

healthmonitor





Date started: / /

If found please return to:

Doctor's Name:

.....

Address:

.....

Phone:

Or

Australian Hepatitis Council
PO Box 357
Curtin ACT 2605

Acknowledgements

The *Health Monitor* is published by the Australian Hepatitis Council and is funded by the Commonwealth Department of Health and Ageing. It has been developed in conjunction with State and Territory Hepatitis C Councils, people with hepatitis C and liver clinic nurses.

The *Health Monitor* is based upon the *Health Record*, produced by the Hepatitis C Council of Western Australia for the Hepatitis C Shared Care Project, funded by the Western Australian Sexual Health Program.

For additional copies of this resource, or more information about hepatitis C, contact your State or Territory Hepatitis C Council (see 'Information and support services' on page 56).

Design by Design Direction, Deakin ACT.

© Commonwealth of Australia 2001.

Contents

using the health monitor 1

my details 3

My contact directory 5

my health records 9

Personal health targets 9

My appointments 12

Monitoring therapies and
medications 19

Side effects and symptoms diary 24

My test results 37

health information 41

Keeping healthy 41

Tests 45

Treatments and therapies 49

Side effects of therapy 53

information and support 55

Information for my general
practitioner, specialist and health
professionals 55

Information and support services 56

Common terms 62



The Health Monitor aims to help people with hepatitis C achieve and maintain good health and develop useful relationships with health care workers.

What is health monitoring?

Health monitoring means regularly observing and recording details about your health. For people with hepatitis C, monitoring your health can mean having routine check-ups with your general practitioner (GP), specialist or other health care worker, and recording the results of the check-ups and services provided.

Health monitoring also involves monitoring parts of your lifestyle that can affect your health and well being, such as diet and exercise.

Why monitor my health?

Keeping a record of your health can help you make better health care decisions.

The Health Monitor can help GPs, specialists and other health care workers participate in shared care arrangements (see Common terms on page 62) for people with hepatitis C. Talk to the Hepatitis C Council in your State or Territory about shared care programs.

If you visit your GP or other health care worker regularly, you can discuss any concerns that have arisen since your last visit, have a general check-up, and monitor the health of your liver.

Being aware of the choices you make in your life can make you more conscious of behaviours you



would like to change, such as reducing your alcohol intake or improving your diet. Maintaining a healthy lifestyle can reduce some of the symptoms related to chronic hepatitis C, as well as some hepatitis C treatment side effects. It can also help your immune system 'fight' disease.

Keeping a health record

Take the Health Monitor with you each time you visit a health worker. The information you record in this book is for your personal use and is not an official medical record.

Wherever you see this symbol you can record your personal health information.

Use the Health Monitor to record:

- contact details of health care workers
- information about allergies, vaccinations and other personal health details
- personal health goals
- test results
- your appointments and things to remember
- medications, treatments and therapies you are using
- symptoms or side effects you experience.



Initials.....

Date of birth.....

Private health insurance policy number

.....

Blood type.....

Allergies/cautions.....

.....

.....

.....

.....

.....

GP Patient number(s).....

.....

Hospital file number.....

.....

In case of an emergency, please contact

1.....

Ph: (h).....(w).....

Mob:.....

2.....

Ph: (h).....(w).....

Mob:.....



Vaccinations	Date course completed
Hepatitis A	
Hepatitis B	
Tetanus	
Other	

Current medications.....
.....
.....
.....

Contraception.....
Family medical history details.....
.....
.....
.....

Other relevant information (eg Medicare number)
.....
.....
.....

My contact directory



General Practitioner(s)

1 Name:

Address:

.....

Ph:..... Fax:.....

Email:.....

2 Name:

Address:

.....

Ph:..... Fax:.....

Email:.....

Pharmacist(s)

1 Name:

Address:

.....

Ph:..... Fax:.....

Email:.....

2 Name:

Address:

.....

Ph:..... Fax:.....

Email:.....



Specialists/Hospitals

Hospital 1

Specialist:

Ph:.....Fax:.....

Email:.....

Nurse:.....

Ph:.....Fax:.....

Email:.....

Hospital 2

Specialist:

Ph:.....Fax:.....

Email:.....

Nurse:.....

Ph:.....Fax:.....

Email:.....

Hepatitis C Council

Contacts:

Street address:.....

.....

Postal address:

.....

