the waters.

S**St John's Wort**

A herbal preparation used to treat mild to moderate depression. It interacts with a range of medications, including HIV treatments and can cause extra sensitivity to the sun.

Salvage therapy

A treatment strategy for managing HIV in people who have developed resistance to existing therapies.

Seroconversion

The time at which a person develops antibodies to HIV, so their HIV antibody status changes from negative to positive.

squamous intraepithelial lesion (SIL)

Cancerous growth within the cells lining the cervix. Untreated, it can lead to invasive cancer of the cervix.

SSRI drugs

Selective serotonin reuptake inhibitors, a class of antidepressant drugs.

STI

(Sexually Transmissible (or Transmitted) Infection); Infections spread by the transfer of organisms from person to person during sexual contact. Previously called venereal disease (VD) (an older public health term) or sexually transmitted diseases (STDs).

Strain

A variant characterised by a specific genotype.

Swab

A pad of absorbent material that may be attached to a stick or wire. This pad may be used for the collection of cells from, for example, the cervix.

Symptoms

A perceptible indicator of disease.

Symptomatic

Having symptoms.

Systemic

Acting throughout the body rather than locally.

T

T-cells

A type of immune system cell which is damaged in the course of HIV infection. CD4 and CD8 cells are both sub-types of T cell.

Trimester

The approximately 40 weeks of pregnancy is often divided into three roughly equal time periods known as trimesters.

Thrush

A fungal infection of the mouth, throat or genitals, marked by white patches. Also called candidiasis.

Toxicity

The extent or ways in which a drug is poisonous to the body.

U

Undetectable viral load

When the level of HIV replication is lower than 50 copies/ml of blood, which is the lowest level that standard Australian viral load tests can detect.

V

Viral load

A measurement of the quantity of HIV RNA in the blood. Viral load blood test results are expressed as the number of copies (of HIV) per cubic millilitre of blood plasma. High viral loads indicate a greater risk of disease progression (becoming sick with HIV-related conditions). Response to treatment is measured by a drop in viral load.

Virologic response

The effect of treatment on viral load.

Viral replication

The process by which a virus multiplies itself in the body.

Virus

A microscopic germ which reproduces within the living cells of the organism it infects.

Virulence

The power of bacteria or viruses to cause a disease. Different strains of the same micro-organism can vary in virulence.

W

Wild-type virus

Virus that has not been exposed to anti-HIV drugs before.

Wasting

Muscle and fat loss.

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