



The new name for the British Liver Trust
and Children's Liver Disease Foundation

Decompensated cirrhosis



A guide to
understanding
advanced
liver disease

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Welcome

Welcome to your guide to understanding advanced liver disease (sometimes referred to as '**decompensated cirrhosis**').

This information has been written for: **adults with decompensated cirrhosis**.

Unusual or medical words are highlighted in bold and explained in the glossary at the end of this booklet.

This booklet is one of a series about living with advanced liver disease. The other booklets include **hepatic encephalopathy (HE)** or brain fog, **varices and bleeding**, and **ascites**.

Visit our website to read and download all our information on cirrhosis.

Use this QR code to view our resources or visit **www.liveruk.org/cirrhosis**



How to say it:
si-ROE-sis



What is liver cirrhosis?

Advanced liver disease and cirrhosis can have several causes including drinking too much alcohol, viral infection such as **hepatitis B or C**, **metabolic diseases** such as **metabolic dysfunction-associated steatotic liver disease (MASLD)**, or other conditions such as autoimmune hepatitis.

These things all injure the liver. It repairs itself by replacing damaged cells with new ones. This usually works well but, when too much damage occurs or lasts a number of years, some of this repair work can leave scars (fibrosis). Having a lot of severe scars in your liver is known as **cirrhosis**. At this point, if care is taken, the liver can usually cope with the damage and maintain its important functions. During this period, which can last years, there can be very few symptoms or even none at all.

In advanced liver disease (decompensated cirrhosis) the scarring can become so great that the liver can no longer repair itself or function properly.



This can cause linked conditions like hepatic encephalopathy, ascites, variceal bleeds or liver cancer. In this booklet, we focus on general health and wellness.

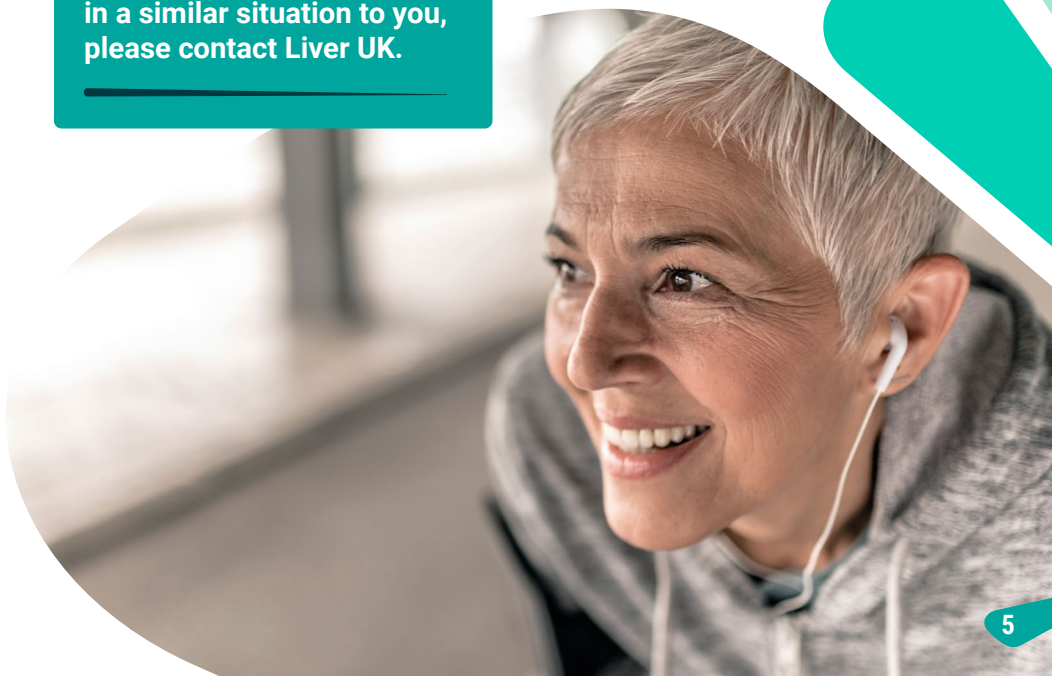
What can I do to look after my health?

Knowing that your health is at risk can be worrying. Being well informed and following advice from professionals should give you the best chance of living well with your condition. It's also important to remember, you are not alone.

Even if you have a serious condition, looking after yourself as much as possible can still provide you with some real benefits. It is important to try and maintain as healthy and normal a life as possible. Mostly, that means taking all your medicine just as your doctor and medical team have advised you to, eating and drinking well, avoiding alcohol and cigarettes, staying active and trying to prevent additional health problems like flu or pneumonia. It's a lot to think about but reading this leaflet can help to keep it simple.



