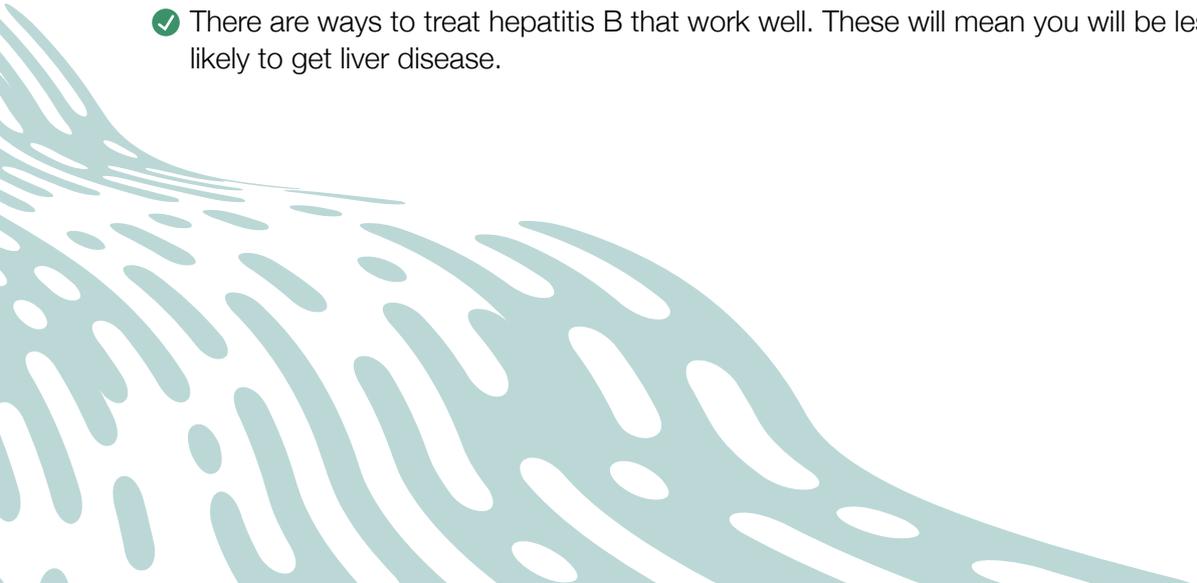


## Living with cirrhosis

**This resource is for people who have cirrhosis from hepatitis B or hepatitis C. It's also for their families and carers.**

