

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.kchaclد@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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This leaflet is available in digital format at
www.kch.nhs.uk/document/acld

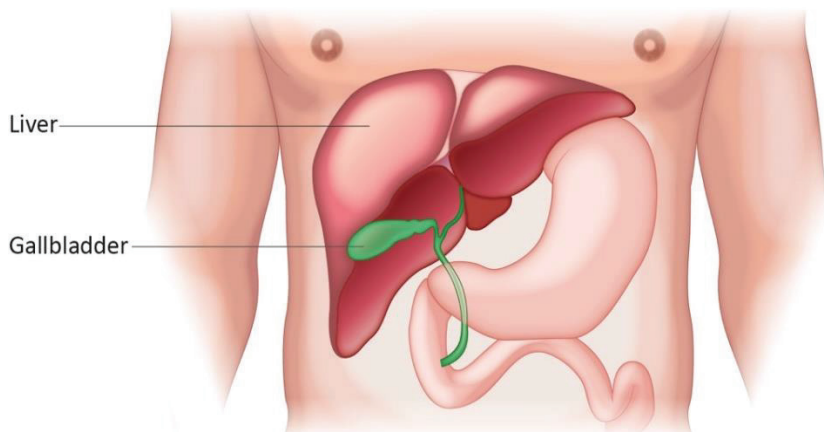


1. Introduction

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)?

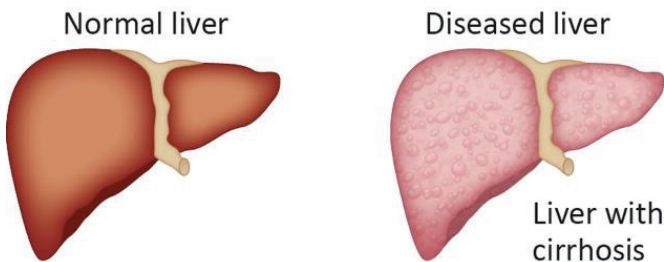
ACLD (sometimes referred to as advanced fibrosis or cirrhosis) is when there is a build-up of scar tissue (fibrosis) in the liver. Scar tissue is formed when your liver is damaged (inflamed) over time from one of many different causes (including metabolic-dysfunction associated fatty liver disease, alcohol, 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 at later stages and reflect advanced disease when the liver can no longer repair itself or function properly.

Useful words:

- fibrosis: scarring of the liver
- cirrhosis: permanent serious liver damage
- compensated cirrhosis: a stage of cirrhosis where the liver is scarred, but you do not have any symptoms of liver disease
- decompensated cirrhosis: a stage of cirrhosis where the liver is scarred and cannot work properly, causing serious complications
- recompensation: when decompensated cirrhosis goes back to being compensated cirrhosis



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 the 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).

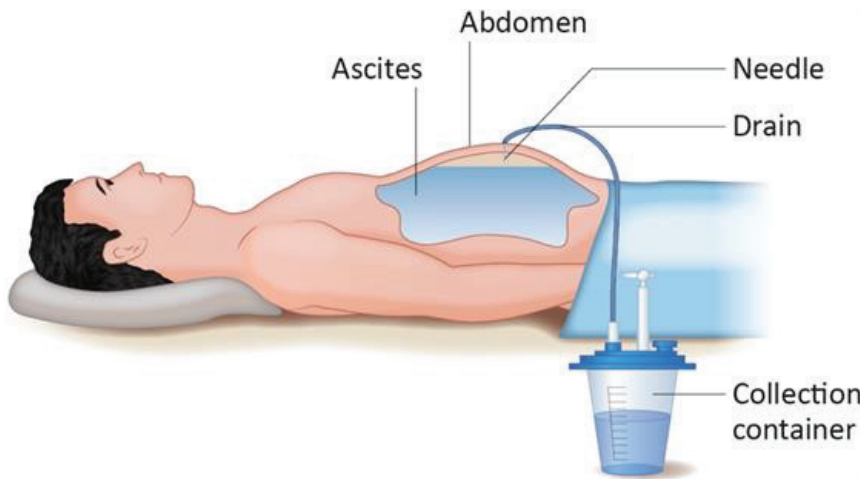
Medication

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.