Ph:.....Fax:.....

Email:.....



Dietitian

Name:

Address:

.....

Ph:..... Fax:.....

Email:.....

Complementary therapist

Name:

Address:

.....

Ph:..... Fax:.....

Email:.....

Shared care coordinator

Name:

Address:

.....

Ph:..... Fax:.....

Email:.....



Other

Other useful contacts may include counsellors, psychologists, dentists, researchers, physiotherapists or other people that have been recommended to you.

Name	Address	Telephone	Fax	Email

Personal health targets

Setting health targets, or goals, can help you improve your health and well-being. Health targets include reducing the amount of alcohol you drink, reducing the number of cigarettes you smoke, making changes to your diet or making time for regular exercise.

Use the table on the following pages to record goals or personal targets.

Set realistic targets. You can ask your GP, health care worker or a friend to help set targets and work out how to reach them. If you set goals that are too difficult, you may give up and revert to your old habits.

If you don't meet the targets you set, don't give up hope – maybe your targets were too hard, or maybe you need a bit more practice and support.

Tips for using the Health Targets table

- The standards included to measure your health behaviours are provided as a guide and can be changed to suit your own needs. For example, you may wish to adapt the standard used for exercise from minutes per week to minutes per day if you already exercise on a daily basis.
- Use a pencil to make entries so that you can erase outdated entries and revise your targets as needed.
- Insert the date each time you make an entry to monitor your progress.



Health targets

Health behaviour	Current level	Date	Health care worker's advice	My target/goal	Change or goal achieved	Date achieved
Alcohol <i>Number of standard drinks consumed each week</i>						
Smoking <i>Number smoked each day</i>						
Exercise <i>Type of exercise in minutes each week</i>						
Weight <i>Kilograms</i>						



Health targets

Health behaviour	Current level	Date	Health care worker's advice	My target/ goal	Change or goal achieved	Date achieved
Stress reduction <i>Number of times participated in stress reducing activities per week, eg: counselling, yoga, meditation</i>						
Diet <i>Increasing the number of vegetables consumed to 3-5 serves per day or reducing fat intake to about 35g per day</i>						
Others <i>Contact a Hepatitis C Council to join support group and receive latest news and information</i>						

Making the most of your appointments

- Take the *Health Monitor* with you to your appointments.
- When making appointments, let the receptionist know that you will need extra time if you have questions to ask the GP or health care worker. Be specific; ask for a 15 or 30-minute appointment.
- If your appointment is finished and you still have questions, make another appointment, or ask if the GP or health care worker can phone you later to answer your remaining questions.
- Take a friend, family member, or 'patient advocate' with you to the appointments. Some Hepatitis C

Councils have 'patient advocates' that can attend appointments with you. When making your appointment, ask the receptionist to let your GP know that you will be bringing a support person to the appointment.

- If you don't understand what the health care worker has told you, ask them to repeat the information – it is their responsibility to make sure you understand what they are saying.
- Make sure that your GP and other health care workers know about all the medications you are taking. This includes prescription and over-the-counter medicines, dietary supplements such as vitamins and herbs, and other drugs.

Monitoring therapies and medications

Recording the medications and therapies you use and telling your GP and specialist what you are taking, can reduce the possibility of being prescribed medications that could have dangerous results.


Make sure you give your GP and specialist details of your medical history and everything you are taking, including over-the-counter and prescription medications, complementary and alternative therapies, or dietary supplements.



Record any symptoms or side effects you experience in this diary. It can help you identify the causes of your symptoms and side effects, predict health problems, and check your response to treatment. Take this information with you when visiting health care workers.

Side effects and symptoms diary

Space provided for 52 entries – pages 24 to 35

Day/date	Current treatment regime	Symptoms of hepatitis C (refer to page 36)	
Tuesday 14/5/01	Ribavirin daily and interferon on Mondays, Wednesdays and Fridays	Very tired	



➤	Side effects (of treatment)	Frequency	Severity rating (1 low - 10 high)	Action taken
	Nausea and stomach cramps	In 'waves', every 5-10 minutes	6	Rest and peppermint tea



➤	Side effects (of treatment)	Frequency	Severity rating (1 low - 10 high)	Action taken



➤	Side effects (of treatment)	Frequency	Severity rating (1 low - 10 high)	Action taken



Side effects (of treatment)

