








Hepatitis C

Testing Information



Contents

	Introduction	2
	Hepatitis C: a snapshot	4
	The symptoms of hepatitis C	6
	Transmission	8
	Testing for hepatitis C	11
	The tests	12
	Who is notified of my test results?	17
	Obtaining information and support	17
	Post-test information	18
	Looking after yourself	19
	Monitoring your health	23
	Protecting yourself and others	25
	Telling other people	31
	Counselling	35
	Contacts	37



Introduction



I

f you are preparing for testing for hepatitis C, if you have just found out you have hepatitis C, or if you have known for a while that you have hepatitis C and want to learn more, this booklet is for you.

If you have at any time injected drugs or you have emigrated from a country with a high prevalence of hepatitis C, or have undergone tattooing or body piercing, or have had a blood transfusion prior to 1990; this booklet is also for you.

The first section of the booklet – ‘Hepatitis C: a snapshot’, deals with general questions:

- What is hepatitis C?
- What are the symptoms of hepatitis C?
- How is hepatitis C transmitted?

The second section – ‘Testing for hepatitis C’, answers more specific questions:

- Why get tested?
- Should I be tested?

- What is the test for hepatitis C?
- Who is notified of my test results?
- What if I do have hepatitis C?
- Where can I get more information and support?

The third section – ‘Post-test information’, goes into more detail about aspects of hepatitis C. It explains what it means to have hepatitis C. The doctor or counsellor who told you that you have hepatitis C might have discussed some of these things with you, but that might have been a while ago. Here are some of the questions this booklet answers for you:

- How can I look after my health and have a healthy lifestyle?
- How do I monitor my health?
- How can I protect myself and others?
- Who should I tell?
- Can I join a support group?

Importantly, this booklet provides contact details for organisations that can give you more information about hepatitis C. The names and addresses are in the ‘Contacts’ section at the end of the booklet; these organisations can help you find answers to questions not dealt with here.

More copies of this booklet can be obtained from your state or territory hepatitis organisation; see the ‘Contacts’ section for details.



Hepatitis C: a snapshot



The hepatitis C virus causes liver inflammation and liver disease. It is transmitted by blood-to-blood contact and was first identified in 1989. Before then, it was often called non-A, non-B hepatitis or post-transfusion hepatitis.

Many people who have just been diagnosed with hepatitis C are confused about the term 'virus' and what viral infection means. Hepatitis C is totally different from hepatitis A or B, and it is not related to HIV.

Hepatitis C, which affects millions of people around the world is a slow-acting virus, and for many people it will not result in serious disease or death. Research has shown that about 25 per cent of people infected with hepatitis C will clear the virus within two to six months of becoming infected, but will continue to carry antibodies to the virus. People who do not clear the virus will have ongoing, or chronic, infection.

The treatment for hepatitis C is a combination therapy of pegylated interferon and ribavirin. About 50 or 80 percent of people treated with combination therapy will clear the virus, (50% for genotype 1 and 80% for genotypes 2 and 3). Treatment success depends largely on the particular genotype, or strain, of the virus. See the section 'Testing for Hepatitis C' for an in-depth explanation on the tests you will need.

At present there is no vaccine for hepatitis C.

Take time to read this booklet and don't be afraid to ask for help.



The symptoms of hepatitis C

When first infected, only 5 per cent of people experience any noticeable signs of illness. The initial, or acute phase of infection can bring with it a flu-like illness. Some people develop nausea, abdominal and back pain, and extreme tiredness. Jaundice is not a common symptom of acute infection. Most people do not experience any symptoms for the first 10 years or more after the acute infection phase.

Symptoms of ongoing chronic infection can range from mild to severe, and can occur continuously or in bouts. The most common symptoms are:

- tiredness
- lethargy
- nausea and discomfort in the abdominal region
- feeling ill if you drink alcohol or eat fatty foods
- depression.

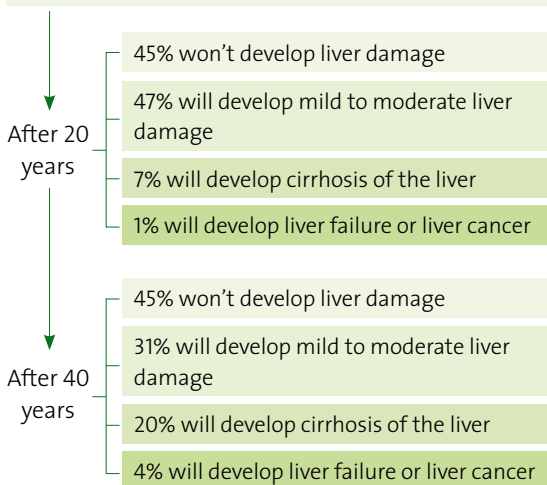
Individual experiences of hepatitis C can vary enormously. Remember that you might feel well, even though the damage to your liver is progressing. If you have hepatitis C and drink alcohol regularly, your chances of developing more serious liver damage, such as cirrhosis, are higher.

