

Advanced chronic liver disease (ACLD)



Information for patients

This information leaflet answers some of the questions you may have about advanced chronic liver disease. It explains the causes of the disease, the symptoms and provides advice on treatments. It also explains what you can expect when you attend the clinic. If you have any other questions or concerns, please do not hesitate to speak to the doctors or nurses caring for you.

ACLD clinical nurse specialist: **020 3299 6882**

ACLD email: **kch-tr.kchaclid@nhs.net**

Confirming your identity

Before you have a treatment or procedure, our staff will ask you your **name** and **date of birth** and check your **ID band**. If you don't have an ID band we will also ask you to confirm your address.

If we don't ask these questions, then please ask us to check.

Ensuring your safety is our primary concern.

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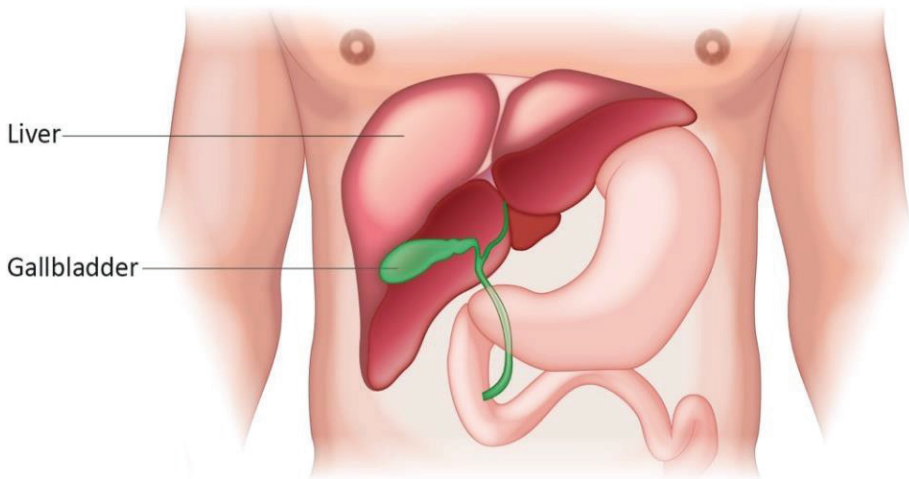


1. Introduction

This leaflet aims to help you understand advanced chronic liver disease better. It describes what it is, the symptoms and how we treat them.

2. What is the liver?

The liver is the largest solid organ in the body. It is located in the upper right portion of your abdomen, under the diaphragm and near the stomach.



The liver is an organ that carries out many necessary functions. Importantly, the liver:

- helps break down food and convert it into energy, storing carbohydrates and maintaining a good balance of glucose levels in the blood
- processes waste products produced by the body (one waste product is called ammonia, which can be broken down in the liver to a less toxic substance called urea, which can then be passed out in the urine)



- helps you fight infections
- creates proteins that are responsible for blood clotting
- helps the body process medication and alcohol.

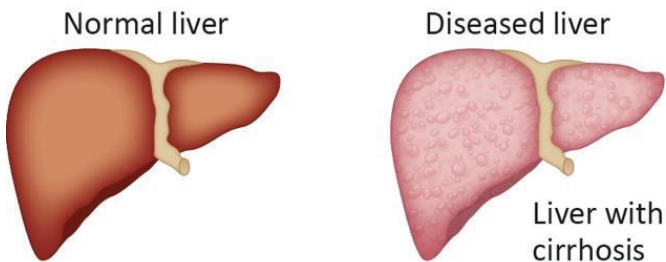
To prevent damage to your liver, it is important to have a healthy diet, exercise and avoid excess alcohol.

3. What is advanced chronic liver disease (ACLD)?

ACLD (sometimes referred to as advanced fibrosis or cirrhosis) is when there is a build-up of scar tissue (fibrosis) in the liver. Scar tissue is formed when your liver is damaged (inflamed) from one of many different causes (including metabolic associated fatty liver disease, alcohol, viral infections and autoimmune liver disease).

The scarring in the liver forms irregular bumps (nodules) that replace the smooth liver tissue and the liver becomes harder. The scar tissue changes the liver's shape (which affects the blood flow through the liver) and also changes how the liver works.

Most people don't have any symptoms in the early stages of liver disease. Symptoms tend to develop in advanced stages of ACLD.



