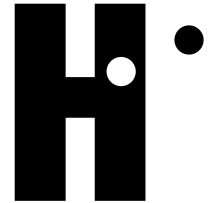


Hepatitis C: information for people with bleeding disorders - No. 1

February 2007



HAEMOPHILIA FOUNDATION AUSTRALIA

ABOUT HEPATITIS C

- Many people with bleeding disorders treated with plasma derived clotting factor concentrates before these products were inactivated for hepatitis C virus (HCV) were exposed to the virus
- Some people clear hepatitis C naturally from their blood, although they will still have HCV antibodies in their blood to show they have come in contact with hepatitis C
 - *To tell whether you still have hepatitis C virus in your blood, you would need to have a hepatitis C RNA PCR test*
- Other people go on to develop chronic hepatitis C, which can cause liver damage in some people
- There are 6 main genotypes (strains) of hepatitis C virus. Genotype 3 seems to respond better to treatment than genotype 1
 - *If you do not know your genotype and are interested in treatment, talk to your doctor about a HCV genotype test.*

LOOKING AFTER YOUR HEALTH

- Regular checks on your liver health if you have hepatitis C can help you to maintain or improve your health
- Even when you are feeling well there may be some damage occurring to your liver
 - *Speak to your Haemophilia Centre or hepatitis clinic about useful tests to check the health of your liver*
- Other things to do to look after your health
 - *Stress management*
 - *Have a healthy diet*
 - *Reduce the amount of alcohol you drink, or give up alcohol*
 - *Make sure you get enough rest or sleep*
 - *Consider complementary therapies.*

TREATMENT

- Current recommended medical treatment for hepatitis C is pegylated interferon and ribavirin. This has had much better results than earlier treatments. In Australia a number of people with bleeding disorders have cleared hepatitis C with treatment
- People who are co-infected with hepatitis C and HIV are encouraged to discuss treatment for their hepatitis C with their HIV specialist. This could help to prevent liver damage and to tolerate HIV drugs better
 - *If you have any questions about treatment, speak to your Haemophilia Centre or hepatitis clinic.*

AVOIDING PASSING ON HEPATITIS C

- Hepatitis C virus is carried in the blood. Reduce opportunities for other people to come in contact with your blood (see TRANSMISSION for more information)
- Health care workers should follow standard infection control procedures with all patients.

LIVING WITH HEPATITIS C

- You do not have to tell anyone about your hepatitis C unless you want to. Some circumstances require you to disclose, but you can avoid these situations if you wish
- It is against the law to discriminate against someone because they have hepatitis C
- If hepatitis C is preventing you from working, you may have entitlements regarding Centrelink payments, superannuation and disability insurance
 - *For more information, talk to your Haemophilia Social Worker/Counsellor or local Hepatitis C Council.*

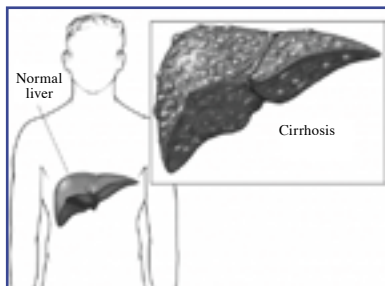
ABOUT HEPATITIS C

What is hepatitis C?

Hepatitis C is a virus carried in the blood that can affect the liver. Before scientists identified the virus in 1988, the hepatitis C virus (HCV) was known as one of the 'non-A non-B hepatitis viruses'.

Understanding hepatitis C

The liver cleans and purifies the blood supply, stores sugars, fats, vitamins and minerals, makes some chemical substances and breaks down others.



Chronic hepatitis can lead to cirrhosis in some people. Cirrhosis causes the liver to shrink, harden and scar.

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Why is hepatitis C relevant to people with bleeding disorders?

