Chapter 3

Hepatitis C & HIV

Viruses & Antibodies

Viruses are very tiny organisms, so small that about 30 million could fit on the end of a needle. They can only be seen with a very powerful microscope.

Viruses take over living cells, where they make copies of themselves (or replicate), usually disrupting the normal job of the cell and sometimes even destroying it.

Antibodies are the body's main form of defense against anything foreign that gets into the bloodstream (eg. viruses, bacteria, other germs and proteins). Antibodies stick to anything foreign that they find, making it difficult for the foreign stuff to get into body cells. It can take up to 6 months before antibodies to some viruses are made. Many vaccines work by stimulating an antibody response.

There are a number of cells in the body that help in the defence against foreign materials and organisms. Macrophages travel around the bloodstream and when they run into something with antibodies on they move in to engulf, and then destroy it. Killer cells are a type of T cell (or white blood cell) that also play a role in the body's defense. These cells release toxic granules that destroy infected cells.

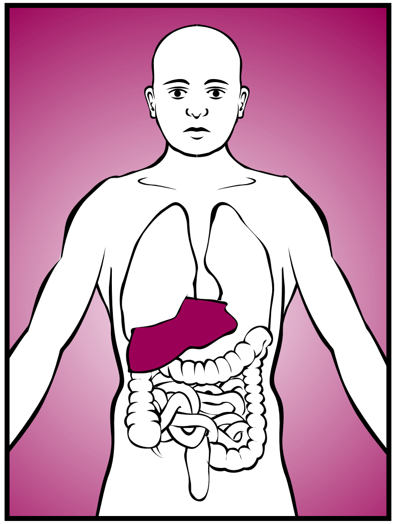
Some viruses like hep C and HIV are masters of disguise. So although the body's defenses may get rid of lots of viruses there are often many which have changed appearance, aren't recognised and therefore survive.

Viral Hepatitis

Hepatitis means "inflammation of the liver", so hepatitis can be caused by anything that leads to inflammation with swelling of the liver and often pain. This includes alcohol and other drugs, chemicals, pollutants and viruses such as Hep A, B and C.

Hep C

Hep C was discovered in 1988 and an accurate test to detect it became available in Australia in 1990. In 2007, about 278,000 people were thought to have been exposed to the Hep C virus and had Hep C antibodies.At the end of 2008, an estimated 211,700 people were living with chronic Hepatitis C infection. The number of new diagnoses has fallen to around 10,000 cases each year . This is far too many and sharing fits and other injecting equipment is still the way that most people get Hep C.



Liver

Hep C genotypes

We're used to hearing and saying "Hep C" as if it's a single virus. But, in fact, it's a group of similar viruses. Scientists have identified 6 main "families" of Hep C viruses around the world, each differing slightly from each other in their genetic makeup. These are called genotypes (1, 2, 3, etc.). Within each genotype, scientists have identified further sub-groups (a, b, c, etc.). In Australia the most commonly found kinds of Hep C virus are 1a, 1b and 3a.

At present, there appears to be no connection between genotype and severity of liver disease. However, some forms of Hep C respond better to treatment than others. More importantly, some people, often through treatment, have been able to get rid of ("clear") one kind (or genotype) of Hep C and then later get another. The point is: having many kinds of Hep C (genotypes) usually means that the problem can be more complicated to treat.

What does Hep C do?

In the long term, Hep C, usually means bad news for the liver. Hep C reproduces by making many copies of itself in the liver and eventually causes liver inflammation and liver disease.

When they first get Hep C some people have flu-like symptoms. They may find their urine gets dark and in some cases their eyes and skin turn yellow (this is called jaundice). Although these symptoms may disappear within a few weeks, it doesn't necessarily mean that the infection is gone. During this early period the amount of virus in the blood rises dramatically until the body's immune system starts to produce antibodies.

About 20-25% of people who get Hep C get rid of ("clear") the virus naturally within 12 months.

This means they may still have antibodies, but do not have active Hep C virus. Between 75-80% of people who get Hep C do not "clear" it. They have both antibodies and the Hep C virus, which is an active infection. If you clear the virus naturally (or with treatment), you are not immune to Hep C and can be re-infected.

Hep C is a slow-acting virus and for most people does not lead to serious disease or death. However, this is not the case for everybody for some people, over time, Hep C gradually stops their livers working well. From what we know at present, almost half the people who live with Hep C without treatment for 20 years will have some kind of liver damage. Of this half, most will have cirrhosis with a smaller number having liver failure and a smaller number again having liver cancer. A small number develop cirrhosis of the liver, liver failure, or liver cancer. After 40 years of living with untreated Hep C, those numbers are significantly higher.

Other factors known to increase the risk of liver damage from Hep C include:

- having Hep C as well as Hep B and/or HIV (this is called co-infection)

- drinking more than 4 standard drinks of alcohol daily over time
- having a 'fatty' liver usually associated with being overweight and/or having diabetes

How can you tell if you have Hep C?

Natural history of Hep C

There are now several tests to tell if Hep C is in someone's blood.

Of 100 people with chronic Hep C who remain untreated . . .

After 20 years	45% won't develop liver damage	47% will develop mild to moderate liver damage	7% will develop cirrhosis of the liver	1% will develop liver failure or liver cancer
After 40 years	45% won't develop liver damage	31% will develop mild to moderate liver damage	20% will develop cirrhosis of the liver	4% will develop liver failure or liver cancer

Testing for Hep C

Hep C antibody test

The first step is the Hep C antibody test, which looks to see if someone has come into contact with Hep C. A positive test means that antibodies, not actual Hep C virus, have been found. If people have cleared the virus, they still keep the Hep C antibodies. Sometimes 6 weeks to 3 months need to pass after initial exposure to Hep C before an antibody test will be accurate. This is called the 'window period'.

A negative antibody result means that the person has not been exposed to the virus up to the point of the 'window period'. A positive result means that antibodies were found, which means the person has been exposed to Hep C at some point but it does not show the presence of the actual Hep C virus.

One situation in which antibody testing has not been reliable is with newborn babies. Babies born to Hep C positive mothers can have a positive antibody result for up to 12-18 months after birth, but they don't necessarily have any Hep C virus.

PCR test

The PCR test looks for actual Hep C viruses, as opposed to antibodies, in the blood.

There are three kinds of PCR tests:

The PCR viral detection test is used to see if someone actually has the Hep C virus. Anybody who has a positive or inconclusive antibody test should go on to have a PCR viral detection test.

The PCR viral load test looks for the Hep C virus and estimates the amount of Hep C virus present in someone's blood.

The PCR genotype test looks to see what kind (or genotype) of Hep C virus someone has. It is very useful for making decisions about treatment.

Where to go for testing?

Testing for Hep C is now widely available and free in Australia. To find out where to go in your State or Territory, contact your State/Territory Hepatitis C Council or local drug user organisation (listed in the State/Territory directories at the back of this handbook).

Pre- and post-test discussion

Prior to taking a Hep C test, the GP, specialist doctor or nurse doing the testing should give you a brief explanation of how the test works and find out how you're likely to respond to the result positive or negative. They will also try to discuss other things, such as whether you have been at risk of getting Hep C, whether you've had any symptoms of Hep C infection, the benefits of testing and the confidentiality of the results. They should be clear that you have had the test of your own free will and understand its implications.

The results of a Hep C test should always be given to you in person, regardless of the reason for the test and whether the result is positive or negative. They should discuss the 'window period' and the possibility of 'false' test results (i.e. if you've been exposed to Hep C within the 6 months prior to the test, it may not turn up on the test). If the result is negative, the service provider should provide counselling and information that helps you to remain Hep C negative. If the result is positive, they should re-visit some of the pre-test counselling issues and discuss any issue that you want to explore, including the options for treatment.

Sometimes, test results come back as neither positive nor negative and further tests requiring different technologies are required.

All States and Territories have established protocols for how pre-/post-test discussions should be conducted. Most importantly, it should happen in private and use language and words that you understand.

If you are thinking of being tested for Hep C, be sure you can access pre-/post-test discussion.

Giving consent for testing

You can't be forced to take a Hep C test. You have to give your consent. If you are having blood taken for testing, for any reason, you can ask what you are being tested for. You cannot be tested for Hep C without your knowledge. Hospitals have been known to test people for Hep C, Hep B and HIV without letting the person know. You have a right to know what you are being tested for and to refuse a test if you don't want it done.

Some prisons conduct compulsory testing for blood borne viruses, including Hep C.

Hep C transmission

How is Hep C spread?