4. What to expect when you come to clinic

We normally see patients referred from other hospitals within two weeks of receiving the referral. When you attend clinic, the hepatology (liver) team will review your medical history, check through your medication list and examine you. We will summarise the results of your previous blood tests and/or procedures, and coordinate further investigations if needed. Treatment options can include medication or procedures that will be explained in more detail during the appointment and in this leaflet.

Please, bring your updated medication list every time you come to clinic.

At the end of the consultation, you may have a blood test and a further appointment will be given (if appropriate). If you do not receive a further clinic appointment, please contact us.

5. How we assess your liver disease

Blood tests used to assess the liver are known as liver function tests. The results of these tests may be normal at different stages of liver disease. All the results will be explained to you in the clinic.

When the liver is functioning less well and there is significant damage, we use specific liver blood tests to monitor the liver function (these are bilirubin, albumin and clotting levels). Kidney function can also be affected, we will monitor this and body's salt (sodium) levels.

We may choose to perform some additional tests which include different types of scans: ultrasound scan, CT scan, MRI scan, fibroscan and/or others procedures like gastroscopy, colonoscopy or liver biopsy. If you need one of these tests we will give you more information about them.



6. What are the symptoms of ACLD?

In a normal healthy liver, the blood flows with no or minimal resistance. As ACLD develops and the liver becomes stiff it is harder for blood to flow into the liver. This causes increased pressure in the veins flowing into the liver. This in medical terms is called portal hypertension. Portal refers to the portal vein (blood vessel supplying blood to the liver). Hypertension means increased pressure in this vein. Symptoms of ACLD are a combination of changes within the body as a result of portal hypertension and they are explained below.

a) Abdominal and leg swelling

A build-up of fluid can cause swelling in the abdomen and legs. In the abdomen, this is called ascites. Ascites occurs due to high pressure in the vessels around the liver. This causes fluid to accumulate in the abdomen. You may also experience leg swelling.

Treatment for ascites

Diet

We recommend a no-added salt diet as salt causes fluid retention. Avoid adding salt to your food or consuming products that are high in salt (like processed food items).

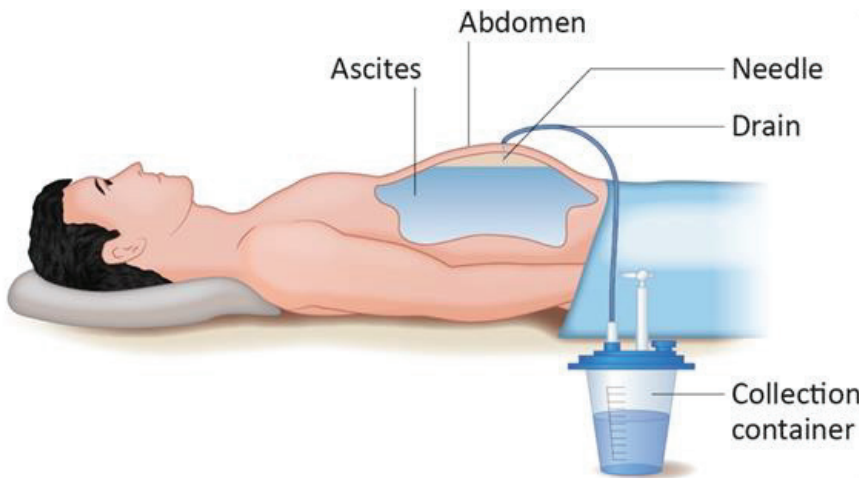
Medication

Water tablets (diuretics) are medications designed to help your kidneys get rid of extra water and salt from your body through the urine. The more common tablets are furosemide and spironolactone. The dose of the medications may be changed over time depending on your response to them. We rarely ask patients to restrict their oral intake, but we may ask for your help in monitoring your weight daily to check for fluid losses.



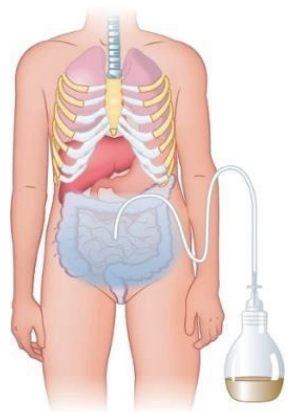
Ascitic drain

If the ascites is not controlled with tablets, or you cannot tolerate the tablets, you may be offered an ascitic drain (paracentesis). This procedure is performed with local anaesthetic to numb the skin at the site of insertion and refers to a temporary small plastic tube that is inserted to allow the fluid to drain out. The procedure is usually performed as a day case with the drain left in for a maximum of six hours. You will also likely receive albumin solution depending on the amount of fluid drained. Frequent drains may be required depending upon how quickly the fluid builds up again.