Many people treated with plasma derived clotting factor concentrates before these products were inactivated for HCV were exposed to the virus. During 1990 hepatitis C antibody testing became available and was used to test blood plasma in Australia. Plasma derived clotting factors currently in use are treated to eliminate hepatitis C. An antibody test shows if a person has come into contact with the hepatitis C virus. If so, their body will have produced antibodies to the virus, which are substances produced by the body's immune system to fight against the hepatitis C virus.

The number of people with bleeding disorders who have hepatitis C in Australia is not known. It is thought that up to 85-90% of people with haemophilia who had been treated with plasma derived blood clotting factor concentrates may have been exposed to HCV before the late 1980s. More specific information on this is currently being collected.

What might happen to someone with hepatitis C who also has a bleeding disorder?

Overseas studies have found that of 100 people with bleeding disorders

Around 20 may clear the hepatitis C virus from their blood naturally. This means they no longer have hepatitis C and cannot pass hepatitis C onto others, although their body still carries antibodies to the virus.

Around 80 may go on to develop chronic hepatitis C, which occurs when infection with hepatitis C lasts longer than 6 months. Chronic hepatitis C can cause liver damage in some people.

After 20 years without treatment, around 20% of this group may develop more serious liver disease.

Source: Posthouwer, 2006.

Symptoms of chronic hepatitis C may not become obvious for years after people have been infected with the virus, often around 10 to 15 years later. People with bleeding disorders, particularly haemophilia, are sometimes uncertain which symptoms are caused by haemophilia and which ones by hepatitis C. Discussing symptoms with your hepatitis specialist and your haematologist can be very helpful. Liver test results can tell you how much your liver has been affected by the virus and can explain some symptoms.

Common symptoms of hepatitis C are:

- Irritability, physical and mental tiredness
- Depression
- Abdominal pain and nausea
- Forgetfulness, poor concentration, sleep problems
- Joint pain, general body pain

These symptoms can vary in how severe or intense they are and how long they last. They may not be related to the degree of liver damage. Symptoms like these also occur in other health problems and they may not be caused by hepatitis C. Check any ongoing symptoms with your specialist.

How do I know if I have cleared hepatitis C?

Generally the first hepatitis C test people receive is a hepatitis C antibody test, which shows whether they have ever come into contact with the hepatitis C virus. Approximately 20% of people with bleeding disorders infected with hepatitis C may clear the virus from their blood naturally in the first 6 months.

To see whether you still have hepatitis C virus in your blood, you will need to have a hepatitis C RNA PCR test. This test looks for a particular part of the virus (“RNA”) and tells you if there is detectable virus actively multiplying in your blood. If your hepatitis C antibody test was positive and the hepatitis C RNA PCR test is also positive, you still have hepatitis C. If the hepatitis C RNA PCR test is repeatedly negative on at least two occasions, you no longer have hepatitis C virus in your blood and will not infect other people. If you are not sure whether you have had this test, ask your doctor or nurse where you receive your health care to check your medical record for you.

It is thought that a number of people with bleeding disorders who tested antibody positive for hepatitis C in the past have not had HCV RNA PCR testing to check whether they still have the virus. Haemophilia Centres around Australia are working with people who are hepatitis C antibody positive to encourage them to check their hepatitis C status and liver health.

What is a genotype?

The genotype is the type or strain of hepatitis C virus. There are 6 main types of hepatitis C virus. Some genotypes appear to respond better to treatment for hepatitis C than others. For example, people with genotypes 2 or 3 are more likely to have successful treatment than those with genotypes 1 or 4.

Do nearly all people with bleeding disorders have genotype 1?

This may not be the case. One study of people with haemophilia in Western Australia found that

- 65% had genotype 1
- 30% had genotype 3.

This is similar to the rest of the Australian community.

The Australian Bleeding Disorders Registry is collecting information about the genotypes of people with bleeding disorders and hepatitis C and this information will be available later in 2007.

If you do not know your genotype and you are interested in treatment for hepatitis C, talk to your doctor about a hepatitis C genotype test.

