

My Passport



Name:

Date of birth:

This passport has been developed to help you keep track of important information related to your condition – Hepatic Encephalopathy (HE). You can use this passport to record important details such as the medications you are taking and instructions you have been given from your healthcare team.

Having this information to hand will help your healthcare team to understand what you are going through. It is recommended that you take this passport to all of your appointments.

Please note, this booklet should not replace the conversations you may have with your doctor or healthcare team. To view the passport online or to download a copy go to www.britishlivertrust.org.uk or www.liver4life.org.uk

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Healthcare team



Use this page to list all relevant information relating to members of your healthcare team.

Complete the details below to ensure that your passport can be returned to you in the event that you lose it.

| | | | | |
|--|-----|--------------------------|----|--------------------------|
| Hospital name and contact details | | | | |
| Consultant name and contact details | | | | |
| I am on a transplant waiting list | Yes | <input type="checkbox"/> | No | <input type="checkbox"/> |
| Transplant centre name and contact details | | | | |
| Transplant coordinator contact details | | | | |

| Team member | Name and contact number |
|-------------------|-------------------------|
| GP | |
| Carer/Next of kin | |
| Specialist nurse | |
| Community nurse | |
| Dietitian | |
| Social worker | |
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Information related to your condition

What's Hepatic Encephalopathy (HE)?

Hepatic encephalopathy (HE) refers to a decline in brain function caused by chronic advanced liver disease (often called cirrhosis). In this condition, the liver cannot adequately remove toxins from the bloodstream; toxins build up in the blood, reach the brain and reduce its ability to work properly.

What's the liver?

The liver is an organ, located in the right side of your abdomen, which is like a 'factory', carrying out many jobs that are vital for your life, such as processing food, producing chemicals, storing nutrients, fighting infections and diseases, destroying poisons and drugs and cleaning the blood.

How does HE develop?

If the liver is damaged, in cirrhosis, and unable to break down toxins properly, the levels of toxins, such as ammonia, in the blood increase. These toxins then enter the brain and can cause both mental and physical change in your body, which is called HE.

What triggers HE?

Triggers for HE may include:

- Constipation
- Dehydration
- Infections (such as pneumonia)
- Electrolyte disorder (such as a decrease in potassium after vomiting or taking diuretics)
- Use of medications (such as tranquilisers)
- Recent surgery or trauma



Symptoms to look out for

HE can reduce both mental and physical function. HE may be a 'one-off' occurrence or it may be recurrent, with multiple episodes throughout your life, although repeated cases are usually seen in people with severe liver disease.

The symptoms of HE can vary from mild to severe, can develop rapidly or slowly over a period of time and can be different from person to person. The mild symptoms of HE may be easily missed because they are subtle and difficult to spot, while the moderate-to-severe symptoms are clearly visible and concerning.

Symptoms of mild HE may include:

- poor concentration
- poor judgment
- forgetfulness
- difficulty thinking
- personality changes
- change in sleep patterns
- a musty or sweet breath odour
- problems with handwriting or loss of other small hand movements

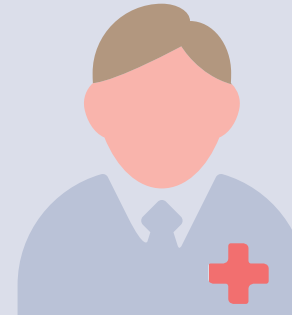
Symptoms of moderate-to-severe HE may include:

- anxiety
- agitation
- confusion
- disorientation
- shaky hands or arms
- slow movements
- slurred or jumbled speech
- sleepiness or fatigue
- severe personality changes
- in very serious cases, coma

What to do

...if you experience any of these symptoms

HE can be an emergency; it is therefore important to seek advice from your doctor as soon as your symptoms begin.



If you have already been diagnosed with HE and you feel like your condition is getting worse, seek medical help as soon as possible.

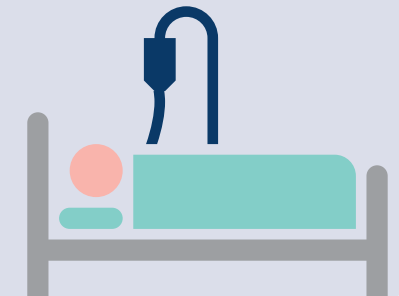
If you have moderate-to-severe symptoms of HE, **ask to be taken to A&E or call 999 right away.** These symptoms can lead to a coma if they're not treated quickly.

How HE is managed

...by the healthcare team

HE is a treatable condition; however the severity of the condition and any causes of the episode will determine the treatment that a person will be given.

HE may require a hospital admission. In hospital, the body functions are supported and any factor that has triggered HE is identified and treated. Medications are used to remove toxins from the blood and to reduce the production and absorption of toxins from your gut to the bloodstream.



How to reduce the risk of HE

HE episodes may be difficult to get through, so to help prevent the development of symptoms, you may require continuous care and lifestyle changes.

The best way to reduce the risk of HE is to prevent your liver disease from getting worse and to avoid any triggers for HE. One of the best ways to take control of your condition is for you to play an active role in managing it and work with your healthcare team. Following the below lifestyle recommendations will help you to do this.

