LIVER UK

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

Hepatic encephalopathy (HE)

A guide to understanding advanced liver disease

Contents

Welcome

Welcome to your guide to understanding **hepatic encephalopathy (HE)** which people often call brain fog. HE can develop in people with advanced liver disease (sometimes referred to as '**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 **decompensated cirrhosis**, **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:
hep-AH-tic en-SEF-ah-lop-ah-thee
or
hep-AH-tic en-KEF-ah-lop-ah-thee
Or you can just say
HE

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.

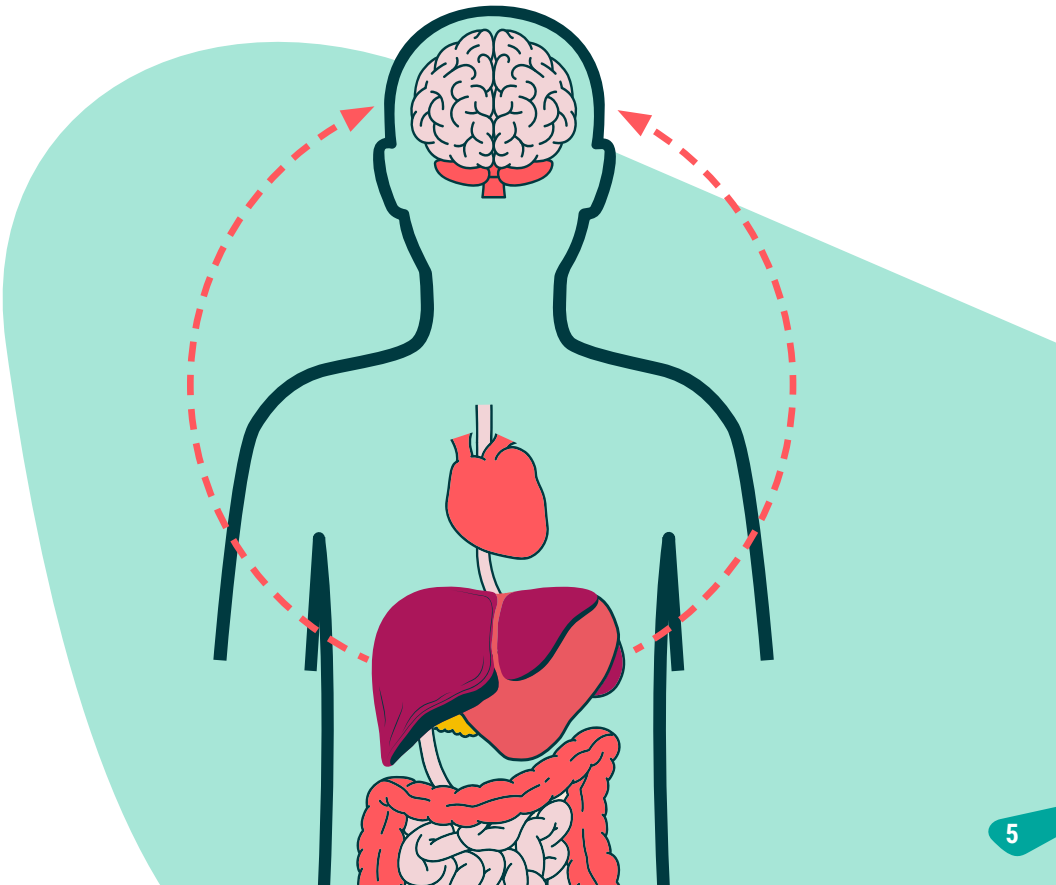
This can cause linked conditions like hepatic encephalopathy, ascites, variceal bleeds or liver cancer. In this booklet, we focus on hepatic encephalopathy.

Why can cirrhosis lead to HE?

HE is a brain disorder caused by toxins building up. One of the liver's main jobs is to help remove harmful toxins from the body. But it cannot do this properly when it is very damaged.

