

A guide to understanding  
advanced liver disease

# Information for patients and carers about Hepatic Encephalopathy (HE)





## Introduction

Welcome to your guide to understanding advanced liver disease and **hepatic encephalopathy (HE)**. Throughout this guide, any unusual terms are highlighted in bold and explained at the end of this leaflet in the glossary. If you have any questions, remember to ask your doctor or nurse at your next appointment. We hope you find it informative and useful.

There are five other booklets available in this series, which cover general health and wellness, **varices** and **variceal bleeding**, **ascites**, **hepatocellular carcinoma** and nutrition. If any of these interest you, be sure to ask your doctor about them.

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## What is liver cirrhosis?

When a healthy liver gets injured by a virus, a toxin like alcohol or another specific liver disease, it repairs itself by replacing damaged cells with new ones. This is usually an efficient process, but when too much damage occurs and/or lasts a number of years, some of this repair work can leave scars. This 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, the scarring can become so great that the liver can no longer repair itself or function properly.*

This can cause associated conditions like HE, ascites, variceal bleeds or hepatocellular carcinoma. In this booklet, we focus on HE.

Advanced liver disease and cirrhosis can have several causes including long term alcohol abuse, viral infection such as **hepatitis B or C**, metabolic diseases such as **non-alcoholic related fatty liver disease (NAFLD)**, or other conditions such as autoimmune hepatitis.



## Why can cirrhosis lead to HE?

When a liver is seriously damaged, like with cirrhosis, it is unable to filter out the harmful toxins carried in our blood as it would normally do.

*These toxins then continue to flow through our bloodstream until they reach the brain, where they begin to gather.*

After a while, these toxins start to cause physical damage to the brain and even affect the way we think and act. This is what is known as HE.



