

# moving on after treatment

a post-treatment guide for people with hepatitis C

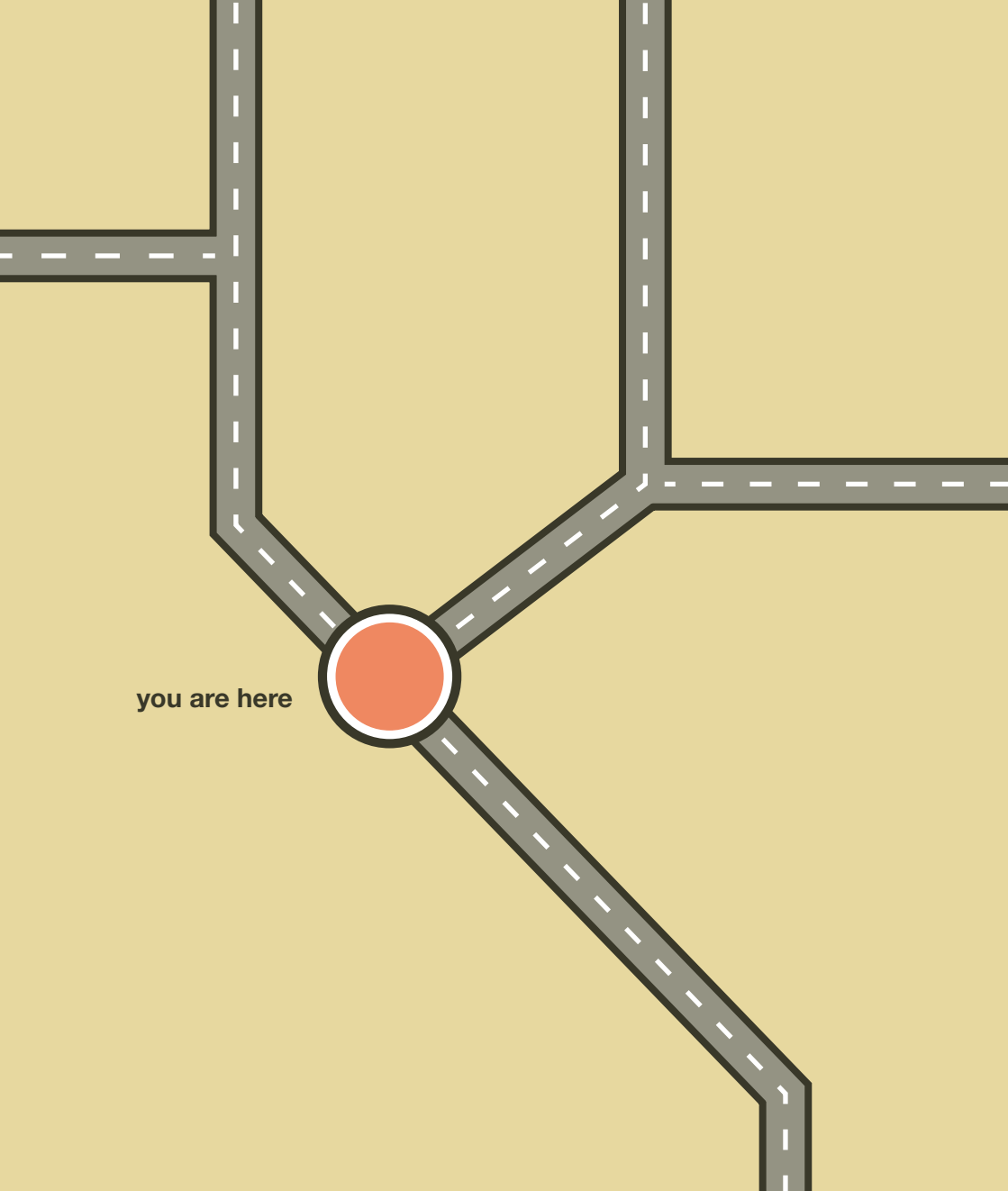




<b>Introduction</b> .....	1
<b>Chapter one – health and well-being</b> .....	5
Physical changes from treatment.....	7
Anaemia .....	7
Eyesight.....	7
Hair loss .....	7
Headache.....	8
Joint and muscle pain .....	8
Liver pains .....	8
Mouth ulcers.....	9
Muscle tone.....	9
Skin conditions.....	9
Thyroid.....	9
Tinnitus.....	10
Other health problems or changes.....	11
Impact of treatment on other areas of your life.....	15
Alcohol consumption.....	15
Methadone Maintenance Therapy (MMT) .....	16
Blood awareness .....	17
Cirrhosis.....	17
Contraception.....	17
Eating and food.....	18
Energy.....	20
Libido.....	21
Quality of life.....	22

*continued...*

Other interventions or procedures.....	22
Contact with health professionals after treatment.....	23
Post treatment considerations.....	25
<b>Chapter two – work.....</b>	<b>29</b>
Workforce issues.....	30
<b>Chapter three – relationships.....</b>	<b>33</b>
<b>Chapter four – stigma and discrimination.....</b>	<b>37</b>
Your rights.....	38
At work.....	38
In the home.....	41
In the community.....	41
Healthcare settings – hospital and community.....	42
<b>Chapter five – support.....</b>	<b>43</b>
Allowances and benefits.....	46
Family Carer Allowance.....	46
Where to get support.....	47
Hepatitis Councils.....	47
National organisations.....	48
Glossary.....	49



you are here

introduction →

This resource is for people who have used antiviral treatment for hepatitis C. It provides information about some issues they may have to deal with now that their treatment with monotherapy (interferon) or combination therapy (interferon and ribavirin) has finished.

Partners, families and friends of people who are on treatment or who have completed treatment may also find this resource useful in understanding issues that people who have undertaken treatment have to deal with.

Many people with hepatitis C are only now discovering what it is like to have undertaken treatment and are now either living with, or without, the virus. They have experienced the ups and downs of taking therapy and are now thinking about their life and health after treatment.

Through the personal experiences of others who have been through treatment, this resource provides suggestions for how you can move on with your life after treatment.



**‘It is now five months after my last [interferon] injection. I survived. That in itself is something to be proud of – I count it as one of my greatest achievements.’**

## How to use this resource

In using this resource, it may help to understand the terms and language used by treatment centres to explain how you responded to treatment.

An end of treatment response	This is measured at the end of a course of therapy (eg, 24 weeks or 48 weeks) by looking at your ALT values and a PCR test (also called a HCV RNA test).
A sustained virological response	You completed treatment and tested PCR negative (no detectable virus six months after the end of treatment). A successful treatment outcome. While your specialist will have monitored your response to treatment during therapy, your treatment outcome is not measured until six months after the end of treatment.
A relapse*	During treatment, your ALT values become normal and hepatitis C virus is undetectable; but the end of treatment, your ALT values are abnormal and hepatitis C RNA (HCV-RNA) is detected (eg, you were PCR negative after week 12, but PCR positive at week 24 or 48).
A non-response*	You may have stopped treatment, either because of side effects or you did not have a normal ALT or undetectable HCV-RNA (from a PCR test) during the course of treatment.

*\*While a relapse and a non-response are sometimes referred to as unsuccessful therapy, this does not necessarily mean that you have 'failed' treatment – it means that treatment has not worked for you.*

Having now finished or stopped treatment, you fall into one of the areas below:

- you have been successful in clearing hepatitis C; that is, the virus is undetectable (PCR negative)
- you have relapsed and the virus is still present (PCR positive)
- the virus did not respond to treatment and treatment was stopped, which means the virus is still present (you remain PCR positive)
- you ceased treatment because of side effects or other reasons and the virus is still present.

The five chapters of this resource provide information about some topics you can think about now that treatment is over.





**‘Because of treatment I re-assessed my priorities. It’s quite true: a bout of ill health means we value in retrospect our good health. It makes us realise how much of this precious life we waste on the mundane, the petty and the inconsequential.’**

Many people may feel that they are not the person they were before treatment. Partners, families and friends of people on treatment sometimes notice changes. These relate to the physical, mental, emotional and life changes that treatment can bring.