Frequency

**Severity rating
(1 low - 10 high)**

Action taken

Side effects (of treatment)	Frequency	Severity rating (1 low - 10 high)	Action taken



Side effects (of treatment)

Frequency

Severity rating
(1 low - 10 high)

Action taken

Side effects (of treatment)	Frequency	Severity rating (1 low - 10 high)	Action taken



Side effects (of treatment)

Frequency

**Severity rating
(1 low - 10 high)**

Action taken

Side effects (of treatment)	Frequency	Severity rating (1 low - 10 high)	Action taken

Symptoms of hepatitis C

Only five per cent of people who get hepatitis C will experience any signs or symptoms. When first infected, you may experience a flu-like illness. Some people develop nausea, abdominal and back pain, and extreme tiredness. Most people will not be aware that their liver is not working properly until hepatitis C has developed into a chronic illness.

Symptoms of chronic infection can range from mild to severe. They can occur occasionally or can be continuous. The most common symptoms are:

- fatigue or tiredness
- lethargy
- nausea
- discomfort in the abdominal region
- feeling ill after you drink alcohol or eat fatty foods

Note that some of these symptoms can also be caused from the side effects to treatment. It may be difficult to decide which is a symptom and which is a side effect. Keeping a diary of your symptoms of hepatitis C and side effects of treatment may help you 'map' your response to treatment.



My test results

The following tests are often ordered before your GP refers you to a specialist. Your GP may not need to order all of these tests. Depending on the test results, you may be referred to a gastroenterologist, hepatologist or other specialist for further treatment (see page 45).

Recommended tests before referral to a specialist	Why	Results
Full blood count, including platelets (FBC)	To detect anaemia and rule out other conditions.	
Alpha fetoprotein (AFP)	To detect liver cancer.	



Recommended tests before referral to a specialist	Why	Results
HIV, hepatitis A and hepatitis B screening (pre-test counselling should be provided by your GP whenever you have a HIV test)	<p>Determines whether you have been infected with HIV or hepatitis A or B.</p> <p>Having hepatitis C and contracting hepatitis A or B can result in severe liver damage. It is suggested that people with hepatitis C be vaccinated against hepatitis A and B.</p>	
Prothrombin times/coags	<p>This test checks liver function by testing the efficiency of blood clotting. When the liver is damaged, it may not produce enough blood clotting factors.</p>	



Recommended tests before referral to a specialist	Why	Results
Ferritin/transferrin saturation	Iron studies to exclude haemochromatosis <i>(see Common terms)</i> .	
Liver and biliary tree ultrasound	To assess the anatomy and appearance of the liver.	
Thyroid function tests (TFTs)	To provide baseline measures to assess thyroid function, which can be affected during treatment.	



Other tests

Test	Date of test	Result due	Results

Hepatitis C – a snapshot

Hepatitis C is transmitted by blood to blood contact. Blood containing hepatitis C must enter the bloodstream of another person for transmission to take place. Even the smallest amounts of blood can transmit hepatitis C.

Transmission can occur by contact through:

- sharing injecting drug equipment
- unsafe tattooing, body piercing and skin penetration procedures
- pregnancy and childbirth
- household practices (such as sharing razor blades and toothbrushes)

- occupational procedures (eg, needlestick and sharps injuries)
- certain sexual activity.

Keeping healthy

Diet and nutrition

A well-balanced diet provides you with many benefits, including:

- energy
- boosts your immune system
- helps you keep a healthy weight
- reduces the risk of developing heart disease and some cancers.

People with hepatitis C can follow the same healthy eating guidelines that are recommended for the general population. However, if you have liver disease (such as cirrhosis), your specialist should provide you with specific dietary advice.

Some people with hepatitis C, including those on treatment, experience nausea and diarrhoea which can lead to malnutrition. If this happens to you, you may need to see a dietitian.

Alcohol and other drugs

There is a higher risk of developing liver disease, including cirrhosis, if you have hepatitis C and drink alcohol - although it is unclear how much alcohol puts you at higher risk. Alcohol is also likely to affect your response to treatment, making treatment less effective.

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

To reduce your alcohol intake:

- set a limit, such as two standard drinks per day
- switch to low alcohol or alcohol-free drinks
- avoid situations where there is pressure to drink, such as drinking in rounds
- mix beer or stout with lemonade
- mix wine with mineral water
- alternate a non-alcoholic drink with an alcoholic one
- aim to have one or two alcohol-free days each week.

