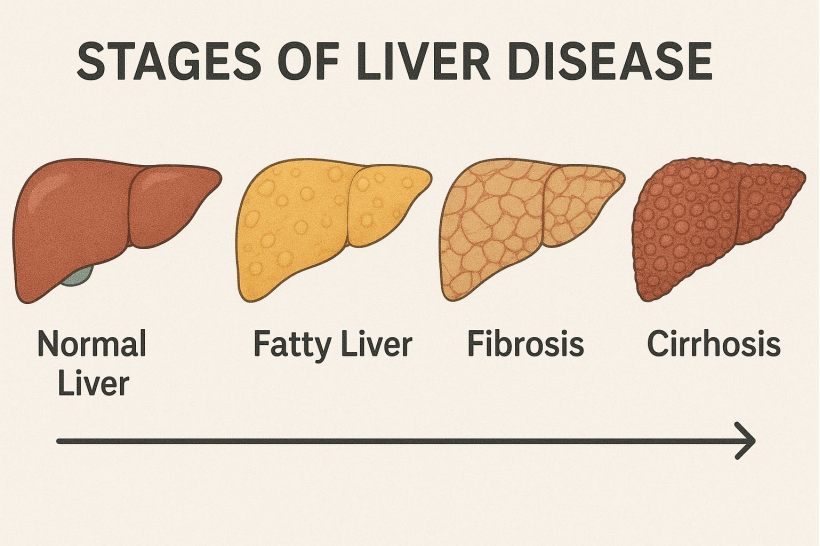
Decompensated Liver Cirrhosis – A symptom guide

Contents



1. Understanding your condition

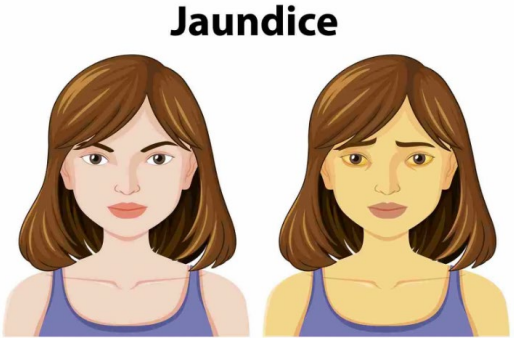
1.a What is decompensated cirrhosis?

Cirrhosis refers to extensive scarring of the liver, often due to long-standing liver damage. In the UK, this is most commonly caused by:

- Alcohol-related liver disease
- Fatty liver (NAFLD)
- Viral hepatitis (e.g., Hep B or C)
- Autoimmune liver conditions
- Genetic conditions like haemochromatosis

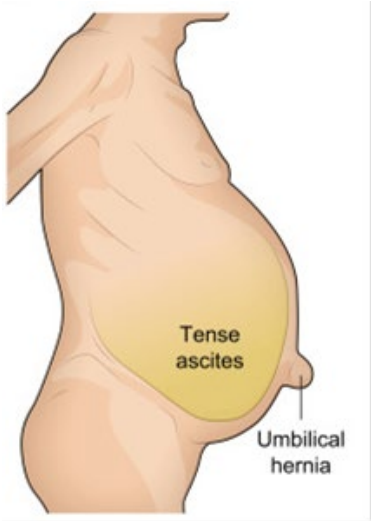
In its early stages, the liver can still function—this is known as compensated cirrhosis. As the damage worsens, the liver's ability to carry out vital tasks declines. This stage, when complications arise, is called decompensated cirrhosis. Key complications include:

1. **Ascites** – accumulation of fluid in the abdomen
2. **Hepatic encephalopathy** – confusion, personality changes, or even coma due to the liver's inability to clear toxins like ammonia
3. **Variceal bleeding** – vomiting blood or passing black stools due to bleeding from enlarged veins (varices) in the oesophagus or stomach
4. **Jaundice** – yellowing of the skin and eyes due to buildup of bilirubin
5. **Hepatorenal syndrome** – kidney failure due to advanced liver disease
6. **Spontaneous bacterial peritonitis (SBP)** – infection of the fluid in the abdomen



1.b Why this guide exists
This booklet is designed to help you understand common symptoms of advanced liver disease and the ways they can be managed. It also supports forward planning, so that you can make choices about your care, either alone or with those close to you.

1.c Planning ahead
In the appendix, we share an example of how illness may progress and outline different treatment paths, including intensive, ward-based, and palliative care. These options aim to support you in considering what matters most should you become seriously unwell.