Hepatitis C co-infection with HIV and/or hepatitis B

Before HIV testing began in Australia in 1985, some blood products were contaminated with HIV. A number of people with bleeding disorders were infected with HIV and/or hepatitis B as well as hepatitis C from clotting factor products they used for treatment before 1985.

Why bother about hepatitis C if I also have HIV?

Over the last ten years new HIV treatments have greatly improved the health of many people living with HIV. This has meant that it has become more important to manage the hepatitis C of people who are co-infected with HIV:

- Liver damage may occur more rapidly in people who are co-infected with HIV and can lead to serious liver problems such as cirrhosis and liver cancer
- If they have liver damage, people who are co-infected may find it harder to tolerate their HIV drugs.

It is essential for people who are co-infected to work with their HIV specialist to consider the best individual treatment options for them.

Co-infection with hepatitis B and C can also cause liver disease to advance more rapidly. Vaccination against hepatitis B has meant that most people with bleeding disorders have not been co-infected with hepatitis B.

Why is monitoring important?

Regular checks on your health, particularly your liver health, when you have hepatitis C can help you make decisions about appropriate treatments and lifestyle changes. This can assist you to maintain or improve your health.

Tests

Even when you are feeling well, there may be some damage occurring to your liver. Routine blood tests, such as Liver Function Tests (LFTs) can help to show if there are any problems. If you would like to know more about these tests, your Haemophilia Centre or the hepatitis clinic will have plain language information sheets explaining them.

Your specialist may recommend an ultrasound of the surface of your liver or a liver biopsy to assess the state of your liver more accurately.

Ultrasound: a scan of the outside of your liver and the blood flow through your liver. It will help your doctor to assess the state of your liver but is not as thorough as a liver biopsy.

Liver biopsy: a procedure to remove a small amount of your liver. This part of your liver is assessed for any scarring (fibrosis) or inflammation in the liver tissue. Liver biopsies can cause complications in people with bleeding disorders. Transjugular liver biopsies are now recommended for people with bleeding disorders, as there is less chance of bleeding than with biopsies through the abdomen. A wire is guided through the jugular vein in the neck down to the liver and a small sample of liver tissue is taken.

The Australian Haemophilia Centre Directors' Organisation recommends that liver biopsies should only be carried out if the results are important to diagnosing whether there is any scarring or progressive liver disease or will make a difference to treatment options, and that factor replacement should be monitored at the Haemophilia Centre.

Questions for your doctor if a liver biopsy is recommended:

- Why do I need the biopsy?
- What will it show?
- How will it affect my treatment options?
- How will my bleeding disorder be managed?

Is there any treatment for hepatitis C?

Current recommended medical treatment for hepatitis C is pegylated interferon and ribavirin. These drugs work together to help your immune system to fight the virus in the blood. They can reduce the amount of virus in the blood and often clear it altogether. The treatment usually entails weekly injections of interferon and tablets of ribavirin taken twice a day. People starting treatment are taught how to inject the interferon.

Is the treatment better than it used to be?

Pegylated interferon and ribavirin treatment has had much better results than earlier hepatitis C treatments. The number of people in the general community with hepatitis C who have cleared the virus after treatment:

- Around 50% of people with genotype 1
- Around 80% of people with genotypes 2 or 3

Overseas studies of people with haemophilia show similar treatment results to these.

A number of people with bleeding disorders around Australia have cleared their hepatitis C with treatment.

Why think about treatment now if I'm young and well?

- It is currently thought that the earlier and younger that people have treatment, the more likely it is to be successful.
- Early treatment is also likely to prevent long-term problems, such as liver disease.

What if I have genotype 1, or my treatment failed, or I relapsed?

To improve treatment results for people with genotype 1, and other people whose treatment failed or who relapsed after treatment, hepatitis clinics are involved in a number of new clinical trials. Some trials, like the international CHARIOT study, have been studying the effect of different drug doses. Other new treatments are also being developed. Speak to your local hepatitis clinic for more information on clinical trials.