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

Smoking

Smoking causes many health problems including heart disease, strokes and cancer. If you smoke, try to cut down or give up completely. To quit smoking, you need to prepare yourself and plan strategies to cope with any physical or psychological symptoms that you might experience. Call the National QUIT line on 131 848 for further assistance and support. Talk to your GP or pharmacist about other treatments that can help you to stop smoking (such as nicotine replacement therapy).

Illicit drug use

All drugs have potential to put stress on your liver and can bring on a range of health problems.

Injecting unsafely increases your chance of developing infections such as chronic gingivitis, bacterial endocarditis (an infection of the heart valves), blood-borne viruses and skin infections. If you inject drugs and share equipment, you risk being infected with another strain (genotype) of hepatitis C in addition to your existing infection, or becoming re-infected with hepatitis C if you have cleared the virus.

If you inject drugs, use new injecting equipment each time and avoid sharing needles, syringes, swabs, filters, spoons, water, utensils and tourniquets. You can get

sterile needle and syringes from needle and syringe programs and many pharmacies. Information about these programs can be obtained from Hepatitis C Councils or peer-based user groups in your State or Territory.

Exercise

Exercising regularly can give you an overall sense of well-being and improve your quality of life. Any exercise is helpful. You don't have to go to the gym or engage in strenuous activity to exercise – activities like gardening, walking, swimming and yoga help to keep you healthy.

Managing stress

Everybody lives with stress. If you are stressed for long periods, you may feel as though you are losing control over situations. This can bring about physical symptoms such as fatigue, excessive perspiration and high blood pressure.

Regular exercise, adequate sleep, relaxation and rest will help you deal with stress. Some people manage their stress through counselling, meditation, yoga or massage. Talk to your Hepatitis C Council and health care worker about strategies to help deal with stress.



Tests

Some of the different blood tests used to monitor your health if you have hepatitis C are described below.

Polymerase Chain Reaction (PCR) test

PCR tests for the presence of the virus and can determine whether or not you have hepatitis C. A PCR test can also be used if your antibody test is unclear and is useful to monitor treatment progress. PCR results need to be looked at with other test results and clinical signs.

Other PCR tests can measure the amount of virus in your blood (viral load) and the type of hepatitis C strain (or genotype).

Liver function tests

A profile of your liver's health is built through results of liver function tests done over time, from biopsies and the physical signs and symptoms of liver disease.

The most common test for people with hepatitis C to monitor their health is the Liver Function Test (LFT). This blood test measures the levels of chemicals (called enzymes) in your blood stream and the function of your liver. These enzymes leak out of inflamed or damaged liver cells and high levels usually indicate some kind of liver damage. Bilirubin, albumin, protein and coagulation studies also measure liver function.

Liver function tests, by themselves, will not identify liver damage and it is possible for a blood test to show that you have normal liver enzymes, but you may still have liver damage.

It is a good idea to have a regular pattern of liver function tests. Keeping a record of your results in the *Health Monitor* and taking photocopies of your results, will help if you need to see a different GP or specialist.

Alanine aminotransferase (ALT)

For people with hepatitis C, the enzyme ALT is the most relevant enzyme measured by a liver function test. ALT is an enzyme in the liver that can leak out into your blood when liver cells are inflamed.

Aspartate aminotransferase (AST)

AST is found in a variety of body tissues, including the liver. In people with hepatitis C, AST levels are usually elevated, along with ALT levels.

GGT or GGTP (Gamma, glutamyl transpeptidase)

This enzyme is made in bile duct cells and this test can be used to assess biliary disease (see *Common terms*). Viral hepatitis, liver disease, alcohol and drugs can increase GGT levels.

Bilirubin

Bilirubin is formed from the breakdown of a substance in red blood cells called 'haeme' and is normally processed by the liver. It is the main bile pigment responsible for the yellowing associated with jaundice. Elevated levels of this substance can indicate obstructed bile ducts, anaemia, liver disease and other diseases.

Protein (protein, albumin, globulin)

The liver forms and releases a variety of proteins including albumin, total protein (combined measure of proteins in the blood) and blood clotting factors. This test, along with others, can help to confirm blood disorders, gastrointestinal disorders, kidney disorders, liver disease, protein deficiency and tumours.