2. Managing ascites

2.a Reducing salt and taking Diuretics

To manage ascites (fluid in the abdomen), a no-added salt diet is advised. Ready meals should be avoided. Water tablets like Spironolactone and Frusemide help remove excess fluid. Side effects can include dehydration or kidney strain, so regular blood tests and weighing yourself two–three times per week are recommended.

2.b Large volume paracentesis (LVP)

If tablets no longer control the fluid, you may be offered a drain procedure every few weeks. Under local anaesthetic, a tube is inserted into the abdomen to remove fluid. You'll also receive albumin via a drip to support circulation. This is usually a same-day hospital procedure.

2.c TIPSS (Transjugular Intrahepatic Portosystemic Shunt)

A TIPSS is a stent placed in the liver via X-ray guidance to reduce portal pressure and fluid build-up. It is only offered to carefully selected patients, as it can carry risks, especially in those with poor liver function, heart conditions, or prior encephalopathy.

2.d Long-term drains

For patients nearing the final months of life, a long-term ascitic drain might be appropriate. Fluid is removed at home by a nurse several times per week. While it can improve comfort, it carries infection risks and typically requires long-term antibiotics.

3. Hepatic encephalopathy (HE)

3.a What causes it?

When the liver can’t clear toxins like ammonia, they build up in the bloodstream and affect brain function. Triggers include:

- Infection
- Constipation
- Bleeding
- Electrolyte imbalance
- Certain medications (e.g., opiates)

3.b Treatment goals

Treatment focuses on removing triggers and lowering toxin levels. This includes laxatives, antibiotics, and sometimes addressing infections or bleeding.

3.c Lactulose

A syrup laxative that helps flush out toxins. Aim for two–three soft stools daily.

3.d Rifaximin

An antibiotic that reduces ammonia-producing bacteria in the gut. Taken long-term, it can prevent future episodes of HE.

3.e Lifestyle Tips

Frequent, smaller meals and a bedtime snack may help. Dietitians can support you in maintaining good nutrition.

4. Variceal bleeding

4.a What is it?

Varices are swollen veins in the food pipe or stomach caused by portal hypertension. If they burst, it can cause vomiting of blood or black stools, this is a medical emergency and will require an A&E assessment.

4.b Medication

In hospital, you'll receive medications to stop bleeding, replace lost blood, and prevent infection.

4.c Endoscopy

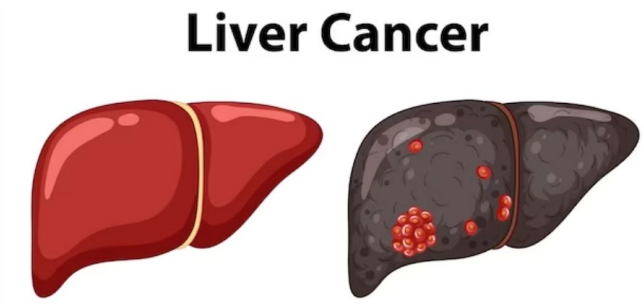
An urgent procedure using a camera to band or inject bleeding varices.

4.d TIPSS or other treatments

TIPSS may be considered if bleeding can't be controlled by endoscopy, especially in high-risk cases. Rarely, a balloon device or surgery may be used.

4.e Comfort-focused care

In some patients, aggressive treatment may not be suitable. Comfort-based care focuses on relief of distress and preserving dignity. Sedatives and pain relief are used to keep you comfortable.



5. Liver Cancer (Hepatocellular Carcinoma - HCC)

5.a Diagnosis

CT or MRI scans assess the size and spread of tumours. Your case is reviewed by a multidisciplinary team (MDT) including liver specialists and oncologists.

5.b Surgery

Options may include resection (removing part of the liver) or transplant, but only if liver function and general health are suitable.

5.c Radiology options

Minimally invasive procedures can target tumours and may shrink or slow growth, though not usually curative.

5.d Chemotherapy

Used when other treatments aren't possible. Aims to extend life, but not cure.

5.e Comfort-Only Approach

For frail or very unwell patients, a focus on symptom control with the palliative care team may be most appropriate.