The physical and mental aspects of treatment, such as weight loss, loss of muscle tone and mental health issues, may leave people feeling changed both in body image and in how they think. Emotionally some people feel different. This includes their feelings about close friends, their family or partners, work and the loss (or gain) of relationships.

After treatment, some people make changes to their priorities in life. Time becomes more precious and their preferences and attitudes may change. Their focus now turns to quality of life issues and decisions, such as health and lifestyle, work (including changing work times or places) and relationships.

For some, the time after treatment is one of relief, happiness and closure. They may have been successful in clearing the virus and feel like they have a whole new life. Their energy levels rise, they feel healthier and their confidence and self-esteem is high. While having hepatitis C and going through treatment may have been a frightening and gruelling experience, they are recharged and stronger.

Even if you were not successful in clearing the hepatitis C virus, your health may have benefited from having undertaken treatment. Treatment for hepatitis C can reduce or slow down liver damage and this can have a positive impact on your overall health and well-being.

# Physical changes from treatment

Some of the physical changes you may experience during and after treatment are mentioned below. Detailed information about how these changes affect your health and what the implications are for you should be sought from your doctor, as these changes affect each individual differently.

## Anaemia

A common side effect of ribavirin is anaemia. This means your blood counts need to be monitored closely by your doctor, especially during the first few weeks of treatment. This type of anaemia is caused by a destruction of red blood cells and the release of haemoglobin. It is often experienced as reduced energy, feelings of lethargy, shortness of breath and sometimes weakness.

Ribavirin-induced anaemia responds to a reduction in the dose of ribavirin, and it usually settles down within a number of weeks of completing treatment.

## Eyesight

Some people with hepatitis C report being more sensitive to light and, after starting treatment, experience an even greater sensitivity to light. Many people find that they need to wear sunglasses more often which can help reduce the amount of light exposed to the eyes.

Some people report a rapid deterioration in their eyesight during and after treatment. This is because of changes to the muscles within the eyes that allow us to focus. People on treatment who already have weak eyesight are at a higher risk of this side effect. Persisting eye problems usually require permanent correctives devices like glasses or contact lenses. It is important to report any changes in your eyesight with your doctor and ophthalmologist.

## Hair loss

Hair loss, also known as *alopecia*, is a potential side effect from treatment and it can be worse for the first few weeks following the commencement of treatment. Patchy hair loss may continue for a number of months after treatment, but it is temporary and hair will slowly grow back, although this may take up to 18 months after treatment has stopped.

If you had long hair before treatment, you may be concerned about others noticing your hair loss or thinning hair. A shorter haircut can make hair loss less noticeable.

## Headache

Headaches and migraines are common during treatment. Many people use paracetamol to relieve headache symptoms, but it is advisable to talk to your doctor about managing headaches, the safe dosage level of paracetamol for you and the effects of paracetamol on your liver.

Within a month after treatment, headaches usually become less frequent and severe. Generally, there is no lingering headache or migraine by six months after treatment. Complementary and alternative therapy practitioners can also provide advice about managing headache symptoms.

## Joint and muscle pain

Also known as *arthralgia*, joint and muscle pain may persist after completing treatment. The ankles, knees, wrists and elbows, and occasionally lower back are common areas where pain is experienced. It can be constant and disrupt daily activities like walking, driving a car, grocery shopping, working or general chores. It may also be felt as a 'dull' pain, which is mainly annoying.

Joint and muscle pain may be relieved through massage, relaxation therapies or other manipulative body based systems like osteopathic medicine. If you are experiencing pain during certain activities, take a break and don't be afraid to ask for someone's help.

## Liver pains

Also known as 'right upper quadrant pain' (the area directly under and beneath the lower edge of your right side ribs – where your liver is located). This pain can be experienced as either sharp or 'dull' feelings of discomfort in this region. People who are PCR negative six months after treatment ceases should find a noticeable decrease in this symptom. For others, there is usually a decrease in the discomfort after completing treatment. Some people who have successfully cleared hepatitis C report liver pains beginning again after 12 to 18 months post-treatment. If this happens, it is important to see your doctor.

## Mouth ulcers

Mouth ulcers can be moderate or severe during treatment, although within a month of completing treatment, many people report this side effect has settled down. Doctors may prescribe bicarbonate mouth washes/rinses for treatment of mouth ulcers to alleviate pain and discomfort.

## Muscle tone

A loss of muscle tone can be a side effect of treatment. Some people find that they do not recover the muscle strength and bulk they had before treatment. This impacts on their physical energy levels and on their body image.

A healthy diet combined with regular exercise and slowly building-up to strenuous exercise or physical activity may help you regain muscle tone and bulk, although this can take weeks or months. Remember to take it easy at first and aim not to over-do exercise, as this can be harmful.

## Skin conditions

A common side effect from interferon is dry skin, which in some cases can blister or develop sores. Dry skin can become itchy and develop into a rash, which may be unsightly and cause discomfort. Talk to your doctor about the best treatment for dry skin. This side effect usually decreases soon after treatment has finished.

As interferon affects the immune system, it can also aggravate pre-existing skin conditions such as *psoriasis*. If this is the case, talk to your doctor about appropriate treatment.

## Thyroid

A rare side effect of treatment with interferon is disturbance of thyroid function. During treatment, thyroid function tests will monitor for this effect. Thyroid disorders are generally reversible and your doctor will recommend treatment should this occur.

## Tinnitus

Tinnitus may be experienced as a severe and constant ringing in the ears (when no other sound is present) during treatment. Many people find that the severity of tinnitus has decreased by six weeks after treatment, although over the next few months they may still experience periods of dull ringing. Reports suggest that this side effect has usually totally stopped between three to six months post-treatment. If not, seek medical advice.

Physical changes experienced:	Try...
Anaemia	It's important to talk to your doctor if you experience the effects of anaemia.
Dry skin	Skin conditioners or oil baths may help relieve dry skin. Other fungal skin conditions require pharmaceutical treatment – talk to your doctor.
Hair loss	A shorter cut – it may help disguise any hair loss until your hair starts to grow back.
Headache	During headaches and migraines try to relax, avoid bright light and loud noise. Try paracetamol instead of non-steroidal anti-inflammatory drugs (NSAIDS) or those containing aspirin. Specific aromatherapy oils may also help relieve headache symptoms.
Joint and muscle pain	Massage or relaxation therapies. Chiropractic medicine, osteopathic medicine or reflexology may also help. Talk to your doctor and a qualified manipulative body based therapist.
Liver pains	Reduce your alcohol intake and follow a healthy diet to help reduce liver pains. See your doctor if they are lasting.
Mouth ulcers	Ask your doctor to prescribe appropriate mouth wash treatments to relieve ulcers.





Muscle tone	To regain lost muscle tone, combine a healthy diet with regular exercise, slowly building up activity as you feel better.
Poor eyesight	Talk to your doctor if you experience ongoing eyesight problems.
Thyroid	Medication as prescribed by your doctor.
Tinnitus	Try to focus on other things if possible. Explore the use of herbal medicine. Tinnitus should decrease with time – if not, talk to your doctor.

## Other health problems or changes

Common side effects of therapy are changes in mood, memory and what seems like ‘brain fog’. Some people may experience these mental health issues for weeks or months after completing treatment. Forgetfulness and concentration problems may persist for as long as 12 to 18 months.

Experiences of time distortion or blurring are also common with people often referring to the whole treatment period as a ‘blur’.

**Brain fog** or feeling ‘foggy’ is often described as not being able to think straight, having a shorter attention span or decreased alertness, short term memory problems such as forgetfulness and losing track of thoughts. This should lessen after treatment has finished and within one month, you should feel your own self again. If it persists, discuss the symptoms with your doctor.