Liver biopsy

A liver biopsy involves collecting a small sample of tissue from the liver by passing a thin needle through the rib cage. The sample is examined for signs of inflammation or new or old damage. This helps identify the cause of any liver disease, assess its severity and the rate at which disease is progressing.

Information from the biopsy is used to inform the best treatment for your condition. The biopsy can be done in a day clinic at a hospital.

Blood Ferritin

Blood Ferritin is used to screen for iron deficiency, storage and overload.

Thyroid tests

Chronic hepatitis C is associated with some autoimmune diseases, where a person develops antibodies that attack parts of the body's own tissue. About one-tenth of people with chronic hepatitis C infection have antibodies to the thyroid gland and one-half of these people may develop

hypothyroidism (an under-active thyroid gland). This condition develops more often in women and older people.

Interferon therapy sometimes causes hypothyroidism or hyperthyroidism (over or under-active thyroid gland) in about one-tenth of those treated. There is also a slight risk of other autoimmune problems developing during treatment such as lupus, rheumatoid arthritis and some heart problems.

Ask your GP to test you for potential autoimmune problems before beginning treatment.



Treatments and therapies

Current treatments for hepatitis C include conventional treatment, such as interferon monotherapy and interferon ribavirin combination therapy. Other treatments include complementary and alternative therapies, such as Traditional Chinese Medicine (refer page 52).

Combination therapy is the preferred form of clinical treatment, but individual treatment options vary and you should check with your doctor or specialist about which form of treatment is best for you.

Conventional treatments

Conventional treatment refers to the use of mainstream medical services and pharmaceutical drugs to treat a condition.

Two treatments for hepatitis C have been authorised by the government for use in Australia: interferon as monotherapy, or interferon and ribavirin as combination therapy.

Conventional treatments aim to eliminate the virus, to prevent chronic hepatitis C infection progressing to cirrhosis or liver failure or reduce the symptoms related to chronic infection.

Interferon



Interferons are natural proteins produced by the human body to help defend itself against viral infection. They interfere with the ability of the hepatitis C virus to copy itself and spread throughout the body.

The interferon used in the treatment of hepatitis C is a synthetic compound almost identical to the natural one. Studies have shown that large doses of this synthetic compound can boost the body's immune system, and slow down or stop the progression of liver disease caused by hepatitis C.

MONOTHERAPY

Monotherapy means using one drug to treat a disease. For people with hepatitis C, it refers to the use of interferon on its own to treat hepatitis C.

COMBINATION THERAPY

Combination therapy means using more than one drug to treat a disease. For people with hepatitis C, this means using interferon and ribavirin together to treat hepatitis C. This is now the treatment of choice for people with hepatitis C as it is proven to be more effective than monotherapy.

However, monotherapy remains an option for people with hepatitis C who may be unable to take ribavirin.

Ribavirin

Ribavirin is an antiviral drug, which has been used successfully to treat other viruses, but is ineffective as a sole treatment for hepatitis C.

It is not known exactly how ribavirin works in the treatment of hepatitis C. While it brings down the level of liver enzymes, it has little or no effect on hepatitis C viral load, and liver enzyme levels will often go back up within weeks of stopping ribavirin. The combination of ribavirin with interferon results in a better treatment response than with either drug used on its own.

Ribavirin is manufactured as a capsule or tablet and is taken orally.

Interferon and ribavirin are packaged together for combination treatment. Using combination therapy involves self-administered interferon injections (three times a week) and ribavirin capsules (twice a day) for either six or 12 months. The length of treatment varies depending on your tolerance, response to the treatment and your genotype (the strain of virus).

If you are thinking of using mono or combination therapy, your GP can provide an initial assessment and refer you to your nearest treatment centre, usually located within a hepatitis clinic at a major hospital. Here a specialist will assess your options for treatment. This assessment will be based on certain criteria and the results of various tests (mentioned on page 45).

Pegylated interferon

Pegylated interferon is a modified form of the standard synthetic interferon used in the treatment of hepatitis C. The addition of a molecule to the standard interferon results in a significant change to the action of the drug. By attaching this molecule, it allows the interferon's antiviral activity to last over a longer time. This means the interferon only needs to be injected once a week instead of three times a week.

The slower clearance rate of pegylated interferon from the body provides a more constant level of interferon circulating in the blood.