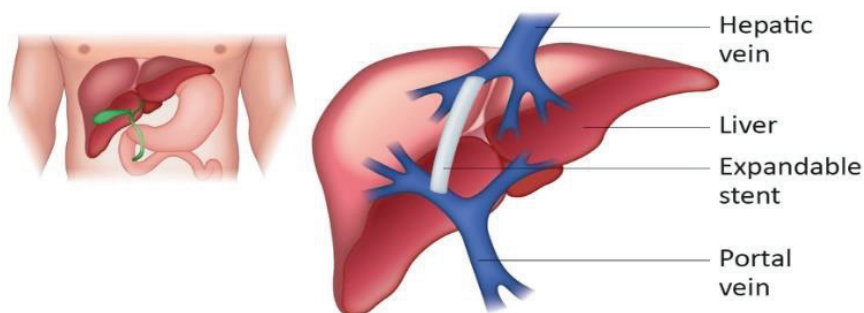
Tunnelled long-term drain

Sometimes your hepatologist may recommend a more permanent indwelling drain to allow small amounts of fluid to be drained at more frequent intervals, which will help avoid repeated admissions to hospital, making it easier for you to manage it at home. District nurses manage the drainage and the dressing as recommended by the hepatology team.



TIPS (transjugular intrahepatic portosystemic shunt)

This is a procedure where a stent is placed in the liver veins, allowing some blood to bypass the liver and reducing the pressure in the portal vein. The procedure is usually carried out under general anaesthetic by a specialist liver radiologist



TIPS is a procedure commonly used in liver disease, but there are some risks and complications which the liver team will discuss with you. The most common risks are the development of hepatic encephalopathy and a worsening of liver function. TIPS is not suitable for every patient and your hepatologist will help you decide if this is the right treatment for you.

b) Abdominal pain

Swelling of the abdomen may cause discomfort but pain can also be caused by spontaneous bacterial peritonitis (SBP). This refers to infection of the ascitic fluid, which can also cause a fever. This condition usually requires assessment and admission to hospital for antibiotic treatment. Most people who have had SBP will be started on a low dose long term antibiotic to prevent further episodes.



c) Yellowing of the skin or white of the eyes

Jaundice (yellowing of the eyes and skin) is due to high levels of bilirubin. Bilirubin is a compound that is left over after the breakdown of red blood cells and usually cleared by the liver. In ACLD the clearance of bilirubin can be affected, so levels build up in the body. We measure the bilirubin at each clinic visit, and this helps to tell us how well your liver is functioning.

Treatment for jaundice

Treatment for jaundice will depend on the underlying cause, in most patients it is a sign of ACLD. However, depending on the underlying cause there could be some specific treatment. Your doctor or nurse will speak to you about this if there is any option.

d) Problems with concentration or memory

The effect of ACLD on the brain is called hepatic encephalopathy (HE). HE occurs when the liver cannot remove toxic substances (like ammonia) from the blood.

Ammonia is a waste product produced by bacteria in the small bowel and in your muscles. Ammonia is normally cleared by the liver, but in ACLD can build up and affect the brain. Many substances can cause hepatic encephalopathy, Ammonia is just one of them.

Hepatic encephalopathy can cause:

- altered behaviour
- changes in mood and irritability
- disturbed sleep
- poor concentration
- poor memory



Symptoms experienced can be subtle but when severe patients can experience drowsiness and confusion and, in extreme cases, coma.

Treatment for hepatic encephalopathy

We may review your current medication list to check there are no medications making this symptom worse and may consider updating your scans to check if there are shunts (large abnormal connections of blood vessels bypassing the liver). We can use a number of medications to reduce recurring episodes of HE. It is important to take the medications regularly.

Medications include:

- **Laxatives (usually lactulose):** this type of laxative changes the acidity of faeces/stool to help prevent the growth of bacteria that produce ammonia in the bowel.
- **Antibiotics (usually rifaximin):** this is an antibiotic used to stop the growth of certain bacteria in the gut. It is usually taken alongside other treatments such as lactulose.

