

A Guide to Hepatic Encephalopathy (HE) for

Carers



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* Based on guidelines for healthcare professionals created by the American Association for the Study of Liver Diseases and the European Association for the Study of the Liver

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Introduction

Hepatic encephalopathy (HE) occurs in around 30 – 45% of patients with cirrhosis, a condition associated with advanced liver disease.¹ It can occur soon after the first signs of liver disease (acute liver failure) or later in those experiencing long-term liver damage (chronic liver disease, known as CLD).²

As a carer for someone with HE, you probably understand the impact of chronic liver disease and cirrhosis. However, HE adds to these problems as it affects memory, mood and physical capabilities, and in severe stages of HE, patients can become confused and disorientated.³

Although patients with liver disease will see healthcare professionals on a regular basis, as a carer you can play an important role in helping to notice the early symptoms of HE and bring them to the attention of the healthcare team involved on their care (multidisciplinary team).

This summary helps you to understand what it means to be diagnosed with HE, and how to help provide care. In addition, this guide explains why the healthcare team follows certain procedures.

Symptoms to watch for

HE may not always be immediately obvious and can sometimes develop slowly.

Mild to moderate symptoms of HE may include the following mental and physical changes:^{2,3}

Mental



- Mild confusion
- Short attention span
- Forgetfulness
- Mood swings
- Personality changes
- Inappropriate behaviour
- Difficulty doing basic maths

Physical



- Change in sleep patterns (e.g. sleeping during the day and staying up at night)
- Difficulty writing or making other small hand movements
- Breath that smells musty or sweet
- Slurred speech

More severe symptoms of HE may include these mental and physical changes:^{2,3}

Mental



- Marked confusion
- Severe anxiety or fearfulness
- Disorientation regarding time and place
- Inability to perform mental tasks such as doing basic maths

Physical



- Extreme sleepiness
- Slowed or sluggish movement
- Shaking of hands or arms (called “flapping”)
- Jumbled, slurred speech that can’t be understood

In the most severe form of HE, people can become unresponsive, unconscious and may enter a coma (a long state of unconsciousness where a person cannot be woken).³

Diagnosis

When symptoms are reported for people with liver disease, a clinical diagnosis of HE is made by excluding other causes.³ Diagnosis can be made easier if the doctor knows that certain risk factors are present, such as infection, bleeding from the gut, taking too high a dose of diuretics (water tablets), and constipation.³ It is important to mention these and any other symptoms to the doctor, as this information in a person with liver disease may help lead the doctor to a diagnosis of HE.

There are two types of HE:

- **Covert hepatic encephalopathy (CHE)** affects the ability of patients to perform certain activities, such as driving, and is associated with lower quality of life and hospitalisation.⁴
- **Overt hepatic encephalopathy (OHE)** is more serious, with a greater likelihood of poor health outcomes including coma and death.⁴

Tests

- When HE is suspected, and depending on the severity of symptoms, a full neurological examination and initial mental state examination may be carried out.³
- Different types of scan, including magnetic resonance imaging (MRI) and computer tomography (CT), may also be carried out to rule out other conditions.³
- Additional tests may determine the extent to which someone is affected by HE in terms of behaviour, sensory functions and movement.

These tests are all routine and indicate how much support is required for the person with HE. Their doctor may classify the patient’s HE according to a number of criteria:³

- Severity of symptoms
- Time course of symptoms
- Triggers/precipitating factors
- Having a portosystemic shunt (sometimes called a TIPS): This is a tube placed in the liver as a surgical procedure to re-route blood flow to relieve high blood pressure in the veins in and around the (portal hypertension)

Things that can trigger HE (precipitating factors)

There are a number of triggers for HE you should be aware of when caring for someone with advanced liver disease.^{3,4}

- Infections
- Constipation
- Dehydration
- Bleeding from the intestines, stomach or oesophagus (the tube that connects the mouth to the stomach) or as gastrointestinal (GI) bleeding
- Portal vein thrombosis
- Kidney problems
- An alcohol binge

As a carer, you have a significant role in helping patients to avoid circumstances that may lead to the onset of HE by encouraging them to stick to medications and in promoting a healthy diet.



