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






May 2010: *Hepatitis C: treat it, beat it.*

If you would like more copies of this booklet, or need more information about hepatitis C, contact your state or territory hepatitis organisation.

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Introduction



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his booklet is designed to help people with hepatitis C make well-informed decisions when considering pharmaceutical treatment.

Despite offering the potential of a cure, decisions around hepatitis C treatment are rarely taken lightly, as the treatment process itself can have an impact on many aspects of your life. This booklet will help you to gather all the information you need prior to treatment and assist you to make preparations to give yourself the best chance of success. The booklet may also be useful for partners, family, and friends of a person who is considering hepatitis C treatment. In addition, it provides information which may assist you in your discussions with your GP and treatment team.

For details of where to obtain more information about hepatitis C treatments, see the '*Contacts*' section at the end of the booklet.

If you are unsure of the meaning of any of the terms used in this booklet, or used by clinicians, please refer to the '*Glossary*' section of the booklet.

Please note that the information and comments provided in this booklet are not intended to replace individual professional medical advice. For expert advice on hepatitis C treatment, you should refer to your GP, liver specialist and/or hepatology (liver) nurse.





Twelve quick facts about hepatitis C treatment

1. The current pharmaceutical treatment for hepatitis C is a 6-12 month course of weekly pegylated interferon injections and daily ribavirin capsules.
2. Most adults with chronic hepatitis C infection, including people who currently inject drugs, are eligible for government-funded treatment.
3. The aim of treatment is to achieve a cure; however, there are some benefits to treatment even if this does not occur. Cure is defined as a sustained virological response (SVR), and is measured by a blood test taken 6 months after the completion of treatment.
4. The number of people who achieve a cure following hepatitis C treatment, and the management of side-effects, has improved significantly in the last 10 years.
5. Achieving a cure is dependent on many factors, but one of the most important is the particular genotype (strain) of infection. Genotypes 2 and 3 are easier to treat, and genotypes 1 and 4 are harder to treat. In Australia, most people with hepatitis C have either genotype 1 or 3.

6. Standard treatment for people with either genotype 2 or 3 infection require 24 weeks of treatment, and has, on average, an 80% chance of achieving a cure.
7. Standard treatment for people with genotypes 1 and 4 infection require 48 weeks of treatment, and has on average, a 50% chance of achieving a cure.
8. Apart from genotype, many other factors have an impact on an individual's chance of achieving a cure. These include your sex, age, weight, the stage of your liver disease, the amount of virus in your blood, and co-infection with hepatitis B or HIV.
9. Treatment may not be suitable for you if you have advanced liver disease.
10. Treatment experiences vary greatly from person to person.
11. Some people have few, or relatively minor side-effects, for others, hepatitis C treatment can be more difficult. It is not possible to accurately predict how you will react to treatment.
12. Even after successful treatment you will continue to have hepatitis C antibodies in your blood, indicating that you have been exposed to the virus in the past. However, these hepatitis C antibodies do not mean that you are immune to hepatitis C, and offer no protection against being re-infected following successful treatment.





Before treatment

Am I eligible for government-subsidised treatment?

The criteria for government-subsidised hepatitis C treatment follow the guidelines laid down by the Pharmaceutical Benefits Scheme (PBS) S100. The current guidelines are:

- Current chronic hepatitis C infection – positive HCV antibody and HCV RNA tests
- Aged 18 years or over
- Women must not be pregnant or breastfeeding
- The patient and their partner must **both** be using effective contraception.

The criteria for treatment have changed significantly in the last 10 years. It is important to remember that:

- You no longer need to have a liver biopsy to access government-funded treatment; this criterion was removed in 2006.

- People who currently inject drugs are eligible for government-funded hepatitis C treatment. Methadone use does not interfere with the medication.
- You do not have to have liver scarring, or be noticeably sick to get treatment. In fact, getting treatment before you develop liver damage can increase your likelihood of clearing the virus and achieving a cure.
- Some people have liver damage that is considered too advanced for treatment to be effective or safe; this is called decompensated liver disease. Talk to your liver specialist about what options they would consider in these circumstances.
- A past history of mild depression, anxiety or other mental health issues does not automatically exclude you from treatment. However, due to concerns about the safety of the medications, people with an unstable, severe mental illness may be excluded from treatment.
- From December 2008, government-funded re-treatment was made available for some people who had previously had unsuccessful treatment, this is considered on a case by case basis. If you are considering re-treatment, it is important to discuss this with your specialist.

Occasionally, a GP is not up-to-date with the current criteria for accessing government-funded hepatitis C treatment, and may provide you with incorrect information. If you are confused by any information provided to you, please contact your local hepatitis organisation for clarification.



What is the role of liver biopsy?

In people with hepatitis C, knowing the stage of liver fibrosis is important in monitoring disease progression, and can assist with treatment decisions.

Liver biopsy has traditionally been considered the 'gold standard' for assessing the stage of liver disease. It is an invasive test that involves the removal of a tiny piece of the liver (about the size of a matchstick), using a fine needle. This is examined under a microscope for signs of disease.

Since 2006, liver biopsy is no longer required to access hepatitis C treatment under the S100 criteria; however, there are some situations when one may be recommended by your doctor. Your informed consent is required for this procedure, and your doctor will discuss the risks and benefits of a liver biopsy with you, and alternatives such as fibroscan.

What is Fibroscan?