How much does it cost?

The Australian government currently pays most of the costs for pegylated interferon/ribavirin treatment for people meeting certain criteria under the Pharmaceutical Benefits Scheme S100 guidelines. You will be charged a pharmacy dispensing fee, which is less if you have a health card. Liver biopsy is no longer required for this scheme. However, the scheme is only available to people who have not had treatment before. There are re-treatment compassionate schemes that have been provided by the two major pharmaceutical companies involved in hepatitis C treatment. If you have been treated previously with interferon and wish to consider re-treatment, ask your hepatitis specialist about these programs.

Who can help me with decisions about treatment?

Talk to the specialist providing your hepatitis care about any questions you have relating to treatment.

Some questions to consider:

- What is the treatment? How does it work?
- How likely is this treatment to be successful for me?
- How long will I have to take the treatment for?
- Will I need to take any special precautions to have treatment, eg contraception?
- What sort of support will I need?
- What kinds of side effects are likely?
- How will treatment affect my ability to work?
- What are my options if I don't have treatment at this point?

You may also find it useful to talk over your decision with the hepatitis nurse or the Haemophilia Social Worker/Counsellor.

What about treatment if I am co-infected with HIV or hepatitis B?

Hepatitis C treatment has been successful for many people with bleeding disorders co-infected with hepatitis C and HIV. However, it is not generally as successful as for people who only have hepatitis C. This can depend on your current level of liver damage, CD4 count, HCV viral load and HCV genotype. Speak to your HIV physician or your specialist for further advice about this.

Treatment for hepatitis B/HCV co-infection can be more complex due to drug resistance issues. At present Australian doctors specialising in the treatment of people with co-infection are working on these issues and looking at combination therapy options.

What about side-effects?

Side-effects of pegylated interferon/ribavirin treatment are similar to previous interferon/ribavirin treatments, but sometimes easier to tolerate. There have also been improvements in the management of side-effects. These can vary for each person and may include: feeling like you have the flu, tiredness, loss of appetite, insomnia, nausea, hair thinning, depression and mood swings.

What else can I do to look after my health?

Many people with hepatitis C find that improving their general health and well-being helps them to manage their hepatitis C better. This includes:

- Stress management – relaxation/meditation, exercise, massage, acupuncture, taking up a hobby or getting a pet
- Having a healthy diet
- Reducing the amount of alcohol you drink, or giving up alcohol. Heavy alcohol drinking with hepatitis C can make liver damage happen more quickly
- Making sure you get enough rest or sleep

If you want to talk to someone about stress management or concerns about sleep, ask your doctor for a referral to an occupational therapist.

You may also choose to consider complementary therapies alongside, or instead of, medical treatment. Therapies to treat hepatitis C and its symptoms include:

- Western herbal medicine
- Traditional Chinese medicine
- Ayurvedic medicine
- Homeopathy
- Aromatherapy
- Acupuncture
- Various forms of massage.

If you are interested in these therapies make sure you consult a practitioner who is qualified and registered by their professional organisation and who understands hepatitis C. For more information on local practitioners, contact your state/territory Hepatitis C Council.

TRANSMISSION

How can I prevent transmission of hepatitis C?

Hepatitis C virus is carried in blood. To spread hepatitis C, the blood of a person who has hepatitis C must enter the bloodstream of another person.

Preventing infection - Standard hygiene precautions

These precautions should be followed in every household or workplace whether people have hepatitis C or not:

- Where you can, clean up your own blood accidents. Wear disposable gloves when you clean up other people's blood accidents. Wipe up blood with paper towels, then scrub the area with good quality detergent or bleach and cold water
- Cover any cuts, abrasions or wounds with waterproof dressings
- Don't share personal toiletry items like toothbrushes, razors, tweezers, nail files, nail scissors or anything else that could puncture skin and carry small amounts of blood
- Put bloodstained personal items such as bandaids, tampons, sanitary napkins and dressings inside two plastic bags and then in the rubbish bin.