Hep C is a virus that lives in the blood. To get Hep C you have to get the blood of an infected person in your bloodstream. It doesn't have to be a large amount of blood. Even a small amount, so small you might not be able to see it, can contain Hep C. This Hep C-infected blood can get into the body through fresh cuts, broken or punctured skin (e.g. after injecting), or by injecting the blood with Hep C into your bloodstream. As the blood vessels underneath the eyelids are very close to the surface, blood containing Hep C that is splashed into the eye may also cause an infection.

The Hep C virus cannot get through unbroken skin and if swallowed, it is killed by the stomach's digestive juices.

The risk of infection is potentially influenced by the level of Hep C virus (viral load) in the infected blood. For this reason, the risk of transmitting Hep C is higher during the first six months after someone catches the virus.

How does Hep C pass from one person to another?

Hep C is passed on when the blood of an infected person gets into the blood of another person (blood-to-blood contact). There are many ways that this can happen. Below are some of the ways in which Hep C can be transmitted from one person to another.

Unsafe injecting

When it's done safely, injecting will not lead to Hep C infection. But it seems that the large majority of people who have been exposed to Hep C did so through unsafe injecting or sharing needles and other equipment.

Body art

Getting tattoos, body piercings, 3-D implants, pearling, scarification where unsterile equipment or procedures were used. You should make sure that anyone doing these procedures (professional or non-professional) is autoclaving (sterilising) any instruments that are being used on more than one person.

Surgical infection

Having unsterile medical procedures or vaccinations (very rare in Australia but can happen in some overseas countries).

Getting a needlestick injury

Even if you do get a needlestick injury, it is VERY unlikely that you will get Hep C. There has not been a confirmed case in Australia of someone getting Hep C from a community needlestick injury. It has been known for health care workers to get Hep C from needlestick injuries in their workplace.

Blood donation

Exposure to unsafe blood and blood products in medical settings – since 1990, all blood donated in Australia is tested for Hep C. Also, people who have Hep C risk factors (tattoos, history of injecting, etc.) cannot give blood. This all means that the blood supply in Australia is very safe. Other countries may not have such stringent controls in place and receiving blood or blood products in other countries can be a risk.

Mother-to-baby transmission

Hep C has been found in the breast milk of mothers who are Hep C positive, but breast milk has not been shown to pass on Hep C. A baby is much more likely to get Hep C from a Hep C positive mum by sucking on cracked/bleeding nipples when being breast fed. There are ways to protect babies by using nipple guards (available from chemists) and expressing breast milk.

Sex & relationships

Although there are still some areas of uncertainty, research suggests that the risk of transmitting Hep C is very low in most sexual activities. Transmission of Hep C through sexual body fluids (e.g. cum, vaginal juices) is rare, but theoretically more likely when levels of Hep C are high (e.g. during the initial stage of infection, or when the immune system is not working well, e.g. due to HIV). Where there is little risk of blood-to-blood contact, there appears to be no need to adopt safe sex practices where one partner is Hep C positive.

Blood-to-blood sex, rough-sex/B&D

On the other hand, where there is risk of blood-to-blood contact during sexual activities (e.g. with some kinds of rough sex and B&D), the risk of transmitting Hep C is higher.

Skin injuries

Blood-to-blood contact though cuts, lesions, bleeding, broken skin and open wounds are places where stuff from the outside can get into the bloodstream. If the blood of a person with Hep C gets into someone else's open cut or wound, there's the chance of transmitting Hep C.

Barbering/hairdressers

Wherever there is the chance of making open cuts or wounds, barbers and hairdressers should always be using new or sterile equipment. You should make sure a barber/hairdresser is autoclaving (sterilising) any instruments that are being used on more than one person and could possibly puncture the skin.

Household transmission

Using razors or toothbrushes that have Hep C positive blood on them carries a risk of Hep C infection. It's not a huge risk, but it's best to have razors and toothbrushes (and other things that can get blood on them) that only you use. Only use your own items, not anyone else's.

Being in jail

There are many drug users in Australian prisons, where new fits are not available. Fits are passed around, being sharpened and re-used for a long time. Bleach may be available, but this often depends on the institution and the situation. Cleaning cannot be guaranteed to kill Hep C and when a syringe is old or has been modified it may be much more difficult to clean properly. If you inject in prison you are risking getting Hep C, as well as HIV. Many people who enter prison Hep C negative and inject while inside leave prison Hep C positive.

There are other ways you can get or pass on Hep C in jail, including using unsterile tattoo needles, sharing razors and toothbrushes, being in a fight, having rough sex, etc. Any way that blood from one person can get into the bloodstream of another person, is a way that Hep C can be transmitted.

Can you get Hep C from a mosquito bite?

No. There are no documented cases of transmission through mosquitoes. Hep C has to be in blood and the other viruses usually passed on through mosquito bites (such as dengue fever, yellow fever and West Nile virus) are passed on through the saliva generated by the mosquito when it bites.

Other ways you can't get Hep C

Hep C is not spread by contaminated food or water and cannot be spread through casual or social contact such as kissing, sneezing, coughing, hugging, or eating food prepared by a person with Hep C.

How to avoid getting Hep C

Being blood aware will help you to avoid getting Hep C. By knowing how Hep C is transmitted and prevented and by being careful, people can inject for years and not get Hep C.

The following main points will help you to stay negative:

- Follow the safer-using practices outlined in Chapter 2 (these will also protect you against HIV and Hep B)
- Avoid blood-to-blood contact, for example during sexual activity (this will also protect you against HIV and Hep B)
- If possible, avoid being sent to prison

Vaccines for Hep C

There is currently no vaccine for Hep C. Researchers are working on developing a vaccine, but it is unclear whether an effective one will ever be available. The best way to avoid Hep C for the foreseeable future is to use safe injecting practices and be mindful of the other ways Hep C can be transmitted (see above).

Other Hep C tests

If you've received a positive Hep C antibody test and a positive PCR viral detection test, you're also likely to have had a PCR viral load and a PCR genotype test. The result of these tests will be important in any decision about starting treatment.

In the course of treatment, your doctor may suggest other kinds of tests. These may include:

Liver function test

The liver can be damaged by Hep C infection, excessive alcohol, or even some prescription and illicit drugs. The LFT is a blood test used to figure out how well the liver is working and if it is damaged. One important piece of information from the LFT is the level of a particular enzyme, alanine aminotransferase (ALT). High levels of enzymes (often referred to as "raised ALT or AST levels") in a blood test usually shows that the liver is inflamed. A positive person with consistently high ALT levels would be wise to discuss referral to a liver specialist.

Other information from the liver function tests is the albumin (a protein made by the liver) and the bilirubin level. Bilirubin casues jaundice when its level is high.

Though the LFT is only part of the picture as far as overall health goes, it's a good idea to have LFT tests done at regular intervals. Your doctor will recommend how often. This test and your physical symptoms (how well you feel) will help you and your doctor tell how well your liver is coping with Hep C over time.

Liver biopsy test

Cirrhosis (advanced scarring) of the liver is one of the most serious effects of long-term Hep C infection. The scar tissue affects the flow of blood and other fluids through the liver. Without good blood flow and with a decreasing number of properly functioning cells, the liver becomes lumpy and hard and can't do its job nearly as well.

In order to determine the extent of damage to your liver, your doctor might recommend that you have a liver biopsy. Usually available through hospital day clinics, this sometimes painful procedure involves inserting a thin needle into the upper abdomen and snipping off a very small part of your liver. The doctors then examine this to see how much scarring you have. Mild to moderate scarring is called fibrosis. Advanced scarring is called cirrhosis.

It is no longer an essential requirement to have a liver biopsy in order to start Hep C treatment. Discussing the pros and cons of a liver biopsy with your treating doctor/s is highly recommended before proceeding.

New ways of determining the amount of liver scarring are being investigated by researchers. Within the next few years it might be possible to have a scan of some kind instead of a biopsy. If your doctor recommends a biopsy, you can always ask if there are any alternative procedures that are non-invasive (i.e. don't involve sticking anything into your body).

What are the treatments for Hep C?

Most people who go onto treatment for Hep C receive two drugs, pegylated interferon and ribavirin. This is called combination therapy. The interferon works to boost your immune system to fight the Hep C virus while the ribavirin attacks the virus directly. Pegylated interferon is taken once weekly as an injection under the skin (sub-cutaneous) and the ribavirin is taken daily as tablets you swallow.

Generally, people with Hep C genotype 2 or 3 are treated for 6 months and people with genotype 1 are treated for 12 months.