6. Online support

- British Liver Trust: www.britishlivertrust.org.uk
- Cirrhosis Care Alberta: www.cirrhosiscare.ca
- BASL resources: www.basl.org.uk
- Liver disease and palliative care: www.getpallitivecare.org

Appendix

Example: Progression of Decompensated Liver Cirrhosis and Treatment Paths

Stage	Clinical Features	Treatment Focus
Early Decompensation	Development of ascites, mild jaundice, and mild confusion (hepatic encephalopathy grade 1-2)	Ward-based management: diuretics for ascites, lactulose for encephalopathy, antibiotics if infection suspected
Acute Deterioration	Sudden severe gastrointestinal bleeding from oesophageal varices, worsening encephalopathy, renal dysfunction (hepatorenal syndrome), and sepsis	Intensive care: airway support, blood transfusion, vasoactive drugs to control bleeding, ICU monitoring, renal support (dialysis if needed)
Advanced End-Stage	Refractory ascites, persistent encephalopathy, malnutrition, repeated hospitalizations, poor quality of life	Consideration of palliative care: symptom control, psychosocial support, discussions about goals of care, comfort measures

Treatment Paths

1. Intensive Care Unit (ICU) Management

- Indications:
    - Severe gastrointestinal bleeding unresponsive to initial treatment
    - Hepatic encephalopathy progressing to coma
    - Multi-organ failure (e.g., kidney failure, sepsis)
    - Need for advanced life support (ventilation, dialysis)

- Treatments:
  - Endoscopic banding for variceal bleeding
  - Vasoconstrictor medications
  - Blood transfusions and volume resuscitation
  - Mechanical ventilation if unconscious or airway at risk
  - Continuous monitoring of vital signs and organ function
  - Renal replacement therapy for kidney failure
- Goal: Stabilize patient, prevent death, and consider eligibility for liver transplant.

2. Ward-Based Care

- Indications:
  - Moderate symptoms manageable without ICU support
  - Controlled ascites, mild to moderate encephalopathy
  - Ongoing management of complications and prevention of deterioration
- Treatments:
  - Diuretics (e.g., spironolactone, furosemide) to manage fluid overload
  - Therapeutic paracentesis for large ascites
  - Lactulose and rifaximin for hepatic encephalopathy
  - Antibiotics for infections such as spontaneous bacterial peritonitis
  - Nutritional support, including protein supplementation
  - Regular monitoring and outpatient follow-up
- Goal: Control symptoms, improve quality of life, and delay disease progression.

3. Palliative Care

- Indications:
  - End-stage liver disease with poor prognosis
  - Patients not eligible for transplant or who decline aggressive treatments
  - Frequent hospital admissions and refractory symptoms
- Treatments:
  - Symptom control (pain, pruritus, nausea)
  - Management of ascites to reduce discomfort
  - Psychosocial and spiritual support
  - Advance care planning and discussions on goals of care
  - Support for family and caregivers
- Goal: Maximize comfort and quality of life, support dignity, and avoid unnecessary interventions.

CPR and Advance Care Planning in Decompensated Liver Cirrhosis

What is CPR?

CPR (Cardiopulmonary Resuscitation) is an emergency procedure performed when a person's heart or breathing stops. It involves chest compressions, sometimes with rescue breaths, to try to restart the heart and keep blood flowing to vital organs.

Why is CPR a Complex Issue in Decompensated Liver Cirrhosis?

Decompensated liver cirrhosis is a severe, life-limiting illness with complications that affect multiple organs. If a patient's heart or breathing stops, CPR is often less likely to be successful

because:

- The liver's failure affects many body systems (blood clotting, kidney function, brain function).
- The overall health status is often very poor, with high risk of serious complications.
- Even if CPR temporarily restarts the heart, the chances of meaningful recovery are often low.

What is Advance Care Planning?

Advance care planning is a process where patients, their families, and healthcare providers discuss and decide on future medical care, especially in emergencies or when the patient cannot speak for themselves.

It helps clarify:

- What treatments the patient would want or not want
- Goals of care (e.g., prolonging life vs. comfort and quality of life)
- Decisions about CPR and other life-sustaining treatments

Why is Advance Care Planning Important in Decompensated Liver Cirrhosis?

- The disease can progress unpredictably, sometimes causing sudden deterioration.
- Having a clear plan ensures patient wishes are respected.
- It helps avoid unnecessary or invasive treatments that may cause suffering without benefit.
- It supports better communication between patient, family, and healthcare teams.

Discussing your wishes in advance can ensure your care aligns with your values.

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