What about sex?

The risk of passing on hepatitis C during sex is very small. Studies of long-term heterosexual partners of people with haemophilia have shown very little transmission of hepatitis C from one partner to another, so it is usually recommended that long-term partners do not need to change their practices. If you are starting a new relationship it is advisable to follow safe sex practices, eg using a condom, to protect both partners against sexually transmissible infections such as herpes.

Pregnancy

The risk of passing hepatitis C on from mother to baby during pregnancy is very low, about 5 per cent. Transmission during breastfeeding is very rare, but it is recommended that breast milk be discarded when nipples are cracked and bleeding.

Hepatitis C prevention messages for all Australians:

- Health care workers should follow standard infection control procedures with all patients
- Injecting drug equipment should not be shared
- If you get a tattoo, make sure the tattooist doesn't reuse needles, dye and dye tubs and uses new disposable gloves for each client
- Follow the 'blood rules' in sport (leave the ground when bleeding, stop the bleeding, dress the wound, clean up the blood, use gloves to handle blood)

If you have any questions about transmitting hepatitis C, speak to your doctor.

Telling people about hepatitis C

Many people with bleeding disorders have already had to think about disclosing their hepatitis C status. If you have hepatitis C, consider who you want to tell, how you want to tell them and when you will tell them. You may wish to give them some printed information to read.

You do not have to tell anyone about your hepatitis C unless you want to.

You may be required to disclose your status in some circumstances, but you can choose to avoid these situations if you wish. These include:

- Donating blood or body parts
- Working in the armed forces
- Performing exposure prone procedures if you are a health care worker
- Applying for health or life insurance, if the question is asked.

Some pre-employment forms ask questions about your health. You do not have to answer any questions about hepatitis C, treatments you have had, or time that you have had to take off previous jobs due to your health unless it is necessary to determine if you can do the essential requirements of the particular job.

You are not required to tell health care professionals that you have hepatitis C as they should all be following standard infection control guidelines. However, you may decide to tell them about your hepatitis C status as this could help them to provide better care, eg monitor dry mouth, check that medications will not harm your liver.

If you are beginning a new relationship, the decision if, when and how to tell your new partner about your hepatitis C status may require some thought, particularly if you are also telling them about your bleeding disorder.

If you would like to talk over these issues or get more information, it may be useful to speak to your Haemophilia Social Worker/Counsellor. You can also contact your local Hepatitis C Council

For more information about disclosure, read

- *My choice to tell* (Australian Hepatitis Council) www.hepatitisaustralia.com/PDFs/MYCHOIC1.PDF
- *Who do I tell about my hepatitis C?* (E&RC, The Alfred) www.hivhepsti.info/fs/hepcnewdiag_tell.pdf

Discrimination

Some people with bleeding disorders have experienced stigma and discrimination relating to their hepatitis C. Being treated unfairly because you have hepatitis C can occur at work, at clubs, at school or university and in health care settings. It can also happen among family and friends.

Everyone has the right to be treated fairly and with respect. It is against the law to discriminate against a person because they have hepatitis C. If you believe you are experiencing discrimination, you can get advice on what to do about it from your Haemophilia Social Worker/Counsellor or your local Hepatitis C Council.

For more information about discrimination, read *My rights* (Australian Hepatitis Council) www.hepatitisaustralia.com/PDFs/MYRIGHT1.PDF

Financial issues

Some people with bleeding disorders and hepatitis C find that their ability to work or work full-time is affected by hepatitis C symptoms like fatigue or pain, or treatment side-effects. If this happens to you, you and/or your carer may be able to get Centrelink payments, eg Disability Support Pension, Sickness Benefit, Carer's Pension.

There is more information about Centrelink payments on the Centrelink web site: www.centrelink.gov.au.