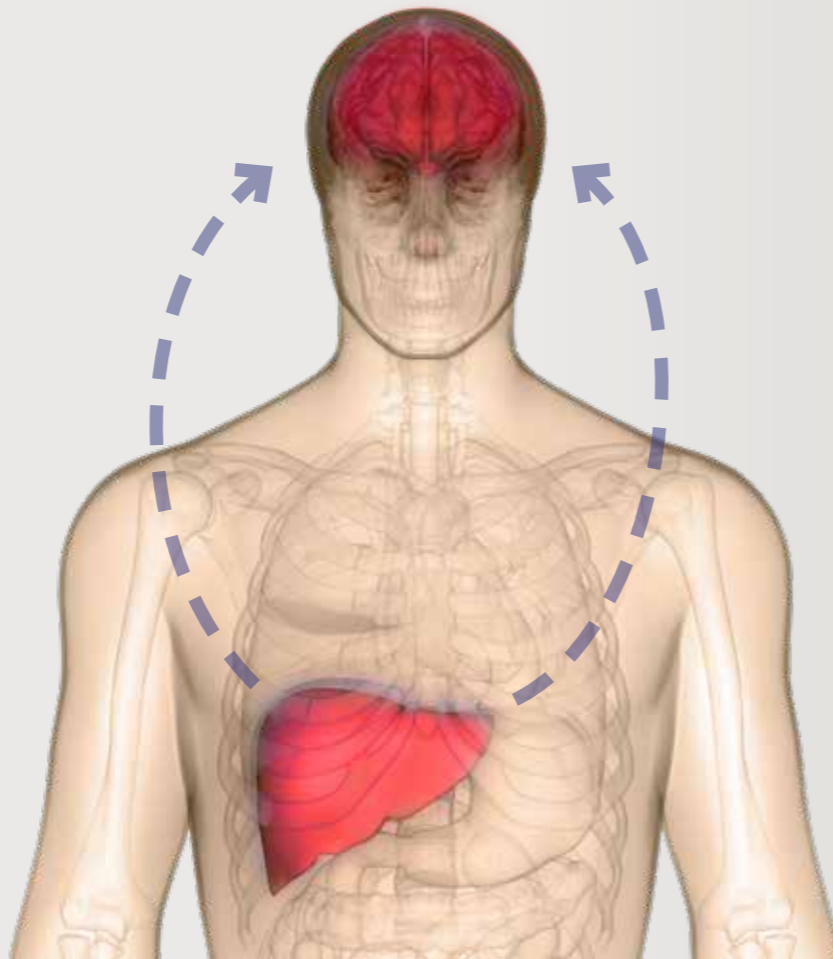


## Tell me more about HE

During the digestion process, chemicals such as **ammonia** are produced, and they make their way into our bloodstream from the gut. This blood then makes its way to the liver, where, in a healthy liver, the toxins are converted to safer substances and filtered by the kidneys, ready to be removed through urination.

However, with cirrhosis, this process is unable to take place properly.

*This means that high levels of ammonia build up in the blood stream, making their way around our body and passing into the brain through the **blood-brain barrier**.*



There are two main consequences of high levels of toxins in the brain. The first is swelling of the brain cells. This is due to absorption of water causing high pressure within the spaces that surround the brain and spinal cord. The second is damage to the signals sent between brain cells.<sup>1</sup> These effects lead to 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.<sup>2,3</sup>

If you would like to find out more about others in a similar situation to you, please see the patient support group information at the back of this leaflet

## 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 the toxins continue to gather in the brain, the symptoms will occur in more definite episodes. These episodes can be mild at the start and get worse bit by bit, or they can occur suddenly.



There are lots of possible symptoms of HE and you may suffer from just a few or many 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.*

If you even suspect that you are experiencing any of the following symptoms, talk to your doctor straight away. Also, make sure to tell your friends and family what to look out for, as some of these symptoms can be hard to spot yourself.

### Mild or moderate HE symptoms

- Short attention span
- Change in personality or behaviour
- 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

- 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 perform 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 and coordination. One of the most important tests is known as 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.

Another type of test used to diagnose HE are brain scans. An **electroencephalography (EEG)** can detect changes in brain activity. **Computed tomography (CT)** or **magnetic resonance imaging (MRI)** scans of the head can detect bleeding or other 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 disorientation, dyspraxia (poor coordination) and asterixis (involuntary flapping movements of the hands) 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 factors.

These include:

- Which symptoms you have
- How severe your condition is
- What things might trigger an episode

What's encouraging to know is, 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 **acute phase** of HE and help to prevent new episodes.

### Toxin reducing treatments

Treatment with Lactulose will increase your number of bowel movements (passing a stool), and help reduce the level of ammonia that could make its way into the blood system.

Rifaximin is an antibiotic that works only in the gut. It can reduce the bacteria that produce ammonia during digestion and help reduce the risk of experiencing more HE episodes. You may be given this antibiotic for much longer than you would for a normal infection.

It is important that you always read the leaflet and take your medication as directed by your doctor.