During the digestion process, toxins such as **ammonia** are produced, and they make their way into the bloodstream from the gut. The blood carries these toxins to the liver. A healthy liver would change them into a safer form so the kidneys can filter them out of the body in pee.

However, with cirrhosis, this process doesn't work properly.



This means that high levels of toxins build up in the bloodstream, making their way around our body and passing into the brain.

There are two main consequences of high levels of toxins in the brain.

- **Brain cells swell putting pressure on the brain.**
- **Signals between brain cells no longer work properly.**

These can affect your physical and mental health in many different ways. So HE can cause a wide range of symptoms.

Knowing that you have HE can be worrying. But it's important to remember you are not alone – approximately 60% of people with cirrhosis will develop symptoms of HE.

Tell me more about HE

Episodes of HE are often triggered by something else, such as:

- **losing too much water (dehydration)**
- **not being able to poo enough (constipation)**
- **infections**
- **certain medicines including diuretics and some tranquilisers and sleeping medicines**
- **bleeding in the bowel, stomach or gullet (oesophagus) also known as varices**
- **kidney problems**
- **surgery**

HE usually stops if it is treated and the trigger is taken away. But a new episode can be triggered in the future. Some people with advanced liver disease have episodes of HE that keep coming back.

It is a good idea to be aware of the triggers. And speak to your clinical team if you think you are likely to be affected by any of them.

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

What are the main symptoms of HE?

To begin with, the symptoms of HE can be quite subtle and easy to miss.

But over time, as toxins continue to gather in the brain, the symptoms will occur in more defined episodes. These episodes can be mild at the start and get worse bit by bit, or they can occur suddenly, as an emergency.

There are lots of possible symptoms of HE and you may suffer from just a few or lots all at once. The symptoms can be physical, mental or a combination of the two. The ones you notice can also differ over time.

Early in the disease process, you may find that other people actually notice your symptoms before you do.

Some of these symptoms can be hard to spot yourself. Let your friends and family know what to look out for and what to do, including in an emergency.

Carry an alert card to let doctors know you have HE in an emergency. You can order one from Liver UK.

Tell your doctor straight away if you suspect you might have any of these symptoms. If you have severe symptoms go to A&E. Tell them you have HE and ask them to let your medical team know what has happened.

Mild or moderate HE symptoms

- Short attention span
- Change in personality or behaviour, mood changes, or poor judgment
- Feeling confused or forgetful
- Difficulty making small hand movements such as handwriting
- Sweet smelling or stale breath
- Change in sleep patterns

More severe HE symptoms

- Seizures
- Feeling very confused or not knowing where you are
- Obvious personality changes, including inappropriate behaviour
- Tiredness or sleepiness
- Anxiety or worry
- Slurred speech
- Poor coordination
- Shaking or flapping hands
- Slow movement

Very severe HE symptoms

- Hardly conscious
- Generally not responding to surroundings
- Extremely confused and not knowing where you are
- Very odd and unusual behaviour
- Eventually, going into a coma

Because many of these symptoms affect your concentration, driving is not recommended when you have HE as it could put you or others at risk.

Talk to your doctor about this if you have concerns.

How is HE diagnosed?

When it comes to diagnosing HE, doctors will usually assess you for signs of physical symptoms and do tests to confirm a diagnosis.

A range of different tests are used to diagnose HE, but it's also important for your doctor to rule out other possible causes for your symptoms in order to correctly diagnose you with HE.

For milder HE

One of the types of tests used for diagnosis is designed to measure mental and physical capabilities:

- **memory**
- **reaction time**
- **problem-solving**
- **coordination**

One example is the Continuous Reaction Time (CRT) test. It measures the length of time it takes you to press a button in response to a repeated sound.

Brain scans are also used to diagnose HE. An **electroencephalography (EEG)** can detect changes in brain activity. **CT** or **MRI** scans of the head can detect unusual changes in the brain.

