



University Hospitals Bristol
NHS Foundation Trust

Patient information service
Bristol Royal Infirmary

Information for patients with advanced chronic liver disease



Respecting everyone
Embracing change
Recognising success
Working together
Our hospitals.

**Above
& Beyond**
Fundraising for Bristol city centre hospitals

1. Looking after yourself

Managing tiredness and fatigue

Many people with advanced liver disease feel very tired and have low energy levels. Fatigue affects people differently and can come and go. One day, you may feel able to live normally and the next, you may have difficulty finding the energy and strength to do even the smallest tasks.

Planning your day and the week ahead is very important if you experience fatigue.

- Plan time to rest or take a nap during the day.
- Think about which things are most important for you and your family and get these done first.
- Be realistic about what you can do and don't try to do too much.
- Ask for help, not just from your family, but also friends or neighbours.
- Explain to people you need to be flexible, for example you may need to leave a social event early.

Some people with liver disease experience extreme sleepiness and can even fall asleep when talking. This can be due to fatigue, but it can also be a symptom of hepatic encephalopathy (see page 4), which can be more serious. If you experience this type of sleepiness, please talk to your doctor about it.

If you are suffering from fatigue or sleepiness that prevents you looking after yourself, you may be eligible for assistance with your care needs (see benefits support section on page 9).

Diet

Eating a good, balanced diet is one of the most important things you can do to keep yourself well. Regular meals containing protein (such as meat, fish or beans), carbohydrate (such as bread, potatoes or rice) and vitamins (in fruit and vegetables) are best.

Many people with advanced liver disease find they have a small appetite or cannot manage normal sized meals. It is important to avoid long periods without eating, as the body will start to use its own muscle tissue or fat to provide energy, which can lead to malnutrition, muscle wastage and weakness.

- Try smaller, more frequent meals and snacks.
- Include a carbohydrate and protein source in these, such as a boiled egg, cheese or beans on toast, or cereal with milk.
- Try to have a carbohydrate-based snack before bed; this helps prevent muscle breakdown overnight.
- Avoid salted snacks and do not add extra salt in cooking or on to your meals.
- You may benefit from being prescribed a nutritional supplement drink if you are unable to eat enough.
- Talk to your GP or hospital medical team and ask to be referred to a dietitian if you are struggling.

Weight

Some patients with advanced liver disease retain fluid in their abdomen or legs. The easiest way to know if this is happening is to keep an eye on your weight. Try to record your normal weight somewhere (e.g. in a notebook or on your phone) so you can check if you are starting to gain weight and discuss it with your GP or hepatologist.

Vaccines

People with liver disease are more vulnerable to infections, and if they do get an illness, are more likely to become severely ill. As a result, it is really important to keep up-to-date with your vaccinations.

Flu

Visit your GP for a flu jab every autumn.

Pneumococcal infection (pneumonia)

Get a jab to protect against pneumonia when you are diagnosed with liver disease and then every 10 years.

Hepatitis A and B

These infections are much more serious in people who already have another liver disease, so visit your GP for the full course of vaccinations and the booster when due.

Hepatic encephalopathy (HE)

HE is a complication of advanced liver disease and occurs because of a build-up of toxins in the body. It can be extremely worrying for you and your relatives when it occurs, particularly for the first time, as it affects the way your brain functions. However, it is usually treatable and reversible.

Early symptoms can include:

- disturbed sleep patterns – sleepy during the day but awake at night
- having difficulty concentrating or remembering things
- seeming a bit less 'with it' and alert
- less clear or shaky writing
- a bit teary or more emotional than usual

More advanced symptoms can include:

- a tremor (shakiness) that makes it difficult to hold a drink without spilling it
- confusion
- personality changes
- staggering or falling

Problems such as HE can be a sign of worsening liver function, so it is important to discuss this with your doctor as soon as possible.

Constipation is the most common cause of HE and it is important that patients with advanced liver disease try to have their bowels open twice a day. Doctors often prescribe the laxative 'lactulose' to help with this. By recognising early signs of HE and keeping an eye on your bowel habit, it is often possible to prevent progression to severe HE by adjusting the dose of your lactulose. Sometimes, you may also require enemas or need to be admitted to hospital.

Ascites and oedema

Some patients with chronic liver disease develop ascites, which is caused by fluid collecting in the abdomen making it swell up. Sometimes, patients also find fluid builds up in their feet or legs, making them swell up and feel uncomfortable, this is called oedema.

Both of these problems are usually managed by tablet medication that helps to get rid of the fluid. These medications are called diuretics or water tablets and the most commonly used are spironolactone and furosemide. They will make you pass more urine than usual and can sometimes cause problems with your kidneys. If you are prescribed them, you will usually need to have regular blood tests and keep an eye on your weight.

Occasionally, ascites cannot be controlled by tablets alone and in this situation, patients may need to have a drain inserted into the abdomen to get rid of the fluid. This procedure is called paracentesis and can be performed in the ambulatory care unit at the Bristol Royal Infirmary (BRI) as a day case.