Fibroscan (Transient Elastography) is a new device used to measure the elasticity or stiffness of the liver – the stiffer the liver, the more severe the liver fibrosis (scarring). It is a non-invasive procedure. The availability of Fibroscan and demand for these tests is increasing around Australia.

The test is considered a very accurate tool for assessing mild or minimal liver disease, as well as advanced liver disease and cirrhosis. It is considered to be less accurate in the assessment of moderate liver disease.

When is the best time to go on treatment?

When considering treatment, think about whether this is the best time for you to commence treatment, and what changes or significant events are happening in your life that may have an impact on your ability to cope with treatment. New relationships, getting married, thinking about starting a family, starting a new job, moving house, or decreasing alcohol and drug use are all significant changes that may have an impact on the best timing of treatment for you.

Deciding the exact time to start treatment can be a difficult decision. Talking with your doctor, family and friends may help you decide. As hepatitis C-related liver disease generally progresses slowly, delaying treatment for a short time, until you are better able to prioritise treatment is a possibility for most people, however, this should be discussed more fully with your treatment team. You are likely to cope better with treatment if you are emotionally and physically ready for treatment and have set up your support plan.

It's taken me 5 years of trying to understand what it's like to endure treatment to make the decision myself... to talk to people face-to-face who have had treatment, talk to people on the internet through the forums and really get to know them ... so now I have a really good idea of what it's like and so I feel more confident in what I'm doing in my management decisions.

Sara – National Hepatitis C Needs Assessment 2008⁴



There are certain times when you must not take the hepatitis C treatment drugs, such as when you are pregnant or breastfeeding. Both men and women will need to discuss contraception before starting treatment, as one of the medications (ribavirin) is known to cause birth defects, and is not safe for babies who are breastfed. Two forms of contraception should be used during treatment and for 6 months after treatment has stopped. Talk with your partner and decide which contraceptives you will use, and arrange to have these available at all times.

What are the drugs used for hepatitis C treatment?

Pegylated Interferon and Ribavirin is the current standard pharmaceutical treatment for hepatitis C; they work together to fight the infection and clear the hepatitis C virus from your body.

Pegylated Interferon

Interferon is a naturally occurring protein that is produced when the body is fighting infection. Man-made Interferon is used to boost the immune response and slow the growth of the hepatitis C virus. The form of interferon used to treat hepatitis C is called pegylated interferon. 'Pegylated' means that the interferon has been changed so that it lasts longer in the body, and therefore only needs to be injected once a week. It must be kept refrigerated, and is injected with a very fine needle just under the skin into the fat of the stomach or thigh. You will be taught how to give these injections to yourself by your hepatology nurse.

Ribavirin

Ribavirin alters the body's immune response to viruses, and slows down the speed at which the hepatitis C virus reproduces. Ribavirin works best when taken in combination with interferon, and is taken orally as a tablet or capsule twice a day. The amount of Ribavirin you will be prescribed will vary depending on individual factors such as your genotype; higher doses are required for the more difficult to treat genotypes.

What questions should I ask my GP and/or Specialist?

Gathering information on what to expect during treatment will assist you to make an informed decision, and help prepare you for treatment.

When reading information and considering treatment, it can be useful to write down a list of questions you would like to ask your GP, Specialist or hepatology nurse.

Your questions might include:

- What tests will I need to have to know how hepatitis C is affecting me?
- What is my individual chance of achieving a cure?
- Can I have treatment anytime?
- What can I do to make a cure more likely for me, and what can I do to look after my general health before and during treatment?
- When and how often do I need to see a liver specialist?

- When and how often do I need to see my GP?
- What costs will I incur if I am a public patient?
- What costs will I incur if I am a private patient?
- What side-effects of treatment should I be prepared for?
- Should I be vaccinated/tested for hepatitis A and B?
- Where can I go for additional information and support before, during, and after treatment?

Remember also, that the hepatitis organisations in each state and territory run telephone helplines which offer you the opportunity to ask questions at your own pace. Sometimes hearing information repeated slowly and in plain English can be very helpful. Some states and territories also offer treatment peer support programs where you can talk to someone who has already been through treatment.

It would have been useful to talk to someone who had had the treatment before I started just to know what I could expect from the treatment.

Soul – National Hepatitis C Needs Assessment 2008⁵



What are the benefits of treatment?

The aim of treatment is to achieve a cure; this is defined as a 'sustained virological response' and is measured by a blood test taken 6 months after the end of treatment to check whether any virus remains in your body.

Even if your treatment doesn't result in a cure, it may still help by allowing your liver time to heal without the normal activity of the hepatitis C virus; this can slow the progress of the disease.

Will I achieve a cure?

This is the question that all people ask prior to starting treatment. Unfortunately, it is impossible to precisely predict individual responses to treatment.

There are many factors that affect your individual chance of achieving a cure; the most important predictor of response is your genotype. People who have genotype 2 or 3 infection require 24 weeks of treatment, and have on average an 80% chance of achieving a cure. People with genotype 1 and 4 require 48 weeks of treatment, and have on average a 50% chance of achieving a cure.

Many other factors also have an impact on cure rates. Treatment success rates are generally greater in those people who are:

- of a younger age
- have a lower viral load
- have minimal liver scarring (fibrosis)
- are female
- are in a healthy weight range
- have a high level of adherence to the treatment regime
- are not co-infected with hepatitis B or HIV.