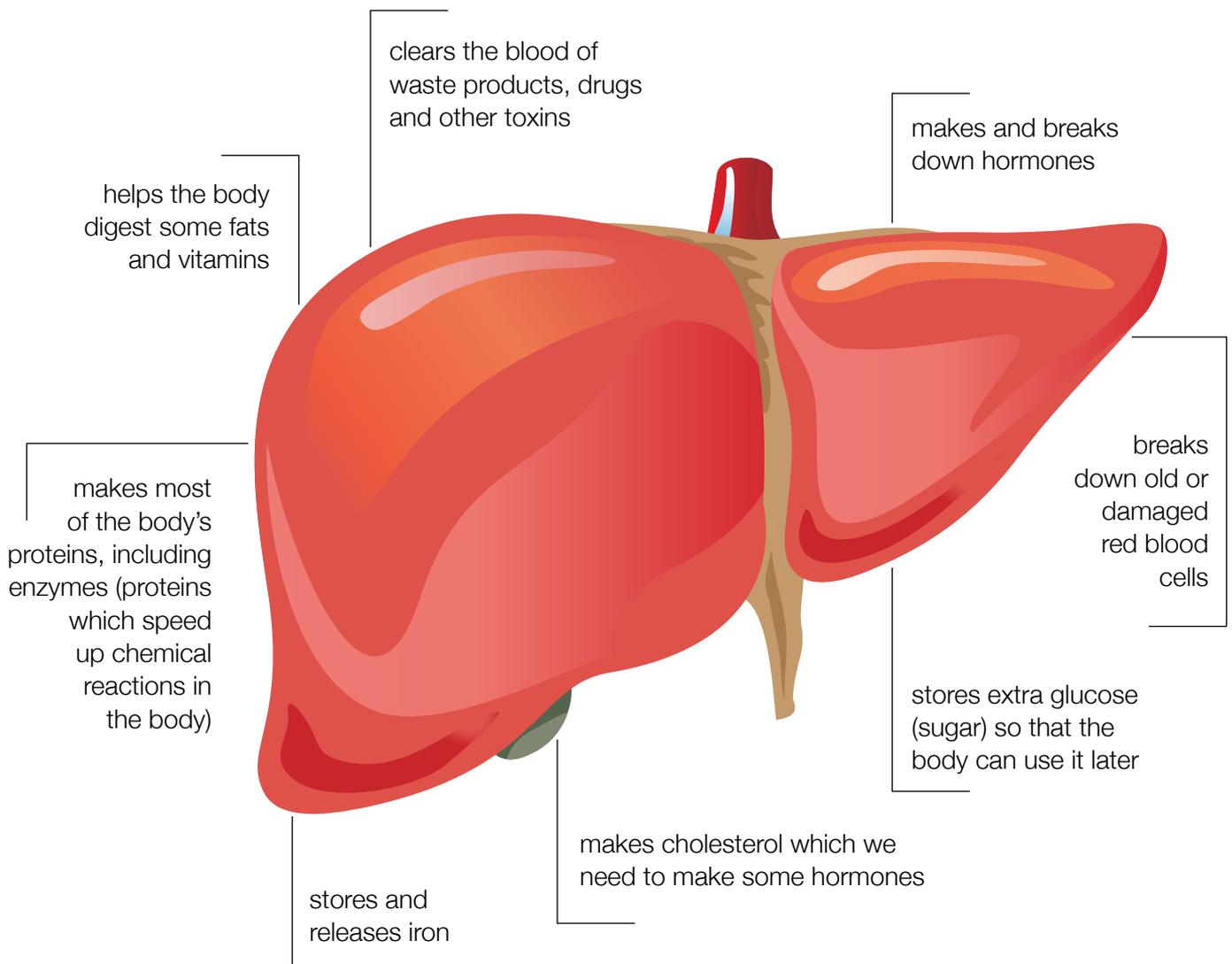
**This resource explains what can happen when you have cirrhosis. It will also tell you how you can look after yourself and live well with cirrhosis.**

- ✓ Having cirrhosis means that you have severe scarring on your liver.
  - ✓ In most cases it is a chronic condition, which means you have it for the rest of your life.
  - ✓ Proper treatment can lower the impact of cirrhosis on your health.
  - ✓ Almost everyone with hepatitis C can be cured. You just have to take tablets every day for up to 12 weeks.
  - ✓ There are ways to treat hepatitis B that work well. These will mean you will be less likely to get liver disease.
- 
- A decorative abstract pattern in the bottom left corner, consisting of light blue and white brush-stroke-like shapes that resemble a stylized wave or a series of overlapping, curved lines.

## Your liver

To understand how having cirrhosis may affect you, it helps to know what your liver does. Your liver is the largest organ in your body. It is important for keeping your body healthy. It makes chemicals in the body and breaks them down, helps us digest food and gives us energy.

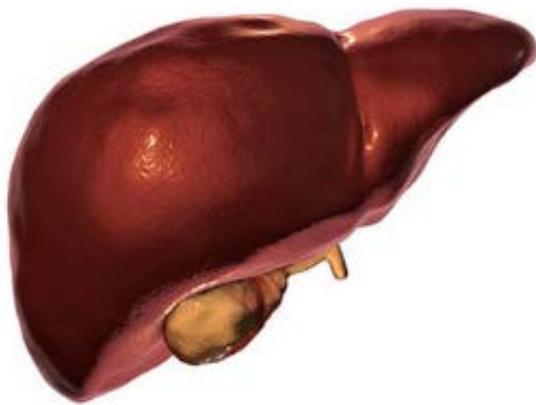
### Every day your liver:



It can still do all of those things even when it is damaged, just not as well. Your liver is also one of the few organs that can create new tissue and grow back.

## What is cirrhosis?

Cirrhosis is a condition where liver cells are damaged and replaced by scar tissue. Both hepatitis B and hepatitis C can cause cirrhosis.