Chronic hepatitis C outcomes chart (natural history)

This chart shows the different outcomes that may occur with chronic hepatitis C (hep C). It does not aim to show individual outcomes (prognosis). Personal factors such as alcohol intake, age when hep C was acquired and current level of liver damage may all influence a person's prognosis. Individuals are advised to seek medical advice regarding their own situation.

On average, one of every four people who contract hep C will clear their infection naturally within the first 12 months. Three of every four people will develop chronic (ongoing) hep C.

Of 100 people with chronic hep C who remain untreated.



This table is reproduced from the Hepatitis C Council of NSW Illness Outcomes Factsheet (2007)

Transmission

Blood containing the hepatitis C virus must enter the bloodstream of another person for transmission to take place. This is called blood-to-blood contact. Minute amounts of blood invisible to the naked eye can transmit hepatitis C.

Injecting drug equipment

It is estimated that about 80 per cent of the Australians who have been exposed to the hepatitis C virus have contracted the virus through injecting drug use, and 90 per cent of new infections are related to injecting drug use. Syringes, needles, tourniquets, swabs, water, spoons, containers, hands, puncture sites and the mixing surface are all means of transmitting the virus. If you injected drugs for a long period, you might have contracted several different strains of the hepatitis C virus.

Blood transfusions and blood products

Some people with hepatitis C contracted the virus through blood transfusions or blood products before 1990. Since 1990, all blood has been screened for hepatitis C, and the supply of donated blood in Australia is now screened for all known blood-borne viruses including hepatitis C. Some developing countries are not as well advanced as Australia in their screening of donated blood.

Tattoos, body piercing and skin penetration

A small number of people may have become infected as a result of unsterile tattooing or body-piercing procedures, needlestick injuries and accidental exposure to infected blood or blood

products, exposure to blood in the home, or some other form of blood-to-blood contact.

Other ways of transmitting hepatitis C

Mass vaccination programs involving the re-use of needles and syringes in the past have resulted in the transmission of hepatitis C to some people. The introduction of standard infection-control procedures, which are based on the assumption that all blood and body fluids are contaminated, has meant that the risk of transmission as a result of non-sterile medical procedures is now very low in Australia.

Some people who have migrated to Australia might have acquired hepatitis C in their country of origin as a consequence of vaccination or another medical procedure.

Unsterile medical and dental procedures

Occasionally sterilising procedures in healthcare settings break down due to mechanical or human error. This can result in the transmission of blood-borne viruses such as hepatitis C from one patient to another.

Sex

It is unlikely that hepatitis C will be transmitted through sexual activity in the absence of blood. It is not classed as a sexually transmissible disease. People in stable, monogamous relationships should discuss safer sex options if either partner is concerned about sexual transmission. People with multiple sex partners should practice safer sex, in particular the use of latex condoms. See 'Can I still have sex?' for more information.

Pregnancy and childbirth

Research shows that the risk of transmission to your baby during pregnancy or childbirth is about 6 per cent. See 'Can I still have children?' for more information.

How Hepatitis C is *not* transmitted

Hepatitis C is not transmitted through normal social contact. Hugging, kissing, sharing food, drinks, plates and eating utensils, sneezing, coughing and sharing laundry and toilet facilities will not result in the transmission of hepatitis C. See 'Protecting yourself and others' for more information.

What about mosquitoes?

Mosquitoes and other insects do not transmit hepatitis C. When a mosquito bites someone, it injects salivary fluid through one passage and sucks blood through a different passage. The blood goes directly to the mosquito's stomach, where it is broken down. Some organisms (such as the protozoans that cause malaria) can live in the salivary glands of mosquitoes and be passed on when the insects feed. Hepatitis C is not found in these glands and cannot be passed on this way.

Can I be reinfected with hepatitis C?

Yes, you can. Even if you already have hepatitis C, another genotype of the virus can reinfect you. You may be told you have hepatitis C antibodies; these do not protect you against reinfection.

The important thing to remember is not to place yourself, or others, at risk of further infection.



Testing for hepatitis C



B

eing tested for hepatitis C will help you make informed decisions. If you find out you do have the virus, you can take steps to reduce its impact on your health and to prevent harm to yourself and other people. For example, you can cut down on alcohol and eat foods that are good for your liver. Nevertheless, the decision to be tested is entirely yours.

Testing for hepatitis C may not be done without your consent. Doctors can refer you to specialists and to support services that will offer you more support when the test results are known. Contact your local hepatitis organisation for more information.



The tests

If you have decided to be tested, make an appointment with your doctor after the test so that you can receive the results in person. Your doctor can explain the results, answer your questions, and recommend follow-up if necessary.