If hepatitis C is preventing you from working, you may also find it valuable to find out your entitlements regarding superannuation and disability insurance.

Speak to your Haemophilia Social Worker/Counsellor for more information.

MORE INFORMATION

Hepatitis C

Hepatitis Councils are important sources of up-to-date information about hepatitis C for Australians. They also provide valuable advocacy and support services, particularly for people who have experienced discrimination relating to their hepatitis C.

Australian Hepatitis Council (www.hepatitisaustralia.com) – phone 02 6232 4257

ACT Hepatitis C Council (www.acthepc.org) – phone 02 6257 2911

Hepatitis C Council of NSW (www.hepatitisc.org.au) – phone 9332 1599
(Sydney) / 1800 803 990 (NSW country callers)

Northern Territory AIDS and Hepatitis Council (www.ntahc.org.au) – phone (08) 8941 1711

Hepatitis Council of Queensland (www.hepatitisc.asn.au) – phone 07 3236 0612 (Brisbane)
/ 1800 648 491 (Qld country callers)

Hepatitis C Council of South Australia (www.hepcouncilsa.asn.au) – phone 08 8362 8443
(Adelaide) / 1800 021 133 (SA country callers)

Tasmanian Council on AIDS, Hepatitis and Related Diseases (TASCAHRD)
(www.tascahrd.org.au) – phone 03 6234 1242 (Hobart) / 1800 005 900 (Tas country callers)

Hepatitis C Council of Victoria (www.hepcvic.org.au) – phone 03 9380 4644 (Melbourne)
/ 1800 703 003 (Vic country callers)

Hepatitis Council of Western Australia (www.hepatitiswa.com.au) - phone 08 9227 8538
(Perth) / 1800 800 070 (WA country callers)

Hepatitis C and bleeding disorders

For more information, support or counselling about hepatitis C and bleeding disorders, contact your local Haemophilia Centre. The staff there will be able to link you to the Haemophilia Social Worker/Counsellor, and/or specialised hepatitis services in your area, and will direct you to other relevant information.

- ACT** - The Canberra Hospital, Haemophilia Centre - phone 02 6244 2188/2286
NSW - Newcastle: Mater Misericordiae Hospital, Haemophilia Centre - phone 02 4921 1240
Sydney: Royal Prince Alfred Hospital, Haemophilia Centre - phone 02 9515 7013
NT - Darwin: Royal Darwin Hospital - phone 08 8922 8888
QLD - Royal Brisbane & Women's Hospital, Queensland Haemophilia Centre -
phone 07 3636 5727 / 8760
SA - Royal Adelaide Hospital, Haematology Day Centre - phone 08 8222 4308 / 5632
TAS - Royal Hobart Hospital, Paediatric Ambulatory Care Unit - phone 03 6222 8045
VIC - Melbourne: The Alfred, Ronald Sawers Haemophilia Centre - phone 03 9076 2178
WA - Royal Perth Hospital, Haemophilia Centre - phone 08 9224 2937 / 2897
Fremantle Hospital - phone 08 9431 2210 / 2886

Web sites - See the Hepatitis C section on the HFA web site to link to the latest information on hepatitis C - www.haemophilia.org.au

Acknowledgements

Some of the information in this fact sheet has been adapted with permission from:

Contact: post-test information for hepatitis C (Australian Hepatitis Council)

Newly diagnosed with hepatitis C? (HIV, Hepatitis & STI Education & Resource Centre, The Alfred, Melbourne)

What do you know about treatment for hepatitis C? (Sandy Breit, Hepatitis C Counsellor, Haemophilia Foundation Victoria)

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Produced by

Haemophilia Foundation Australia

1624 High Street Glen Iris Victoria Australia 3146

Telephone: (03) 9885 7800 Fax: (03) 9885 1800

Email: hfaust@haemophilia.org.au Website: www.haemophilia.org.au

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