**Healthy Liver**



**Liver with cirrhosis**

It usually takes 10-20 years for cirrhosis to happen. First, your doctor might tell you that you have something called fibrosis. If your fibrosis gets worse, it can cause severe liver scarring (cirrhosis). Cirrhosis usually lasts your whole life. But treating it early can mean that your liver isn't harmed too badly.

The scar tissue on your liver affects the flow of blood and other fluids. Without proper blood flow, the liver becomes hard and lumpy. It finds it hard to do its normal functions.

You might also hear your doctor talk about compensated or decompensated cirrhosis.

### **Compensated cirrhosis**

Compensated cirrhosis means your liver is able to make up for the damage. It can do everything it needs to do, even though it is harder.

People with compensated cirrhosis often feel fine. They might not have any signs of illness for many years. If you carefully treat cirrhosis during this stage, you have a much better chance of slowing or stopping further illness.

### **Decompensated cirrhosis**

Decompensated cirrhosis is much more serious. It means the damage to your liver stops it from working properly. You will start feeling unwell and your health will get worse. You need to talk about treating it with your doctor.

# What will happen to me if I have cirrhosis?

Many people are able to live a normal life and feel well for a long time with compensated cirrhosis.

There are lots of reasons why it might progress more quickly. For example, your age and if you have any other health issues.

Not everyone will have the same signs of cirrhosis, but some of the things that can happen are:



**Feeling less hungry, weight loss and weakness.**



**Muscle and joint pain**



**“Ascites”** (pronounced uh-**sai**-teez): more fluid in your belly. Your belly might grow larger and you might feel less hungry. You can also find it harder to breathe. It can also make your ankles swollen.



**Easy bruising and bleeding.** This happens because your blood does not clot as it should.



**“Encephalopathy”** (pronounced en-seh-fuh-**lo**-puh-thee): brain inflammation. Early signs are having trouble sleeping, or sleeping more. You might feel a change in your behaviour or mood (like feeling super happy or depressed). Or you might feel confused. You could even go into a coma because the liver can't get rid of waste from the body.



**Higher sensitivity to medicines and other drugs:** this means you feel the effects of medicines more. This happens because the liver can't clear them from your blood very well.



**Jaundice:** yellow eyes and skin because your body can't clear “bilirubin”. This is the yellow substance made when red blood cells are broken down.



**Skin conditions:** some people get dark spots, rashes, or dry and itchy skin. Some also get ‘spider naevi’. These are tiny red spots with red blood vessels coming out from the centre.



**Liver failure or liver cancer:** some people with cirrhosis may get liver failure or liver cancer.



**“Portal hypertension”:** Early on, this may not make you feel unwell. It happens when you have high blood pressure in the veins coming from the intestines to the liver. Smaller veins can burst from the pressure. This can cause bleeding from the stomach, gullet or rectum. This bleeding is very dangerous and can kill you.

**Some of these issues can be very serious. It is important to speak to your doctor or specialist if you have any of these signs of cirrhosis.**

**If you have any of the signs below, you must go to the emergency department (ED) or call 000 for an ambulance.**

- **Internal bleeding:** poo is black and looks like tar. Or your vomit has blood, or something that looks like coffee grounds.
- **Confusion:** you feel confused, cloudy, or more sleepy than you normally do. Do not drive yourself to the emergency room if you feel like this.
- **Fever:** Infections are more common in people with cirrhosis because the immune system is weaker. Sometimes fluid in your belly can become infected. Or an infection can move to the kidneys, bladder, or lungs. This can be life-threatening, it can kill you.
- **Jaundice:** if your eyes turn yellow, it could be a sign something is going wrong.

You should tell the emergency staff that you have cirrhosis. This will make sure you get the right care.



## What can I do if I have cirrhosis?

For anyone with cirrhosis, it is important to go for liver checks with your doctor. The doctor can check if your liver damage is getting worse (or better). Your doctor can also check for signs of liver cancer.

The sooner they notice any problems, the easier they are to treat.

Your doctor may tell you to get vaccines. For example, they might ask you to get a vaccine for:

- ✓ Hepatitis A and B (if you haven't had it already)
- ✓ Influenza
- ✓ Pneumococcal
- ✓ Shingles
- ✓ Tetanus
- ✓ Diphtheria
- ✓ Whooping cough

If you have signs of cirrhosis like fluid build-up or itching, talk to your doctor. They may be able to give you medicine, creams or tell you about other ways to help you feel better.