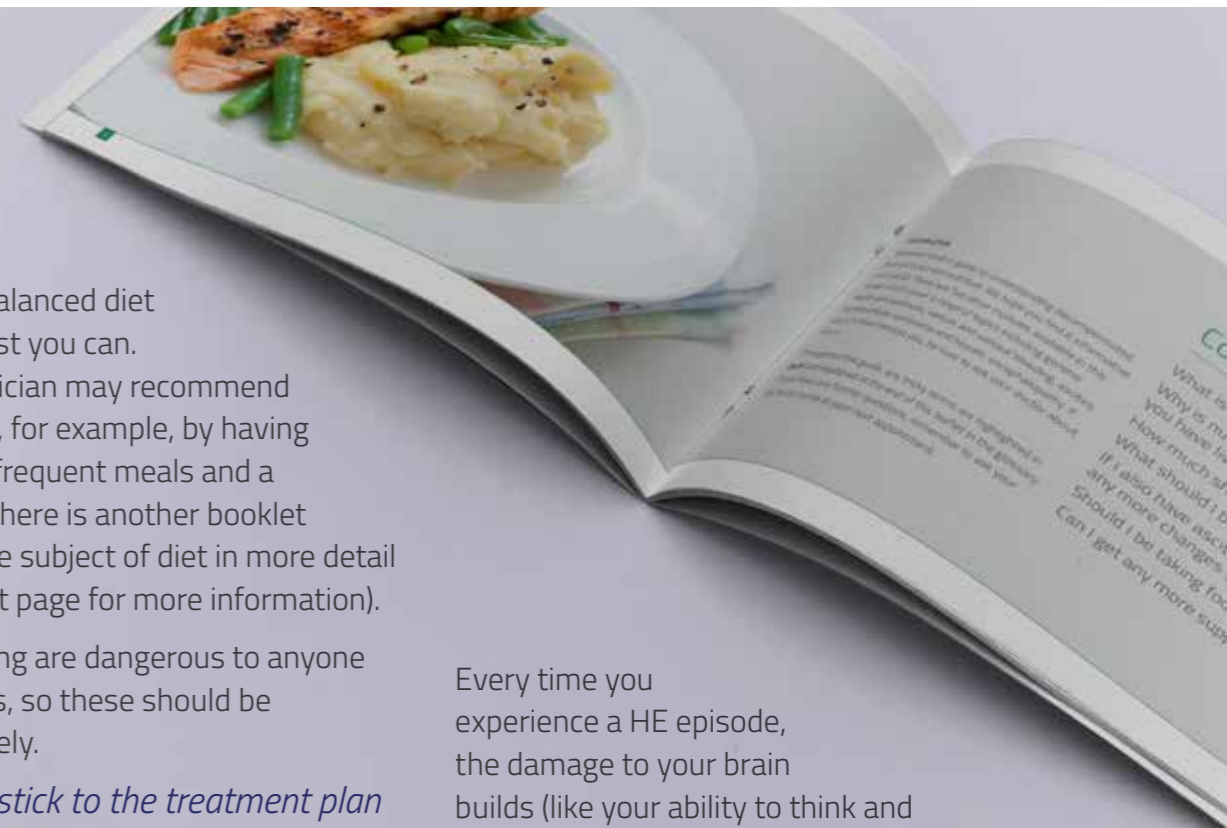
### Diet

You should eat a balanced diet and exercise as best you can. Your doctor or dietician may recommend changing your diet, for example, by having smaller, but more frequent meals and a late-night snack. There is another booklet which goes into the subject of diet in more detail (please see the last page for more information).

Alcohol and smoking are dangerous to anyone with liver problems, so these should be stopped immediately.

*It's important to stick to the treatment plan that your doctor recommends. Don't skip any doses of medication.*

Every time you experience a HE episode, the damage to your brain builds (like your ability to think and remember things), so it's important to try and avoid all the episodes you can.





## 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. There is more information on this at the back of the leaflet.



## Glossary

**Acute phase:** Appearance of severe complications rapidly after the first signs of liver disease.

**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.

**Blood-brain barrier:** A network of blood vessels and tissue that is made up of closely-spaced cells and helps keep harmful substances from reaching the brain.

**Cirrhosis:** Where healthy liver cells become damaged and are replaced with scar tissue.

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

**Electroencephalogram (EEG):** This is a test that is designed to measure 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 that is common in people with cirrhosis.

**Liver:** The largest organ inside the human body. Among other things, it is responsible for removing toxins from our blood, producing certain molecules like hormones and storing and releasing energy from food.