For more advanced HE

This diagnosis is based on further physical examination by a specialist. Part of the process is to rule out symptoms that may be caused by something other than HE.

Some symptoms can be difficult to detect in a physical examination, but feeling very confused or not knowing where you are, poor coordination, and flapping of your hands (asterixis) are very often present and usually signs of more advanced HE.

How is HE treated?

Because HE is complicated with so many different symptoms, the best treatment for you will depend on several different things.

These include your symptoms, how severe your condition is and what might have triggered the episode.

Depending on the stage of your disease, you may be able to get better from HE with the right treatment, so stick with it. Treatments can help improve the symptoms when you have an episode of HE and prevent new episodes.

The first step is to identify what has caused the episode of HE and treat it. This could include:

- Stopping bleeding (varices) in the stomach, bowel (intestine), or food pipe or gullet (oesophagus)
- Treating infections
- Treating kidney failure
- Treatment to get levels of salts and minerals (electrolytes) in the blood back to normal
- Providing life support if the person is in a coma

Medicines to stop toxins building up again

You will usually be given medicine to help prevent any future episodes. Each episode of HE can do more damage to your brain, so it is important to reduce the number of episodes you have.

The long term aim of HE treatment is to reduce the level of toxins in your blood by improving your gut health. There are 2 main treatments, lactulose and rifaximin, which work in different ways (see pages 14–15). Some people only take lactulose and others take both medicines.

You might need to take these medicines over a long period of time. Speak to your doctor if you have any worries or problems with your medicine, they may be able to change it.

It is important to follow your doctor's instructions and take the full course of medicine, even if you feel better. If you stop taking the medicine it could increase the chance of having another HE episode.

Lactulose

Episodes of HE can be triggered by difficulty pooing (constipation). Lactulose is a laxative, which means it makes it easier for you to poo and stops you getting constipated. It works by drawing water into your bowel, which makes your poo softer and easier to pass. It can also make you poo more often.

This stops the bacteria that make toxins such as ammonia from growing in your bowel. So toxins are less likely to reach harmful levels and trigger an HE episode.

Your doctor will help you adjust how much lactulose you take (your dose) so that you do 2 to 3 poos each day. If you get diarrhoea tell your doctor straight away as this can make you dehydrated and lead to an HE episode.

Lactulose comes as a sweet liquid. Some people don't like the taste or find it makes them feel sick. You can mix lactulose with water or fruit juice to make it taste better. Do this just before you take it and make sure you have the full dose of lactulose. If the taste makes you feel sick, try taking lactulose after meals.

Some people get side effects from lactulose, usually these are not serious.

Common side-effects include:

- **Mild tummy pain**
- **Farting**
- **Feeling sick**
- **Diarrhoea**

If the side-effects are hard to live with or make it difficult to take lactulose, tell your doctor.

Rifaximin (Targaxan®)

Rifaximin is an antibiotic that only works in the gut. It kills some of the toxin-producing bacteria in your bowel. This reduces the level of toxins in your blood and helps stop them building up in your brain.

Rifaximin is taken as tablets. Most people take it as well as another medicine such as lactulose.