Developing a support plan

Due to the possible side-effects of the pharmaceutical treatment for hepatitis C, it is important you consider their potential impact prior to commencing treatment, so that you can set up a good support plan to assist you to complete treatment. A support plan will involve you being fully informed about possible side-effects of treatment and ensure you have a network of equally well-informed people available to help and support you.

Part of your support plan could be to ask a friend or family member to be your dedicated support person during treatment. You may like that person to accompany you to appointments and may also choose to give them permission to contact your healthcare team if they are concerned about you. Don't forget to let your healthcare team know that you have a support person, and what they can and can't discuss with them. You may need to have this documented in your file so the team will know that you have given permission for them to talk directly to your support person.

Having people you can turn to for practical support is also important to consider, as you may need additional help at home.

Many liver clinics, and some hepatitis organisations run treatment support groups for people who are undergoing treatment.

I find it really useful to talk to other people who attend the support group who may have tried something or heard about something that can help with symptoms ... talking to people who understand is so important.

Serena - National Hepatitis C Needs Assessment 2008¹

What is the process of starting treatment for hepatitis C?

Before treatment can commence, the first step you should take is to get a referral to a hepatitis C treatment specialist from your general practitioner (GP). It is highly unlikely that a GP would refuse to provide you with a referral to a liver specialist if you request one, however, if you encounter any difficulties, you can contact your local hepatitis organisation.

Once you have a referral to a specialist, the next step is to make an appointment at a liver clinic where you can speak to a liver specialist about your treatment options. Sometimes there may be a wait of several weeks or months to get this initial appointment time. If you are concerned about the wait, speak to your GP or local hepatitis organisation. When you go for the appointment, either before, or after speaking to the specialist, you will also generally speak to a hepatology nurse at the liver clinic. The specialist and/or nurse will assess your suitability for treatment, and discuss their assessment with you. If you decide to start treatment, a set of blood tests will be done prior to commencing to provide a baseline from which to measure the effect of the treatment.

Once treatment is started, you will have a series of appointments booked either with the specialist, and/or hepatology nurse, where blood tests will be taken to monitor how the treatment is working. It is very important that you attend all these appointments. This is a good time to discuss any problems you are having with side-effects and how to manage them.

As hepatitis C treatments are classified as highly specialised drugs, they can only be prescribed by specialists in liver clinics (usually in public hospitals), or specifically trained professionals such as nurse practitioners or GPs who have completed special hepatitis C treatment training.

The drugs are only dispensed through pharmacies that participate in the Highly Specialised Drug Program. The staff at the liver clinics will be able to advise you where to go.

What if I live in a regional or remote area?

As many people live far away from metropolitan and regionally-based liver clinics, models of shared care have evolved to expand the availability of hepatitis C treatment in rural Australia. Shared care allows people who live in remote areas to have access to specialist treatment, but have their care managed in a collaborative model between specialists in metropolitan based liver clinics and local GPs and other health care services.

To find out if there is a liver clinic near you, contact your local hepatitis organisation on the hepatitis infoline: 1300 437 222.

Public or Private Treatment?

You may decide to have your treatment either through the public system (generally liver clinics in public hospitals), or privately through a liver specialist of your choosing. If you are considering private treatment, be sure to find out the full cost of treatment and all associated costs before you start.

You will not need to pay for hepatitis C treatment as a public patient provided that you are eligible for Medicare. Medicare should cover the majority of the costs associated with blood tests, medication, appointments and procedures such as a liver biopsy or fibroscan. However, you may need to pay a dispensing fee each month for the medication and have some other out-of-pocket expenses. The cost of medications to manage any side-effects may also not be covered. You should discuss any out-of-pocket expenses further with your doctor or hepatology nurse.

'My treatment was through a local gastroenterologist who is in private practice. I understand that is fairly unusual and most people access treatment through their liver clinic, but I personally found my experience in many ways better than what I hear described. There was great flexibility in my appointments, both in the availability and in the time my doctor spent with me. He sent regular letters to my GP, and my GP managed most of my side-effects.'

I realise most people get treatment through their liver clinic but perhaps it should be emphasised that the option of treating privately might be available and might be more suitable for some people.'

Christa – HepC Australasia online support forum³



What are the side-effects of treatment?

It is important to remember that side-effects will vary greatly, both over the course of treatment, and between individuals. Some people report no, or few, side-effects during treatment, while others may have significant side-effects.

Doctors often report that side-effects will resolve soon after completing treatment, however, recent research has suggested that for some people, side-effects may linger for up to 6-12 months or longer after treatment has finished.

A common side-effect shortly after having the pegylated interferon is flu-like symptoms such as fever, chills and muscle pain. Fatigue, itchy dry skin and temporary hair loss are also common side-effects.

Interferon can lead to some people having either mild, or significant changes to their mood, and/or thinking processes. These can include irritability, loss of concentration, forgetfulness, mood swings, feeling aggressive or highly agitated, panic attacks and sleep problems. Signs of depression or psychosis need to be carefully monitored and managed.

Loss of appetite, nausea, vomiting, and diarrhoea can lead to weight loss. A dry cough, sore throat and sinus problems can also be troublesome.

Anaemia may develop resulting in shortness of breath and extreme tiredness. Thyroid disorders and diabetes can also emerge, or existing problems worsen. As mentioned previously, ribavirin can cause significant harm to unborn and newborn babies if taken when a woman is pregnant or breastfeeding.