**Fatigue** can impact on work, family relations and other activities. It can cause you to be withdrawn, moody, cranky and irritable, have outbursts of anger and a lack of energy or feelings of physical weakness.

A good night’s rest will not always help you overcome fatigue. Making adjustments to your work, family and social life might help and professional counselling can provide an ongoing supportive environment, while helping you to learn new strategies to manage fatigue.

Fatigue can be difficult to manage because it can involve other factors, such as depression. Chronic fatigue is a recognised factor in the development of depression. Early warning signs are:

- not feeling refreshed after a good sleep
- trouble sleeping or falling asleep
- waking in the night and not able to return to sleep
- early waking (referred to as insomnia)
- wanting to sleep all the time.

**Depression** may be a significant problem both during and after treatment.

As your brain settles back into normal functioning after treatment, you may feel full of energy, happy and have a new appreciation for life. After a while, this can be followed by feeling down, finding life less enjoyable or losing interest in things that were important to you. Talk to your doctor if this is the case. Your mind and body have been through an ordeal and this can be a challenge for your body to cope with.

Feelings of being overwhelmed and not having much to look forward to are common. Sharing these concerns with your family, friends, doctor or local Hepatitis Council can help. Group or individual support networks may also be useful and these can be found through the Hepatitis Council or peer based drug user group in your state or territory.

Other approaches that may help include complementary medicine and/or alternative therapies, or talking through your feelings with a psychologist or counsellor. It is important to find one that you feel comfortable with. A doctor or psychiatrist may prescribe anti-depressants until your mood is stabilised.

If you were placed on anti-depressant medication during treatment, DO NOT stop your medication now that treatment has finished – even if you feel better. While it is suggested that you remain on your medication for up to twelve months after treatment (in total) before stopping to avoid a relapse of depression, you should discuss this with your doctor.



‘Three months after finishing treatment I decided to stop taking the antidepressant, as I was enjoying my life to the fullest and felt quite unstoppable...Five months on and I found it hard to believe that I could have found so many anxieties in my day-to-day routine as I once had. Why did I used to sit at the kitchen table and cry into my cup of tea before work? I felt like I had woken up from a bad dream.

It’s now 10 months since I completed treatment and unfortunately I’ve slipped back into depression. It’s hard to believe, when I had such clarity earlier in the year. Both my doctor and my counsellor say that my brain chemistry is still fragile. It’s not as bad as it was during treatment.’

Once treatment has finished, some people may find themselves ‘in limbo’. This refers to a feeling that they should somehow be or feel different after treatment, when in fact they don’t feel anything at all. Expectations that perhaps the treatment experience should have made you feel happier, better or more alive are not realised and this can create mental health problems.

Feelings of being ‘in limbo’ can linger for as long as six months after treatment. To reduce this feeling, try making short to medium term plans or start something that will bring short-term focus to your life (like a short course or hobby class). If anything, this may temporarily remove feelings that you haven’t moved forward or changed in any way.

Should you consider re-treatment with combination therapy, you may find that your mental health reactions to interferon are stronger than the first time you were on treatment.

Pre-treatment screening and counselling will help identify the likelihood of reactions occurring. Insist on having a pre-treatment ‘screening procedure’ if this is not offered. Regular health monitoring and follow-up over the first number of weeks of re-treatment will also identify any reactions to treatment.

**After treatment mental health issues summary:**

Brain fog	Should decrease within one month after treatment – if not, talk to your doctor.
Fatigue	Make changes to your work, family and social life if needed. Seek professional counselling to help you manage fatigue.
Depression	Share your concerns with family, friends or doctor. Counselling and complementary medicine may help. Your doctor may prescribe anti-depressant medication to help stabilise your mood. Check with your doctor before you stop taking prescribed anti-depressants.
“In limbo”	This feeling may last for about six months post-treatment. Make short to medium term plans or goals, which focus on ‘now’.
Re-treatment	Observe if you are feeling different or having different reactions to treatment this time around. Insist on pre-treatment counselling and screening. Discuss any issues with your treatment centre, specialist or doctor.

# Impact of treatment on other areas of your life

## Alcohol consumption

Regardless of your treatment outcome, it is important to remember that alcohol on its own causes liver inflammation. Given this, think about whether or not you wish to start or continue to drink alcohol and consider the advice of your specialist, doctor or treatment centre.

### Recommendations for alcohol intake based on stage of liver disease and duration of infection

Stage of fibrosis and duration of infection	Alcohol intake (upper limit)
Stage 0-1 (more than 20 years)	1-2 standard drinks per day (women), and 2-3 standard drinks per day (men)
Stage 0-1 (10 to 20 years)	1-2 standard drinks per day
Stage 2 (more than 10 years)	0-1 standard drinks per day
Stage 2 (less than 10 years)	No alcohol
Stage 3-4 (any duration)	No alcohol

*Stages of fibrosis:*

0 = no scarring

1 = minimal scarring

2 = moderate scarring

3 = severe scarring

4 = cirrhosis



**'I was prescribed complete abstinence from alcoholic beverages. It was difficult. I obliged and it was followed by an immediate disappearance of the discomfort felt on my right side.'**

If cutting out alcohol entirely is not an option for you, consider reducing the amount you drink or trying one week without it. Then measure how you felt in the week you reduced or gave up alcohol compared to the week you drank. The change in your health state may be noticeable enough for you to consider longer-term strategies for reducing or giving up alcohol. Some of these are outlined below and can be used to maintain good liver health:

### **Alcohol Management Guidelines for a person with Hepatitis C**

- Avoid binge drinking – it places a heavy strain on the liver to detoxify and metabolise the alcohol.
- Start with a non-alcoholic drink, especially if you are thirsty. This will help reduce the amount of alcohol being processed by your liver over a short period of time.
- Alternate usual drinks with alcohol free or low alcohol drinks. This gives your liver a chance to metabolise the alcohol already in your body without over-burdening your liver for a long period of time.
- Switch to low alcohol drinks altogether.
- Try not to drink in rounds. Determine your own drinking pace rather than being locked into other people's.
- Have at least two alcohol free days a week. This allows your liver a chance to recover from the effects of alcohol consumption. It will also leave your liver in a better state when you next consume alcohol.
- Contact an alcohol information and support service if appropriate.



**'It is no use to tell a person with hepatitis C they have to give up drinking. They need to be provided with the tools and support to make that change.'**

If you need support for any concerns about alcohol, your local Hepatitis Council or alcohol and drug services can provide information and referral contact details.

### **Methadone Maintenance Therapy (MMT)**

Using methadone while on treatment for hepatitis C appears to have little, if any, impact on the outcome of treatment. Using heroin, and some other

drugs, can result in a lower sustained viral response (SVR).

If you are receiving MMT, and have completed treatment for hepatitis C, your GP and specialist should be advised (as they would be pre-treatment). There do not appear to be any negative consequences with the use of methadone before, during or after treatment for hepatitis C.

## Blood awareness

It is important to be aware of the different ways that you could be reinfected with hepatitis C, so maintaining blood awareness is crucial.

Blood awareness is particularly important where any injecting equipment is reused, handled or passed to other people. You could be reinfected with a different strain of hepatitis C that is not as responsive to treatment.

More information about blood awareness when injecting, or in the household, is available from your local peer based drug user organisation or Hepatitis Council (see support directory on page 47).

## Cirrhosis

If you have cirrhosis, going on treatment may have had a beneficial effect on your liver and helped improve your overall health. However, you are likely to experience low levels of energy after treatment and this may continue for some time. To maximise energy, it is important to have adequate rest and maintain a good diet. It is also important that you have regular health check-ups so that your doctor and specialist can monitor your condition.



**‘I was glad to finish. I had counted down the days and tried to imagine what ordinary life was like and was plagued by the notion that I would feel no different after I finished treatment.’**

Detailed information about the impact of cirrhosis is provided in the booklet, *Living with Cirrhosis*, available from your local Hepatitis Council.