The effectiveness of pegylated interferon for people with hepatitis C is still being studied. Pegylated interferon is currently only available in Australia through clinical trials and a compassionate access scheme.

Complementary and alternative therapies

Many people with hepatitis C use complementary and alternative therapies (or natural therapies), dietary supplements or Traditional Chinese Medicine. These aim to help manage the symptoms of hepatitis C infection and/or side effects of conventional treatment.

Complementary and alternative therapies can include holistic therapies, massage and touch therapies, acupuncture, yoga, Tai Chi, Qi Gong, meditation, herbal therapies, vitamin and dietary supplements, and aromatherapy. Qualified and registered practitioners such as nutritionists, dietitians, naturopaths, acupuncturists and herbalists provide alternative therapies and/or dietary supplement regimes.

It is important to consult your GP, specialist (if you have one) and a qualified practitioner of complementary or alternative therapies to obtain more information before starting any of these therapies. Hepatitis C Councils will also have information about these therapies.

Side effects of therapy

Side effects of interferon

Some people report no side effects, while others may have flu-like symptoms, especially in the first few months of treatment, or become forgetful, short-tempered, tired or depressed. Fortunately, most side effects disappear once treatment has stopped.

Side effects of combination treatment

Side effects of combination treatment can vary with each person and often become less severe as treatment continues. The side effects are similar to those experienced with interferon alone, and may include: fever, chills, muscle aches and headaches. Some people experience tiredness, or a loss of appetite, insomnia, nausea, vomiting, skin dryness and itching, dry throat, hair thinning, and weight loss.

Ribavirin usually lowers your red blood cell count, platelet count and your haemoglobin. This may cause tiredness, shortness of breath and decreased energy. Mood swings or depression may also occur. Other side effects such as thyroid disorders can occur but are less common. Most of these side effects stop when treatment ceases.

Tests on animals show that ribavirin can cause birth defects, so combination treatment is not recommended for women who are pregnant or breastfeeding, or for anyone (men and women) not using contraception during, and up to six months after treatment.

Side effects of pegylated interferon

The side effects of pegylated interferon are similar to those experienced with standard interferon and can vary for each person.

The most common side effects are flu-like symptoms, such as headache, muscle aches, fatigue and fever.

When to seek medical advice for your symptoms or side effects

Occasionally, the side effects of either of these drugs can be life threatening, so you will need to be regularly monitored and have regular visits to your GP, specialist or nurse. It is important that you talk about your symptoms because this can help to prevent potential problems from arising.

If you experience any of the following symptoms, contact your GP or specialist immediately: breathlessness, chest pain, rapid losses of energy, dark urine, pale stools, confusion or dizziness, fluid retention (particularly around the abdominal area), rapid weight loss, deep depression or extreme fatigue.

For more information about managing your symptoms and side effects, ask your GP, specialist, clinic nurse or local Hepatitis C Council.

Information for my GP, specialist and health professionals

The Health Monitor is a patient-held record to assist people with hepatitis C to better manage their health.

Health professionals can help people manage their health by providing written instructions, educational material and records of important outcomes from the consultation.

Through participating in *shared care* or *enhanced primary care* programs, health workers can help to improve the quality of care that people with hepatitis C receive. *Shared care* is the joint participation of general practitioners and hospital consultants in the planned management, coordination and delivery of care for people with chronic disease.

The Commonwealth government has established enhanced primary care Medicare Benefits Schedule items to enable general practitioners to undertake or participate in care planning and case conferencing for people with chronic conditions, such as hepatitis C, and multi-disciplinary care needs. Refer to the *Medicare Benefits Schedule* to determine whether your patient is eligible for enhanced primary care items.

Educational programs have also been established in many States and Territories to support general practitioners who care for people with hepatitis C. Contact the Hepatitis C Council in your State or Territory to find out how to participate in shared care programs.

Information and support services

Getting information and support can help you find new ways of living with hepatitis C.

There are organisations throughout Australia that provide services to people with hepatitis C including Hepatitis C Councils and peer-based drug user groups. These services can help you by talking or listening to you over the phone, formal counselling, providing written information, education, support and referral, or by helping you to make contact with other people with hepatitis C.

Contact any of the services in your State or Territory for support and assistance.