- Avoid drinking alcohol (very important) – even small amounts of alcohol can cause problems when you have cirrhosis
- Avoid smoking (very important)
- Avoid high-fat foods
- Lose excess weight and maintain a healthy weight
- Eat healthily and at regular times
- Exercise or try to keep yourself physically active
- Don't use recreational or non-prescription drugs or share needles
- Avoid sleeping tablets or tranquilisers
- Tell a member of your healthcare team if you get constipated
- Ensure you take the medications you have been instructed to take by your doctor
- Mention to your doctor if your abdominal area seems bigger than usual or swollen
- Discuss with your doctor if at any point you change any of your medicines, including herbal remedies
- Discuss with your doctor if you have any problems doing your job or carrying out usual activities

Information for relatives and friends

It can be helpful to share information with your relatives and friends so they know how best to support you.

It's a good idea to make sure your close relatives and friends are familiar with your condition and how it affects you. If they know what symptoms to look out for, they can help you get medical assistance when you need it.

Relatives and friends will want to provide help and support. It may be useful to have practical support with day-to-day activities, like shopping, housework or collecting children from school. Talk to the people around you about what support you may require and how they can help.

As well as taking care of yourself physically, it is important to look after your emotional health. Talking about your worries and concerns can make them seem less daunting, as well as helping your family and friends to feel involved.

If you are finding it difficult to cope with your condition, speak to your doctor, who will be able to discuss support options to suit you or arrange professional support if necessary.



Advice for GPs and A & E departments

This is for you to show to your GP or the A & E department at your local hospital if you experience an episode of hepatic encephalopathy.

Dear Doctor

This patient is being managed for complication of liver disease, in particular for hepatic encephalopathy (HE), at:

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.....

If the patient experiences an episode of HE, they may exhibit the following precipitating factors, which you may need to manage:

- Constipation
- Electrolyte disorder
- Gastrointestinal bleeding
- Diuresis
- Infection
- Sedative medications

Please do not hesitate to contact the patient's healthcare team for advice and refer the patient to us for further evaluation. Ring the hospital switchboard (see below) and ask for the gastroenterology/hepatology registrar. See the front of this booklet to identify the appropriate consultant team. During office hours, if the registrar is not available, ask for the specialist nurse.

Hospital tel. no.

Information

Work with your healthcare team to complete the information below.

Having this information to hand when attending all your appointments will help your team to understand your management objectives and work together to achieve them.

| Appointment date | dd/mm/yy | dd/mm/yy | dd/mm/yy | dd/mm/yy |
|--|----------|----------|----------|----------|
| <i>Number of previous HE episodes</i> | | | | |
| <i>Date and severity (Conn score) of last HE episode</i> | | | | |
| <i>Date and volume of last ascitic drain</i> | | | | |
| <i>Date and conclusion of last creatinine blood test</i> | | | | |
| <i>Grade of varices</i> | | | | |
| <i>Date of last ultrasound and the findings</i> | | | | |
| <i>Last MELD (M) or Child-Pugh (CP) score</i> | | | | |
| <i>Dietary advice</i> | | | | |

Current medication

Please use the table below to list ALL of the medications you are taking. These include both prescription and non-prescription medicines.



Pharmacy name and address:

Allergies:

| Medication | | Condition I take it for | When do I take it? | | | | Start date | Stop date | Prescribing doctor | Special instructions |
|------------|------|-------------------------|--------------------|------|---------|---------|------------|-----------|--------------------|----------------------|
| Name | Dose | | Morning | Noon | Evening | Bedtime | | | | |
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Prescription medicines: Medicines that have to be prescribed by your doctor and issued by a pharmacist.

Non-prescription medicines: Also known as ‘over-the-counter’ medicines, these are medicines that you can buy without a prescription from your doctor. These include vitamins, herbal medications, pain relief medications, dietary supplements, and cough and cold medications.

Appointments

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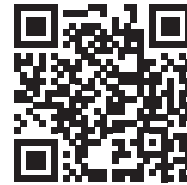
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Medical ID app

Make sure you fill out your Medical ID app with important information about your condition and its management.



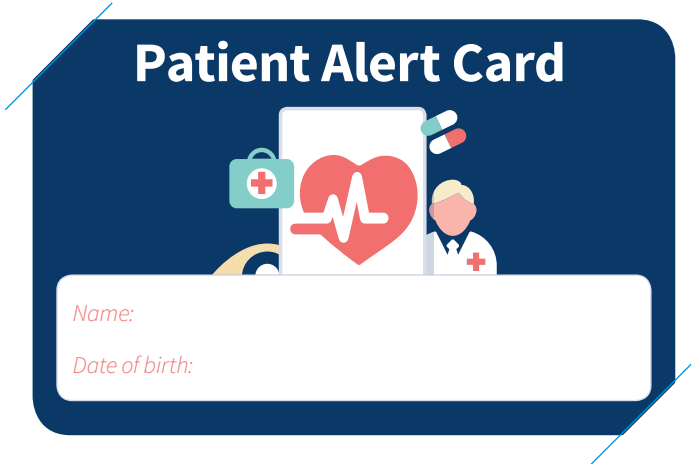
For Apple devices, see advice online:
<https://tinyurl.com/y7t9bttd>

Tick when complete



Alternatively, for Android devices, download your Medical ID app from: <https://tinyurl.com/yc3hfsnt>

Tick when complete



Useful organisations



6 Dean Park Crescent
Bournemouth
BH1 1HL

Helpline: 0800 652 7330
(10am to 3pm Monday to Friday)
E: helpline@britishlivertrust.org.uk
W: www.britishlivertrust.org.uk

Liver4Life

Holme Cottage, Croft Road
Neacroft, Christchurch
Dorset, BH23 8JS

Free helpline: 0800 074 3494
E: info@liver4life.org.uk
W: www.liver4life.org.uk