## Contraception

To prevent pregnancy during treatment and for six months following the end of treatment, both you and your partner are required to use contraceptives.

This is because ribavirin causes birth defects. Ribavirin stays in your body for weeks after treatment and is present in all body fluids, including sexual fluids.

If you or your partner believes there is a chance of pregnancy, talk to your doctor and seek advice. If pregnancy is confirmed through testing, your doctor will assess the danger to the foetus and counsel you further about your options.

## Eating and food

Interferon is known to cause nausea, appetite loss and weight change. Many people find that it can be hard to eat well and minimise their weight loss during treatment. Food that was once enjoyed may not taste the same or have the same appeal. Other people find it hard to prepare and eat food because they don't feel hungry.

After treatment many people may find that their approach to food changes. They are able to eat more and food becomes satisfying again. There is often a need to gain the weight they lost during treatment, so eating more becomes a necessary part of moving on after treatment.

To help you and your liver stay as healthy as possible:

### 1. *Eat a balanced diet*

- Choose a variety of foods from all food groups.
- Be aware of your fat intake (especially if this was an issue before treatment).
- Try new foods in moderation, particularly if you are feeling better. If you found it difficult to eat during treatment, give your body time to adjust to larger quantities of food. Eating smaller meals more often may help – it can also relieve bloating or discomfort from eating larger meals.

### 2. *Moderate your alcohol intake*

If you stopped drinking alcohol before and during treatment, and want to include it in your diet, take it slowly – your liver needs time to cope with alcohol again (this relates to the enzymes used to metabolise alcohol). Depending on your treatment outcome, get advice from your specialist, doctor or Hepatitis Council about whether drinking alcohol is recommended. Refer to the following table for further information.

Treatment outcome	Eating	Drinking alcohol
Sustained response	Consider a healthy diet with adequate water intake. A well-balanced diet can help you maintain a healthy weight, boost your immune system and give you more energy. Reacquaint yourself with certain foods slowly and in small amounts. Make note of foods that make you feel sick and consider alternatives or other food options.	You may want to reintroduce alcohol into your diet again, but are worried about how it will affect your health. Take it easy – your liver has to recover from the impact of the virus.
Relapse	You may need to build up to eating food that you avoided during treatment. You may notice a change in how certain food reacts with your liver now. If considering further treatment, eat healthy food, increase your weight and build your strength before trying again.	If you drink alcohol, reduce the amount you drink, particularly before reconsidering treatment. If you stopped drinking during treatment, try to continue this in preparation for any further treatment.
Non-response or treatment stopped	A well-balanced diet has many benefits – it can give you more energy, boost your immune system, help you maintain a healthy weight and reduce your risk of diseases like heart disease and cancer. Ask your doctor to refer you to a dietitian or nutritionist for advice about healthy eating goals. Complementary medicine can help managing symptoms.	The risk of developing cirrhosis is higher for people with hepatitis C, particularly if they are heavy drinkers. Think about reducing or giving up alcohol and get support to help you do this.

## Energy



**'I am off it [treatment] for a month. I feel better than when I began but still tire easily... I gave up a lot of things that I used to like to do.'**

Your energy levels may gradually increase now that treatment has finished. Make the most of the times you feel OK, but take it easy and increase your physical activity over time.

If you push yourself too hard or do more than your body can handle, you may feel fragile or 'off-colour' for a few days afterwards. This feeling can persist for between six to twelve months after treatment.



**'I've learned to pace myself – or rather I broke the habit of rushing frantically from one place to another. I learned that there is no need to rush, ever. If I'm late, then I shall arrive organised and unflustered.'**

Daily low impact activities can help build fitness. Simple things are best – like bicycle riding – ride a little further each day/week, getting off at the bus stop one stop earlier and walking, or taking short walks and increasing the distance each day or week.

If you have less energy, or feel like your energy levels increased for a while but then started to decline, talk to your doctor. Physical exhaustion is often associated with mental exhaustion. Constant low energy levels or decreasing levels of physical energy can be an initial sign of fatigue associated with mental health matters.

Sometimes your doctor might want to do follow-up blood tests on your liver and thyroid function. Thyroid problems can affect your energy. If your doctor finds anything irregular, it is important that you both discuss the right approach for you.

If after treatment, you are experiencing tiredness and chronic fatigue (not related to mental health issues), adequate rest, a good diet, time and moderate exercise can help relieve and overcome these symptoms. Other strategies that can help include:

- planning each day carefully and allowing adequate rest times
- moderate exercise
- avoiding exercise programs or competitive sports that involuntarily force you to do more than is practical or reasonable for your body.

Exercise is effective in reducing fatigue and depression, and increasing energy. If you want to exercise, choose an activity that you enjoy, can participate in on a regular basis and one that involves rhythmical breathing (eg. swimming and walking). Talk to your doctor or specialist if fatigue becomes severe and lasts for more than a few weeks. More information about fatigue is on page 11.

## Libido

During treatment, some people find that their desire and need for sex stops due to interferon's actions on the brain. Other reactions such as nausea, tiredness, stress, anxiety and depression can also contribute to a lack of sex drive.

Once you have completed treatment, your sex drive should return to normal. If this hasn't happened six months after treatment, talk to your doctor. It could mean there are other health problems causing a decrease in your libido.

A loss of sex drive also affects your partner/s, who may pressure you or be frustrated at your lack of interest in sex. Often these reactions are due to a lack of understanding about the physical and psychological impacts treatment has. It is important to discuss these issues with your partner/s. Your doctor, support groups or counsellors are people to turn to for help – often an independent person can lessen the stress, remove any blame and help build a new understanding of each other's wants and needs.

## Quality of life

It is likely that you lived with hepatitis C for years before you used treatment, so you may well be aware of the impact the virus has on your quality of life. Even if your treatment was successful and you cleared the virus, your liver will have suffered damage to some extent and you may continue to live with the effects of having had hepatitis C for some time.

Treatment is in itself one approach to living with hepatitis C but not the only one. Using more than one approach can be helpful to different areas of your life, but all have a beneficial impact on your health, longevity and quality of life. These include the use of a range of alternative therapies, adopting healthy lifestyle changes (including diet, exercise, sleep management and stress reduction) and using support networks to help bring your concerns about hepatitis C out into the open.

Support groups can help you cope with isolation, stigmatisation, family issues, treatment side effects and other issues. You may wish to continue to use support and therapy services as you move towards putting your life in order following treatment.

## Other interventions or procedures

Pharmaceutical drugs and medicines, complementary and alternative therapies and surgery can affect your liver after treatment.

Pharmaceutical medicines are metabolised in the liver and broken down, so that your body can use them. Many medications can be hepatotoxic. This means that they are toxic to your liver and can cause liver injury or damage.

Examples of these are:

- *Paracetamol* – generally safe for people without severe liver disease if taken at prescribed doses.
- *Anti-parasitic medications* – available from pharmacies for treating intestinal worms and can cause major alterations to your liver enzyme levels. Some of these may be available without a prescription.

- *Anti-fungal medications* – available from pharmacies for treating fungal infections (usually available by prescription only) and can also affect your liver.

*Your doctor or pharmacist can advise you about the safe use of medicines. As a general rule, check with them before taking any medicine.*

Depending on the outcome of your treatment, you may be considering using complementary medicine or alternative therapies to either help with hepatitis C symptoms or as an alternative to pharmaceutical medicine.

Get advice from a complementary medicine practitioner about the appropriate alternative therapies to use. If you have a supportive doctor and complementary health practitioner, it is wise to keep both informed about the types of medicines and therapies that each has prescribed.

If you need surgery, be aware that anaesthetics (especially general anaesthetics) often build up toxic products in your liver, which can take a number of days to remove. For people with hepatitis C, this can have adverse effects on liver function and greatly increase liver enzymes. Sometimes severe hepatotoxicity can also result. For surgery involving general anaesthesia, ask that *Propofol* and/or *Sevoflurane* be used. These are the safest agents for anyone with liver problems. *Isoflurane* and especially *Halothane* anaesthetics should be avoided as they have much higher rates of hepatotoxicity.