STATE AND TERRITORY ORGANISATIONS

Australian Capital Territory

ACT Hepatitis C Council
PO Box 993
Dickson ACT 2602
Ph: 02 6253 9999
Fax: 02 6253 9992
Email: info@acthepc.org.au
Web: www.acthepc.org.au

Canberra Injectors Network
19 Bunda St
Civic ACT 2600
Ph: 02 6262 5299
Fax: 02 6262 8381
Email: cin@apex.net.au

Western Australia

Hepatitis C Council of Western Australia

PO Box 8060

Perth Business Centre WA 6849

Ph: 08 9328 8538

Freecall: 1800 800 070 (WA country callers)

Fax: 08 9227 6545

Email: hepcwa@highway1.com.au

Web: www.hepcwa.highway1.com.au

Western Australian Substance User's Association
(WASUA)

PO Box 290

Maylands WA 6931

Ph: 08 9227 7866

Fax: 08 9227 7855

Email: wasua@wantree.com.au

Queensland

Hepatitis C Council of Queensland

PO Box 179 Albert Street

Brisbane QLD 4002

Ph: 07 3229 3767

Freecall: 1800 648 491 (QLD country callers)

Fax: 07 3229 9305

Email: hepcq@hepatitisc.asn.au

Web: www.hepatitisc.asn.au

Queensland Intravenous AIDS Association (QuIVAA)

185-191 Brunswick Street

Fortitude Valley QLD 4006

Ph: 07 3252 5390

Fax: 07 3252 5392

Email: quivaa@powerup.com.au

Sunshine Coast Intravenous AIDS Association
(SCIVAA)
59 Sixth Ave
Maroochydore QLD 4558
Ph: 07 5443 9576
Fax: 07 5479 1918
Email: scivaa@peg.apc.org

Drug User's Network Education and Support
(DUNES)
2019 Gold Coast Highway
Miami QLD 4220
Ph: 07 5520 7900
Fax: 07 5520 7344
Email: info@ddunes.org.au

New South Wales

Hepatitis C Council of New South Wales
PO Box 432
Darlinghurst NSW 1300
Ph: 02 9332 1599
Freecall: 1800 803 990 (NSW country callers)
Fax: 02 9332 1730
Email: hccnsw@hepatitisc.org.au
Web: www.hepatitisc.org.au

New South Wales Users and AIDS Association (NUAA)
45 Bedford Street
Newtown NSW 2042
Ph: 02 9557 1476
Fax: 02 9557 1736
Email: nuaa@zipworld.com.au

Victoria

Hepatitis C Council of Victoria

Suite 5

200 Sydney Road

Brunswick VIC 3056

Ph: 03 9380 4644

Freecall 1800 703 003 (VIC country callers)

Fax: 03 9380 4688

Email: hepcvic@vicnet.net.au

Web: www.hepcvic.org.au

Victorian Intravenous AIDS Association (VIVAIDS)

765A Nicholson Street

Carlton VIC 3054

Ph: 03 9381 2211

Fax: 03 9381 2287

Email: drugsafe@vicnet.com.au

South Australia

Hepatitis C Council of South Australia

PO Box 782

Kent Town SA 5071

Ph: 08 8362 8443

Freecall: 1800 021 133 (SA country callers)

Fax: 08 8362 8559

Email: hepcsa@senet.com.au

Web: www.hepcouncilsa.asn.au

South Australian Voice for IV Education (SAVIVE)

64 Fullarton Road

Norwood SA 5071

Ph: 08 8362 9299

Fax: 08 8363 1046

Email: savive@camtech.net.au

Tasmania

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

GPO Box 595

Hobart TAS 7001

Ph: 03 6234 1242

Fax: 03 6234 1630

Email: mail@tascard.org.au

Northern Territory

TopEnd User's Forum (TUF)

PO Box 835

Parap NT 0804

Ph: 0415 162 525

Fax: 08 8981 3294

Email: tuf@lobbyist.com

Territory Health Services

PO Box 40596

Casuarina NT 0811

Ph: 08 8999 2709

1800 353 755

NATIONAL ORGANISATIONS

Australian Hepatitis Council

PO Box 357

Curtin ACT 2605

Ph: 02 6232 4257

Fax: 02 6232 4318

Email: info@hepatitisaustralia.com

Web: www.hepatitisaustralia.com

Australian IV League
PO Box 1552
Canberra ACT 2601
Ph: 02 6279 1600
Fax: 02 6279 1610
Email: aivl@aivl.org.au
Web: www.aivl.org.au

Haemophilia Foundation Australia
213 Waverley Rd
East Malvern VIC 3145
Ph: 03 9572 5533
Fax: 03 9572 0622
Email: hfaust@haemophilia.org.au
Web: www.haemophilia.org.au



Common terms

Alanine aminotransferase (ALT) – a protein when found in elevated quantities generally indicates liver inflammation and possible cell damage.