The Pharmaceutical Benefits Scheme (PBS) works to reduce the cost of medication to people who need it. Treatment for Hep C is usually between $22,000 and $27,000 per year. You can access subsidised Hep C treatment if you meet certain criteria. To be eligible for subsidised combination therapy through the PBS, you must:

- be 18 years or older
- have had a positive Hep C antibody test
- have active Hep C (tested with PCR)
- not be pregnant or breastfeeding, or for men your partner must not become pregnant while you are on treatment and up to 6 months after treatment has ceased (due to the possibility of birth defects from the medication)
- use contraception, with both partners taking precautions to prevent pregnancy

If you receive subsidised treatment, the medication is free but you may have to pay a dispensing cost of around $20 - $30 per month. Other prescription drugs you might need to take will cost you the usual amount/s.

You cannot be refused treatment because you inject drugs or use any illicit drugs.

Those people considering treatment are usually referred to their nearest treatment centre. Most often these are liver clinics which are located in major hospitals.

What's the success rate of Hep C treatment?

About 80% of those with genotype 2 and/or 3 and about 50% of people with genotype 1 who finish treatment will clear the Hep C virus. If you are still clear of the virus 6 months after you finish treatment, you are said to be cured.

What about future treatments?

Researchers are constantly aiming to produce new drugs that will make Hep C treatment more effective. In the next few years there may be advances in treatment that result in higher percentages of people being cured. Your local Hepatitis Council and/or drug user organisation may be able to give you more information about future Hep C treatments (see Contacts at the back of this booklet).

Treatment adherence . . . sticking with it

Once you start Hep C treatment it is important to take your antiviral medication as prescribed. If you miss doses, you lower the amount of medication in your blood and it won't be as effective as if you'd taken your full doses. Taking the right amount of medication at the right times is known as "adherence".

If you do miss a dose, do not double your next dose. Just take the next dose when it is due. Talk with your Hep C nurse or doctor for more information.

Sticking with your treatment can make a difference to your chances of clearing Hep C. It has been found that by taking all your medication at all the times you should for the full length of your treatment, you can greatly improve your chances of a cure.

Are there side-effects to Hep C treatment?

Yes, there usually is. While it is true that a very small number of people report no side-effects, we know others who have had a difficult time of it. The most widely reported side-effects include flu-like symptoms, such as fever, chills, muscle aches and headaches, lethargy and fatigue, depression, forgetfulness, irritability and even loss of hair.

These side-effects are mostly due to the interferon. Ribavirin can also have some side effects like a change in taste and a fall in your red blood count causing anaemia.

For some, these side-effects are more powerful during the first months of treatment. For others, they can last the whole way through treatment. Others still have few side effects early in treatment but get some later on. For the majority of people, the side-effects end when the treatment stops, though some people have side effects for some time after stopping treatment. Life-threatening complications are rare.

Your treating doctor/s will closely monitor your side effects and you should report to them anything that you feel is a result of your treatment. If you get bad side effects, you may need to have your treatment adjusted to make things easier for you.

No-one can predict how any individual will respond to treatment or the kinds of side-effects he/she may experience. Having few side-effects does not mean that the treatment is not working. Nor does it mean that you won't get side-effects at some other stage in your treatment.

Some people who have stopped injecting or are trying to stop may have some reservations about using needles to take their interferon. If you find that this is the case for you, you might like to talk to people who have been in the same situation. Try calling your local drug user organisation (see Contacts) or call 1300 Hep ABC – this number will connect you to your local Hep C information and support line.

Complementary and alternative therapies

'Complementary therapies' are health practices used alongside conventional or mainstream medical approaches. 'Alternative therapies' are health practices that do not follow conventional or mainstream medical approaches. Sometimes the terms are used interchangeably. There are a wide variety of complementary and alternative therapies, including traditional Chinese medicine, acupuncture, aromatherapy, naturopathy, herbalism, food supplements, chiropractic, reiki, Qi Gong, meditation, yoga and Tai Chi.

There has been no comprehensive assessment of the benefit of complementary therapies for people with Hep C. That said, we are aware of individuals who say they have used complementary therapy with good results, sometimes to offset the side-effects of the interferon and ribavirin, or to improve general quality of life. There are others who say they've been no help at all.

It is always a good idea to let all your treating practitioners know what other therapies you are using and/or considering using. Some alternative and complimentary therapies may have an effect on your liver that you are not aware of, or they may interact with interferon and/or ribavirin. Also, your natural therapist will need to know if you are taking any medication, including interferon and ribavirin.

Here are some handy hints if you are considering complementary/alternative therapies:

- Find out if the practitioner has experience and qualifications in their area and if they are registered with a professional association for that therapy
- Find out what, if anything, a potential practitioner knows about Hep C
- Find out how many treatment sessions may be required and how much they might cost
- Find out if there are any risks associated with the therapy, any potential problems in combining it with mainstream therapy (e.g. some herbal treatments are highly recommended for the liver; some can cause the liver damage)

If you have concerns about any of these issues, think carefully about proceeding. The State/Territory Hepatitis Councils and drug-user organisations can help you work through these concerns (see Contacts). They will also be able to tell you which herbs, etc. are not good for your liver. Your liver specialist/GP may be able to help as well.

Getting as much information as possible about complementary and alternative therapies will help you to make good decisions about your health.

Deciding on treatment

Hep C is usually a slow-acting disease, so most people can take time to consider their treatment options.

Pharmaceutical treatment for Hep C is not easy. Some people experience serious side-effects. These can affect all areas of your life - family commitments, relationships, work, recreation, etc. It may help to have someone you can talk to who understands these issues or has been through a similar experience.

Here are some things worth thinking about before you start treatment:

- Why do you want to go for therapy? Many people find the combination of doctors' appointments and side-effects stressful
- Hep C therapy usually takes 6-12 months. It's a pretty big commitment and you need to be fully aware of what it involves. Time off work might be necessary
- Are you prepared for your end-of-treatment result? No longer having Hep C can change your life. Not clearing the virus can be a very emotional experience.Can you cope with either of these results?
- Is it the right time to start treatment? If you are having your liver function regularly checked by a doctor with a good understanding of Hep C, s/he will know the best time to refer you to a specialist or a liver clinic to be assessed for treatment. Studies have shown that therapy has a better chance of success if it is provided early in the development of fibrosis
- Do you meet all the criteria for subsidised treatment? If you don't meet all the criteria, you will have to pay for treatment yourself (and it's very expensive)
- Can you wait for improvements in treatment that may give you a better chance of clearing Hep C?This is particularly relevant for people with genotype 1 Hep C

Deciding you want to start treatment doesn't automatically mean that you will be accepted for treatment. It's important to talk over your treatment options with your doctor.

The Hepatitis C Council and drug-user organisation in your State/Territory can help you access support groups or other kinds of support. (See the Directory at the back of this booklet).

Where to go for Hep C treatment

Choosing a good doctor (usually a general practitioner or GP) is important when you have Hep C. If you are attending the same doctor regularly to monitor your health through liver function tests, they will have a clear and continuous picture of your liver's response to Hep C. They will be alert to important changes and will be able to identify the best time to refer you to a specialist or liver clinic.

Your doctor will be able to set up a "shared care" partnership in which s/he will liaise with any specialists or hospital clinics involved in your care.

If you have a good relationship with your doctor they can contact the specialist service (gastroenterologist or liver clinic) that they refer you to and request to be a part of your therapy program (i.e., to "share the care"). This means that they work in partnership with the liver clinic to monitor your health before, during and after therapy. The benefit to you is fewer visits to the liver clinic, more visits to your (hopefully) familiar and friendly local GP.

This is particularly important for people who want to get specialist care but live in regional and remote places. Having a good relationship with your doctor will make antiviral therapy less stressful. If you are able to find a doctor who is already offering shared care to other people with Hep C, they may be willing to offer the same arrangement. For information on shared care contact your State/Territory Hepatitis Council or drug-user organisation. They may also be able to help you find a 'Hep C friendly' GP.

Health & lifestyle issues for people with Hep C

Good health is dependent upon a range of factors, including:

- physical factors (e.g. genes)

- social factors (e.g. whether you have access to transport to seek medical advice)
- mental factors (e.g. whether you have people around you to support you)
- lifestyle factors (e.g. regular exercise/physical activity, good diet)
- financial factors

Some of these things are beyond our control. Some aren't. The next sections look at some issues where healthy lifestyle choices can affect well-being.

Hep C and nutrition

Good nutrition is an important consideration in staying healthy with Hep C. A good, balanced diet can:

- help relieve some of the symptoms of Hep C infection and Hep C treatment, e.g. nausea
- provide your body with the nutrients necessary to help repair old liver cells and build new ones
- help combat tiredness and fatigue and provide the energy needed for daily activities
- give your immune system a healthy basis to work well
- help maintain a weight and body mass that's right for you
- reduce the risk of many diseases, such as heart disease, diabetes, obesity and some cancers

Generally speaking, it's good to be eating foods rich in vitamin C (e.g. citrus fruits/strawberries), lean meats and fish (to get a good supply of protein and vitamin B12) and wholegrain cereals and a variety of fresh vegetables and fruit.