## Contact with health professionals after treatment

Whether you have completed or stopped therapy, it is important that you remain in contact with your doctor or specialist for after-treatment care. You may find this useful if you wish to have ‘closure’ after the treatment process. Likewise you may also find it difficult, particularly if your dealings with health professionals have been unsatisfactory and not supportive of your health care needs.



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

It is your right as a health consumer that you receive adequate follow-up from health care professionals. In some circumstances, this may mean you have to be pro-active in making appointments and requesting the care you need. It is difficult to know the level of care you will require after treatment, but discuss your health fears, doubts and needs with your doctor on finishing treatment.

An after-treatment health care schedule may involve:

- Appointments with your treating specialist every two weeks for the first six months and then every three months.
- A shared-care arrangement between your specialist and your doctor. This means your specialist and doctor will manage the level of care and visits you require. For example, where the doctor identifies particular concerns, it usually involves referral back to the specialist.
- Sometimes your doctor will not prescribe medicines if you have advanced liver disease (cirrhosis), preferring that your specialist be involved in recommending the medicine you can take.
- Contacting the Clinical Nurse Consultant or Liver Clinic Nurse at your local treatment centre. You would be familiar with these health care professionals having been through treatment and they can help organise quick referrals to doctors and provide local support contacts.
- Accessing support services or groups. Qualified counsellors, psychologists or social workers often provide support services. Support groups are designed to meet the before and after treatment needs in dealing with life and treatment fears, frustrations and many other matters.

## Post treatment considerations



‘A few weeks before my last injection I compiled a list of all the good things that treatment had brought, quite apart from the possible health benefits. I carry that list with me constantly now. It reminds me to embrace all of the fundamental changes in my life. Irrespective of the medical outcome, the treatment is already a success.’

Treatment outcome	Points to remember
<b>Sustained response</b>	
<i>“Six months after finishing treatment I was PCR negative. This was wonderful news. I have the reward I was hoping for, plus a dose of humility. I feel like I am getting on with my life since my diagnosis four years ago.”</i>	<ul style="list-style-type: none"><li>• You may have cleared the virus and normalised your liver function, but you still need to look after your health.</li><li>• Allow your liver time to recover from the impact of the virus – manage your alcohol use and play it safe with medicines and drugs.</li><li>• Eat a healthy diet, drink water and allow rest.</li><li>• Keep in contact with your doctor for six-month follow-up blood tests to check liver function and PCR status.</li></ul>

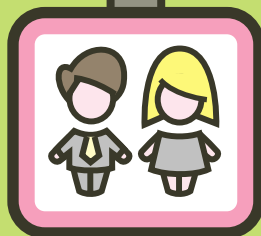


Treatment outcome	Points to remember
<p><b>Relapse</b></p> <p><i>"I only lasted three months on combination therapy due to my PCR tests not giving the doctors the results they wanted – even though my ALTs had dropped considerably. I was extremely disappointed with being taken off the medication. Afterwards, I still had regular blood tests and now have had three abnormal ALT tests. Treatment was worth the go. As they say, no pain no gain. Relapse is a kick in the guts, but I will get up there again and wait for the next treatment to come out and I will do it again. I pray each day that I will finally be rid of the virus."</i></p>	<ul style="list-style-type: none"> <li>• You haven't failed treatment – in this instance, treatment hasn't worked for you.</li> <li>• Be positive – you may have decreased your viral load, which can provide significant benefits to your health, liver function and quality of life.</li> <li>• If you wish to continue therapy to improve your chances of a PCR negative result, consider pegylated interferon. This is currently subsidised by the Government for monotherapy only, or may be available through the Compassionate Access Scheme as combination therapy (with ribavirin). Talk to your doctor about whether you are eligible.</li> <li>• Complementary medicine may help improve your general well-being.</li> <li>• Stay in contact with your doctor to monitor your health.</li> <li>• Have a liver function test every year.</li> <li>• Your local Hepatitis Council can provide support if needed.</li> </ul>



Treatment outcome	Points to remember
<p><b>Non-response</b></p> <p><i>“Even though interferon is not my answer, I am not disheartened or dispirited – quite the opposite. Having failed to respond to treatment, I have decided to be positive, live as healthy and enjoyably as possible (including the occasional light beer) and wait for future developments. The interferon program, at least in my case, was not a horrid experience and even being a non-responder was NOT the nightmare I initially envisaged.”</i></p>	<ul style="list-style-type: none"><li>• You didn’t fail treatment – treatment in this instance has failed you.</li><li>• Maintain a good diet and a healthy lifestyle.</li><li>• Consider complementary and alternative therapies, to help reduce stress, fatigue and improve well-being.</li><li>• Keep in regular contact with your doctor – other treatments may become available and it is important to monitor your health.</li><li>• Get support and information from your local Hepatitis Council.</li></ul>
<p><b>Treatment stopped due to side effects</b></p> <p><i>“I gave treatment a go, but had to stop part way through. It was exhausting and brought on depression and related anxieties. I thought about myself constantly for six months and felt little connection with anyone else. I was working full time and it was tough. Halfway through I went onto an anti-depressant for anxiety and depression. I had counselling also. It was a time of great pain, but also great personal growth for me. With the anti-depressant and counselling, I feel like I can give treatment another go.”</i></p>	<ul style="list-style-type: none"><li>• Consider anti-depressant medication if treatment was stopped due to mood changes. Once anti-depressant therapy is established (usually in six to eight weeks) you may be able to recommence combination therapy. Discuss this with your doctor.</li><li>• Complementary medicine and alternative therapies may help with the symptoms of hepatitis C.</li><li>• Hepatitis C information and support is available from your local Hepatitis Council.</li></ul>





work →

While on treatment, you may have made changes to your working life.

Many people use treatment expecting that afterwards they will be able to return to working more hours or a higher paid job, and other people may have this expectation of you. It can be disappointing to everyone, including yourself, if you cannot do this after treatment. It is important to remember that you have not failed. Regardless of your treatment outcome, therapy has made a direct impact on your health and it takes time to recover.

## Workforce issues

After treatment, readjusting to working can take time, particularly if you decreased your work hours during treatment. Side effects can persist for several months after treatment and you may need to increase your work hours gradually. Over-estimating your stamina and ability may put your physical and mental health under pressure and can result in fatigue.

Use time outside of work hours to rest, relax, exercise moderately and build your strength so that you can handle the demands of returning to work.

Some people change their employment before treatment so that their working reputation does not suffer if their ability to perform is reduced during treatment. They may take a position with less responsibility, less hours and less money so that they can focus on their health. If this is you, take time to return to higher duties or greater responsibility. Allowing yourself to recover from treatment means you are better equipped to cope with workplace pressures.

If you worked full-time during treatment but remain unwell since finishing, think about decreasing your work hours to give you time to recover. Consider changing to part-time employment if this is an option.

Centrelink may be able to provide income support. Check your award or certified agreement for information about options (in your terms and conditions of employment) and decreasing hours or changing from full time to part time or casual employment.



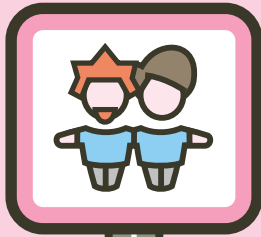
**‘Now, three years later I am still clear of the virus by yearly PCR tests. The treatment was hard to take but I was able to keep working full time by sacrificing everything else but my family and my job.’**

Financial or family responsibilities may have made it impossible to decrease work hours during treatment. If this was the case, practical options to help now that treatment has finished include:

- do one particular chore each evening so that the weekend is not full of house work and you have enough rest
- if you have access to the Internet, use home shopping – it can save time and reduce your fatigue
- ask other family members, housemates or friends to take turns at cooking or helping out with other household duties
- start a chores roster
- a cleaner for a few hours each fortnight/month can reduce your workload and save your energy for family and work.