It is important for you to use laxatives (if needed) to open your bowels at least two to three times per day passing soft form stools.

e) Vomiting blood or passing blood in stools

Sometimes in ACLD, the blood vessels (veins) near the stomach and gullet can become swollen. These swollen veins are called varices. Varices can burst and cause internal bleeding. If this happens you might notice blood in your vomit or pass black stools. **If you notice this, you should call an ambulance as you need to go to your local the Emergency Department.**



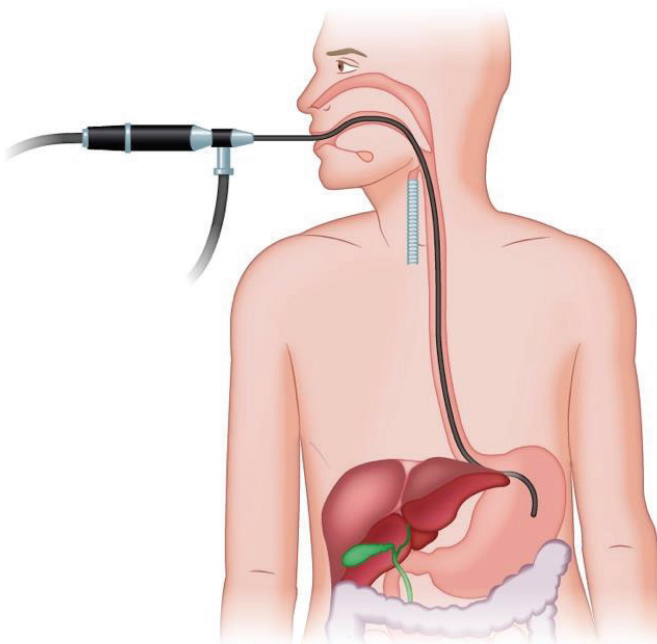
Treatment for varices

Medication

If you develop varices we may start you on tablets called beta-blockers. That medication prevents the risk of bleeding by reducing pressure in these blood vessels.

Endoscopic band ligation

This is performed during a gastroscopy test. A camera on the end of a long flexible tube is passed through the mouth, oesophagus and into the stomach. Small elastic bands are applied to the varices with the purpose of collapsing and causing scarring. The procedure is usually performed in the endoscopy unit under mild sedation. You may require more than one procedure to treat the varices and you will be monitored for recurrence varices by ongoing endoscopies.



f) Itching

Itching (pruritus) is the desire to scratch the skin. It is thought that itching occurs due to a build-up of toxins in the skin. Itching can be distressing and cause problems sleeping.

Treatment for itching

Topical creams

Moisturising creams help the skin absorb the medication and have a cooling effect.

Oral medication

Various tablets can be trialled to help with the symptom of itching. Try to avoid scratching as it can break your skin.

7. General advice

Patients with ACLD can have one, a few or all of the above symptoms. The general measures to take for all of them are:

- keeping active, including weight bearing exercises
- making changes to your diet – see information below
- avoiding alcohol
- keeping up to date with vaccinations. We advise you to have the flu and COVID-19 vaccines.

COVID-19

It is recommended that everyone with liver disease is fully vaccinated for COVID-19. Patients with ACLD have been identified as being clinically extremely vulnerable given their underlying diagnosis.



Travel

Patients with liver conditions may be at increased risk of some travel-related illnesses. Please check with your doctor or travel health adviser before you travel. If you are travelling abroad it is important to make sure your travel vaccinations are up to date.

Driving

Some patients with ACLD (such as those with hepatic encephalopathy) may be recommended to avoid driving. If you would like to have more information about your condition and driving, please contact your Doctor or contact the DVLA.

Bone thinning

People with liver disease may develop bone thinning (osteopaenia or osteoporosis). This is diagnosed by bone density scanning (DXA scan). If the scan shows you have this condition, it is likely that your hepatology doctor will provide you with vitamin D and/or calcium supplements to reduce the risk of bone fracture.

8. Dietary advice

When you have liver disease, it is important to maintain a good nutrition intake, as it helps to support the liver and plays a crucial role in your general health.