It's good to avoid saturated fats from fatty meats and full-fat dairy products. Refined sugars can have a negative impact on health in a number of ways, so it's best to try to keep your sugar intake to a minimum if possible.

If you want to know more about recommendations for healthy balanced diets, contact your State/Territory Hepatitis Council or drug-user organisation (see Contacts at the back of this booklet).

Drug use & Hep C

Using alcohol when you've got Hep C

It is best to try and avoid alcohol when you have Hep C because alcohol can increase the rate of liver damage. People who consume large quantities of alcohol are advised to reduce their intake. There is a higher risk of developing liver disease, including cirrhosis, if you have Hep C and drink alcohol. Alcohol is also likely to affect your response to treatment and make treatment less effective.

Keep in mind that the government's suggested alcohol intake is based on people who are in perfect health. Government recommendations for alcohol intake are:

For men

- No more than 4 Standard Drinks on a single day.
- One or two alcohol-free days per week.

For women

- No more than 2 Standard Drinks on a single day
- One or two alcohol-free days per week.

These guidelines assume, amongst other things, that you are in perfect health and do not have a condition that can be made worse by consuming alcohol. People with Hep C may want to drink at levels below those recommended for the general population.

If you have chronic Hep C, but not cirrhosis, consider limiting your alcohol to no more than seven standard drinks per week and having one or two alcohol free days per week. If you have cirrhosis, it is recommended that you do not drink any alcohol.

Contact your GP or your local community health centre for a referral if you need help in reducing the amount of alcohol you drink.

Using tobacco when you've got Hep C

Those of us who smoke have probably seen enough warnings on cigarette packets to have a least a vague idea of what smoking can do.

As far as Hep C is concerned, smoking can lead to a worsening of gum conditions and dry mouth associated with Hep C. Some evidence also suggests that smokers who are Hep C positive have higher rates of some cancers.

There is currently no evidence to suggest that using tobacco has any significant effect on progression of liver disease.

Injecting when you've got Hep C

The problems that might arise when we've got Hep C and continue injecting are more about what substance is being injected and how we inject. All the drugs we take get processed in the liver. So, depending on the state of your liver, how much of and which drug you're taking, injecting can put unnecessary stress on the liver.

Unsafe injecting and sharing of equipment and tastes puts you at risk of getting another strain of Hep C in addition to the one you may already have. If you inject after you have cleared the Hep C virus, you can be reinfected with Hep C.

Illicit drugs and Hep C treatments

Hep C affects the liver and people who are having Hep C treatment usually have some degree of liver damage. The body uses the liver to break down (process, use, get rid of) the drugs that we take, including prescription drugs, alcohol, heroin, speed, etc. The amount of damage your liver has will affect how well it can deal with some of these and other drugs. The interactions that may normally be fairly harmless might become more serious.

If your liver is not working well, taking these drugs could have a negative impact. For example, heroin and morphine are not of themselves damaging to the liver, but the stuff they're mixed with can be. Speed (meth, ice, etc.) can damage the liver. Taken in large quantities, cocaine and ecstasy have been known to cause liver toxicity and liver failure. Hallucinogenic mushrooms contain many chemicals that the liver can't deal with well. Take special care with anything that causes dehydration.

It's hard to make generalisations, because much depends on how healthy the liver is in the first place and how much of the drug in question is being taken.

If you trust your doctor it might be worth telling them about your drug use. This is important when they are prescribing medication for you. It is likely that they will suggest that you stop or reduce your illicit drug use during therapy. Of course, the decision is up to you.

If you want to know more about how a particular drug might affect your liver, we suggest getting in touch with your local drug-user group or Hepatitis Council, your local needle & syringe program or drug and alcohol service and discussing your situation with them.

Using cannabis when you've got Hep C

Using marijuana on a daily basis has been linked with the progression of liver fibrosis in people with Hep C.

However some people use cannabis to help relieve the symptoms of Hep C and/or the side effects of treatment. In this case, you can look for alternatives to marijuana, or make a decision based on your quality of life. If you have an understanding doctor, you might like to talk to them about using cannabis.

Other lifestyle factors

Dental care/dry mouth

Many people with Hep C have problems with dry mouth. It could be caused by, or made worse by certain medications like methadone or anti-depressants. Having plenty of saliva means that there's lubrication for speech, taste and chewing food. It also helps prevent bacteria, viruses and funguses from causing infections in the mouth, as well as preventing tooth decay and gum disease. You can increase the levels of saliva in your mouth by taking frequent sips of water and/or chewing sugarless gum.

People who have dry mouths or are taking certain medications (e.g. interferon) can be susceptible to getting mouth ulcers and/or thrush (Candida) in the mouth. Mouth ulcers that can't be relieved by being treated with chlorhexidine gel should get checked out by a dentist.

A daily dose of good quality yoghurt with live cultures in it may help with thrush. In some cases, an antifungal medication may be necessary to clear it up.

Getting rest and sleep

For the large majority of us, rest and particularly sleep, are essential for normal functioning of our bodies and brains. Getting a good night's sleep can be just as important as good food and exercise. People with Hep C often have disturbed sleep and night sweats, which, as for anyone, can make them irritable, depressed, stressed and just plain tired. Lack of sleep can lower energy levels and our ability to cope, which in turn affects how well we sleep. It's a cycle that's hard to break.

If you have Hep C and having difficulties with sleep, get in touch with your local user organisation or State/Territory Hep C Council (see Contacts) for some tips on improving the chances of a good night's sleep.

Getting physical exercise

Physical exercise can help relieve tension and improve overall levels of health. For people with Hep C, daily low-impact activities can over time help build or maintain their fitness. But don't overdo it. Listen to your body and if you feel ill and need rest, take it easy.

Exercise stimulates the lymph system, which helps to remove toxins from the body. This in turn boosts the immune system, helping your body to cope with Hep C, reducing stress and improving your general well-being.

Stress and emotional well-being

These days, some consider stress a normal response to lifestyle, work and living in general and if it's handled well, not necessarily an entirely negative thing.

But when pressure is ongoing, increasing or unchecked, the impact on physical and mental health can be severe. Symptoms like insomnia, headaches, neck, shoulder and back pain, heart palpitations, fatigue, irritability, panic attacks, loss of concentration, low-esteem, changes in appetite, diarrhoea, abdominal cramps, even increased desire for drugs (including alcohol and tobacco) may be indications of stress.

For many, living with a chronic illness like Hep C can be stressful in itself. Coping with its physical affects may require some adjustments to how you live. This is also true with respect to the negative feelings about having Hep C in the first place.

Some of us have found that being informed about where we are in relation to Hep C helps establish a foundation for getting over that stress. Other strategies that various people have used include: physical exercise, rest and relaxation, massage, talking things over with friends, counsellors, social workers and therapists, good diet and nutrition and that old chestnut, “developing a healthy attitude”.

Disclosure - telling others about having Hep C

“Disclosure” means telling people something about yourself, in this case that you have Hep C. For some it can be daunting - we worry how people will react or if they’ll treat us differently. And there’s always the threat of discrimination. But disclosure can have benefits too.

Friends and family who know what’s going on with us, can be a great source of support. Here are some things to think about:

- Knowing something about Hep C can be useful when you’re telling someone that you’ve got it. Accurate information can help correct misconceptions about people with Hep C and Hep C in general (e.g. how it can be spread). Give the person time to come to terms with this new information. It may help to give them a contact for further information, such as a Hep C helpline (ph 1300 Hep ABC)
- When we tell people we’ve got Hep C, some are going to ask or make assumptions about how we got Hep C in the first place. If you’ve got Hep C through injecting, do you feel comfortable talking about that too?
- Some find it helpful to practice disclosing in their mind or to a friend, confidant, counsellor, or hepatitis worker, before disclosing to others in their life
- Choose your time carefully. Some times are better than others for telling people intimate things about your life and situation. It’s good to have the discussion when there’s time to give the subject time and attention
- When you’re disclosing, have a way to get in touch with a supportive person/people if the need arises. This kind of support can help whether the person you’re telling has a positive or negative reaction
- Different people will react differently. If someone reacts negatively, it’s important to remember that this is not a reflection on you and you are not responsible for their reaction

There are a small number of situations in which you may be required by law to tell others you have Hep C:

- If you’re giving blood to the blood bank, donating body organs or other body fluids (e.g. sperm). Blood banks will not accept donations from people with Hep C. All the blood they do receive is screened for a range of blood borne infections, including Hep C

- Health care workers who are HCV RNA positive must immediately cease 'exposure-prone procedures'. There is no obligation to inform their employer but they have a professional obligation to seek formal advice about personal care, monitoring and work practices from a medical practitioner with appropriate expertise. In some jurisdictions, a health care worker has a legal responsibility to report their BBV status to their professional board. Following successful treatment (indicated by 2 negative HCV RNA tests at least 6 months after treatment) health care workers may be able to resume 'exposure-prone procedures' on the advice of the treating clinician.
- Some insurance policies, (e.g. life insurance) require you to disclose any infections, disabilities, or illnesses that might influence the insurance company's decision to insure you. Not disclosing this information may affect any future claims you make
- If you are a member of the Australian Defence Force, you are required by Defence regulations to declare your health status with respect to disease, illness or injury. The purpose of this declaration is to ensure that you receive appropriate health care and that you are employed in a manner which does not jeopardise your health or safety or that of others. If you want to join the Australian Defence Force, you are required by law to disclose any existing medical conditions on application. If you are found to have hepatitis C whilst serving you will be given appropriate clinical management and a decision on your future career is decided on a case by case basis taking into account factors such as the outcome of your treatment.