The antibody test

The initial screening test for hepatitis C is a blood test that checks for the presence of hepatitis C antibodies. (The human body produces antibodies in response to the virus). It can take up to three months for these antibodies to appear in your blood following infection, although the test is usually positive by six weeks. This is known as the ‘window period’, and during this time antibody testing might not produce an accurate result.

A negative test result usually means that a person has not been infected with the virus, although the blood sample might have been taken during the window period, before antibodies are detectable. If this is the case the test would need to be repeated later.

A positive test result means that antibodies were found, which is evidence that the virus has infected you at some time. As noted, about 25 per cent of people who develop hepatitis C antibodies in response to infection get rid of, or clear, the virus within six months. When this happens, the antibodies remain in the blood for some time — possibly for the rest of the person’s life. This means that a positive antibody test result doesn’t necessarily mean someone has the virus. A different

test, the polymerase chain reaction (PCR) test, is used to see whether you have the virus (as opposed to the antibodies) in your blood.

The antibody test is not reliable with newborn babies. Babies born to mothers infected with hepatitis C can have a positive antibody test result without actually being infected. This 'maternal antibody' usually only lasts 12 to 18 months, and it is recommended that testing of children not be done until after this time.

Polymerase chain reaction (PCR) test

Unlike an antibody test, the polymerase chain reaction test can detect whether the virus (as opposed to antibodies to the virus) is present in your blood. The hepatitis C virus is usually found in low levels in the blood, and the PCR test uses a laboratory technique to amplify the genetic material of the virus (hence the term 'chain reaction'). There are three types of PCR test: the viral detection test, the viral load test, and the genotype test.

The PCR viral detection test

The basic PCR viral detection test is used to determine whether a person has the virus; it is formally called the 'qualitative' test. This test is especially useful in the case of someone who has an inconclusive hepatitis C antibody test when their liver function tests are consistently normal, or when their liver function tests are abnormal but there are other possible causes of liver disease. **It is recommended that anyone who is antibody positive have the PCR viral detection test done to see if they still have the virus.**

Unlike the antibody test, a PCR viral detection test can also confirm if the virus is present during the window period after infection; the virus can be detected in the blood as early as two weeks after infection. This test can also be used to confirm hepatitis C status when a person is immunodeficient (because of HIV infection, for example) or has been immuno-suppressed by drugs (as in organ transplantation), since immuno-suppression can also be associated with a false negative hepatitis C antibody test result.

The PCR viral load test

The PCR viral load test is used to estimate the amount of hepatitis C virus circulating in someone's blood; it is formally called 'quantitative' test. This test can help in determining the likelihood of response to treatment, particularly for people with genotype 1 of the virus.

The PCR genotype test

The genetic make-up of the hepatitis C virus is highly variable, and this has led scientists to divide the virus into six genetic groups, or genotypes. The PCR genotype test is used to determine the particular genotype of the virus a person has. This can help predict a person's chances of responding to therapy. For example, with combination therapy



of pegylated interferon and ribavirin, people with genotypes 2 and 3 have a higher chance of cure (about 80 per cent) than people with genotype 1 (about 50 per cent); they also have a reduced treatment period — six months for genotypes 2 and 3 in contrast with 12 months for genotype 1.

Being ‘cured’ is defined as having no virus present immediately after therapy and for six months after that.

Liver function test

The liver function test, a blood test, provides an indication of whether the liver is functioning properly. The test measures the amount of particular chemicals (enzymes) in the blood, and this allows possible damage to liver cells to be gauged. The damaged cells release enzymes into the bloodstream. The damage to the liver can be caused by many things, including the hepatitis C virus, other viruses, alcohol and some drugs.

For people with hepatitis C, the enzyme alanine aminotransferase is the most relevant enzyme measured by a liver function test. ALT is a liver enzyme that can leak out into the bloodstream when liver cells are inflamed. Elevated ALT levels suggest liver damage. Damage to your liver can occur, even with normal ALT results. The liver function test provides a basic guide and it should only be viewed as part of the overall picture of your health.

If your ALT levels are consistently elevated, it is important to discuss with your GP the possibility of

referral to a liver specialist. If your test results show a particular pattern, or don't seem to correspond with your symptoms, your doctor might suggest different tests.

Liver biopsy

Cirrhosis is a condition in which, as a result of chronic inflammation, liver cells are damaged and replaced by scar tissue. The scar tissue affects the flow of blood and other fluids through the liver. Without good blood flow and with a reduction in total liver cells, the liver cannot function properly, and it becomes lumpy and hard. Scar tissue can form in the liver as a consequence of the inflammation that occurs with hepatitis C. A liver biopsy shows how much scar tissue has formed in your liver and whether or not you are developing fibrosis or cirrhosis.