While this list of possible side-effects may seem daunting, it is important to remember that some people have very few side-effects while on treatment. The management of the side-effects has improved substantially over the last few years. Knowing what to do, and where to go for help if you do experience side-effects, is an important part of your pre-treatment preparation. The hepatology nurses in the liver clinic, and/or counsellor, and also your local hepatitis organisation are good sources of support, if you need it.

Some practical advice on managing treatment-related side-effects can be found in the section '*During treatment*'. Some of these suggestions may, or may not, ease the effect of the treatment. If symptoms persist, it is best to talk to a health professional for further advice.

... The stories I heard about treatment that people get really sick, they were enough to put me off having treatment. But my doctor was able to reassure me that not everyone gets sick on treatment.

Sarah – National Hepatitis C Needs Assessment 2008⁶



Who should I tell that I'm on treatment?

Before you commence treatment, you should consider who you tell about your treatment very carefully. Remember that some people often judge others, because they lack knowledge about hepatitis C, which may result in the wrong conclusions being made, and as a consequence of this judgement, treat you differently.

Some people just tell their family, or one close friend or supportive colleague at work. Other people prefer to tell everyone about the treatment they are undertaking, while some prefer to tell people they are undergoing a type of chemotherapy, but don't disclose the details of the treatment. You may need to adjust work hours due to side-effects or to attend medical appointments, so think carefully about what would work best in your situation before you disclose any information about your treatment.

There is more information on this subject in the publication *My Choice: My Rights* available from the hepatitis organisations listed in the 'Contacts' section towards the back of the booklet.

Where will I find support during treatment?

Support is potentially available from a variety of clinical and non-clinical people, such as:

- specialist doctor
- GP
- hepatology nurse
- hepatitis Infoline 1300 437 222

- online forums with other people with hepatitis C
- support groups with other people undergoing treatment
- treatment peer support programs
- friends and family and designated support person
- the emergency department of your local hospital (for urgent issues).

It's important to remember that support and information is available from people who have experienced treatment. So if you are considering treatment, plan ahead and talk to people with experience.

My nurse from the clinic, was an angel sent down to help me ... she told me I could call her any time of the day or night ... even in the middle of the night, which was just so amazing ... of course I never rang her in the middle of the night, but it was so comforting to know she was there if I needed her.

Samantha – National Hepatitis C Needs Assessment 2008⁷

I've heard there are new treatments for hepatitis C, what are these?

Treatment for hepatitis C has improved significantly over the last 10 years and will continue to evolve in coming years. Before any new drugs can be used widely in the community, they need to be thoroughly tested in a clinical trial setting.

Clinical trials are conducted with a small number of patients to determine the safety and tolerability of new drugs in humans; the appropriate dose and the potential side-effects. These clinical trials and the subsequent government approval processes can take many years.

Currently there are two new types of drugs being trialled for hepatitis C treatment around the world; they are called polymerase and protease inhibitors. It was initially hoped these drugs would replace pegylated interferon and ribavirin, but it has become clear during the clinical trials that they work best when they are added to existing medications. The clinical trials are aimed at combining medications to improve cure rates, particularly for patients with harder to treat genotypes and also to monitor side-effects.

In addition to clinical trials of these new drugs, other trials are being conducted which explore the effect of varying the dose and duration of pegylated interferon and ribavirin treatment, according to individual patient needs.

If you are interested in learning more about the clinical trials available in Australia, speak to your specialist or hepatology nurse.

You can have all the clinical information in the world. But what is most useful is to talk to other people with hepatitis C ... because it shows you that you're not alone.

Saba – National Hepatitis C Needs Assessment 2008⁸



During treatment

What tests will monitor the success of treatment?

There have been many advances in our understanding of hepatitis C treatment over the past decade. We now know that the faster someone responds to treatment, the higher their chance of achieving a cure.

Therefore, the success of treatment is monitored by measuring the amount of virus in the blood at certain times during the treatment course. These include:

- **Rapid Viral Response (RVR):** there is no virus in the blood at week four of treatment.
- **Early Viral Response (complete) (cEVR):** there is no virus in the blood at week 12 of treatment.
- **Early Viral Response (partial) (pEVR):** there has been a significant drop in the amount of virus in the blood (viral load) at week 12 of treatment but the virus is still detected.



An early decrease in viral load indicates that the treatment is working. Research shows that people who respond early and rapidly have a better chance of being cured.

Unfortunately, some people do not respond well to current treatment regimes. If the virus is still detected in your blood at week 12, and there has not been a significant drop in the viral load, you have a very low (less than 5%) chance of achieving a cure, and you are not eligible to continue with government-funded treatment. This is more common in people with genotype 1 infection. The news can be very disheartening, and ongoing support may be required. You can discuss with your specialist and/or GP ongoing monitoring and self-management strategies to minimise disease progression, and also the potential for you to participate in future clinical trials.

The regularity of other checkups during treatment will depend on how your treatment is going, other health issues, and the amount of liver damage you may have.

How can I manage the side-effects of the treatment?

You may experience some, or many, of the side-effects of the treatment. The list below may help you manage symptoms as they occur. It is important to talk to your doctor or hepatology nurse about any side-effects you experience.

Feeling tired:

- Planned rest periods during the day may help restore your energy levels.
- Short, mild exercise, such as walking, also reduces tiredness.
- Talk to a dietician or your local hepatitis organisation for tips on healthy eating.
- Read the *Hepatitis C: guide to healthy living* booklet available from your local hepatitis organisation.