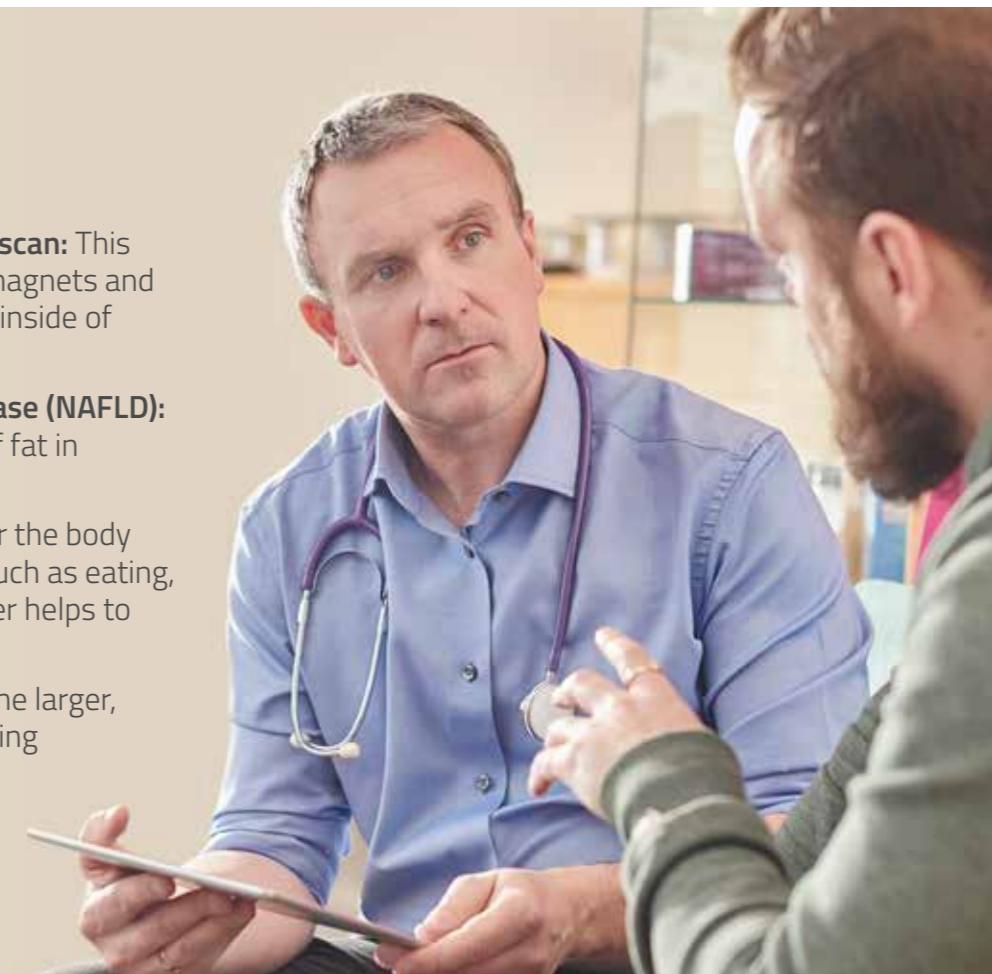
**Magnetic resonance imaging (MRI) scan:** This is a painless scan that uses strong magnets and radio waves to create images of the inside of your body.

**Non-alcohol related fatty liver disease (NAFLD):** NAFLD is when you get a build-up of fat in your liver.

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

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

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



### Reporting of side effects due to prescribed medicines

If you get any side effects, talk to your doctor, pharmacist or nurse. This includes any possible side effects not listed in the package leaflet. You can also report side effects directly via the Yellow Card Scheme at [www.mhra.gov.uk/yellowcard](http://www.mhra.gov.uk/yellowcard).

By reporting side effects, you can help provide more information on the safety of this medicine.

### References:

1. Cichoż-Lach H and Michalak A. Current pathogenetic aspects of hepatic encephalopathy and noncirrhotic hyperammonemic encephalopathy. *World J Gastroenterol* 2013; 19(1): 26-34.
2. Romero-Gómez M, *et al*. Subclinical hepatic encephalopathy predicts the development of overt hepatic encephalopathy. *Am J Gastroenterol* 2001; 96(9): 2718-2723.
3. Das A, *et al*. Prevalence and natural history of subclinical hepatic encephalopathy in cirrhosis. *J Gastroenterol Hepatol* 2001; 16(5): 531-535.

### Disclaimer:

The images are being used for illustrative purposes only. Any persons depicted are models.

### Primary reading:

<https://www.webmd.com/cancer/hepatocellular-carcinoma#1>

<https://www.healthline.com/health/treating-hcc/treatment-options>

<https://www.healthline.com/health/cancer#growth>

### Support groups:

European Liver Patients' Association:  
<https://www.elpa-info.org>



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