How HE is managed and treated

If the patient has been admitted to hospital, the medical team should confirm and explain their condition before they are discharged. They will explain how to avoid HE triggers, what medicines have been prescribed and self-care plans.³

The aim of HE treatment is:⁵⁻⁷

- To improve quality of life
- Prevent worsening of the disease
- Prevent hospital re-admission as a result of another HE episode



Prescriptions

If there is a risk of the person with HE's neurological functioning getting worse, certain medicines, such as non-absorbable disaccharides (lactulose) and antibiotics (rifaximin- α) will be prescribed. These medicines work as preventive therapies.^{2,5}

If medicines are prescribed on leaving hospital, it is important to speak to the patient's GP, to continue receiving the prescription. This is important to reduce the chances of experiencing further HE episodes.⁹

Lactulose:⁹

- Reduces the amount of the chemical ammonia in the blood by drawing it into the gut where it can be removed from the body
- Helps reduce severity of episodes during HE recurrences and makes them less likely to occur again

Rifaximin- α :⁹

- Works by stopping the growth of certain bacteria in the gut that create toxins from digested food
- Helps to prevent HE recurrences and reduces the chance of re-hospitalisations

For the greatest benefit from these medications, it's important that they are taken as prescribed – which means taking the appropriate dose in the correct way and at the correct time for as long as necessary. By taking medicines correctly, the progression of HE can be slowed and sometimes even stopped.⁹ Refer to the patient information leaflet/package insert when necessary.

Following other aspects of the treatment plan is also important to improve the HE patient's outcomes. Communicating with members of the healthcare team, keeping appointments, taking laboratory tests, and following an appropriate diet, will help the chances of treatment success and minimise potential problems.⁹

If you notice any side effects from these medicines, 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.

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

Nutrition

Malnutrition (not getting enough nutrients from diet) and HE are two of the most common complications of liver cirrhosis and have negative impacts on patients' treatment.⁸

Nutrition is important and a member of the healthcare team should advise about specific diet recommendations, based on the HE patient's condition and their response to treatment.³

A certified dietitian or nutritionist is often involved and can provide a structured dietary assessment based on the specific needs of each person.³

The AASLD/EASL Guideline for the nutritional intake of someone with HE:³

- Daily calorie intake of 35–40 kcal per kg of bodyweight
- Daily protein intake of 1.2–1.5 g per kg of bodyweight
- A late-night snack rich in complex carbohydrates

Food type^{10,11}

- 1 chicken breast, grilled and skin removed (113g)
- Tuna, (canned in brine)
- Chicken egg
- Beef steak (lean, grilled)
- Salmon (grilled)

Protein content per 100g¹²

- 32.0g
- 23.5g
- 12.5g
- 31.0g
- 24.2g

Table 1. Protein content of some common foods – British Nutrition Foundation (<https://www.nutrition.org.uk/nutritionscience/nutrients-food-and-ingredients/protein.html>)

If it is not possible to eat the required dietary intake, specialised dietitian support may be required.³

In 2013, an expert panel⁸ suggested:

- A diet rich in vegetable and dairy protein
- For patients with an intolerance to dietary protein, certain types of supplements can be an option, and you can ask a dietician for help and advice
- A course of multivitamins may be given with advanced liver disease
- A diet containing 25 to 45 g of fibre daily

Food type^{10,11}

- Apple (100g)
- Banana (100g)
- Bran flakes (40g)
- Almonds (13g)
- Strawberries (100g)

Fibre content (g)¹³

- 2.4
- 1.5
- 8.0
- 1.3
- 1.5

Table 2. Fibre content of some common foods – British Nutrition Foundation (<https://www.nutrition.org.uk/healthyliving/basics/fibre.html>)

People with HE should eat three regular meals and snacks, including a late-evening snack at bedtime. They should also avoid drinking alcohol, even in small amounts, as it can damage liver cells.¹⁴

Treatment monitoring

The patient's GP should provide regular check-ups. The majority of stable patients with HE can be successfully managed at home.

Caring for someone with HE

Caring for people with HE means you may have to make changes. Your role will depend on the severity of their symptoms, and their capabilities and needs:⁹

Caretaker

- Household activities such as shopping, cooking, cleaning and finances
- Helping with bathing and dressing
- Managing medical care
- Watching for signs and symptoms of HE, side effects of medication, and generally monitoring their health

Navigator

- Scheduling appointments
- Learning the roles of healthcare team members involved in an HE patient's care
- Working alongside the team and navigating the healthcare system

Caring for someone with HE is often unexpected and requires patience to remember that it is not their fault. HE is unpredictable and can put a lot of mental and physical stress on carers; it is very important to take steps to avoid burnout. It can also impact friends and other family members, affecting their relationships. It is important to explain the situation and to make allowances for:^{3,9}

- Poor memory – inability to accurately recall and share memories from before their HE
- Reduced independence – less able to make decisions
- Inappropriate behaviours – in social situations and in public
- Mood swings – often frustrated and angry
- Distress – seeing their loss and confusion

Communicator (and/or interpreter)

- Communicating with healthcare services and potentially social service providers