Fever:

- Check with your doctor regarding the correct medication to take for lowering your temperature. If fever is associated with your interferon injections, taking a medication such as paracetamol before your injection can be helpful.
- Increase your intake of water and other clear fluids, such as juices and soups. Avoid increasing your fluid intake with tea, coffee, and soft drink.
- Wear cotton night clothes, as natural fibres are cooler and reduce perspiration
- A cold face washer or a fan may also help.



Nausea:

If the nausea is severe, your specialist or GP may prescribe medication to decrease the nausea. Other tips for avoiding nausea are:

- Eat small amounts of food frequently during the day.
- Avoid fatty meals.
- Avoid having an empty stomach.
- Avoid drinking liquids during meals, but drink them after eating and when feeling better.
- Try light, easy to digest food, like soup.
- Eat most when feeling hungry.
- Cook meals when you are feeling well and not nauseous.
- Try ginger tea made from root ginger for nausea.
- Nausea is common after the interferon injection. Try having your weekly injection at a time when you are able to rest afterwards.

Weight loss:

- Eat foods high in vitamins and proteins, such as dried fruit, nuts, cheese, yoghurt, tofu, soy or milkshakes.
- Stimulate your appetite by trying different tastes such as bitter, sour, salty or sweet.
- Special nutritional supplements can be used if you are losing too much weight. Talk to a dietician to choose the correct supplement.



Loss of concentration:

Commonly known as 'brain fog', it can be related to anxiety and/or depression. Here are some suggestions some people have found helpful:

- Vitamin B and Omega 3 fish oil are usually safe to use for people with hepatitis C, and can improve mental function, focus, energy and memory.
- If you need to make any important decisions during treatment, ask your support person to assist you.
- Try making lists to keep you on task.

'Sometimes I was unable to make a good decision ... there is the need to have contact with someone who can give sound advice and reasoning.'

Sean – Hep C Australasia online forum⁹

Sleep problems:

- Avoid drinking coffee after midday.
- Try relaxation activities such as tai chi, yoga and meditation.
- Establish a regular sleep ritual as this is helpful for good sleep; try to go to bed at the same time each night, and if you nap during the day, keep it short and earlier in the day.
- Try soft foam ear plugs to help you get to sleep and stay asleep if it is likely you will be disturbed by noise.
- Keep your bedroom temperature cool, and don't have a television in the bedroom.

- Light can also interfere with a good night's sleep, so close the blinds before you go to bed.
- Consider a warm bath before bed to relax your body. Adding a few drops of lavender oil to the bath may help relax your mind.
- Take prescribed sleeping medications if approved by the specialist or hepatology nurse.

Mood Swings, Irritability, Depression and Psychosis:

- Consider counselling or prescribed medications for control of these symptoms during treatment.
- Consider doing some regular light exercise such as walking, to improve your mood and give you a sense of wellbeing.
- Talk to family and friends, or call your local hepatitis organisation to discuss your feelings.
- Explore relaxation techniques.

Skin irritation and hair problems:

- Try gentle creams without perfumes.
- Try gentle shampoos that contain wheat germ oil.
- Try soothing oil baths (such as Pinetarsol bath oil).

Joint and muscle pain:

Some people have generalised pain in the muscles and joints while others have pain in only one area of the body.

To relieve the pain try:

- heat packs, warm baths and massage
- pain relief medication approved by doctor
- complementary and alternative therapies approved by your doctor.

Be aware that some herbal therapies can be toxic to the liver.

What happens if the side-effects are getting too much?

If you are having difficulties with physical or emotional side-effects, the liver clinic staff are trained to support you to manage your symptoms. The patient/nurse relationship should be one of the closest you have during treatment, therefore, the hepatology nurse is a good person to ask for advice and receive support.

Other ways to obtain support are:

- attending face-to-face support groups which are organised on a regular basis by some local hepatitis organisations and liver clinics
- asking your local hepatitis organisation for details of online social networking forums such as hepcaustralasia.org
- accessing peer support programs which are a one-to-one form of support involving a person who has experienced treatment mentoring other people going through treatment. Ask your hepatitis organisation if this is available locally.

If the side-effects are severe and can't be controlled, the best option is to reduce, or stop, the treatment. This option should be discussed between you, your specialist, GP, and hepatology nurse.

How do I manage my life while on treatment?

You can manage your hepatitis C treatment in many ways. Small changes can make a big difference. Different strategies work for different people:

- Eat a healthy balanced diet. The booklet *Hepatitis C: guide to healthy living* is available from your local hepatitis organisation.
- Try to stop or decrease alcohol and tobacco use.
- Participate in regular, moderate exercise.
- Try to decrease stress and find relaxing activities.
- Continue with your favourite activities.
- Use support offered by family, friends and community services, and if possible the workplace.
- Increase your knowledge around the virus, symptoms and treatment options. This can help you take control of your health.

... I had to learn to give in to the treatment process and let it do its job, to win.'

Sam – Hep C Australasia online forum¹⁰



How do I manage work while on treatment?

Some people will find work very important during treatment, because it provides something to focus on besides their health.

It is helpful to know how much sick leave and annual leave you can take while on treatment. You may need to take some of your annual leave during the treatment period if you have used all your allocated sick leave entitlement.