Before April 2006, all people who wanted to have government-funded hepatitis C treatment had to have a liver biopsy first. **That is no longer the case**, although if you are considering treatment your doctor might recommend that you have a liver biopsy, if so, you should discuss with the doctor the pros and cons of having the test.

A liver biopsy is generally performed in a hospital day clinic. It involves removing a tiny sample of your liver by inserting a thin needle into your upper abdominal region.

Fibroscan

Fibroscan is an ultrasound-like device that assesses the degree of liver damage, such as scar tissue (fibrosis), through the measurement of liver stiffness. It is a non-invasive procedure that takes only a few minutes to perform.

Fibroscan, as opposed to liver biopsy, is a more patient-friendly option, with minimal anxiety attached. If performed on a yearly basis, over time, the results can be used to track your liver disease, and determine whether liver scarring is increasing.

In some cases Fibroscan has not replaced the need for liver biopsy. While it is extremely efficient at picking up mild or minimal liver disease, and diagnosing cirrhosis, for those with more moderate levels of disease, a liver biopsy may give a better indication of disease progression.

Who is notified of my test results?

The doctor who requested the test and the health department are notified of your results. If you test positive for hepatitis C, the laboratory that tests your blood is required by law to inform your state or territory health department. This information is used only for statistical purposes. Your personal details cannot be disclosed to anyone else.

Obtaining information and support

In each state and territory, you can obtain free information and support from:

- hepatitis organisations or support groups in all capital cities and some regional areas
- haemophilia organisations
- peer-based injecting drug user groups
- a range of other community-based organisations or government agencies.



Post-test information



E

ven though you might feel well, the damage hepatitis C causes to your liver can still be progressing. For example, if you have hepatitis C and drink alcohol regularly, your chance of developing more serious liver damage such as fibrosis or cirrhosis is higher; you don't have to give up alcohol completely, but if you consume more than 10 grams of alcohol a day (that's one standard drink) you are increasing your chances of long-term liver damage.

Discovering that you have hepatitis C can be frightening and causes people to react differently; you might feel angry, confused or depressed, or you might feel nothing at all. Not everyone feels the same way about their diagnosis, but everyone is affected emotionally one way or another.

It is so important to remember **you are not alone**.

It can help to speak with other people who have hepatitis C; they will probably understand some of the feelings you are experiencing. Speaking with a counsellor can be helpful, too.

The 'Contacts' section at the end of this booklet provides contact details for organisations and other services that could be useful.

I didn't know who to tell. I needed support, but I didn't know where to get it. Would my friends and family reject me? It took a while, and slowly I worked out who I could trust. Talking about having hepatitis C has been a great relief.

Looking after yourself

There are several things you can do to improve your health and your ability to cope with hepatitis C:

- Keep to a healthy diet.
- Reduce the amount of alcohol you drink.
- Get plenty of rest.
- Avoid or manage stress.

Adopting healthier behaviours such as giving up smoking, for example, will improve your general health and wellbeing, as well as help your body deal better with the hepatitis C virus. Reducing or avoiding substances that are harmful to your liver such as alcohol in particular, is essential.

I contacted the hepatitis C council, who were able to put me in touch with a good naturopath, a doctor I could relate to and other people who are positive. It was great. Suddenly I was not alone.



Vaccination against other forms of hepatitis

Infection with another hepatitis virus on top of your hepatitis C infection can make the damage to your liver worse. **It is highly recommended to be vaccinated against Hepatitis A and B.**

Medications

Many prescription and over-the-counter drugs can be harmful to a damaged liver if taken for a long time or in high doses. Paracetamol is fine as long as you take less than 4 grams (2 x 500mg tablets equals 1 gram) a day and do not use it for extended periods. Aspirin can be harmful to people with liver problems. Check with your doctor about any medications you are taking.

Some dietary or health supplements, such as vitamins, can have negative effects on your liver. Similarly, some complementary medicines are toxic to the liver and should be avoided. Ask your doctor about this.

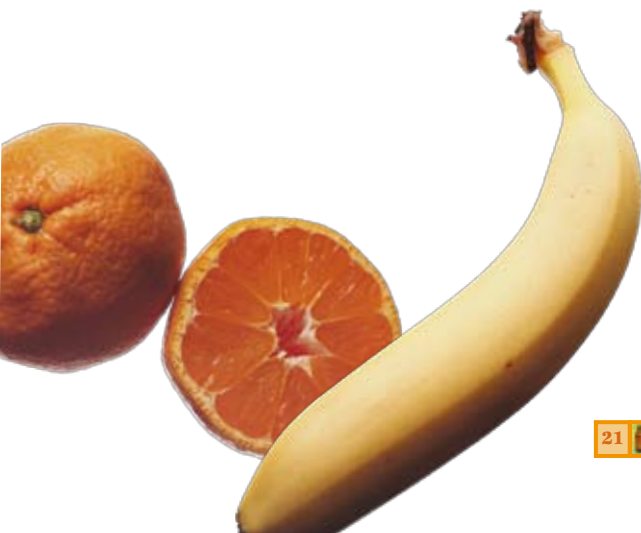
Street drugs

Many street drugs can be harmful to the liver, so if you can't avoid them altogether, it's a good idea to take precautions so as to reduce their harmful effects. Some drugs are not directly toxic to the liver, but the substances they are cut with can be. Certain combinations of drugs can be particularly harsh. If you inject drugs, among the precautions you can take are the following:

- Don't use if you are feeling sick or run down.
- Take breaks from using.
- Use only one drug at a time.
- Look after yourself by remembering to eat well, rest and drink plenty of water.
- Use filters whenever possible.
- Never use alone.
- Find out the location of your nearest needle and syringe programs and syringe vending machines.
- Above all, don't share any injecting equipment. Using new fits and clean equipment will help prevent you being re-exposed to hepatitis C.

See the 'Protecting yourself and others' section for more information about injecting drugs and hepatitis C.

If you need more information about how drugs affect your health when you have hepatitis C, see the 'Contacts' section for the contact details of organisations that might be able to help.



Alcohol

People with hepatitis should consider drinking only infrequently and well below the current levels recommended. If you have cirrhosis, it is strongly recommended that you avoid alcohol completely. If you want to continue drinking alcohol, it is essential that you apply some simple guidelines to reduce the harm to your liver:

- Make your first drink a non-alcoholic one.
- Alternate drinks with alcohol-free or low-alcohol drinks.
- Switch to low-alcohol drinks permanently.
- Break the habit of buying in rounds.
- Have at least two alcohol-free days a week.
- Remember that alcohol causes liver inflammation.
- Contact an alcohol information and support service if you're having difficulty reducing the amount of alcohol you drink.
- Remember that consuming more than 10 grams of alcohol a day (one standard drink) can increase your risk of developing serious liver disease.
- Avoid alcohol when you are taking prescription medicines and non-prescription drugs. The combination can be unpredictable and can cause even greater liver damage.
- Above all, avoid binge drinking — that is, drinking more than three alcoholic drinks in one sitting.

Reducing the stress on, and damage to your liver is vital for staying healthy.

Monitoring your health

Building a partnership with your doctor

It's great having a doctor I can talk to and trust. I ask questions, talk freely and participate actively in planning my health management.

Developing a good relationship with your doctor is important. You need to feel comfortable talking with them. Choosing a doctor who is close to where you live or easy to get to is essential and they should have some experience dealing with hepatitis C. The groups listed in the 'Contacts' section can help you find a suitable doctor.

Visiting your doctor regularly for routine tests can alert you to potential problems and help you plan how to stay healthy. This is called 'health maintenance and monitoring'. **It is important to remember that damage to your liver might be occurring even if you feel well.**

Being honest with your doctor about your alcohol and other drug use is important, too. Tell him or her about any alternative or complementary therapies you are using and about your health in general. This information might affect the advice your doctor gives you. Your doctor should allow you to be honest, without making you feel judged or uncomfortable. Honesty is important if you and your doctor are going to become partners in looking after your health. If you feel you cannot build this sort of relationship with your current doctor, find another one you feel more comfortable with.

Monitoring your health

When you have hepatitis C, monitoring your health, particularly the health of your liver, is mainly done through routine blood tests. Sometimes you might have to undergo other tests to find out how severely your liver has been affected by the virus. Testing allows you to make decisions about treatments. You and your doctor can discuss things such as alternative therapies and lifestyle changes that can maintain and improve your health.

The most common health-monitoring test for people with hepatitis C is the liver function test; see 'The tests' section. By regularly having liver function tests and by looking at other physical signs and symptoms of liver disease, you can develop a profile of your liver's health. It is a good idea to get into a pattern of having liver function tests done regularly. Taking photocopies of your results will help if you need to see a different doctor.

A liver biopsy, or fibroscan, determines how much scar tissue has formed in your liver and whether or not you are developing cirrhosis. A polymerase chain reaction test can also be used if your antibody test is unclear and also to monitor treatment progress. The test results need to be looked at with other test results and clinical signs in mind. See 'The test' section.

After looking at the various signs of hepatitis, your symptoms and your test results, you and your doctor might decide to begin or modify a particular form of treatment.