Listener

- Listening to the HE patient and providing the necessary emotional support

Advocate

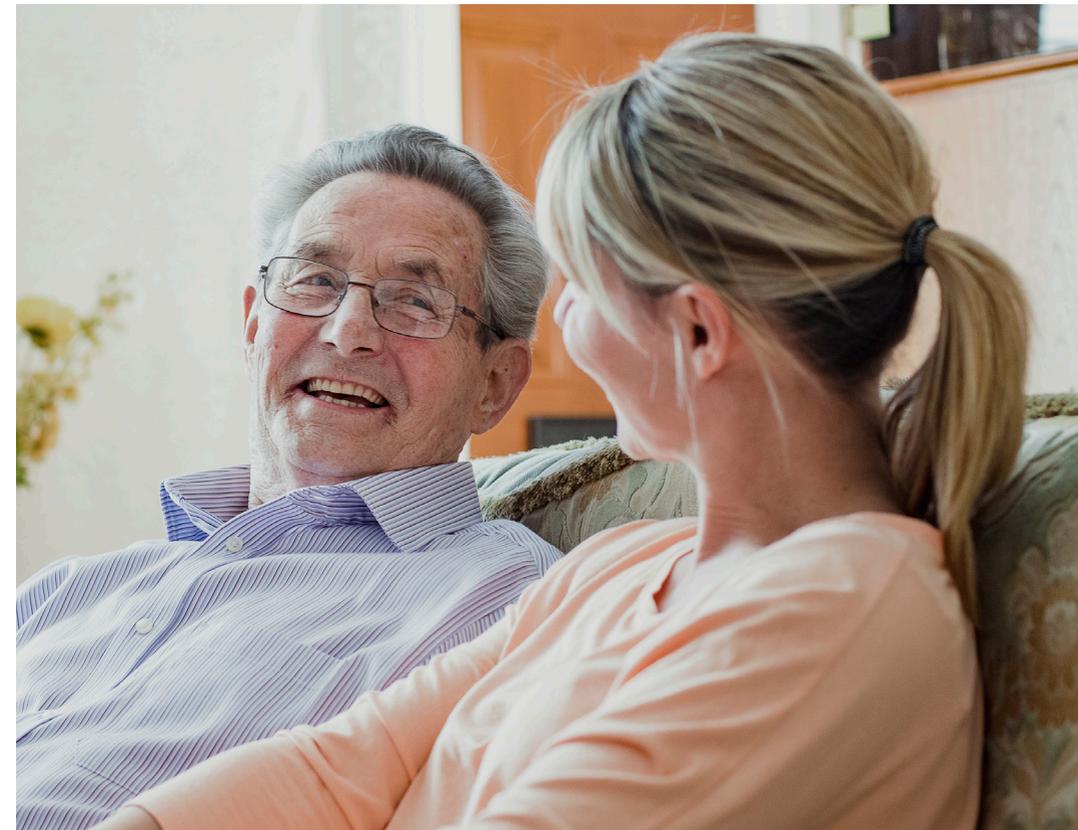
- Promoting their interests: this may include securing the required medical care, dealing with health insurers, and keeping up-to-date with HE information

Challenges

People with HE can be sleepy, anxious, paranoid or show other personality changes.³ You can ask how these symptoms can be managed, and when intervention from the medical team is needed. You will of course get support from different members of the healthcare team including:⁹

- Routine GP appointments each month
- Gastroenterologist/specialist appointments approximately every three months
- Regular scans and laboratory tests

GPs should closely monitor disease progression and help to encourage medication taking. GPs should also ensure that HE patients and their carers are informed about prescribed medications and the potential side effects, how to identify HE symptoms and what action to take when such symptoms arise (e.g. contact GP, attend hospital).³





Summary

Unfortunately, the signs and symptoms of HE can often go unnoticed² so it is important to understand the symptoms, and report any that you notice to a member of the healthcare team, as soon as possible.

Once HE is diagnosed, appropriate treatment and dietary changes are, in most cases, effective in reducing symptoms and preventing further HE episodes. However, as a carer this will require a lot of understanding and practical assistance with daily tasks, avoiding trigger factors, ensuring a healthy diet and encouraging patients to take their medications.

Looking after patients with HE can be hard for carers but we hope that this guide will make it easier for you to understand the diagnosis and the treatment of HE, how to be supportive and how the healthcare team can help.

Further information & support for HE patients & their carers

<https://www.britishlivertrust.org.uk/find-support/>

<https://www.ihelpc.com/hepatic-encephalopathy-h-e-support-group/>

<https://www.elpa-info.org/sites/default/files/project-documents/Hepatic%20encephalopathy%20Factfile.pdf>

<https://liverfoundation.org/wp-content/uploads/2017/10/Caring-for-a-Loved-One-With-Hepatic-Encephalopathy-HE-2013.pdf>

<https://www.inspire.com/groups/american-liver-foundation/>

<https://patient.info/doctor/hepatic-encephalopathy>