It is not necessary to tell anyone at work that you are on treatment and disclosure should be considered carefully due to possible negative consequences. However, it is important to know that an employer is required to make allowances for medical appointments, disability, or impairment, and make all reasonable adjustments to your workload or tasks to assist you when dealing with health concerns. There is more information on this subject in the publication *My Choice: My Rights* available from your local hepatitis organisation.

Will I be able to travel overseas while on treatment?

In Australia, and when travelling to some countries, you are able to travel with your medication if you have a letter from your doctor and you can keep the medication cool.

The doctor's letter should explain your health status, the treatment needed, and how the medication is to be taken; it should also note that the medication must be kept cool. The letter can further describe your medication, the active ingredients, its presentation, and the quantity or volume you are carrying. It must state that the product is for your

personal use and that the vials must not be opened when security officials are checking them. The product must be carried in its original packaging, and you should declare it at security points and customs' barriers.

'I recently had a short trip overseas and was pleasantly surprised at how easy it was to travel with my hep C medication. I had a letter from my treating doctor stating that I needed to travel with my medication, both injectable medication and tablets and that it would need to be refrigerated. I phoned the airline a few days ahead of time and they recorded the information with my booking information. I carried the medication with me onto the plane and it was then refrigerated for me. A very positive experience.'

Sally, Community Reference Member¹

Healthy living while on treatment

Looking after yourself both before and during treatment will put you in the best position for optimum liver health, clearing the virus, and achieving a cure.

By eating a healthy, balanced diet, stopping or reducing your alcohol intake, getting regular exercise and enough rest, and generally looking after yourself, you may find your overall psychological and physical wellbeing improves.

Further information can be found in the Hepatitis Australia booklet, *Hepatitis C: guide to healthy living*.

Can I use complementary and alternative medicine during treatment?

Many people use complementary and alternative medicine (CAM) to reduce stress and promote a sense of wellbeing during the treatment process. Acupuncture, massage, aromatherapy and relaxation techniques are often used for stress reduction.

Herbs such as milk thistle, CH100 (Chinese herbal product) and dandelion can help manage symptoms of hepatitis C before starting treatment. However, it is unclear at this point if some of these liver-friendly herbs interfere with the effectiveness of combination therapy, therefore many people use these herbs while preparing for treatment, but not during treatment. You should discuss your use of herbs with your GP and specialist.

There are also many herbs that are considered dangerous for people with hepatitis C. For more information on herbs and therapies that can be dangerous to the liver see *Hepatitis C: guide to healthy living*.





After

treatment

**Y**

ou will not know the final outcome of treatment until 6 months after treatment has finished.

It is common for people who have finished treatment to still have contact with their specialist or hepatology nurse. However, some clinics do not have the time or resources to offer treatment aftercare to former patients and some people live a long distance from their specialist and/or liver clinic. In these circumstances, it is advisable to have an alternative source of accessible medical care, like a GP, in case you need ongoing help after treatment is finished.

What are the tests after treatment is finished?

Cure of hepatitis C cannot be determined until 6 months after treatment has ceased. In the meantime, you may be asked to have blood tests at regular intervals to monitor your health after treatment.



These tests include:

- **LFT** – Liver Function Test – used to regularly monitor liver function.
- **PCR test** – used after treatment to detect if the virus has cleared from your body.
- **Viral Load** – used to follow your response to treatment by comparing the amount of virus in the blood before, during, and after treatment. This helps to show if the treatment is working, and the level of hepatitis C virus in the blood.

Other tests will be ordered as needed to check on your general health.

If I clear hepatitis C, will I be immune?

Fifty to eighty percent of the people treated for hepatitis C will clear the virus and achieve a cure. However, it is important to know that even if you clear the virus you are not immune to hepatitis C; you can get hepatitis C again.

Emotional support after treatment

It is important that you continue with support after treatment.

Some people are excited to be cured of hepatitis C, and feel it closes a chapter of their life they have left behind, and others have a sense of change and new beginnings. However, for others, living with hepatitis C has been part of their identity for many years and it is therefore not unusual to experience some confusion in living without hepatitis C and needing a period of adjustment.

You may have started on antidepressants and other prescribed medications such as relaxants and pain killers during treatment. If you wish to stop these medications, you should discuss this with your doctor, who will monitor your mood and advise you how to slowly reduce the amount you take. It can be dangerous to stop these medications abruptly.

What does viral relapse mean?

Viral relapse occurs when you initially clear the virus, but in the 6 months after treatment finishes, the virus reappears and starts reproducing again.

Viral relapse can be very disappointing and people require support to deal with this situation as they often experience a deep sense of loss. While viral relapse demonstrates that the virus initially had a good response to treatment (which might mean you are a good candidate for re-treatment), it can be devastating to a person who thought they had cleared the virus. Seek support from family and friends, your health care team and/or local hepatitis organisation to cope with this outcome.

A relapse can occur at any point in the 6 month period after treatment stops, but only very rarely after this time.

If you don't clear the virus, there can be other benefits to completing treatment. Many people have a reduced viral load, improved liver health and report an overall improvement in their health.

Talk to your specialist about the possibility for re-treatment in the future, and/or participation in clinical trials, and also discuss ways to keep your liver healthy and strong.

I sort of had a talk with the gastroenterologist about [not responding to treatment], and basically he sort of made me feel a bit better in that he said “Well, but having the treatment you have basically cleared your system of [the virus] for X amount of time, which is not going to do you any harm in the long term.” And my blood levels have been actually better post-treatment than pre-treatment even though I have still got the virus. So I am happy about that side of things. So that made me feel a bit more positive about it being worth while going through the regime ... So I don't see now that it was a waste of time. And hopefully there will be some other treatments come.