Your doctor may also tell you to you take some medicine to stop some of the more serious effects of cirrhosis.

Some medicines and procedures can help manage portal hypertension. These lower the chances of bleeding from the throat, stomach or rectum.

When you have cirrhosis, your body is more likely to feel the effects of drugs. This includes medicines from your doctor or pharmacy, herbal medicines, supplements, and traditional Chinese medicines. You should talk to your doctor before taking any type of medicine.

If the treatment of your cirrhosis works, it can help slow it down or stop it from getting worse. Sometimes it can get better. Which treatment you get depends on what type of hepatitis you have.

## Treatment for hepatitis C

There are now medicines for hepatitis C that work really well. These are direct-acting antivirals (DAAs). These are really simple to take.

You need to take 1 to 3 pills per day, for 8 to 12 weeks. They work more than 95% of the time. If you have cirrhosis, you will most likely need to see a specialist doctor to treat hepatitis C.

Sometimes taking this medicine can reverse cirrhosis. If you no longer have hepatitis C, and have cirrhosis, there are things you can do to look after yourself. To learn more, read the next section.



## Case Study

Julie\* got hepatitis C more than 30 years ago from getting blood from another person (transfusion). This was before we screened blood products properly. So it wouldn't happen now. She found out she had hepatitis C when she was in her late 60s. By then she had quite severe cirrhosis. Before treatment, her liver showed a Fibroscan® score of 25 kPa (kilopascals). A score over 12.5 kPa means you have cirrhosis.

Julie then took medicine (direct-acting antivirals) to cure her hepatitis C. She also changed her lifestyle:

- ✓ First she stopped drinking alcohol. Since she cleared the hepatitis C, she sometimes drinks a glass of wine but no more.
- ✓ She drinks more water.
- ✓ She gave up smoking.
- ✓ She now eats less fat and sugar.

- ✓ She eats less processed foods (like microwave meals, biscuits and cereal).
- ✓ She goes for a daily walk when she can.
- ✓ She gets plenty of rest.
- ✓ She saw her doctor every 3 months before getting treated. She still sees her doctor every 6 months to check on her liver.

Two years on from taking medicine, Julie is free from hepatitis C. Her Fibroscan® score is now 11.4.

Julie has to keep an eye on her blood pressure. She takes medicine for her blood pressure too. She tries to be less stressed. She tries not to put on weight, as this makes it worse for her liver. She is now quite well for a woman in her mid-70s with mild cirrhosis who has cleared Hepatitis C.

\*Not her real name

## Treatment for hepatitis B

At the moment there is no cure for hepatitis B. But there are treatments that work well to lower the impact of hepatitis B on your liver.

If you have cirrhosis, you will likely need to have treatment for the rest of your life. Talk to your doctor about whether to start treatment, and what treatment is best for you. You will also need to have check-ups often to check the health of your liver.

There are also some lifestyle changes you can make to help you live well with cirrhosis. You can read about these in the next section.

## Liver transplant

In some cases where cirrhosis is very bad and your liver has stopped working, you may need a liver transplant.

This is when you get someone else's liver put into your body. You should talk to your doctor about this if you have decompensated cirrhosis.

# How can I look after myself if I have cirrhosis?

There are lots of things you can do to lower the impact of cirrhosis and help your liver function well.



## Get regular liver checks from your doctor

If you have cirrhosis, you must get your liver tested every 6 months to check if there are

changes. This is the only way to know if the damage is getting worse. It helps your doctor work out if there should be any changes made to your treatment.

Liver checks often involve blood tests. They may also involve an ultrasound or transient elastography using a Fibroscan®. This test checks how stiff your liver is. Your doctor or specialist may also tell you to get a liver biopsy. A biopsy is when they remove a small piece of liver tissue using a needle.



## Drink less or do not drink alcohol

Alcohol can damage your liver. So if you have cirrhosis, drinking alcohol is likely to make the

damage worse. It is best to stop drinking alcohol completely. This can be hard, even if you don't drink a lot.

You can talk to your doctor if you need help to drink less alcohol. Or you can visit the [Alcohol and Drug Foundation](#) website to find support services near you.

These days there are lots of alcohol-free beers and wines, and other low-alcohol options that can help you drink less.