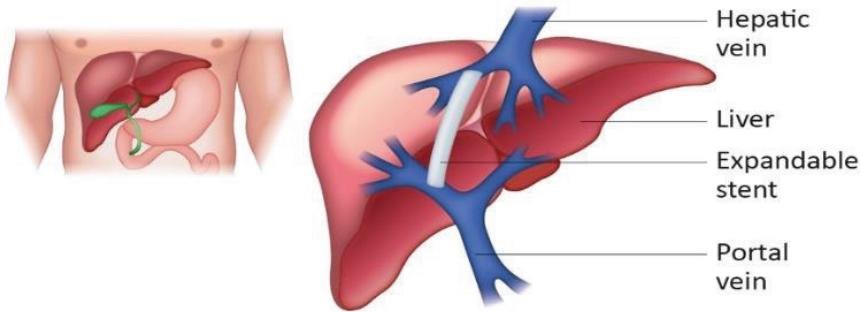
TIPS (transjugular intrahepatic portosystemic shunt)

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 poo 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 poo at least two to three times per day passing soft form poos.

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

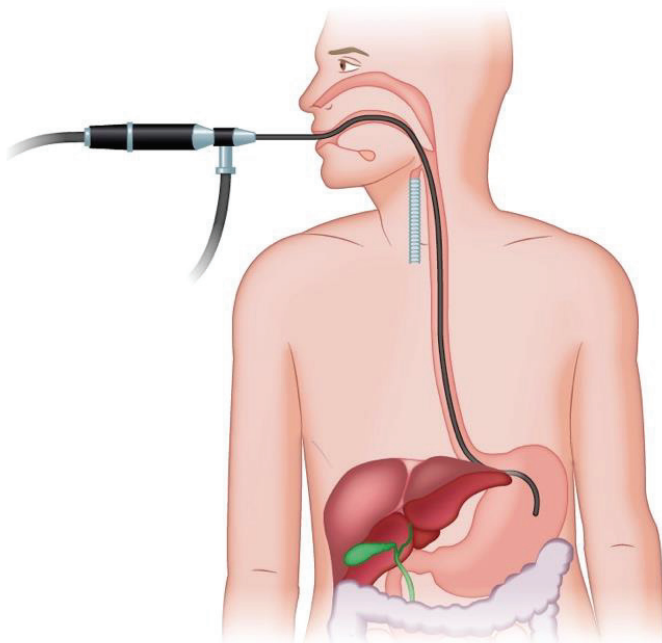
Medication

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

Vaccinations

The UK Health Security Agency recommends all individuals with chronic liver disease should receive the annual influenza vaccine, pneumococcal, hepatitis A and B vaccination, and SARS-CoV-2 vaccination in line with government guidelines for people at higher risk of COVID-19, in addition to all routine vaccinations.

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.