Protecting yourself and others

There are a number of simple precautions you can take to minimise the risk of transmitting hepatitis C to other people:

- Reduce or eliminate all opportunities for other people to come into contact with your blood.
- Do not share personal toiletry items such as toothbrushes and razors or any other items that might puncture skin and draw blood. Keep your own gear in a toiletry bag to reduce the chance of others using it accidentally.
- Keep a good first aid kit on hand.
- If you have any cuts, abrasions or wounds, keep them clean and covered with waterproof dressings.
- Clean up any blood spills with paper towels and soapy water and then diluted bleach. If there's a chance of bare skin coming into contact with the surface, follow up with undiluted bleach, straight from the bottle. Remember, though, that bleach is not guaranteed to kill the hepatitis C virus.
- All blood-stained items, such as bandaids, dressings, tampons and sanitary pads, should be placed in a plastic bag before being put in a rubbish bin.



Injecting drugs

The longer that people inject their drugs, the more at risk they are of getting hepatitis C. I take great care to be 'blood aware' when I am around people who are injecting.

Hepatitis C can be difficult to avoid if you are injecting drugs because it takes only tiny amounts of blood to transmit the virus. Even amounts of blood so small that they cannot be seen are a risk to you and others.

When you inject, you pierce your skin and cause bleeding; those injecting with you are also piercing their skin. It is very easy to transmit hepatitis C through sharing injecting equipment, even tourniquets. What's more, the virus can live for some time outside the body.

Safer injecting is important to prevent infection and re-infection with hepatitis C and to protect against other infections, such as hepatitis B and HIV.

Safer injecting

People who inject drugs should use new, sterile needles and syringes (or 'fits'), new filters, spoons, tourniquets and new ampoules of water each time, and make sure their other equipment is clean. They should wash their hands before and after every injection and should also clean the surfaces they are using to prepare their equipment before and after every injection. This applies to people who are self-administering prescribed drugs such as insulin, interferon and clotting factor, as well as illicit drugs.

Being 'blood aware'

If you inject drugs you need to be 'blood aware'. Any injecting equipment that is re-used or handled by, or passed to other people is potentially infectious. Hepatitis C can enter your bloodstream:

- through blood left in a syringe that someone else has used
- through blood left in the water, spoon or filter near a used fit
- from blood left on a tourniquet that brushes against the injection site
- from blood left on a person's finger (when they apply pressure after their shot) which ends up on your skin when they help you inject
- from blood left on the filter by someone tearing it up after their shot
- from blood you get on your own hands after touching an object or surface that someone else with blood on their fingers has touched
- through blood left in a needle that someone else has used.

Remember: the blood does not need to be visible for transmission to occur.

Using new injecting equipment

Always use new injecting equipment — syringes, needles, swabs, water and filters — and a clean spoon and glasses and your own tourniquet. New equipment is available through needle and



syringe programs, syringe vending machines and most pharmacies.

Washing your hands

It is important to wash your hands before and after injecting. Wash your hands thoroughly with hot water and soap before and after every shot, before and after you touch any equipment or surfaces being used while injecting, and before and after helping anyone else inject.

Safe disposal

After injecting, dispose of the needle and syringe in a rigid, puncture-proof container (a sharps box or plastic soft drink bottle with a cap) to reduce the risk of needlestick injuries. Return the container to a needle and syringe program or a hospital for disposal.

Can I clean a used syringe?

Cleaning used syringes is not advisable. Current research shows that rinsing twice in cold water then twice in bleach, then twice in new water — the 2x2x2 bleaching method — might not get rid of the hepatitis C virus. If you have to re-use a syringe, make sure it's your own.

If you don't have a clean syringe and are thinking of using someone else's used fit, contact your local needle and syringe program (NSP). If this is not an option, it would be best to take the drug another way: swallow it, smoke it or insert it into your bottom.

Contact your local hepatitis organisations, drug and alcohol hotline or drug user organisation for details of a NSP in your area. Knowing the

location and hours of your local NSP, as well as the location of your local syringe vending machines, may prevent you from finding it necessary to reuse a fit. Needle and syringe programs will give you sterile equipment and a needle disposal bin. A list of organisations and services that provide information on needle and syringe equipment is at the end of this booklet.

Other ways of taking drugs

Some people believe hepatitis C is so easily transmitted through injecting drug use that it is safer to take drugs another way — for example, snorting, swallowing, smoking or using the drug like a suppository (putting it up your bottom). These methods greatly reduce the risk of catching or transmitting hepatitis C.

If you snort drugs, always use your own new straw or banknote. Small amounts of blood can get onto a straw or banknote from blood vessels inside your nose which are sensitive and bleed easily. Don't share straws and banknotes with other people when snorting drugs.

Contact local peer-based drug user groups or needle and syringe programs, or speak to your doctor for more information about ways of drug taking that pose little or no risk of contracting or transmitting hepatitis C. The locations of needle and syringe programs in your area can be obtained from the peer-based drug user groups or hepatitis C organisations listed at the back of this booklet.

To summarise: If you inject drugs, there are four essentials to remember:

- Be 'blood aware'.
- Don't share any injecting equipment.
- Wash your hands before and after injecting.
- Dispose of used kits and other injecting equipment safely.