If you would like to find out more or connect with others in a similar situation to you, please contact Liver UK.



Taking medication as prescribed

This is really important. Your condition is very serious and complicated and it is often the case that you will have other illnesses at the same time.

You may have many different medicines to take at different times of the day. They will all come with their own instructions. Get to know each of their names and what they do.

It's important to find a way that works for you to fit taking your medicines in with your life.

Try these tips:

- **Keep a diary or timetable.**
- **Ask a friend or family member to remind you.**
- **Add reminders to your smartphone or tablet.**
- **Use a dosette box.**
- **Keep your medicine somewhere you can easily see it - like keeping it by your toothbrush to remind you to take it when you wake up or before you go to bed.**



Be sure to keep taking your medication for as long as you have been instructed, even if you are feeling better or the symptoms seem to be easing.



Eating and drinking well

Getting your diet right is really important.

The nature of your illness means that your body has difficulty getting the energy and nutrition it needs from a normal diet.



It helps to have foods and drinks that are highly nutritious like vegetables, fruit and smoothies.

It's also important to have foods that are high in energy and protein. Try spreading out when you eat by having four to six smaller meals each day. And eat something before you go to bed. Starchy foods like cereal, porridge, or rice pudding are good choices.

Talk to your doctor or dietitian about creating a diet that is simple to follow and designed for your needs including any other conditions you have.



Read our Diet and Liver Disease booklet for detailed information and advice.



Alcohol and smoking

Drinking even a small amount of alcohol with your condition can be very dangerous.

This is even the case if your cirrhosis wasn't caused by alcohol. Drinking alcohol now will cause further damage to your liver, as well as being bad for your health in other ways.



Lots of people need some help to stop drinking alcohol, so there's no need to feel embarrassed. Talk to your doctor, they can refer you to your local alcohol service.

If you are dependent on alcohol, it can be dangerous to stop drinking suddenly. You might need medicine to help with withdrawal if you have symptoms including feeling anxious, sweating and tremors or shaking, feeling or being sick.

If you smoke, it's important to stop. Smoking can make your liver damage worse and puts you at higher risk of developing liver cancer.

Contact your local free stop smoking service or ask your doctor to refer you. They can help you find the best way to quit for you, even if you've tried before. Getting help from a stop smoking service makes you 3 times as likely to quit for good.

If you are being assessed or waiting for a transplant, it is very important that you do not drink alcohol or smoke.

If you are finding this difficult, talk to your transplant team.

**For advice about alcohol and smoking
visit www.nhs.uk/live-well**



Staying active

Sometimes, being active will be the last thing you want to do. After all, tiredness is one of the symptoms of your condition and your doctor may well have talked about the need for rest. However, when you are not resting, it is really important to stay as active as possible.

When you are active your heart and lungs work harder. This makes you carry more oxygen in your blood. The oxygen gets transported to your liver and helps it to work better.

Being active also helps build up your physical strength and resistance which helps you keep dangerous infections away.



Another issue with cirrhosis is that your body can struggle to maintain its usual muscle mass, because it's harder for your body to take in protein from food. Exercising your muscles can help to combat this.

The type of physical activities that are good for you come in many forms. From simply being active around the house, to being out and about walking, cycling, even playing sports. They can all help you become healthier and may even improve your chances of survival.

If it has been some time since you have really been active, or exercised, it is important that you begin at a level that is right for you. This might just be a light walk of 10-15 minutes in the beginning, some light swimming, seated exercises like leg marches, or using tins of food as weights.

Your doctor can recommend exercises for you to try. Or if you need more support ask them if they can refer you to a physical activity specialist who can create a personalised programme for you.

Whatever you choose to do, try to stick with it. The benefits of exercise may not always be obvious to begin with and it may take a while for you to notice any improvement.

But if you can keep going, after a month or two, you should start to feel stronger, healthier and a bit more positive.



Preventing other illnesses

Because of your condition, you will find that your general level of **immunity** to other illnesses is also a bit low. You will need to be extra careful to avoid catching things like colds or the flu.

People with advanced liver disease are at higher risk of being seriously ill if they catch COVID. Follow the latest government and health advice. And take any steps that help you not to worry, like wearing a mask or using hand sanitiser regularly.

You should talk to your doctor about vaccines for COVID, flu, pneumonia or other viruses, particularly in the winter.



If you are travelling abroad, make sure you have any vaccinations for that destination well before you travel.



Stress or depression

Having cirrhosis can put a lot of mental pressure on you, making you more likely to suffer from stress or depression.

Confusingly, some of the symptoms that can come with stress or depression are the same as those you might have because of your condition. But take a look at the list of symptoms to the right, and see if this sounds like something you are experiencing. If it does, talk to your doctor just to be sure as there are treatment options available and they may be able to help.