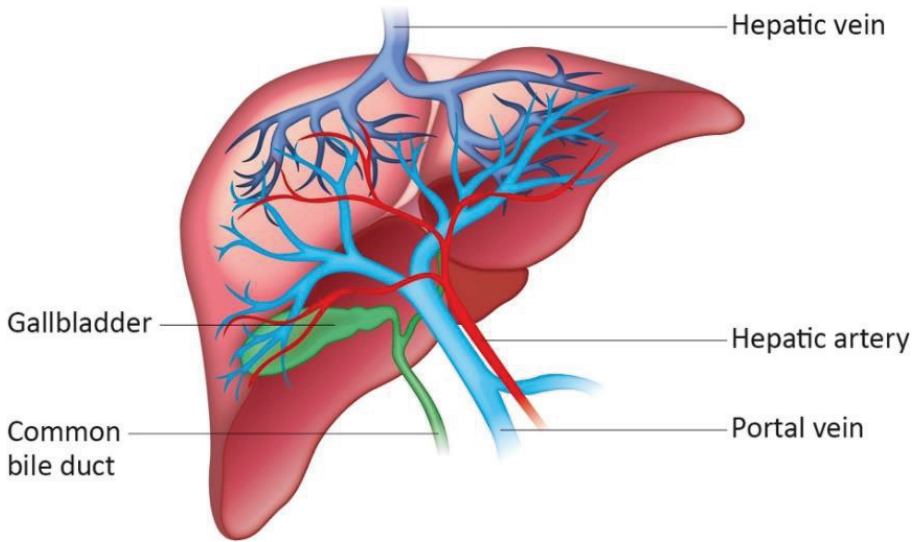
In liver patients, we recommend:

- 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 (aim for 1.2g to 1.5g per kg of your body weight per day). A protein and carbohydrate supper or evening snack reduces overnight fasting, reducing protein and muscle breakdown
- 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.



10. Research

King's is always working to improve the care we provide for patients with ACLD. One of the ways we do this is through clinical research. You may be invited to take part in a research study or clinical trial. Participation is entirely voluntary. Whether or not you decide to take part will not affect the care you receive in any way.

Research studies

Research studies do not involve any changes to how we would normally care for you. They usually include providing additional samples (such as blood or urine) or completing questionnaires. These are often carried out on the same day as your clinic visit. While these studies do not offer a direct benefit to you, they help us better understand liver disease and improve care for future patients.

Clinical trials

Clinical trials usually involve a change to your treatment or a new procedure that is not currently part of standard care. Taking part in a clinical trial may mean additional hospital visits or tests. You will be monitored closely throughout, and will be able to contact the research nurse at any time with questions or concerns. The clinical trials team work alongside your usual doctor or nurse to ensure you continue to receive appropriate care. While these trials may not offer a direct benefit to you, they help us to better understand liver disease and improve care for future patients.

If you are interested, we are always happy to discuss the options available and try to find the most suitable one for you. Please speak to your clinical team if you would like to know more.



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ACLD clinical nurse specialist: **020 3299 6882**
ACLD email: **kch-tr.kchacld@nhs.net**
NHS Direct website: **www.nhs.uk**
Patient UK website: **www.patient.info**

British Liver Trust

The British Liver Trust is a charity that supports people with liver conditions. They offer free, confidential advice and provide helpful information to patients and their families.

You can visit their website to learn more about liver disease, find patient stories, join online support groups, and download leaflets and videos to help you understand your condition.

- Website: **www.britishlivertrust.org.uk**
- General enquiries: **01425 481320**
- Email: **info@britishlivertrust.org.uk**

Detailed information about cirrhosis and the complications it can cause:

britishlivertrust.org.uk/cirrhosis



Having a liver condition can affect many parts of your life. Find out more about living with a liver condition:

britishlivertrust.org.uk/living-with-a-liver-condition



The British Liver Trust offers a range of support to anyone living with a liver condition and to their families and carers. You can call their nurse led helpline on

0800 652 7330

britishlivertrust.org.uk/support



MyChart

Our MyChart app and website lets you securely access parts of your health record with us, giving you more control over your care.

To sign up or for help, call us on 020 3299 4618 or email kings.mychart@nhs.net. Visit www.kch.nhs.uk/mychart to find out more.



Sharing your information

King's College Hospital NHS Foundation Trust has partnered with Guy's and St Thomas' NHS Foundation Trust through the 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' hospitals. King's College Hospital and Guy's and St Thomas' NHS Foundation Trusts share an electronic patient record system, which means information about your health record can be accessed safely and securely by health and care staff at both Trusts. For more information visit www.kch.nhs.uk.

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 Hambleden 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 4618**

Email: **kings.pals@nhs.net**