Combination therapy is a form of chemotherapy (chemical therapy). Telling other people this can often help in their understanding of the type of treatment you have been on and its effects. Chemotherapy can be more socially acceptable and workplaces often understand problems with chemotherapy-based treatments better.





relationships →

People who are closest to you, whether they are your family, partner, housemates or friends have also experienced the realities of your treatment.

They have watched you deal with feeling ill and your physical and mental reactions to treatment. This may have had a lasting impact on your relationship with them – it could be stronger, it could be the same with no change to the way you feel about each other, or they may not be in your life any longer.



**‘In retrospect, it [treatment] strengthened my close relationships. It’s wonderful to watch them spring back into place, altered of course but fundamentally strengthened.’**

You may need to establish new relationship boundaries now that your treatment has finished. Your partner may not be able to tolerate certain behaviours, which were acceptable during treatment. Setting new boundaries can result from a better understanding of each other and acknowledging that treatment was hard on the relationship.

Your treatment experience may also have shifted your focus to your family being more important.



**‘Hepatitis C can impact on parenting and families. The impact of symptoms on the ability to have the physical energy to look after, interact with and raise children, as well as transmission risks are just a few.’**

Young children may find it difficult to accept or understand extended illness, as is the case with combination therapy. Living with a chronic disease like hepatitis C can mean making adjustments to your relationship with children and finding ways to help them learn and understand the impacts for you and themselves.



**‘My nurse educator is the best. She is available to me day or night and was able to give my kids a much better understanding of what I’m going through and put their minds at rest.’**

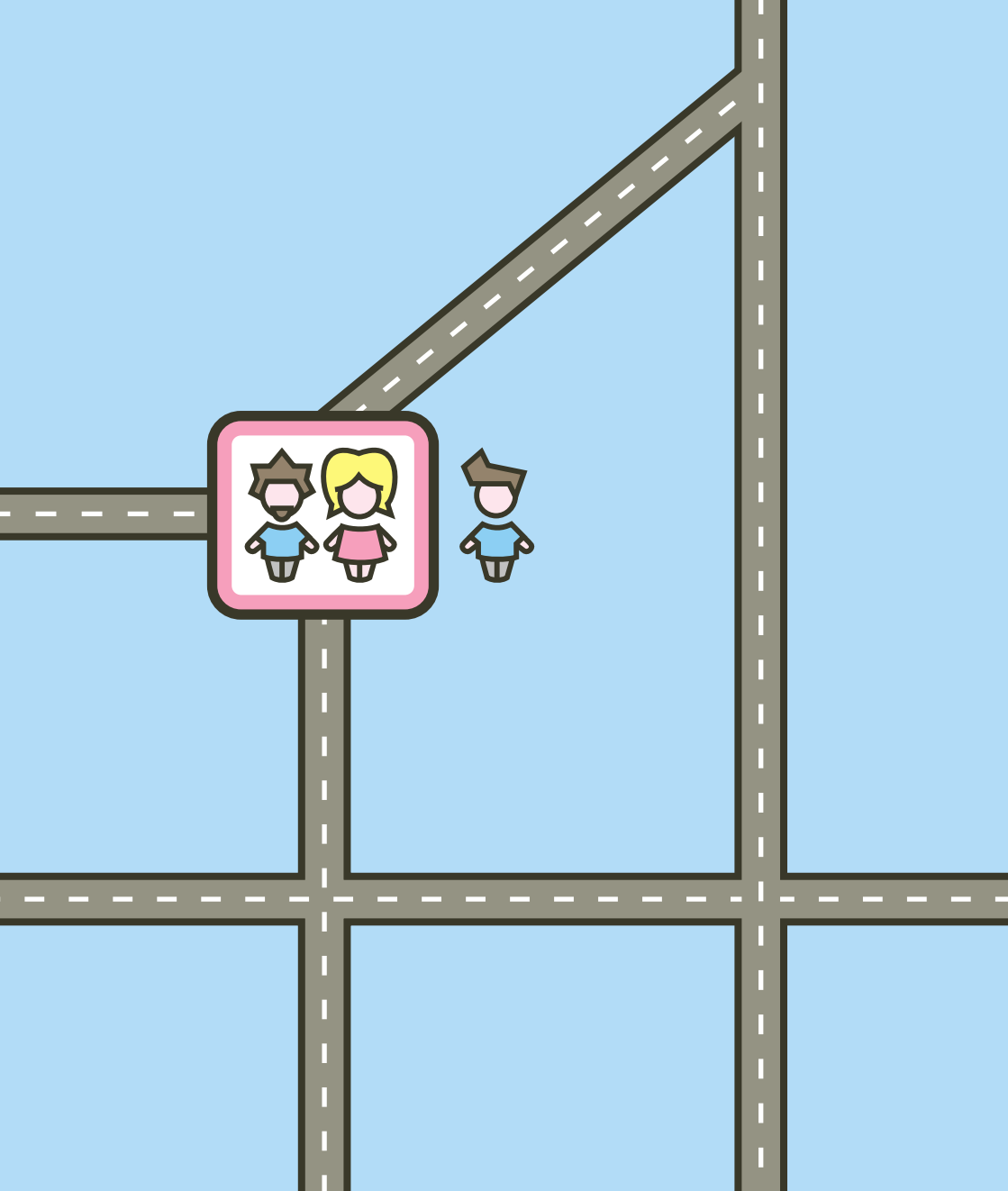
Missing out on family experiences because of hepatitis C can leave you feeling tired (fatigued), ill or depressed. After treatment has finished, involve those close to you in activities you can do together. Suggestions include going out to dinner, seeing a movie rather than getting a video, visiting an art exhibition, museum or seeing a stage show or going to the park for a picnic.

Sharing experiences together can be the focus of any activity. Having a rest before any outings will mean you are refreshed and able to be fully involved in the activity.



**‘The greatest cost to me has been all the experiences I’ve missed out on, especially with my children.’**





stigma and discrimination →

Stigma and discrimination about hepatitis C can come from family, social contacts, the community, workplace and health care settings – even from other people with hepatitis C.

Telling others that you were, or are, on treatment for hepatitis C can mean people may treat you differently. Their reactions to this information can differ depending on how much they know about hepatitis C, their relationship to you and their personal beliefs and assumptions.

Disclosing that you were on treatment may bring an expectation that you are now ‘cured’, when this is only one possible outcome. Some people find it easier to tell others they were on treatment because it helped explain their behaviour during treatment. Now that you have completed treatment, you may not think it necessary to tell anyone – regardless of your treatment outcome.

Ultimately, it is your decision whether or not you tell people that you have hepatitis C or are/were on treatment for hepatitis C.

## Your rights

Discrimination against people infected with hepatitis C or assumed to have hepatitis C is unlawful under the Commonwealth *Disability Discrimination Act*. If this has happened to you and you wish to take action, contact the Human Rights and Equal Opportunity Commission – they administer the Commonwealth *Disability Discrimination Act*. They can provide confidential advice by phone. Another way of making a complaint under the Commonwealth legislation includes contacting the Disability Discrimination Legal Centre in your state or territory.

In addition to Commonwealth law, there are *Anti-Discrimination Acts* in each state and territory, which outlaw discrimination based on disability. These *Acts* differ from jurisdiction to jurisdiction, but all the *Acts* cover discrimination against people with hepatitis C. Contact your local Anti-Discrimination body directly or talk to your local Hepatitis Council.

## At work

The workplace is a common site where people experience negative responses to having hepatitis C.



‘They’d associate hepatitis C with drug use so it would not have good implications for me. If I’d caught it some other way, or if the general understanding is that it can be caught some other way, then I would declare it. I’m sure that if it was common knowledge at work that I have hepatitis C, then I would not be promoted any higher.’

In any workplace, stigmatisation and discrimination can be as subtle as:

- being over-looked for promotion
- being excluded from conversations
- having workstations re-positioned or creating barriers (like using furniture, plants or other items to distance people)
- comments or discussions about your character
- not having opportunities for career advancement and training
- being dismissed.