Nathan – Recovery from hepatitis C treatments¹²

If treatment doesn't work for me, can I get re-treated?

From 1st December 2008, people who did not respond to treatment the first time became eligible for government-funded re-treatment. If you are considering re-treatment, consult with your specialist to discuss this possibility and whether re-treatment has a realistic chance of success.

If you did not respond well, and the virus wasn't clearing or significantly dropping the first time you did treatment, you may have a similar response the second time you try it.

However, many people who did treatment many years ago with standard interferon (given three times a week), with or without Ribavirin, may have a better chance of clearing the virus with the new Pegylated interferon and Ribavirin combination therapy.



Some people experienced disruption in their lives or personal problems the first time they did treatment. Therefore, having the opportunity to do treatment again may greatly increase their chances of clearing the virus second time around, because they will be able to plan more accurately for the possible side-effects and implement a support network.

If I clear hepatitis C, can I drink alcohol and use other drugs again?

It is best to talk to your specialist about your current and future alcohol intake. Some people have normal, healthy liver function after treatment, and may be able to tolerate alcohol which previously may have made them feel unwell, or caused damage.

However, if the liver is scarred or damaged, it is important to take care of your liver health and restrict your alcohol intake. Talk with your doctor about what is right for you.

If you are using other drugs like opiates, cannabis or methamphetamines, it would be better for your liver health and general health if you reduced these as far as possible. If you need help with this, contact your doctor or your local peer-based drug user organisation for advice.



How do I manage the side-effects after treatment has finished?

For most people, the side-effects of the treatment will slowly go away over a 6-12 month period after treatment has finished, although a small research study has suggested that for some people, treatment side-effects can linger for much longer.

Information on the common side-effects and how best to manage them, are provided in the 'during treatment' section. If you notice anything new, or your symptoms persist, contact your doctor.

What support is available after treatment?

Once treatment is completed, support from your liver clinic can be dependent on whether they have the resources to offer you treatment aftercare. Apart from your GP, specialist, and hepatology nurse, support is available from:

- your local hepatitis organisation
- online forums with other people with hepatitis C
- peer-based drug user organisations
- friends, family, and your support person
- your local hospital if you experience an emergency.

Well, I kind of got all of the support that I needed after treatment, because I finally got onto [a state based hepatitis council]. And see they have a help line ... I rang them, and got onto to this great guy ... The first conversation that I had with him ... was

around the time I'd stopped, and I learned more from him in the first ten minutes than I had from any of my doctors. And I sort of started talking to him regularly and it was like just 'Oh, yes! I finally have someone I can talk to! A sane voice, who understands what I'm going through.' Because he's been through it [treatment] ...

Elly – 'Recovery from hepatitis C treatments' study¹³



References

1. Hepatitis Australia (2009), *Do you C what I C?: Report on the information and support needs of people living with hepatitis C in Australia*. Canberra:Australia.
2. *ibid.*
3. *HepC Australasia Online Support Forum* (2009).
4. Hepatitis Australia (2009), *Do you C what I see?: Report on the information and support needs of people living with hepatitis C in Australia*. Canberra:Australia.
5. *ibid.*
6. *ibid.*
7. *ibid.*
8. *ibid.*
9. *HepC Australasia Online Support Forum* (2009).
10. *ibid.*
11. Community Reference Member (2009).
12. Hopwood, M. (2009). *Recovery from hepatitis C treatments* (Monograph 6/2009). Sydney: National Centre in HIV Social Research, The University of New South Wales.
13. *ibid.*



Glossary

ALT or Alanine Aminotransferase. Alanine aminotransferase (ALT) is the most relevant enzyme (chemical) measured by a liver function test for people with hepatitis C on treatment. ALT is a liver enzyme that can leak into the bloodstream when liver cells are inflamed or damaged. The hepatitis C virus can cause liver cell damage. Therefore, elevated ALT levels suggest liver damage. Damage to your liver can still occur when the ALT level is normal. The ALT provides a very basic guide and snapshot of the activity in your liver on the day the test is taken; it should be viewed as part of the overall picture of your health.

Cirrhosis. A condition in which scar tissue develops in the liver, to the extent that the scarring becomes extensive and permanent, and interferes with the normal functioning of the liver.

Clinical trial. Before new drugs can be used widely in the community, they need to be thoroughly tested in a clinical trial setting.

Combination therapy. The use of pegylated interferon and ribavirin for the treatment of hepatitis C virus infection. A form of chemotherapy.

Complementary and alternative medicine.

Complementary and alternative medicine (CAM) is a collective term that includes natural, alternative and holistic remedies. CAM includes herbal treatments, vitamin supplements, homoeopathic or naturopathic remedies, mind-body therapies such as yoga and meditation, and allied health services such as acupuncture and chiropractic.

Decompensated liver disease. Advanced liver disease where the liver is unable to function as normal. The liver's ability to manufacture albumin and clotting factors is affected, leading to swelling and bleeding problems. Hepatic encephalopathy also causes mental confusion and drowsiness.

Early viral response (complete) (cEVR). Viral clearance at week 12 of treatment. If you have a viral load of less than 50 IU/mL you have a good chance of being cured.

Early viral response (partial) (pEVR). Significant drop in viral load at week 12 of treatment, two log drop in viral load, e.g. from 600,000 IU/mL down to 6,000 IU/mL.