Itching

Some patients with advanced liver disease have problems with itching which can be extremely distressing and cause problems sleeping. It is thought the itching occurs because of a build-up of bile salts in the skin. There are medications that can help (colestyramine, colesevelam, rifampicin and naltrexone) so mention this symptom to your GP or hepatologist (liver doctor) if it is troubling you.

Sex

Many patients with advanced liver disease experience problems with sexual function, as advanced liver disease can reduce your sex drive (as can some of the medications used to treat it). This can make it difficult to have sex. This is a sensitive area, but one you and your partner should not be afraid to discuss with your GP, as they may be able to offer some advice or refer you on to a specialist. Counselling, for you and your partner on the impact of liver disease on your relationship, may also be helpful.

Driving

If you experience sleepiness, confusion or severe fatigue, it is important to think about whether some activities put yourself or others at risk. For example, it may not be safe to drive, operate machinery or do things where you have responsibility for others. If you are diagnosed with chronic (persistent) hepatic encephalopathy (HE), the DVLA (Driver and Vehicle Licensing Agency) states you are not permitted to drive.

2. Liver specialist nurses

At the BRI, there is a hepatology (liver) specialist nurse who is able to give advice and support to patients with chronic liver disease and their carers. She works closely with the hepatology consultants to coordinate patient care. She also runs the outpatient paracentesis service for patients who have developed ascites as a result of their liver disease.

Contact number: **0117 342 7250**
(9.00am to 5.00pm, Monday to Friday – answerphone available)

Liver secretaries
(if specialist nurse away): **0117 342 7261 / 7262 / 7264**

3. British Liver Trust

The British Liver Trust is the leading UK charity for adults with all types of liver disease. They provide a range of support and information for anyone affected by a liver condition:

Helpline

The British Liver Trust helpline is available to provide information to anyone affected by a liver condition.

Contact number: **0800 652 7330**
(10.00am to 3.00pm, Monday to Friday)

Email: **helpline@britishlivertrust.org.uk**

Health Unlocked

This online liver health community provides an invaluable source of peer support to anyone affected by liver health issues. Members can post questions, share experiences and hear from others on how they, or those close to them, are managing their

condition. Health Unlocked can be accessed via the British Liver Trust website or at: <https://healthunlocked.com/britishlivertrust>

Publications

The British Liver Trust publishes leaflets and factsheets on a range of liver diseases. All information is written by, or assessed by, medical specialists in their field or other health care professionals. The information is available on the website: <https://www.britishlivertrust.org.uk/publications/>

4. LIVErNORTH patient support group

Although LIVErNORTH is based in Newcastle, it offers support to patients and carers nationally. They have lots of information about liver disease on their website and produce a regular newsletter, which you can read online or have delivered. They also run a helpline staffed by LIVErNORTH members who are trained to help other patients with liver disease – there are different numbers for the helpline so check the website.

Email: info@livernorth.org.uk

Website: <http://www.livernorth.org.uk/>

5. Alcohol nurse specialists

Alcohol use can be an issue for some patients with chronic liver disease. The alcohol nurse specialists at the Bristol Royal Infirmary are available to give advice on alcohol related health harm and how to arrange planned withdrawal of alcohol. They have strong links with community support services.

Contact number: **0117 342 7255**
(9.00am to 5.00pm, Monday to Friday – answerphone available)

6. Benefits support

There are different benefits that you may be able to apply for depending on your needs:

- If you need help with care or getting around and are aged 16 to 64, you may be able to claim Personal Independence Payment (replaces Disability Living Allowance). More information on page 12.
- Attendance Allowance can help with care needs if you're 65 or over. More information on page 13.
- If you can't work, you may be able to claim Statutory Sick Pay or get Employment and Support Allowance.
- If you work, you may be entitled to Working Tax Credit.
- If you care for someone who is disabled, you may get Carer's Allowance. More information on page 13.
- You may be able to get other benefits, depending on your circumstances, for example Housing Benefit if you are on a low income or benefits because you have children.
- You may be able to claim Council Tax Reduction.
- Even if you cannot claim any benefits, you may be able to get national insurance credits if you are unable to work or you are a carer.
- You may be entitled to other help apart from benefits and tax credits, for example, cheaper public transport, parking concessions and practical help with care from your local council.

Where to get help with benefits

Citizens Advice Bristol

This is a good place to start as they will be able to give you advice about what benefits and services you may be eligible for. There is lots of information available on the website and a drop-in service is available at the Fairfax Street office and at several outreach sites. Check the website for times of the drop in sessions, but you may need to arrive up to an hour early to ensure you are seen. There is also a national phone number for general enquiries.

Contact number: **03444 111 444**

Website: <https://www.bristolcab.org.uk/>

North Bristol Advice Centre

This centre offers free and independent advice and support to people in North Bristol and South Gloucestershire. They specialise in welfare benefits and debt advice. You will need to make an appointment to be seen, either by enquiring online or by telephone.