Disclosing to sexual partners

Hep C is not classified as a sexually transmissible infection. In the rare cases where Hep C has been passed on during sexual contact, it has involved blood-to-blood contact. This can happen, for example, during rough sex or if one or more partners have an STI (sexually transmitted infection) where sores or broken skin is present.

If there's the risk of blood-to-blood contact during foreplay or sex, or a risk of sexually transmissible infections, we recommend that you follow safe-sex practices, such as using condoms.

If you are practicing safe sex, whether or not to disclose your Hep C status to a sexual partner is your choice.

Disclosing to health-care workers

You are not required to disclose to health care workers about Hep C unless you are about to donate blood, body fluids, or body organs. All health care workers are required to follow standard infection control procedures. This means that they have to assume all blood is infectious and take all necessary precautions to ensure their own safety and that of their patients.

Given that there have been reported cases of health care workers discriminating against people with Hep C, you may decide not to disclose if your quality of care is going to be affected by your Hep C status.

Sometimes people with Hep C will find certain prescription medicines damaging to the liver. If you've got Hep C and are given medications, it's useful to find out how they are likely to affect your liver.

Disclosing at work

You don't have to tell an employer about your Hep C status unless you work in, or are about to join, the Australian Defence Force (ADF), a police service or are a healthcare worker who performs exposure prone procedures.

Some employers (e.g. ADF, police) ask job applicants to answer questions about their health. Unless it is relevant to your ability to meet the essential requirements of job, you do not have to answer any questions about Hep C.

Even if you have to take time off work due to Hep C or treatment for Hep C, if you are not comfortable disclosing, you can inform your employer that you have another condition or need to take time off for another reason.

Any information that you give to your employer or other people you work with about your health is private and confidential and cannot be passed on without your permission.

Most States have confidentiality laws that prevent people in the course of their work (e.g. doctors, nurses and other health care workers) from telling people about your Hep C status. These laws do not apply to ordinary members of the public (e.g. friends, family and acquaintances).

If you are in any doubt about disclosing to others, it is recommended that you don't and that you get some advice.

If you have any questions with regard to disclosure of your Hep C status, contact your local Hep C Council or drug user organisation (see the Directory at the back of this handbook).

Managing Hep C symptoms

People with Hep C can experience a range of symptoms at various times:

- flu-like infections lasting a few days to a week
- fatigue and sleep disturbances
- dry mouth and mouth ulcers
- dry eyes
- mood swings, anxiety and depression
- changes in ability to think and function
- nausea and poor appetite
- pain/discomfort in the liver
- muscle and joint pain
- fever and night sweats
- skin conditions

Sometimes it's difficult to tell if these symptoms are directly related to Hep C. There are things we can do ourselves to manage these. It can also be useful to talk these over with your doctor to find what the causes might be and what might be done to alleviate them. Alternately, some people have found complementary/alternative therapies useful in managing some symptoms.

For more information, contact your State/Territory Hep C Council or local user organisation (see the Directory at the back of this handbook).

A word about pain management

People with chronic Hep C can sometimes experience episodes of abdominal pain, especially on their right side below the ribs where the liver is located, as well as joint pain, headache and pain in muscles and joints. And of course, people with chronic Hep C suffer from the same sprains, strains and body aches as everyone else.

If your liver's in relatively good health and you've got Hep C, pain relief medicines, both over-the-counter and on prescription, are usually ok for treating temporary liver pain, but there are exceptions - if you've got a damaged liver, many over-the-counter medications can be harmful, (eg. paracetamol).

If you've got access to sympathetic medical advice, we think it's worthwhile discussing symptoms and pain management options with your doctor or complementary/alternative therapist.

Hep B

Like Hep C and Hep A, Hep B is a virus that affects the liver. It is the most common of the hepatitis viruses. Between 90,000 and 160,000 Australians are thought to be living with chronic Hep B infection.

What does Hep B do?

When it enters the body, Hep B travels via the bloodstream to the liver, where it attaches itself to healthy liver cells, enters them and multiplies. This causes a reaction in the immune system, though people are often unaware they have been infected with Hep B at this stage.

The symptoms of Hep B include loss of appetite, nausea and vomiting, tiredness, abdominal pain, muscle and joint pain, yellowish eyes and skin (jaundice), dark urine and pale-coloured faeces are often not present until about 12 weeks after exposure, when the infection becomes acute. Some people become very sick. However, not everyone gets these symptoms. Many don't know they have Hep B.

Most adults (about 95%) who get Hep B clear the virus within 6 months. A small number (about 5%) will go on to develop chronic (ongoing) Hep B infection.

Some people with chronic (long-term, ongoing) Hep B infection will not be aware they are infected. Others may experience symptoms like tiredness, depression, irritability, pain in the liver (upper right side of abdomen), nausea, vomiting, loss of appetite, joint aches and pains. Long-term Hep B infection can lead to cirrhosis (scarring of the liver), liver cancer or liver failure if it is not diagnosed and managed. About 20%-30% of people with chronic Hep B eventually get serious liver disease.

People who have recovered from Hep B or have been vaccinated against Hep B are immune from further infections of Hep B.

How do you get Hep B?

Hep B is found in blood and body fluids, including saliva, semen, vaginal secretions and breast milk. It is a blood borne and sexually transmitted infection. The most common ways of getting Hep B include:

- unsafe sex
- unsafe injecting
- household transmission - through the use of razors or toothbrushes that have traces of blood with Hep B on them, or by getting Hep B positive blood in cuts or wounds during first aid

Hep B is not spread by contaminated food or water and cannot be spread through casual or social contact such as kissing, sneezing, coughing, hugging, or eating food prepared by a person who has Hep B.

How do you know if you've got it? Testing for Hep B

There are a variety of blood tests for detecting Hep B. They are used to find out if someone currently has a Hep B infection, how active the infection is, or of the person has had Hep B in the past and cleared the virus. Liver function tests can tell if someone needs treatment, or if the treatment they are using is working.

Testing is available through GPs and most general health clinics, including sexual health clinics.

How can Hep B be treated?

People who are immune to Hep B do not need treatment. People with chronic Hep B infection and no liver damage do not need treatment, but will benefit from close monitoring with regular (6-monthly) liver tests. Someone with liver damage from Hep B infection should certainly consider having treatment.

There are several kinds of treatment available through the Pharmaceutical Benefits Scheme (PBS), depending on how Hep B is affecting someone.

For more information on Hep B treatment, see your GP or contact your local Hepatitis Council or drug user organisation (see the Directory at the back of this handbook).

Disclosure

People with Hep B do not have to inform employers of their infection. There are no specific employment laws for people with Hep B.

If someone with chronic Hep B infection lets family members and sexual contacts know about their situation, those people can consider getting a Hep B vaccination.

Vaccinations for Hep B

You can be vaccinated against Hep B either by itself or in combination with Hep A.

The Hep B vaccination consists of 3 injections. These are usually spaced out over 6 months, but you can have an accelerated vaccination schedule that involves the 3 injections over 3 weeks. For the fast 3-week schedule, a booster is recommended at 12 months.

There is currently a combined Hep A/Hep B vaccine available in most parts of Australia. The combined vaccination is highly recommended for injecting drug users. A second dose of the combined vaccine is required for long-term protection.

Vaccines are available through your GP, as well as community health and sexual health clinics. Some States and Territories offer free vaccination to people at risk of infection. These include people who inject drugs (see table below).