Can I still have sex?

Transmission of hepatitis C through sex is unlikely. Hepatitis C is transmitted by blood, so the risk is fairly low.

Use condoms and dental dams (for oral sex) if you are menstruating. Use condoms during anal sex or if there are cuts, sores or abrasions on anyone's genitals, hands or fingers. The presence of other sexually transmitted infections increases the risk of infection.

Even if you have only one sexual partner, safe sex is necessary when blood is present. If you have more than one partner, or you change partners regularly, safe sex is essential. Safe sex also helps protect you from hepatitis B and HIV, as well as other sexually transmitted infections such as herpes, genital warts and chlamydia.

Safe sex means using a condom and a water-based lubricant during penetrative sex, using condoms and dental dams during oral sex, and using latex gloves when penetration with the hands or fingers occurs.

Can I still donate blood?

The Red Cross Blood Bank does not accept blood from people infected with hepatitis C.

Telling other people

The question of who to tell you have hepatitis C is a difficult one: people have differing relationships, differing friends and differing needs.

Don't let yourself be pressured into telling anyone when you first learn you are infected with the virus. Take time to think about what you want to say, who you want to say it to, and why you want to tell them. Ask yourself why particular people might need to know, whether you trust them, and whether telling them will help you in some way.

Telling someone about being infected can be threatening because of what it can bring up in a relationship, especially in connection with past or current injecting drug use. Disclosure might also expose you to various forms of discrimination. Additionally, telling someone can result in rejection, making you feel even worse.

Hepatitis organisations and counsellors can be useful for helping you decide who you want to tell and can help you prepare for handling other people's questions and reactions.

For more information on telling someone, refer to the booklet *My Choice, My Rights* that is available from your local hepatitis organisation.



Should I tell health care workers?

People with hepatitis C don't have to tell health care workers that they have the virus. Many health services recommend that people inform health care workers of their hepatitis C antibody status, but there is no legal obligation to do so.

If a health care worker (this includes a dentist) is likely to come into contact with your blood as a result of treating you, that person should be taking standard precautions which reduces the risk of either you infecting them or them infecting you. 'Standard precautions' refers to the procedures for infection control. The assumption is made that all blood and body fluids are contaminated, and the following actions should be taken:

- Cover cuts and abrasions with waterproof dressings or bandaids.
- Wash hands before and after using a toilet or preparing food — and especially after contact with blood.
- Wear rubber or latex gloves when cleaning up blood spills.
- Use disposable materials such as paper towels when cleaning up blood spills and then dispose of the towels in sealed plastic bags in bins.
- Use full-strength bleach to clean surfaces where blood or body fluids have spilled.

Some health care workers might be judgmental, and treat you differently after they find out you have hepatitis C. For this reason, finding a good dentist, doctor and counsellor is important. Hepatitis C organisations, support groups and peer-based injecting drug user groups can help you find supportive health care workers.

For more information on telling someone, refer to the booklet *My Choice, My Rights* that is available from your local hepatitis organisation.

Health care workers with hepatitis C

The Communicable Diseases Network Australia currently advises that health care workers who have a positive Hepatitis C PCR test 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 hepatitis C status to their professional board. Following successful treatment (indicated by 2 negative hepatitis C PCR 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.

To protect your privacy, you can anonymously contact the services listed at the back of this booklet for advice.

Regardless of who you tell, talking with people about being infected with hepatitis C can be important for your health. People who understand will help you cope with having hepatitis C and the stress it can create. Support groups offer a safe space for discussing hepatitis C and working through any difficulties you are having. The groups listed at the back of this booklet provide understanding listeners, even if you just need to talk.

Members of the Australian Defence Force

If you are a member of the Australian Defence Force, you are required by Defence regulations to do so 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.

What if I am discriminated against?

With the possible exception of insurance and superannuation companies, it is against the law for anyone to discriminate against you because you have hepatitis C, nor can you be denied access to education, be refused accommodation or be fired because you have the virus. You are protected from this sort of discrimination under the *Commonwealth Disability Discrimination Act 1992*. Most states and territories have their own anti-discrimination legislation, too. The Commonwealth Act also guarantees your right to receive medical treatment.

If you feel you have been discriminated against, make notes immediately about what was said and what happened. This will help you prepare a formal complaint if you decide to do so. The services listed

in the back of this booklet can provide advice about what to do next.

For more information on telling someone, refer to the booklet *My Choice, My Rights* that is available from your local hepatitis organisation.

Counselling

It might be helpful for you to talk to a counsellor or doctor. It can be difficult to do this, but the difficulty itself can be discussed too. Counselling can help you understand your feelings about having hepatitis C; it can also help you decide who you should tell and what you can do to prevent further transmission of the virus.