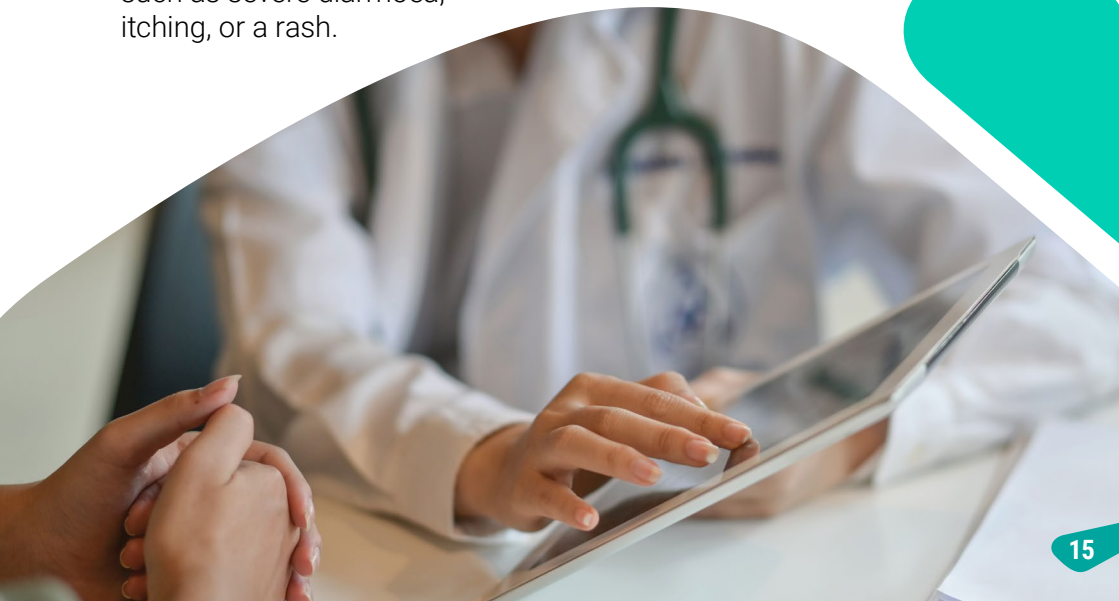
Unlike taking an antibiotic for an infection, you might take Rifaximin for a long period of time. It is very important to take all the tablets and follow your doctor's instructions, even if you feel better. Stopping taking the tablets can lead to your HE symptoms coming back.

Rifaximin causes side-effects in some people. The side effects of Rifaximin are usually mild.

Tell a doctor straight away if you get more serious side-effects such as severe diarrhoea, itching, or a rash.

Common side-effects:

- **Feeling or being sick**
- **Tummy pain**
- **Dizziness**
- **Diarrhoea**
- **Feeling very tired (fatigue)**
- **Headaches**
- **Tightness in your muscles**
- **Joint pain**



Eating well to help manage HE

It's important to eat as well as you can. You should follow the advice for people with cirrhosis and have a high protein, high energy (calorie) diet made up of 4 to 5 smaller meals plus a bedtime snack.

Ask your doctor to refer you to a dietitian. They can give you personalised advice on your diet.

In the past, people with HE were advised to have a low protein diet. It is now known that this is wrong and that people with HE should follow a high protein diet. Protein is mostly found in foods such as beans and pulses, dairy foods, fish, poultry, and meat, as well as some vegetarian meat alternatives such as tofu and Quorn.

- Avoid taking lots of protein in one meal. Spread it out over the day.
- Try to take most of your protein from vegetable sources as they are better tolerated than dairy or meat. Try lentils, beans, peas, nuts, oatmeal, wild rice, soybean products such as soy milk, tofu and edamame.
- Protein from dairy sources like eggs and cheese can be better tolerated than protein from meat. Fish and poultry are better sources than red meat.

For more information on HE, cirrhosis and diet visit our website or read our Diet and Liver Disease booklet.

Can I get any more support?

If HE becomes more severe, you may benefit from getting support from a caregiver. This could be somebody you know or a healthcare professional.

You may need a lot of emotional support too, from family, friends or other people going through the same experience – talk to your doctor about special groups you could join or places to get specialist advice. Contact Liver UK for more information.

The **HE patient passport** helps you keep track of important information about your condition. It includes an alert card you can carry to let doctors know about your condition in an emergency.

Visit our website or contact our office to get your patient passport.

Glossary

Ammonia: A chemical formed in the digestion process that can cause damage in the body when present at high levels.

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.

CT scan: This is a painless scan where multiple x-rays are used to create a 3D image of the inside of your body.

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

Electroencephalogram (EEG): A test that measures electrical activity in the brain.

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.

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

MRI scan: This is a painless scan that uses strong magnets and radio waves to create images of the inside of your body.

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 in 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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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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