Access to Hepatitis B Vaccine for IDU by State/Territory

State/Territory	Situation re: Hepatitis B Vaccination for IDU
South Australia	Free to IDU (2008)
Northern Territory	Free to IDU (2000)
New South Wales	Free to IDU if clients of NSWAHS sexual health clinic and/or NSW public methadone clinic (2001)
Western Australia	Free to IDU if clients of sexual health clinic, methadone clinic, WASUA or newly diagnosed with hepatitis C
Victoria	Recommended for IDU, limited free access
Queensland	Recommended for IDU but not listed as free
ACT	Recommended for IDU but not free
Tasmania	Recommended for IDU but not listed as free

Vaccination and co-infection

If you have Hep C and Hep B, you are said to be co-infected with these viruses. Having Hep B and Hep C co-infection can mean faster progression of liver disease. If you have Hep C (or HIV), it's a very good idea to get vaccinated for Hep B.

Hep A

Hep A is a virus, that, like Hep C, affects the liver. It can survive in the environment on hands for several hours and in food kept at room temperature for considerably longer. In Australia there have been fewer than 300 cases reported for the past three years. Once you've had Hep A you can't get it again.

What does Hep A do?

Hep A can cause a severe, but relatively short, infection in the liver.

The period between exposure to Hep A and developing symptoms is usually around 30 days, but can vary between 15 and 50 days.

The majority of adults who get Hep A will show symptoms like fever, weakness, fatigue, loss of appetite, nausea, joint aches and pains, vomiting, yellowish eyes and skin, dark urine and pale-coloured faeces. Despite usually being a short-lived illness, Hep A infection can be serious for some. Not everyone with Hep A has obvious symptoms. Some have wondered if the real number of new infections may be higher because people don't know they have it and do not get tested.

How do you get Hep A?

You can get Hep A if you get particles of faeces from an infected person in the mouth. This can happen when:

- you use food, liquid, or eating utensils that have been in contact with an infectious person
- you touch nappies, linen and towels that have the faeces of an infectious person on them
- you have direct contact (including sexual contact and especially rimming) with an infectious person

How do you know if you've got Hep A? Testing . . .

There are two kinds of Hep A antibodies. One kind of antibody is present when the infection is in full swing.

The other kind remains after the infection and shows that that person is immune.

You can get tested for Hep A through your GP or any general health clinic.

How can Hep A be treated?

There are no medical treatments available for Hep A. The symptoms can often be relieved by rest and good fluid intake. Alcohol is not recommended for people with Hep A.

Is there a vaccine for Hep A?

Currently in Australia we have three Hep A vaccines (two of which have junior versions.) There is one combination vaccine with Hep B (Twinrix™) and one combination vaccine with typhoid (Vivaxim™) Vaccines are available for people 2 years and older. A second dose of the vaccine is required for long-term protection.

People who inject drugs, men who have sex with men, travellers and long-term visitors to developing countries are recommended to have a combined Hep A/Hep B vaccine. Pregnant women should delay immunisation until after delivery of the baby unless there is a substantial risk of exposure. People who are in close household or sexual contact with someone with Hep A should get a normal human immunoglobulin shot within two weeks of exposure.

This will protect them for approximately 6 weeks. Hep A vaccines can be given at the same time as the immunoglobulin.

Where to get the vaccine?

The vaccine is available from your local GP.

Want to know more?

Contact your local user group (see the Directory at the back of this handbook).

Other types of Hepatitis

Other forms of hepatitis have been identified in the past few years. The most important are Hep D and Hep E.

Hep D is found in blood. It is confined to people who also have Hep B, it seems that it is spread similarly to Hep B and that infection occurs at the same time as Hep B infection.

It can be spread through shared injecting equipment. Although the least common kind of hepatitis and relatively rare in Australia, Hep D can cause very severe hepatitis.

There are tests available to detect the presence of Hep D antibodies, but as yet no specific treatments are available. The good news is that vaccinations against Hep B also protect against Hep D.

Like Hep A, Hep E can be spread by eating food or drinking water contaminated with small particles of faeces from an infected person. It can cause a short but severe illness, which can be fatal, especially in pregnant women. A very small number of cases have been reported in Australia.

Want to know more?...

Contact your local user Group (see the Directory at the back of this handbook).

HIV & what it does

The Human Immunodeficiency Virus (HIV) attacks the body’s immune system which protects us against bacteria, viruses and substances that appear foreign and harmful.

For HIV to be transmitted, a sufficient quantity of the virus needs to be passed from the bloodstream of an infected person into the bloodstream of another. The bodily fluids which can contain HIV in these sufficient quantities are blood, semen, vaginal fluids and breast milk.

Once inside the bloodstream, HIV targets the blood cells which make up the immune system, infects them and begins to multiply. Over time and without treatment HIV diminishes these CD4 (or T-helper) cells to such an extent that they are unable to fight off infection and this leaves the body susceptible to disease.

Shortly after someone has been exposed to HIV they may experience severe flu-like symptoms, perhaps accompanied by a rash. This is known as a seroconversion illness. Some people don’t go through a seroconversion illness so the only way to be sure that HIV infection has taken place is to have a HIV test. When someone has been recently infected with HIV they are especially likely to pass on the virus to others – not only because they may not realise they have HIV but also because the levels of HIV in their body are especially high during seroconversion.

Many people with HIV remain well and symptom-free. HIV can live in the body for years without causing obvious damage. But over time, people may experience diarrhoea, minor skin and mouth infections, fatigue, night sweats and persistently swollen glands. Without antiretroviral treatment, HIV eventually causes the immune system to break down to a point where the body cannot cope with illnesses and infections.

HIV & AIDS

A person with HIV is described as being HIV-positive which means that they have been exposed to HIV and antibodies have been detected in their blood.

A diagnosis of AIDS (Acquired Immune Deficiency Syndrome) is only applied when someone with advanced HIV infection has contracted an opportunistic or AIDS-defining illness. Since the advent of Highly Active Antiretroviral Therapy (HAART) in 1996, people do not advance to AIDS as often as they used to.

The term 'HIV/AIDS' is becoming outdated and the appropriate current term is people living with HIV or people with HIV.

How HIV is transmitted

Anal and vaginal sex can transmit HIV to either receptive or insertive partner. In Australia, unprotected anal sex between men remains the most common way HIV is transmitted. This is because the majority of people with HIV in Australia are men who have sex with men. Condoms used with water-based lubricant remain the best protection against transmission of HIV and other sexually transmitted infections (STI) during anal and vaginal sex.

Reusing injecting equipment is a very efficient way of transmitting HIV. Small amounts of blood can remain in a fit and if it is reused by someone else this blood can be injected directly into their bloodstream. In the course of injecting, blood can also get into water and on to spoons, filters, tourniquets and other surfaces therefore it is recommended that new equipment is always used by each person involved.

Mother to child transmission may occur during pregnancy, birth or breastfeeding. The chance of transmission is greatly reduced when the mother receives appropriate antiretroviral treatment, has a Caesarean birth and doesn't breast feed.

Tattooing, body-piercing, pearling, 3D implants, scarification or any activity that involves puncturing the skin has the potential to transmit HIV. Commercial practices that offer these services must follow strict infection-control guidelines.

Needle-stick injuries occur frequently to people working in health care however only a small number have ever contracted HIV through this type of exposure.

Oral sex is considered low-risk for transmitting HIV but semen in the mouth does pose some risk particularly when there are cuts or sores in the mouth.

Sex toys such as vibrators and dildos can spread a range of infections, including HIV. Thoroughly washing them and changing the condom between users will considerably reduce the chance of HIV infection.

Esoteric sexual practices that involve breaking the skin surface pose an HIV infection risk and should always be practiced safely.

How HIV is not transmitted

- Kissing
- Touching
- Shaking hands
- Hugging
- Mosquito bites
- Swimming pools
- Public toilets
- Household contact such as sharing cups, plates and cutlery

Post exposure prophylaxis

Despite many years of research, there is no effective vaccination for HIV. However, if you have had a high risk exposure to HIV there is a treatment available which will reduce your chance of seroconverting if taken within 72 hours after the event. It is called Post Exposure Prophylaxis (PEP) and involves taking a series of HIV antiretroviral drugs for a number of weeks. This treatment is best accessed from the accident and emergency department of your nearest hospital.

The HIV antibody test

The HIV antibody test is a widely-available blood test to find out if you have HIV. The immune system of a person who has been exposed to HIV will develop antibodies to fight the infection. These are what the HIV antibody test looks for.

As with hepatitis C, there is a window period between the time that HIV enters the body and when antibodies start to appear. This time can vary but is usually between ten days and three weeks. It can take up to six months for HIV antibodies to be detected with a HIV test.

HIV antibody tests are usually done free by GPs, sexual health clinics and family planning services. You should be asked for your consent for the HIV antibody test to take place. The results take about a week to come back and they should not be given to you by telephone or by a receptionist but in person at a post-test discussion.

Pre- & post-test discussions

Services that do HIV antibody testing are required to provide information and counselling sessions both before and after the test.

