



Hepatitis C

Testing Information



Contents

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Acknowledgements

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Disclaimer

Hepatitis Australia takes care to ensure the information provided in this booklet is accurate, however, it is for general information only and not intended as medical advice. Hepatitis Australia encourages all readers to seek independent medical advice before making any decisions based on the information provided in this booklet.

Further information

For further information about hepatitis C please visit the Hepatitis Australia Website www.hepatitisaustralia.com or call the National Infoline 1300 437 222

Feedback

If you would like to provide feedback about the information contained in this booklet please email admin@hepatitisaustralia.com

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Introduction

- 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?

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 ++ end of the booklet; these organisations can help you find answers to questions not dealt with here.



If you are preparing for testing for hepatitis C, or if you have just found out you have hepatitis C, 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, have undergone tattooing or body piercing, have ever been in prison 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?



Hepatitis C: a snapshot

 **T**he 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, however, these antibodies do not provide any protection against reinfection. People who do not clear the virus will have ongoing, or chronic, infection.

At present there is no vaccine for hepatitis C.

Hepatitis C Treatment - The future's bright

Hepatitis C has for many years been treated with interferon and ribavirin and has significant side-effects. That is changing as new medicines become available. Before the end of the decade, we anticipate that at least 9 out of 10 people can be cured of hepatitis C by taking tablets (with very few side-effects) once a day for 12 weeks or less.

The journey towards this end goal commenced in 2013 with the first of the new hepatitis C treatments becoming available for people who have hepatitis C genotype 1 infection (boceprevir and telaprevir). This journey will continue as clinical trials finish and new medicines become available. Initially, interferon will remain an essential part of treatment for most people. In general the new combinations of medicines will be given over a much shorter period and will have far fewer side-effects than current treatments and also have the benefit of resulting in a cure for many more people including those with cirrhosis, co-infections and other health problems.

For the most up to date information on hepatitis C treatments available in Australia, talk to your specialist or call the Hepatitis Information Line on 1300 437 222.



A word about waiting for new hepatitis C treatments

It is easy to understand why you might prefer to wait for interferon-free treatments to become available. However, some people may be putting their health at risk if they wait too long for treatment. People with hepatitis C in Australia are getting older, and we know that liver disease speeds up the older you get. We also know that symptoms of liver disease may not be felt until the liver is significantly scarred.

To ensure you don't unknowingly put your health at risk by waiting too long for treatment, it is important that you visit your doctor to have a liver health assessment at least once a year. A liver health assessment involves a clinical examination and blood tests. Increasingly doctors are using Fibroscan® tests to assess the urgency for treatment. Similar to an ultrasound, the quick non-invasive test measures the level of liver scarring to determine the severity of liver disease. However, Fibroscan® is not available everywhere.



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 many years 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.

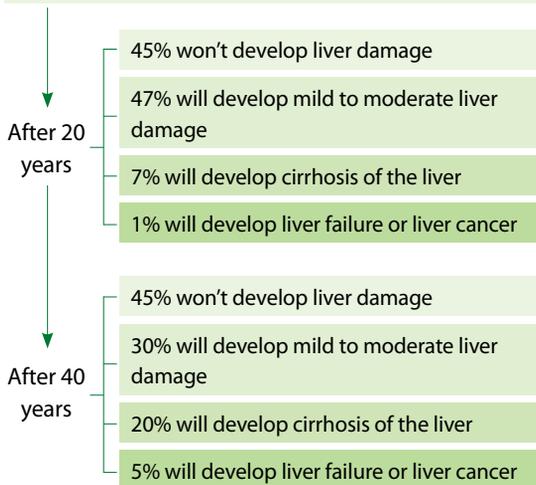
Individual experiences of hepatitis C can vary enormously. You might feel well, even though the damage to your liver is progressing. If you have hepatitis C and drink alcohol regularly, your chance of developing more serious liver damage, such as cirrhosis, is higher.

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 NSW Illness Outcomes Factsheet (2010)

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.

Because hepatitis C doesn't cause symptoms for many people who are infected, or causes non-specific symptoms, the advice to be tested is usually based on previous risk activities or exposure to blood-to-blood contact, rather than symptoms or illness.

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. If you have injected drugs, even just once, it is recommended that you are tested for hepatitis C.

Blood transfusions, blood products, organs and tissues

Some people with hepatitis C contracted the virus through blood transfusions, blood products, organ or tissue transplants 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.