Disclosing does not mean that everyone in the workplace is entitled to know about your hepatitis C or your treatment outcome. No one should know about your hepatitis C status that you have not told personally, or given consent to other people being informed. Insist that confidentiality is maintained and limited to those you disclosed to.



‘There has been a huge breach of confidentiality at work about my condition. The area director said to my manager: ‘I hear you have someone with hepatitis C working in your unit.’ To this day I don’t know how they found out. I feel I shouldn’t have told anyone. I blame myself for the breach. They couldn’t chuck me out, but they wanted to.’

In both the public and private sectors, the Commonwealth *Privacy Act* requires that any health and personal information collected is maintained in the strictest confidence and is used for and in the manner it was originally collected. Write to the Federal Privacy Commissioner with any complaint that you feel breaches this principle in the workplace, or in healthcare settings. Remedies can include written apology, reinstatement to the same position or one of equal value, or compensation.



**'I told them and I got the sack. That was it. On the grounds that I might bleed.'**

Pre-employment medicals often require you to disclose any disabilities, which might affect your ability to do a job. Hepatitis C is recognised as a disability under these circumstances. The requirement to disclose hepatitis C to new, or existing, employers' can cause anxiety. It can mean that you will be less likely to apply for particular jobs where this is a mandatory requirement, and it may mean you are unable to work in your qualified area or trade.

It is up to you whether to disclose that you have hepatitis C and there should be no obligation to do so if hepatitis C does not directly affect your working ability. However, where this inhibits you from seeking particular employment, you may wish to discuss your options with the Human Rights and Equal Opportunity Commission (or your local anti-discrimination agency) and your local Hepatitis Council (contact details on page 47).

Disclosing does mean that your employer is required to accommodate your needs so that you can carry out the requirements of your job. These arrangements might include reducing the amount of physical activity required, adopting flexible working times, changing from full-time to part-time employment or working from home. Depending on your treatment outcome, you may wish to update your health records with your employer.

Workplace counselling services or unions may help if you are having problems with discrimination in the workplace. They are obliged to maintain your privacy and not discuss your situation with anyone in your workplace, unless you consent. These services are often a good point of contact to help you decide whether an incident has occurred and help you work out a solution.

## In the home

Discrimination in the home is often a result of a lack of knowledge of hepatitis C and the ongoing effects of therapy and can be seen by a 'pulling away' or 'distancing' from relationships or close contact. Educating the household about hepatitis C can help and ways to do this include:

- Leave information pamphlets about hepatitis C around the home to encourage those close to you to read about the realities of living with hepatitis C, the effect of treatment and being blood aware.
- Calling a Hepatitis C Helpline.
- Seek formal counselling with a trusted doctor or community health centre to explore options in your relationships in a neutral environment.



**'Friction with my husband made things difficult. It was a fear born of ignorance. He said: 'What about our child. If you've given it to her then I'll....' By the time they'd been tested, I'd got onto the Hepatitis Council. They gave me information which I gave to my husband.'**

## In the community

Discrimination in the community usually caused by ignorance, fear of infection or a lack of knowledge about hepatitis C can result in social isolation, refusal of services, poor service, harassment, open hostility, ridicule and sometimes physical abuse.

You have the choice not to disclose your hepatitis C status to members of your immediate community. It is generally easier to only tell people that you are 'unwell' before, during and shortly after treatment. If you remain unwell after treatment, (for example are still PCR positive), you can say you are continuing to need treatment for your condition. Being vague or unclear may save you from getting a negative response.

Hepatitis Councils and similar community organisations are involved in holding awareness-raising activities designed to reduce discrimination in the general community.

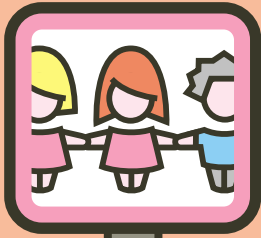
## Healthcare settings – hospital and community

Having been through treatment you may have already experienced both good and bad reactions in healthcare settings.

Healthcare workers are employed to provide high quality and informed non-judgemental compassionate care to everyone. This means that they should not judge you or discriminate against you because of hepatitis C infection.

If you experience discrimination in a community healthcare setting (eg. local doctor, specialist's rooms or dentist surgery), discuss the incident with the practitioner concerned or the practice manager. If this is too confronting or difficult, find a doctor/dentist whose practice is supportive of people with hepatitis C, who are professional and impartial, and who accept you for yourself. Your local Hepatitis Council, liver clinic or support group may be able to provide information about more supportive practices. As well, your Hepatitis Council may be able to advocate with you or on your behalf.

If you feel you have been discriminated against in a hospital, speak to the unit director or the medical co-ordinator, or put your complaint directly to the director of nursing, chief medical officer or the executive officer of the hospital. Consider putting your complaint in writing and request both an investigation and a written reply detailing all results. Provide detail about the incident; explain how this made you feel and your intention to pursue the matter further. Your complaint may inform the service/unit that changes in policy and attitude are needed.



support →

Depending on your treatment outcome, you may need to keep informed about hepatitis C and new treatments becoming available. Information and support can also help you find new ways of living with hepatitis C.



**‘Until I started treatment, I had neither met nor spoken to anyone who had Hep C. Now I realise just how isolated I felt, and how lacking in real knowledge about the virus I was.’**

Hepatitis Councils and peer-based drug user organisations provide services to people with hepatitis C including talking or listening to you over the phone, counselling, providing written information, education, support and referral, or by helping you to make contact with other people with hepatitis C.

Other places to look for support include:

Type of support	Where to look
<p>Family support</p> <p><i>Counselling for families</i></p>	<p>Community organisations such as Centacare, Relationships Australia, The Smith Family, the Salvation Army and community health centres offer support, education and counselling services for families in distress.</p>
<p>Support</p> <p><i>Support groups offer the chance to discuss issues you have with people in similar circumstances to yourself</i></p>	<p>Your local Hepatitis Council offers support services for people with hepatitis C (see page 47). You could also approach your local treatment centre to see if they have support groups.</p>
<p>Counselling</p> <p><i>Personal counselling can help you cope with the effects of hepatitis C (including mental health concerns)</i></p>	<p>Counselling services are often attached to public hospitals and treatment centres. They can suggest professional counsellors who specialise in hepatitis C related issues. Your local Hepatitis Council may also suggest relevant services. Other community and private organisations offer health counselling – look under Counselling-Marriage, Family &amp; Personal or Community Health Centres and Services in the Yellow Pages directory.</p>
<p>Other support services</p> <p><i>For specific community groups</i></p>	<p>Organisations such as peer-based drug user organisations, haemophilia organisations and government agencies provide support services.</p>

## Allowances and benefits

If you were unable to work during treatment, you may know about the *Newstart Allowance (incapacitated)*. This allowance lets you register for Newstart with appropriate medical evidence, usually a Centrelink doctor's certificate (most doctors have this form). It gives you time to recover without needing to attend interviews, write applications or work. However, there are strict criteria and limits on the amount of benefits that can be claimed and the benefit itself is asset tested.

If you lost your job while on treatment but are well enough to work, then Centrelink will usually place you on *Newstart Allowance*. To get this benefit you have to apply and attend a certain number of interviews per fortnight or work for the community good (the Work for the Dole scheme). Volunteer work for a community organisation is a good way of gaining new work skills, updating old skills and contributing to the community. Community organisations value the contribution of volunteers and often offer ongoing training courses.

Returning to work may not be an option for people with more advanced liver disease (cirrhosis) or those who continue to be unwell from hepatitis C treatment. The Centrelink *Disability Support Pension* may help in this case. The criteria for this benefit include:

- rating 20 points or more under the Centrelink Impairment Tables – this table rates severity of medical condition and symptoms
- being unable to work fulltime (or retained for fulltime employment) for at least two years
- being over 16 years of age but under retirement age.