The pre-test discussion explores the activities that might have exposed you to HIV, the impact that a positive or negative result might have on you, your sources of support and other health matters.

The results of the test should be given to you in person at a post-test discussion and this provides the opportunity to discuss HIV, STI and other blood borne virus prevention plus get referrals to a counsellor, drug user organisation, AIDS council or dietician if needed.

If you've received a negative result at the post-test discussion, another HIV test may be needed in three month's time. A second negative test confirms that you are HIV negative provided you haven't been exposed to HIV within that three-month window period.

If your test is positive, another test will be ordered to confirm the result. If the second test shows the same result, it means that you have HIV. It is usual to feel overwhelmed at a positive test result. HIV can affect your physical and mental wellbeing, relationships, finances, work and ideas about the future.

You have every right to take as much time as needed to sort out whom you are going to tell and how. But keep in mind that any of your sexual or injecting partners who may have also been exposed need to be encouraged to get tested. There are a number of ways this can happen and you don't have to be the one who contacts them.

Learning more about HIV and how others live with the virus is something that many people have found useful. Check out the Directory at the back of this book for your local drug-user organisation, AIDS council or HIV positive group.

Treatments for HIV

Since 1996, the lives of people with HIV have been significantly changed by Highly Active Antiretroviral Therapy (HAART). There are now a range of drugs that used in combination can target HIV at different stages of its life cycle. The number of deaths from AIDS has fallen dramatically since these drugs were introduced so now people with HIV have a much longer life-expectancy.

CD4 cell counts indicate when treatment should start and viral load tests, which measure the amount of HIV in the bloodstream, show whether the treatments are working. Some people develop resistance to certain treatments and have to change the drugs they're taking. If you don't understand the meaning of these and other tests, ask your doctor to explain what they mean for you.

These days we also have a clearer idea of the side effects of these drugs and how they can be managed.

Managing HIV & treatments

Having check-ups every three months is a good way to get early warnings about changes in your health and give you time to decide what to do about them. Most people with HIV are monitored by general practitioners (GPs) with experience in treating HIV. These GPs will keep an eye on the following:

- The amount of virus in your body - viral load tests
- The health of your immune system - CD4 or T-cell tests
- Other sexually transmissible infections
- Hepatitis B and C and the health of your liver
- Dental health - especially important if you're using certain illegal drugs or are having drug treatment like methadone
- Pap-smears for women
- General health

HIV treatments and the healthcare system are far from perfect. For some people, beginning treatment raises a number of issues that are best discussed with someone familiar with your situation. State-based drug-user organisations and HIV positive groups are good places to find people like this.

Adhering to treatments

Once you start taking HIV treatments it is important to keep taking them as prescribed. When you miss doses, you lower the amount of antiretroviral in your blood and risk allowing the virus to replicate.

If you do miss a dose, do not double your next dose but take it at the usual time. Look at the reason why you missed the dose and think about ways you can avoid letting this happen again. Dosette pill boxes are a good way of keeping track of your pills and may make it easier for you to adhere to a treatment regimen.

HIV & sex

Some people find it hard to relax about sex when there is the fear they may transmit the virus to someone else. Understanding which sexual practices are safe and sticking to them can relieve this fear. Talking with counsellors and other people living with HIV can also help.

Some people think that HIV can not be sexually transmitted when it is being successfully suppressed by treatments. There is not enough evidence to support this and we should never put anyone else at risk based on this theory.

HIV & other STIs

Some STIs make it easier to get HIV, or pass HIV on to others:

- The presence of inflammatory STIs (chlamydia or gonorrhoea), or an ulcerative one (genital herpes, or syphilis) increases the risk of passing on or getting HIV. This is because HIV is more concentrated at the site of infections
- STIs can also dramatically increase HIV viral load. Having gonorrhoea on your penis can cause a rise in HIV in semen and pre-ejaculation. An increased viral load means there is a greater risk of passing HIV on if you are having unsafe sex
- Women suffer from the same complications of HIV infection as men but also suffer gender specific manifestations.
- Genital and anal herpes increase blood levels of HIV. Herpes also causes an increase in the concentration of HIV at the site of the herpes infection. This occurs whether there are symptoms (blisters) present or not. In fact, most herpes outbreaks are asymptomatic

STIs may be more severe and more difficult to treat if you are HIV positive:

- Genital and anal herpes outbreaks happen more often if you are HIV positive and outbreaks tend to last longer if you are not on HIV treatments. Also resistance to drugs used to treat herpes is more common if you have a damaged immune system

Syphilis acts more quickly if you have HIV and is more likely to cause damage to your nervous system if it isn't treated early. If it is not treated, syphilis may eventually damage your internal organs, including your brain, spinal cord and heart.

- Treatment of hepatitis C is less successful if you have a low CD4 count and it may not be possible to clear the virus

Regular sexual health checks are particularly important for HIV- positive men and women.

HIV & illicit drug use

We know that many illicit/recreational drugs can have a negative effect on your health. When they're taken in moderation the effect can be lessened but it can't be avoided completely.

The situation is complicated if you are HIV positive and even more so if you are taking HIV antiretrovirals. As well as risking adverse drug interactions, taking recreational drugs increases the chance you will miss doses of your HIV treatments. Remembering to take antiretrovirals on time is perhaps the simplest and most effective form of harm reduction when using recreational drugs.

Plan ahead and develop strategies to ensure you don't miss doses. If your drug use is causing you to miss doses frequently, there's a real risk that you could develop resistance to your treatments and your health could suffer enormously.

Drug interactions can also occur between antiretrovirals and illicit drugs. These depend on:

- the level of HIV antiretrovirals in the body (largely a matter of when the last dose was taken)
- how well the liver breaks down certain drugs (there's no way of knowing this on an individual basis)
- the potency, purity and amount of the illicit/recreational drug (often unknown)

Although we are aware of some interactions between specific drugs, there is always potential for new interactions, plus the strength and purity of illicit drugs can vary as can the substance used as a cutting agent.

Ritonavir (Norvir) is often included in a treatment regimen because it helps boost the action of the other treatments. This means it can also push up the level of other drugs including MDMA (ecstasy) and methamphetamine (speed, ice, crystal) to dangerous levels.

Efavirenz (Stocrin) can make some people feel dizzy or disoriented and these reactions can be intensified if taken with illicit drugs.

Reducing the amount of illicit drugs to a third or a quarter as well as taking it and your antiretrovirals a few hours apart will reduce these risks plus give your liver a better chance of breaking down each drug separately.

For information on specific interactions visit:

www.hiv-druginteractions.org

The safest course is not to use illicit/recreational drugs with prescribed HIV medications. If you do, discuss the subject of interactions with a doctor who has some specialist HIV knowledge. They may be able to provide you with more specific information.

The following may also help:

- Reduce the amount of any illicit drug you take. Some HIV drugs increase the effect of illicit drugs leading to the kind of problems that come with using too much of the drug e.g. vomiting, nausea, passing out and overdosing
- Take the illicit drug at a different time to your HIV drugs
- Drink about 600 mls of water per hour to prevent dehydration
- If you think you're experiencing a drug interaction (nausea, vomiting, dizziness, about to pass out) call an ambulance or get yourself to a medical centre or hospital casualty

Telling people you have HIV

Having someone to talk to about being HIV positive is very important to many people with HIV. But some people do not handle this information very well and may require more support than you are able to offer. Before telling anyone, ask yourself whether they need to know, how much you trust them and how telling them might affect your relationship.

- You can't take back disclosure
- Choose the people you tell, carefully
- If you think someone will react badly, wait until you feel more confident that you can deal with the situation. Or choose not to tell that person
- Remind the person that the information is confidential but understand that they may need to talk about it. Be prepared to suggest others they could seek for support
- Having some knowledge about HIV can be useful. Accurate information can help correct misconceptions. If you can't answer their concerns at the time, tell them you will get back to them with the answer
- Some people find it is useful to rehearse what they're going to say

Some people have found that good support can come from outside their own circle and choose to limit their disclosure to counsellors or others they have met through AIDS Councils or HIV positive organisations.

You do have certain responsibilities relating to the transmission of HIV and in some States you are legally required to tell any sexual partner even if you intend to practice safe sex. Because these laws vary from State to State, we recommend checking with your local drug-user or HIV positive organisation to find out where you stand. In the past few years, some cases where people have not disclosed have ended up in court.

People with HIV cannot donate blood, semen, body organs or body tissues. People applying for permanent residency must provide the results of an HIV antibody test. Some life insurance and superannuation companies ask about HIV status. Some may refuse to insure you if you are HIV positive or if you refuse to tell them your status.