Contact number: **0117 951 5751**

Email: team@northbristoladvice.org.uk

Website: <http://www.northbristoladvice.org.uk/>

South Bristol Advice Services (SBAS)

SBAS provides free, professional, confidential advice and information to residents of South Bristol. They offer drop-in sessions for people seeking help with welfare benefits and debt advice at various locations around South Bristol - check the website for details or call the contact number overleaf.

Alternatively, you can complete an online debt advice form or call the free telephone debt advice service.

Contact number: **0117 985 1122**

Telephone debt advice service line: **0117 903 8358**

Email: **admin@southbristoladvice.org.uk**

Website: **<http://www.southbristoladvice.org.uk/>**

St Pauls Advice Centre

This centre provides free, confidential advice about welfare benefits and debt management for the people of St Pauls and East Bristol. They run some drop-in sessions – see the website for details of timing and location. There is also an online referral form or you can telephone or email to make an appointment.

Contact number: **0117 9552981**

Email: **enquiry@stpaulsAdvice.org.uk**

Website: **<http://www.stpaulsAdvice.org.uk/>**

Talking Money

This charity is based in based in West Street, Old Market and offers free, independent, confidential and professional advice on a number of issues including welfare benefits and debt. They run drop in sessions, but days vary so check the website for details. You can also fill in an online debt advice form or call for telephone advice.

Contact number: **0800 121 4511 or
0117 954 3990**

Email: **mail@talkingmoney.org.uk**

Website: **<https://www.talkingmoney.org.uk/>**

Government telephone helplines are another way to get advice about the available services:

Personal Independence Payment

To be eligible, you must be aged 16 to 64 and have a health condition or disability where you:

- have had difficulties with daily living and/or getting around for three months
- expect these difficulties to continue for at least nine months

Before you call, you will need:

- your contact details, for example telephone number
- your date of birth
- your National Insurance number - this is on letters about tax, pensions and benefits
- your bank or building society account number and sort code
- your doctor or health worker's name, address and telephone number
- dates and addresses for any time you've spent abroad, in a care home or hospital

Contact number: **0800 917 2222**

Textphone: **0800 917 7777**

(8.00am to 6.00pm, Monday to Friday)

Website: **<https://www.gov.uk/pip>**

Attendance Allowance

For information about Attendance Allowance, look online or contact the helpline:

Contact number: **0800 731 0122**

Textphone: **0800 731 0317**

(8.00am to 6.00pm, Monday to Friday)

Website: **<https://www.gov.uk/attendance-allowance>**

Carer's Allowance

If you care for someone for at least 35 hours a week, you may be eligible for this. However, Carer's Allowance can affect other benefits that you and the person you care for get, so it is best to get advice. If you would like information, you can ring the Carer's Allowance Unit on:

Contact number: **0800 731 0297**

Textphone: **0800 731 0317**

(8.00am to 6.00pm, Monday to Friday)

Website: **<https://www.gov.uk/carers-allowance>**

7. Carer support

A carer is someone who provides support to family or friends, who could not manage without this help. It is important for carers to look after their own wellbeing while caring for someone else.

In Bristol, the Carers Support Centre is a charity which provides support, information and advice to carers of any age, living in the Bristol and South Gloucestershire areas. They have a phone advice line or an online enquiry form on their website. They can help carers to complete a carer assessment to see if they are eligible for any support from the local council. They also offer training courses and support groups, as they recognise being a carer can be challenging.

Carers Line: **0117 965 2200**

Email: **carersline@carerssupportcentre.org.uk**

Website: **<https://www.carerssupportcentre.org.uk/>**

Carers Support Centre address:

Vassall Centre
Gill Avenue,
Fishponds,
Bristol, BS16 2QQ

At Bristol Royal Infirmary there is a hospital carers liaison service, which supports carers when the person they care for is in hospital, or when the carer themselves is in hospital.

Contact number: **07557 441 613**

Email: **CarersLiaison@uhbristol.nhs.uk**

Notes and queries

Please note that if for any reason you would value a second opinion concerning your diagnosis or treatment, you are entirely within your rights to request this.

The first step would usually be to discuss this with the doctor or other lead clinician who is responsible for your care.

Smoking is the primary cause of preventable illness and premature death. For support in stopping smoking contact **Smokefree Bristol** on **0117 922 2255**.

As well as providing clinical care, our Trust has an important role in research. This allows us to discover new and improved ways of treating patients.

While under our care, you may be invited to take part in research. To find out more please visit:
www.uhbristol.nhs.uk/research-innovation
or call the research and innovation team on
0117 342 0233.

For access to other patient leaflets and information please go to the following address:

www.uhbristol.nhs.uk/patients-and-visitors/information-for-patients/

Hospital switchboard: 0117 923 0000



Minicom: 0117 934 9869



www.uhbristol.nhs.uk



For an interpreter or signer please contact the telephone number on your appointment letter.



For this leaflet in large print or PDF format, please email patientleaflets@uhbristol.nhs.uk.