If you received blood, blood products, or organ or tissue transplants before 1990 it is recommended you are tested for hepatitis C.

If you have received blood, blood products or organ or tissue transplants while in a developing country, you should consider testing for hepatitis C.

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.

If you have ever received a tattoo or other body art from an unlicensed operator (unsterile 'backyard' or prison tattoo), you should consider being tested for hepatitis C.

Prison

Because of the very high rates of hepatitis C in prisons, being, or having been in prison, is a risk factor for having hepatitis C.

If you have ever been in prison, it is recommended that you get a test for hepatitis C.

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

Hepatitis C is not considered a sexually transmissible infection and transmission through sexual activity is considered unlikely in the absence of blood.

Blood to blood contact may occur due to the presence of menstrual blood, skin grazes, sores, cuts, scratches or blisters in the genital, anal or mouth region. In these circumstances, the risk of hepatitis C transmission through sexual contact is increased.

Transmission of hepatitis C among men who have sex with men is an emerging issue and is associated with both unprotected sex and HIV infection co-infection. Some men with HIV choose not to practice safer sex when having sex with other HIV-positive men. These circumstances combine to create an increased risk for hepatitis C transmission.

Around 13% of people with HIV in Australia also have hepatitis C.

Testing is recommended for anyone who thinks they may have been exposed to the hepatitis C virus through sexual activity.

Pregnancy and childbirth

Estimates of the risk of transmission from a pregnant woman with hepatitis C to her baby vary and ranges between 2-5%. Most transmissions appear to occur around the time of birth although infection during pregnancy is also possible. The transmission risk is higher among women who also have HIV infection. If you have hepatitis C and are thinking of having a baby, or are already pregnant, it is recommended that you seek further advice from your doctor.

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.

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



Being 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. They will have a positive antibody test, but they do not have the virus. People who have been through treatment and have cleared the virus will also still test positive to the antibody test. 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.

A positive PCR viral detection test is a diagnosis of hepatitis C.

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 immuno-deficient (because of HIV infection, for example) or has been immuno-suppressed by drugs (as in organ transplantation), since immunosuppression 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.

Viral load results can be very high (even in the hundreds of millions), which is alarming for some

people. Viral load is most useful for predicting the timing of treatment and monitoring whether treatment is working for you.

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, and treatment is currently tailored according to genotype.

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 (ALT) 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.

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 and painless procedure that takes only a few minutes to perform.

Fibroscan®, as opposed to liver biopsy, is a more patient-friendly option. 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.

Liver biopsy

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 under local anaesthetic. It involves removing a tiny sample of your liver by inserting a thin needle into your upper abdominal region.

The IL28B gene test

The IL28B gene is involved in the immune response to certain viruses, including the hepatitis C virus (HCV). There are three IL28B subtypes: CC, CT and TT. People with the CC subtype have a stronger immune response to HCV infection than people with the CT or TT subtype and are more likely to be cured by using pegylated interferon and ribavirin treatment. Research is continuing to determine the impact of IL28B genotype on cure rates using new treatment regimens which include direct acting antivirals (DAAs).

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

If you are diagnosed with hepatitis C, you will most likely have many other questions. It is important to realise that you are not alone, and that information and support is available.

For example, information is available about how to monitor and look after your health, what to think about before disclosing your diagnosis to other people, precautions to minimise the risk of transmitting the virus to others, treatment options and accessing support.

Hepatitis Australia website www.hepatitisaustralia.com is a good place to start gathering information. If you have specific questions, please call the National Infoline: 1300 437 222. Please see the Contacts section for the details of your local hepatitis organisation and other organisations which may be useful.



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: National Information Line 1300 437 222
(HEP ABC)
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.

References

Australasian Society for HIV Medicine (2012), 2013 National HCV Testing Policy v1.0 <http://testingportal.ashm.org.au/hcv>

Department of Health and Ageing (2008), National Hepatitis C Resource Manual 2nd Edition. Canberra Australia

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 and supporting a reduction in hepatitis C transmission.

Hepatitis ACT

T: 02 6230 6344
E: info@hepatitisact.com.au
W: www.hepatitisact.com.au

Hepatitis NSW

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

Hepatitis SA

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

Hepatitis Victoria

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

Hepatitis Queensland

T: 07 3846 0020 or 1800 648 491
E: info@hepqld.asn.au
W: www.hepqld.asn.au

Hepatitis WA

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