You might also find it useful to talk to other people who have hepatitis C. The services listed at the back of this booklet can help you get in touch with people to talk with either anonymously on the phone, individually through counselling, or at a hepatitis C support group meeting. Most states and territories have telephone information and support services that offer free, confidential, non-judgmental information and support.

It is essential that you receive pre-test and post-test counselling. The aims of the pre-test session are to: provide information about the process of being tested; enable you to make a decision about being tested or not to be tested; obtain informed consent if you are going ahead with testing; provide psycho-social support and help reduce the risk of further transmission by providing up-to-date information.

The aims of the post-test session are to: discuss the meaning of the test result; provide information about treatment options if the results are positive

and how to maintain your health; provide psychosocial support and reinforce transmission prevention messages.

Hepatitis organisations and support groups can also recommend doctors and counsellors who are experienced in supporting people with hepatitis C and their partners, families and friends. Obtaining information and support can help sort things out.

Accurate information and emotional support are vital in assisting people to live with hepatitis C, so it just becomes part of your life, not the entire focus. Many people find peer-based support and professional counselling a valuable and transforming experience.

In each state and territory there are organisations that can provide support, assistance and information about all aspects of hepatitis C. Hepatitis organisations, hepatitis C support groups, peer-based injecting drug user groups, doctors, some government health services and other specialist organisations (such as those for people with haemophilia) provide information, counselling, assistance and support for the many people who have hepatitis C. Having support makes you realise you are not alone and helps you learn new approaches to living with hepatitis C.

Just talking to someone can make you feel a lot better about yourself and your situation, and help you get on with life.



Contacts

Hepatitis Australia

Hepatitis Australia was incorporated in 1997 as the peak community organisation to promote national action on matters of importance to people affected by hepatitis C. Our mission is to provide leadership and advocacy on viral hepatitis and to support partnerships for action to ensure that the needs of Australians affected by, or at risk of viral hepatitis are met. Our members are the eight state and territory hepatitis organisations.

T: 02 6232 4257
P: PO Box 716 Woden ACT 2606
E: admin@hepatitisaustralia.com
W: www.hepatitisaustralia.com

For more information on hepatitis C, contact the national infoline 1300 HEP ABC (1300 437 222). The national infoline diverts to information and support lines at your local state or territory hepatitis organisation.

State and territory hepatitis organisations

Hepatitis organisations developed in the states and territories in the early to mid-1990s, emerging from hepatitis C patient support groups. The organisations generally define their core business as providing information and support services to people affected by hepatitis (primarily hepatitis C) and supporting a reduction in hepatitis C transmission.

ACT Hepatitis Resource Centre

T: 1300 301 383
W: www.hepatitisresourcecentre.com.au

Hepatitis NSW

T: 02 9332 1853
E: hnsw@hep.org.au
W: www.hep.org.au

Hepatitis C Council of South Australia

T: 08 8362 8443 (office)
E: admin@hepcouncilsa.asn.au
W: www.hepcouncilsa.asn.au

Hepatitis C Victoria

T: 03 9380 4644
E: info@hepcvic.org.au
W: www.hepcvic.org.au

Hepatitis Council of Queensland

T: 07 3236 0610 or 1800 648 491
E: reception@hepqld.asn.au
W: www.hepqld.asn.au

HepatitisWA

T: 08 9227 9800
E: info@hepatitiswa.com.au
W: www.hepatitiswa.com.au

Northern Territory AIDS and Hepatitis Council

T: 08 8944 7777
E: info@ntahc.org.au
W: www.ntahc.org.au

Tasmanian Council on AIDS, Hepatitis and Related Diseases

T: 03 6234 1242
E: mail@tascahrd.org.au
W: www.tascahrd.org.au

Other national contacts

AIVL – the Australian Injecting and Illicit Drug Users’ League

The national organisation representing state and territory peer-based drug user groups

T: 02 6279 1600
W: www.aivl.org.au

Haemophilia Foundation Australia

The national organisation representing state and territory haemophilia foundations

T: 03 9885 7800
E: hfaust@haemophilia.org.au
W: www.haemophilia.org.au

Alcohol and other drug hotlines:

ACT 02 6207 9977
NSW 1800 422 599
QLD 1800 177 833
SA 1300 131 340
VIC 1800 888 236
WA 1800 653 203
NT 1800 131 350
TAS 1800 811 994

Hepatitis Australia Resources

Hepatitis Australia produces the following booklets that are available from your local hepatitis organisation or available for download from the website.

- *Women & Hepatitis C*
- *Living with Cirrhosis*
- *My Choice, My Rights: disclosure, anti-discrimination and health complaints information for people with hepatitis C*
- *Hepatitis C: treat it, beat it*
- *Hepatitis C: guide to healthy living*
- *Hepatitis B: What you need to know* in English, Arabic, Vietnamese, Chinese.

hepatitis
australia

Infoline: 1300 437 222