Fibrosis. Scar formation resulting from the repair of damaged tissue. If it occurs extensively in the liver it is called cirrhosis.

Gastroenterologist. A physician who specialises in diseases of the gastrointestinal tract.

Genotype. Strains of the hepatitis C virus that are similar enough to be regarded as the same type of virus, but have some minor differences in composition. Genotype is a significant predictor of treatment response.

Hepatitis C. Acute or chronic inflammation of the liver caused by the hepatitis C virus. The term 'chronic hepatitis C' refers to hepatitis C infection of more than 6 months duration.

Hepatocellular carcinoma. Cancer of the liver. A malignant tumour arising in the liver, in most cases occurring as a complication of cirrhosis.

Hepatology nurse. A registered nurse with expertise in caring for people with liver disease, specifically hepatitis C.

Hepatologist. A gastroenterologist who specialises in diseases of the liver.

Interferon. Interferons are proteins the human body produces in order to defend itself against viral infection. The drug interferon is a synthetic compound approved for the treatment of specific viral infections, including hepatitis C.

IU/mL. Measure of the number of international units of virus in each millilitre of blood. (Most people with chronic hepatitis C have between 50,000 and five million IU of hepatitis C virus in each millilitre of their blood).

Log change. Changes in viral load are sometimes expressed in terms of logs: 1-log change means a 10-fold increase or decrease; a 2-log change is a 100-fold increase or decrease.

Naïve patients. People who have never had hepatitis C treatment.

Non-Response. No significant drop in viral load in the first 12 weeks of treatment. Also referred to as non-EVR.

PCR (polymerase chain reaction). PCR technology is used for detecting viruses in the blood (qualitative), measuring the amount of virus (viral load) in blood (quantitative) and determining genotype.

Pegylated interferon. A substance called polyethylene glycol is attached to an immunity-boosting protein (interferon) to extend the duration of activity. The active substance is designed to stay in the body longer before it is broken down and removed.

Protein. Any of a large group of naturally occurring complex organic nitrogenous compounds. Made up of combinations of amino acids and containing the elements carbon, hydrogen, nitrogen and oxygen, usually sulphur, and occasionally phosphorous, iron and iodine.

Rapid viral response (RVR). Viral clearance at week four of treatment. If you have an RVR and your viral load is less than 50 IU/mL you have a greater than 85% chance of cure.

Relapser patients. People whose viral load is not detected and liver function tests normalise while on treatment, but become abnormal once treatment ceases.

Ribavirin. A nucleoside analogue. Can be incorporated in the genetic material of a virus, stopping the virus from replicating.

Shared care. A partnership arrangement between health care professionals, such as a liver specialist and GP, formed in order to improve the care of people with a chronic disease. Patients can participate in the design of their own shared care arrangements (in consultation with their health care team).

Sustained virological response (SVR). Refers to a loss of detectable virus in the blood and normalisation of liver function tests measured 6 months after treatment ceases.

Viral load. The amount of virus present in a person's bloodstream. Measured by PCR technology; the result is expressed as the number of virus particles per millilitre of blood. A high viral load is considered to be above 600,000 IU/mL. A low viral load is considered to be below 600,000 IU/mL.



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 support partnerships for action to ensure 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

Infoline: 1300 HEP ABC

For more information on hepatitis C, please 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 organisations.

State and territory hepatitis organisations

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

ACT Hepatitis Resource Centre

E: business@hepatitisresourcecentre.com.au

W: www.hepatitisresourcecentre.com.au

Hepatitis NSW

T: 02 9332 1853

E: hnswh@hep.org.au

W: www.hep.org.au

Hepatitis C Council of South Australia

T: 08 8362 8443 (office)

E: admin@hepccouncilsa.asn.au

W: www.hepccouncilsa.asn.au

Hepatitis C Victoria

T: 03 9380 4644

E: info@hepcvic.org.au

W: www.hepcvic.org.au

Hepatitis Council of Queensland

T: 1800 648 491 or 07 3236 0610

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



Online Forums

All information and articles provided on our website and forums are to be used as a guideline only. For your own safety, please always consult with a doctor or specialist before making any decisions regarding your health care. Information disseminated through these forums is not necessarily endorsed by Hepatitis Australia or other hepatitis organisations.

Hep C Australasia

W: www.hepcaustralasia.org

Hep C Australia

W: www.hepcaustralia.com.au

Other national contacts

Australian Injecting and Illicit Drug Users' League

AIVL is the peak organisation representing state and territory peer-based drug user groups.

T: 02 6279 1600

W: www.aivl.org.au

Haemophilia Foundation Australia

Haemophilia Foundation Australia is the peak organisation representing state and territory haemophilia foundations.

T: 03 9885 7800

E: hfaust@haemophilia.org.au

W: www.haemophilia.org.au

Telephone Interpreter Service, National

TIS National can provide telephone and on-site interpreters for non-English speakers.

T: 131 450

Australian Acupuncture and Chinese Medicine Association

T: 07 3324 2599
1300 725 334
(for national practitioner referral service)

W: www.acupuncture.org.au

Information in other languages

HIV/AIDS & Hepatitis C

A multilingual website on HIV/AIDS and hepatitis C for people in Australia.

W: www.multiculturalhivhepc.net.au

In Your Language

W: www.health.vic.gov.au/ideas/diseases/language

hepatitis
australia

Infoline: 1300 437 222