## Eat healthy foods

A doctor or dietician can look at how active you are, how hungry you get, and your body. They can give you advice on:

- How often to eat and how much to eat every day. Normally, people with cirrhosis eat a little bit of food often.
- What to eat. They can tell you how much of your food should be protein, carbohydrates, fat and salt

Drinking enough water and getting enough exercise are also important for your liver.

Some research suggests that drinking a bit of coffee is good for your liver health. It says that drinking some coffee can even lower your chances of liver cancer. But remember, it does not replace a healthy lifestyle.



## Stop smoking

Smoking can also damage your liver and can make you more likely to get liver cancer. You can talk to your doctor if you need

help to quit smoking or contact Quitline on 13 78 48.



### **Medicines, supplements and other drugs**

Other medicines can affect your liver, even if a doctor told you to take them. It is important you check with a specialist liver doctor before taking any medicine. This includes medicine you can get from a shop.

There are some supplements you can take which can help with nutrition or bone health if you have cirrhosis. But before you take anything, ask your doctor about it. This is for any type of herbal remedy, traditional Chinese medicine or supplement. Some of these may seem good for you, but they can be hard for your liver to process. This can be dangerous when you have cirrhosis.

Illegal drugs can also harm your liver. And they can make you more likely to get another blood borne virus or get hepatitis C again. If you need help to stop using drugs, you can ask your doctor for help or visit the Alcohol and Drug Foundation website to find support services near you.



### **Mental health**

It is important to take care of your mental health as well as your physical health. Having cirrhosis can impact your mental health in many ways. It can make you:

- feel confused or change your mood. This is due to “encephalopathy”, caused by your liver not clearing waste products well
- feel tired
- feel annoyed
- feel anxious or depressed
- change how you interact with others. For example you might not have much energy to spend time with friends. Or you might worry about telling people that you have liver disease.

You can talk to your doctor if you need more help to look after your mental health. Or contact a mental health service such as Beyond Blue for support on 1300 224 636.



# Useful services to get in touch with

## HepLink Australia: 1800 437 222

HepLink Australia directs you to the community-based hepatitis organisation in your state or territory. The people taking your calls are from organisations that are members of Hepatitis Australia. They give support in local communities and offer friendly and private help. You can find the contact details for hepatitis organisations at [www.hepatitisaustralia.com/local-hepatitis-organisations](http://www.hepatitisaustralia.com/local-hepatitis-organisations)

## Translating and Interpreting Service (TIS) National: 13 14 50

If you have a hard time understanding English, you can contact TIS National. They can give you information in your language. It is free for most people who don't speak English well.

You can visit the TIS National website for more information: [www.tisnational.gov.au](http://www.tisnational.gov.au)

## Alcohol and Drug Foundation

If you need help to slow down or stop using alcohol or other drugs, the Alcohol and Drug Foundation has a list of support services on their website: [adf.org.au/help-support/](http://adf.org.au/help-support/)

## Quitline 13 78 48

Quitline is a telephone advice and information service which is private. It helps people to quit smoking. You can also visit <https://www.quit.org.au/>.

## Beyond Blue 1300 224 636

Being told you have a health problem can be stressful and can lead to feelings of anxiety and depression. Beyond Blue can give you information and support for your mental health. They also have a chat service on their website: [beyondblue.org.au](http://beyondblue.org.au)

## HepBcommunity.org

[HepBcommunity.org](http://HepBcommunity.org) is an online discussion area for people who have hepatitis B. It connects people living with hepatitis B with scientists and doctors.

## Hep Forums

Hep Forums are an online discussion area for people who have Hepatitis B, C or a co-infection. It's also for their friends and family, and others with questions about hepatitis and liver health. To find the forums visit: <https://forums.hepmag.com/>



## MORE INFORMATION

You can find more information at [www.hepatitisaustralia.com/rights-and-responsibilities](http://www.hepatitisaustralia.com/rights-and-responsibilities)

### References

- [The Liver](#), Healthline
- [Cirrhosis of the liver](#), healthdirect
- [Cirrhosis](#), Mayo Clinic
- [What is Compensated and Decompensated Cirrhosis?](#) Hepmag
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- [When to go to the emergency room-Cirrhosis for Patients](#), US Department of Veterans Affairs
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