Members of the Australian Defence Force and police services (and their recruits) are required to disclose their HIV status as well as other medical conditions. The ADF and police services make decisions on whether someone with HIV can remain in the force on a case-by-case basis.

Most States have confidentiality laws that prevent doctors, nurses and other workers from telling people not directly involved in your health care about your status. These laws do not apply to ordinary members of the public.

When you've got Hep C & HIV

Some of us have got to live with more than just Hep C. There's also HIV and Hep B. Infection with more than one virus is often referred to as co-infection.

Hep C & HIV

About 13% of the people living with HIV also have Hep C. We don't know much about how Hep C affects the course of an HIV infection. Sometimes, due to HIV infection, getting accurate readings on the presence of Hep C can require more than the usual blood tests. Current research suggests that HIV aggravates Hep C-related liver disease and can speed up the progression to cirrhosis and liver cancer.

People with HIV can be treated for Hep C, but it can be more complicated than treating each condition on its own. Because some HIV treatments put great strain on the liver, they're not recommended for people who also have Hep C.

If you've got both Hep C and HIV it is important to find a doctor with experience in co-infection and HIV. (AIDS Councils and Hepatitis C Councils will be able to suggest appropriate doctors). Regular liver function tests are an important part of the treatment regime. So is avoiding unnecessary damage or stress to the liver.

Hep C & Hep B

There has been relatively little research on co-infection with Hep B and Hep C. Because of the way the viruses work, one sometimes dominates the other, making both testing and treatment more complicated.

Having both Hep B and Hep C can lead to severe liver disease, including cirrhosis, liver failure and liver cancer.

The treatment for Hep B/Hep C co-infection does not yet have a long track record. At present, the treatment focuses on which ever virus is dominant. There have been encouraging results in trials of treatments for people in whom Hep C dominates. When Hep B dominates, the treatment options are less clear.

Regular liver function tests are an important aspect of the treatment regimes. So is avoiding unnecessary damage or stress to the liver.

Gender considerations around Hep C & HIV

Hep C & women

Women with Hep C face a number of challenges around their reproductive and sexual health. However, the impact of Hep C on reproductive and sexual health is not well understood and needs further research. What do we know so far?

Menstruation. Because Hep C is passed on through blood-to-blood contact and menstrual fluid contains blood and other body fluids, in theory there's a risk of passing on Hep C through contact during menstruation. But the risk seems to be extremely low. There is no evidence that sex during menstruation increases the risk, although, again, in theory, if the sexual partner has open cuts, wounds or abrasions, the risk will be higher. Using dental dams and condoms will reduce the risk of blood-to-blood contact during sex.

Following standard precautions for infection control during menstruation e.g., disposing of tampons and sanitary pads in hygienic disposal units or in leak-proof plastic bags in the rubbish will also lower risk.

Although some may find they miss a period or have shorter periods, most women's periods will not change when they have Hep C.

Birth control. For most women with Hep C, the oral conceptive pill seems to work ok. However, when the liver is badly damaged, it may be unable to break down the hormones present in the contraceptive pill and in hormone replacement therapy (HRT). Women whose livers are severely damaged or experiencing difficult symptoms are advised to consult their doctors about contraception.

Menopause. The hormones present in hormone replacement therapy (HRT) can cause problems for women with Hep C. Not all the hormonal changes experienced by Hep C positive women are due to the presence of Hep C. We recommend seeking medical advice for problems associated with menopause and HRT.

Pregnancy. Hep C does not reduce the chance of a Hep C positive woman becoming pregnant.

Women with low levels of Hep C in their blood (low viral load) are unlikely to transmit Hep C to their babies. Women with high levels of the virus, those with severe liver damage and those in the early acute phase of infection, have a higher risk. A Hep C positive woman is more likely to transmit the virus to her baby during birth than while she is pregnant.

In most cases, babies born to Hep C positive mothers will inherit the mother's Hep C antibodies, not the virus itself and test antibody positive until about 15-18 months old, when the antibodies disappear naturally. Testing for babies for Hep C is not recommended until the child is about 2 years old.

Breastfeeding. There are no confirmed reports of Hep C being passed from a Hep C positive mother to her baby through breast milk. However, the risk of blood-to-blood contact, if the mother's nipples are cracked or there are small tears or scratches in or around the baby's mouth does present a risk. Hep C positive mothers who are breastfeeding are advised to express and discard their breast milk while their nipples are cracked and talk to a breastfeeding counsellor or nurse lactation consultant about how to prevent cracked nipples.

Through the experiences of HIV positive women and their doctors, we now know that HIV affects women in many of the same ways as it affects men. But it can also affect some women differently for example, with hormones, weight and body shape, the reproductive system, menstruation and menopause, lifestyle and social circumstances.

They may experience menstrual irregularities such as an increased or decreased blood flow, missed periods, cramps and increased premenstrual tension, although it is not known whether these are caused by the virus or the drugs taken to fight the virus. There also seems to be a higher incidence of cervical cancer in HIV positive women, linked to the presence of the human papillomavirus (HPV), a sexually transmitted virus that causes genital warts. You may have been exposed to this virus even if you've never had warts. A simple biopsy procedure can tell if you've been exposed to HPV and which strain of the virus you might have. It is very important that HIV positive women have regular Pap smears - at least once a year.

Some HIV positive women get thrush when the levels of a naturally occurring yeast, candida albicans, multiply and get out of control. A range of topical treatments, some of them natural therapies, can be useful.

Being diagnosed with HIV does not mean the end of your sex life, although some women may find that during stressful times, periods of feeling unwell, or adjusting to an HIV diagnosis, they feel less interested in sex. Research shows that HIV positive women often lose interest in sex for the first year or so after diagnosis, but for most, sexual desire does return.

Many women have found that learning to talk about sex and negotiate safe sex with a partner can be difficult. Talking to counsellors or other women living with HIV/AIDS may help. So too will understanding the ways in which HIV can be transmitted, which sexual activities are safe and which ones pose risk. (See the Directory at the back of this handbook).

There's a small but growing amount of information specifically dealing with how HIV antivirals affect women. For example, some doctors believe that, in the past, standard doses of antivirals may have been too high for women, leading to more severe side-effects. Some HIV medications are known to make the contraceptive pill less effective. Your doctor can advise you whether you need to change the type or dose of contraceptive pill, or use other methods of contraception.

While there are only a small number of women with HIV in Australia, State AIDS councils and People Living with HIV/AIDS (PLWHA) groups are becoming increasingly aware and helpful for HIV positive women. Most States and Territories have support groups and organisations specifically for HIV positive women. (See the Directory at the back of this handbook).

If your're HIV positive and pregnant, or thinking about getting pregnant, it may be advisable to talk to a doctor who can help you manage the pregnancy in the safest way. State-based positive women's groups, AIDS councils and PLWHA organisations can make referrals.

A baby can get HIV from its mother during pregnancy, during labour and delivery and through breast-feeding. But the risk is very low when the mum's viral load is low or undetectable, her CD4 count is high, she uses HIV antiviral medications during the pregnancy and delivery, she has access to good obstetric care, she has the birth by Caesarean and she does not breast feed. In Australia, many HIV positive women have had HIV negative babies.

There is no evidence that pregnancy leads to higher levels of HIV or faster immune system damage, unless a woman is ill with AIDS-related conditions. Although a HIV positive woman's immune system is under pressure when she is pregnant, it bounces back after having the baby.

Chapter 4

Troubleshooting

Recognising problems & how to deal with them

This chapter covers some of the main hazards of injecting: problems with veins and the problems that come about through being exposed to bacteria (germs) and viruses. There's a lot more than can be said about each problem than we talk about here, so please don't take these as the last words on the subject.

Anyone who has been injecting for any length of time will probably have some experience of one, or more, of these problems. The thing is, though, by using good injecting technique and following the safer using guidelines covered in Chapter 2, we can avoid them.

A word of warning though: many of the things we describe are potentially very dangerous and the seriousness of the situation increases the longer we delay dealing with them. Many people try to ease pain and discomfort by taking more of a drug or another drug. This might seem a sensible solution at the time, but . . . there's always an overdose (OD) to consider and the real cause of the problem will remain and perhaps get worse. Also some drugs such as methadone or any opiate really, can disguise or cover pain.

Dealing with these problems often requires expert medical attention. Finding expert and sympathetic medical help to deal with these problems can be difficult. The first thing is to recognise when there is a problem.

Problems with veins

Chapter 2 covered how blood works inside the body, the difference between veins and arteries and some of the things to avoid when we inject.

It doesn't really matter if you've been injecting a long or short time, it's in your best interest to take care of your veins. Damage to veins can lead to many complications. Unfortunately, most injectors don't look for expert medical care until things reach a crisis point, which can often lead to permanent damage requiring much more intensive and perhaps, expensive treatment.