Common symptoms of stress:



- **Generally low on energy**
- **Headaches**
- **Trouble sleeping**
- **Tight feeling in the chest**
- **Rapid heartbeat**
- **Upset stomach, including diarrhoea, constipation or nausea**
- **Aches and pains**
- **Tightness in the muscles**
- **Loss of sexual desire**

Common symptoms of depression:



- **Loss of interest in daily life**
- **Feeling hopeless and helpless**
- **Change in your appetite or weight**
- **Generally low on energy**
- **Aches and pains**
- **Trouble sleeping**
- **Low mood or self-esteem**
- **Feeling tearful or full of guilt**
- **Irritated by other people**
- **Having difficulty making decisions**
- **Thoughts of suicide**

If you are struggling with your mental health, the Samaritans are there to listen. Nothing is too big or too small.

Call 116 123 any time you need to talk.



What more can I do for my health?

There is a lot to think about in terms of your health when you have cirrhosis.

To help you avoid feeling overwhelmed, here's a list of top-tips that can help you focus on the most important things and keep it simple and achievable:

- **Always take your medicine as instructed**
- **Eat a well-balanced diet that is high in protein and energy, with plenty of fresh fruit and vegetables**
- **Avoid processed food, fast food and ready meals**
- **Avoid smoking and alcohol**
- **Make sure you get a good balance of work, rest and exercise**
- **Have your vaccinations for COVID, flu and pneumonia**
- **Get help if you notice symptoms of stress, anxiety or depression**

Of course, you might need emotional support too, from family or friends or other people going through the same experience – talk to your doctor about special groups you may be able to join or places you could get specialist advice.

If you would like to find out more or connect with others in a similar situation to you, please contact Liver UK.





Glossary

Ascites: A build-up of fluid in the abdomen.

Cirrhosis: Where the liver has a lot of damage and scar tissue and can no longer repair itself and grow new cells properly.

Decompensated cirrhosis:

When the liver is so scarred and damaged it is no longer able to work properly.

Fibrosis: Scar tissue that can develop as a result of liver damage.

Hepatic encephalopathy:

A change in the brain that can occur in patients with advanced liver disease due to high levels of toxins in the brain.

Hepatitis B and C: Two conditions that cause inflammation of the liver due to viral infection.

Hepatocellular carcinoma:

A type of liver cancer. Cirrhosis increases the chance of developing this condition.

Immunity: This is a measure of how well your body is able to defend itself against infections.

Liver: The largest organ inside the human body. Among other things it removes toxins from our blood, produces hormones, and helps control blood sugar.

Metabolism: How the body produces, uses and stores energy from food.

Metabolic dysfunction-associated steatotic liver disease (MASLD): MASLD is when you get a build-up of fat in your liver.

Toxins: Harmful chemicals that can enter the body through our normal daily activities such as eating, drinking and breathing. A healthy liver helps to remove toxins from the body.

Variceal bleed: When small veins (known as varices) burst, causing serious bleeding.

Varices: Small veins that have become larger, twisted and swollen due to blood being redirected to them.

Follow this QR code for a full list of medical terms and useful words



Useful resources

Advanced liver disease information suite



This booklet forms part of a suite of information for people with advanced liver disease (decompensated cirrhosis).

- **Decompensated cirrhosis**
- **Ascites – swelling of your belly with fluid**
- **Varices and variceal bleeding**
- **Hepatic encephalopathy (HE)**

Find the full information suite at:
liveruk.org/cirrhosis

How Liver UK can help



A diagnosis of liver disease can be worrying, and you may have a lot of questions. The Liver UK support team are here for you and for your family and friends.

Whether you have questions or just need someone to listen, we can help.

Find out how we can help you
liveruk.org/support

Call our nurse-led helpline
0800 652 7330



How we produce information

Feedback and information services

Your feedback is important to us and will help us improve our information. To provide feedback, email **patient-info@liveruk.org**

For more information on how our information was developed, visit our website: **www.liveruk.org**

Thanks

All our information resources are reviewed by medical experts and people living with liver disease.

We would like to thank all of the clinical and patient experts who were involved in creating this booklet.



Disclaimer

This resource provides general information but does not replace personal medical advice. It is important to contact your medical team if you have any worries or concerns.



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We are entirely funded by donations.

To make a gift in support of our work today, please scan the QR code or visit

www.liveruk.org/donate

Liver UK is the UK's leading charity dedicated to supporting adults, children and young people affected by liver disease or liver cancer. Our mission is to transform liver health by raising awareness, promoting prevention, and improving care and support for everyone affected.



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