### Family Carer Allowance

If your partner cared for you during treatment and you still need their continued care after treatment, they may be eligible for the Carer Allowance from Centrelink.

This allowance offers help towards covering expenses, services and programs (carer specific) and accommodation. The benefit is available to individuals who are caring for the frail, aged, people suffering ill health or people with disabilities, such as hepatitis C. It also covers caring for someone where mental health concerns exist.

## Where to get support:

### Hepatitis Councils

#### Australian Capital Territory

ACT Hepatitis C Council  
Canberra Business Centre  
Bradfield Street  
Downer ACT 2602  
Tel: 02 6253 9999  
Freecall: 1800 803 990  
Fax: 02 6253 9992  
Email: [info@acthepc.org.au](mailto:info@acthepc.org.au)  
Web: [www.acthepc.org.au](http://www.acthepc.org.au)

#### Western Australia

Hepatitis Council of Western  
Australia  
85 Stirling Street  
Perth WA 6849  
Tel: 08 9328 8538  
Freecall: 1800 800 070 (WA country  
callers)  
Fax: 08 9227 6545  
Email: [hepcwa@highway1.com.au](mailto:hepcwa@highway1.com.au)  
Web:  
[www.hepcwa.highway1.com.au](http://www.hepcwa.highway1.com.au)

#### Queensland

Hepatitis C Council of Queensland  
Level 2, Northpoint Building  
231 North Quay  
Brisbane QLD 4002  
Tel: 07 3229 3767  
Freecall: 1800 648 491 (QLD country  
callers)  
Fax: 07 3229 9305  
Email: [hepcq@hepatitisc.asn.au](mailto:hepcq@hepatitisc.asn.au)  
Web: [www.hepatitisc.asn.au](http://www.hepatitisc.asn.au)

#### New South Wales

Hepatitis C Council of New South  
Wales  
349 Crown Street  
Surry Hills NSW 2010  
Hep C Helpline: 02 9332 1599  
Freecall: 1800 803 990 (NSW  
country callers)  
Fax: 02 9332 1730  
Email: [hccnsw@hepatitisc.org.au](mailto:hccnsw@hepatitisc.org.au)  
Web: [www.hepatitisc.org.au](http://www.hepatitisc.org.au)

#### Victoria

Hepatitis C Council of Victoria  
Suite 5, 200 Sydney Road  
Brunswick VIC 3056  
Tel: 03 9380 4644  
Freecall: 1800 703 003 (VIC country  
callers)  
Fax: 03 9380 4688  
Email: [hepcvic@vicnet.net.au](mailto:hepcvic@vicnet.net.au)  
Web: [www.hepcvic.org.au](http://www.hepcvic.org.au)

#### South Australia

Hepatitis C Council of South  
Australia  
4 The Parade  
Norwood SA 5067  
Tel: 08 8362 8443  
Freecall: 1800 021 133 (SA country  
callers)  
Fax: 08 8362 8559  
Email: [admin@hepcouncilsa.asn.au](mailto:admin@hepcouncilsa.asn.au)  
Web: [www.hepcouncilsa.asn.au](http://www.hepcouncilsa.asn.au)

## Tasmania

Tasmanian Council on AIDS,  
Hepatitis and Related Diseases  
(TasCAHRD)  
319 Liverpool Street  
Hobart TAS 7001  
Tel: 03 6234 1242  
Freecall: 1800 005 900  
Fax: 03 6234 1630  
Email: [mail@tascahrd.org.au](mailto:mail@tascahrd.org.au)  
Web: [www.tascahrd.org.au](http://www.tascahrd.org.au)

## National organisations

Australian Hepatitis Council  
Suite 1, 20 Napier Close  
Deakin ACT 2600  
Tel: 02 6232 4257  
Fax: 02 6232 4318  
Email: [info@hepatitisaustralia.com](mailto:info@hepatitisaustralia.com)  
Web: [www.hepatitisaustralia.com](http://www.hepatitisaustralia.com)

Australian Injecting and Illicit Drug  
Users League (AIVL)  
PO Box 1552  
Canberra ACT 2601  
Tel: 02 6279 1600  
Fax: 02 6279 1610  
Email: [aivl@aivl.org.au](mailto:aivl@aivl.org.au)  
Web: [www.aivl.org.au](http://www.aivl.org.au)

Haemophilia Foundation Australia  
213 Waverley Rd  
East Malvern VIC 3145  
Tel: 03 9572 5533  
Fax: 03 9572 0622  
Email: [hfaust@haemophilia.org.au](mailto:hfaust@haemophilia.org.au)  
Web: [www.haemophilia.org.au](http://www.haemophilia.org.au)

Human Rights and Equal  
Opportunity Commission - *contact  
for details of State and Territory  
commissions*  
Level 8, Piccadilly Tower  
133 Castlereagh Street  
Sydney NSW 2000  
Tel: 02 9284 9600  
Complaints Infoline: 1300 656 419  
Fax: 02 9284 9611  
Web: [www.hreoc.gov.au](http://www.hreoc.gov.au)

# Glossary

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

**Antibody** – a protein secreted by cells of our immune system in response to infection.

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

**Autoimmune disease** – a disease where the body's immune system attacks other parts of itself, which become recognised as foreign (like viruses and bacteria).

**Chemotherapy** – a term used to describe treatment of a disease with drugs that eliminate or allow the immune system to effectively deal with a disease, when it would otherwise not be able to do so. Often associated with cancer treatment but not limited to this, chemotherapy is also used for treating autoimmune diseases like multiple sclerosis (MS) and rheumatoid arthritis.

**Cirrhosis** – a condition where scar tissue is present in the liver and spread throughout it extensively. It is permanent and interferes with the normal functioning of the liver.

**Combination therapy** – the use of ribavirin and interferon-alpha for the treatment of hepatitis C virus infection. It is a form of chemotherapy.

**Compassionate Access Scheme** – a scheme where a person is assessed and given special access to drugs not yet approved by the Commonwealth.

**Complementary therapy** – collectively considered as all the natural, alternative and holistic remedies that are available. These include herbal treatments, vitamin supplements, homoeopathic or naturopathic remedies and allied health services (acupuncture, chiropractic and others).

**Fibrosis** – scar formation resulting from inflammatory reactions within the liver and the repair of damaged tissue. If it occurs extensively in the liver, it is called cirrhosis.

**Genotype** – refers to the genetic type of the hepatitis C virus. Groups where only minor genetic variation exists are referred to as a particular genotype and have major genetic differences from other genotypes.

**Haemophilia** – a hereditary blood disease where the blood fails to clot and abnormal or excessive bleeding occurs. It can endanger a person's life and often requires medical assistance to aid the clotting process.

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

**Non-responders** – people with detectable hepatitis C (as defined through a viral detection test or PCR) after 12 weeks of treatment.

**PCR (polymerase chain reaction)** – technology used to amplify small amounts of virus to identify and prove that a virus is present. Also allows the viral load (amount of overall virus present) to be measured in a person's blood.

**Pegylated (interferon)** – a substance called polyethylene glycol is attached to an immunity-boosting protein (interferon) to extend 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. Each is made up of large combinations of amino acids, containing the elements carbon, hydrogen, nitrogen, oxygen, usually sulphur, and occasionally phosphorous, iron and iodine.

**Relapsers** – people who initially responded to a course of treatment and whose hepatitis C virus is undetectable, and subsequently return to abnormal ALT values with detectable hepatitis C virus.

**RNA** – ribonucleic acid, a genetic material.

**S100** – Section 100: a particular Pharmaceutical Benefits Scheme (PBS) listing of certain restricted and subsidised drugs. The Scheme establishes the criteria under which patients qualify for subsidised treatment.

**Shared care** – a partnership arrangement between health care professionals, usually with different skills, made to improve the care of patients with a chronic disease. Patients need to participate in the design of their own shared care arrangements.

**Sustained response** – the 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.