Albumin – a protein produced by the liver. Chronic liver disease can cause a decrease in the amount of albumin produced by the liver.

Antibody – a protein secreted by cells of our immune system in response to infection. The antibody binds to a specific part of the hepatitis C virus to prevent the virus from infecting other cells or destroying it.

Antigen – anything introduced into the body that is seen as foreign. An antigen stimulates the immune system into producing cells that attack it.

Aspartate aminotransferase (AST) – a protein when found in the blood in elevated quantities, generally indicates liver damage (although less specific for liver damage than ALT).

Asymptomatic – having no identifiable symptoms.

Biliary – of, or pertaining to bile or to the gallbladder and its ducts, which transport bile. These are often called the biliary tract or the biliary system.



Blood and blood products – components of blood including red cells, platelets and plasma that are separated out by blood banks.

Chronic active hepatitis, or chronic hepatitis – any form of liver inflammation lasting more than six months and causing continuing damage to liver cells.

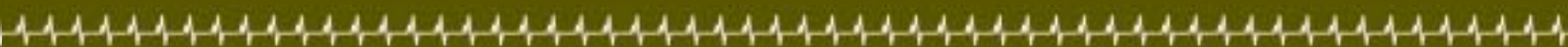
Cirrhosis – a condition where scar tissue develops in the liver, to the extent where scarring becomes extensive and permanent, interfering with the normal functioning of the liver.

Combination therapy – the use of two or more types of treatment in combination, alternately or together to achieve optimum results.

Compassionate access scheme – A scheme where a person is assessed and given special access to ribavirin (provided by the pharmaceutical company) and interferon (provided under the Pharmaceutical Benefits Scheme). Monthly pharmacy dispensing fees will apply in these cases. Sometimes referred to as a Special Access Scheme.

Enhanced primary care – Medicare Benefits Schedule items enabling general practitioners to undertake or participate in care planning and case conferencing for people with chronic conditions and multi-disciplinary care needs.

Fibrosis – scar formation resulting from the repair of tissue damage. If it occurs extensively in the liver, it is called cirrhosis.



Gastroenterology – the branch of medicine specialising in diseases of the liver, stomach, intestines and oesophagus.

Genotype – different genotypes (or strains) of the one virus that are similar enough to be regarded as the same type of virus but have some minor differences in their composition.

Haemochromatosis – a condition that results in excessive iron deposits being stored throughout the body.

Haemophilia – a hereditary blood disease where the blood fails to clot and abnormal bleeding occurs.

Hepatocellular carcinoma – cancer of the liver.

Hepatologist – a liver specialist, usually working in a liver clinic.

Interferon(s) – proteins produced by the human body to help defend itself against viral infection. The drug interferon is a synthetic compound approved for the treatment of certain viral infections, including hepatitis C.

Non-responders – people, who after 12 weeks of treatment, fail to have normalised levels of alanine transferase (ALT) in their blood.

PCR (polymerase chain reaction) – technology used for identifying viruses and genotypes, and measuring viral load in blood.

Platelet – the smallest of the cells in the blood essential for coagulation of the blood.



Protein – any of a large group of naturally occurring, complex, organic nitrogenous compounds. Each is made up of large combinations of amino acids, containing the elements carbon, hydrogen, nitrogen, oxygen, usually sulphur, and occasionally phosphorus, iron and iodine.

Shared care – a partnership arrangement between health care professionals, usually with different skills, made to optimise the care of patients with a chronic disease. The purpose of shared care is to enhance the delivery of optimal expertise, compassionate support, counselling and practical convenience. Patients need to participate in the design of their own shared care arrangements.

Special Access Scheme – see compassionate access scheme.

Sustained response – this usually refers to a loss of measurable virus in the blood and normalisation of liver enzymes (liver function tests) that lasts at least six months after treatment ends.

Viral load – the amount of virus present in a person's bloodstream. It is usually measured by PCR technology and the result is given in number of virus particles per millilitre of blood.