In liver patients, we recommend:

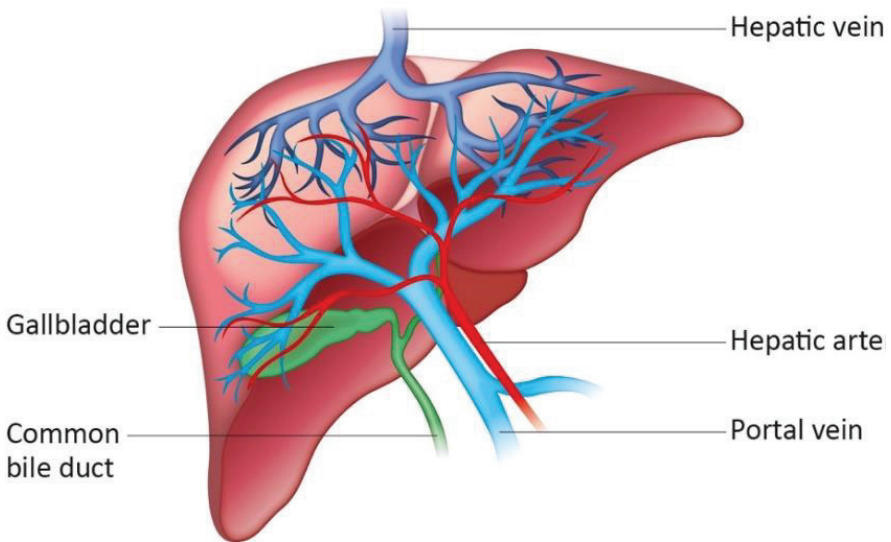
- eat regular meals and, if possible, try to not skip any of them
- have a well-balanced diet, including an adequate amount of calories and proteins
- a diet with no added salt will help reduce excess fluid retention and ascites
- have snacks over the day such as biscuits, crumpets, crackers, fruit, and a bedtime snack such as a bowl of cereal and a piece of fruit, or a milky drink and three biscuits



- monitor your weight – while we expect to see weight loss if on diuretics for ascites or excess fluid, we also know that the liver will break down muscle and patients can start to lose muscle and fat
- your hepatology doctor may refer you to a dietitian and encourage prescription of additional supplemental high energy/ protein drinks.

9. Hepatocellular carcinoma (HCC)

Hepatocellular carcinoma (HCC) is a type of liver cancer. People with ACLD have a slightly higher risk of developing liver cancer. You will be offered regular scans of the liver (usually an ultrasound scan) and blood tests which may help us to detect liver cancer at early stage. Sometimes further imaging in the form of a CT or MRI scan is requested.



Treatment for HCC

The treatment for HCC is different for each patient as treatment is dependent on the stage of the disease, fitness of the patient and function of the liver.

Do you have any questions?

10. Useful contacts

ACLD clinical nurse specialist: **020 3299 6882**

ACLD email: **kch-tr.kchaclد@nhs.net**

NHS Direct website: **www.nhs.uk**

Patient UK website: **www.patient.info**

British Liver Trust website: **www.britishlivertrust.org.uk**



Sharing your information

We have teamed up with Guy's and St Thomas' Hospitals in a partnership known as King's Health Partners Academic Health Sciences Centre. We are working together to give our patients the best possible care, so you might find we invite you for appointments at Guy's or St Thomas'. To make sure everyone you meet always has the most up-to-date information about your health, we may share information about you between the hospitals. The information and feedback provided by you will be also shared within the liver team and the Hospital to make us understand better about liver disease.

Research

King's is always trying to improve the care of patients with ACLD. One way to do this is to use the most up-to-date medication in a clinical research trial or to investigate the blood, saliva, urine or stool of patients with ACLD to find better ways to diagnose complications or who would benefit from treatment. Participation is completely voluntary. If you are interested, please ask your clinical team.

Care provided by students

We provide clinical training where our students get practical experience by treating patients. Please tell your doctor or nurse if you do not want students to be involved in your care. Your treatment will not be affected by your decision.



PALS

The Patient Advice and Liaison Service (PALS) is a service that offers support, information and assistance to patients, relatives and visitors. They can also provide help and advice if you have a concern or complaint that staff have not been able to resolve for you. The PALS office is located on the ground floor of the Hambleton Wing, near the main entrance on Bessemer Road - staff will be happy to direct you.

PALS at King's College Hospital, Denmark Hill, London SE5 9RS

Tel: **020 3299 3601**

Email: **kch-tr.palsdh@nhs.net**

If you would like the information in this leaflet in a different language or format, please contact our Communications and Interpreting telephone line on 020 3299 4826 or email kch-tr.accessibility@nhs.net



