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Liver Cirrhosis

**Self-management toolkit
to help optimise your care
Please bring to every appointment**

NORTH
LIVER PATIENT SUPPORT
run entirely by unpaid volunteers

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Your Information (to be completed by your doctor)

Lead Consultant:					
Underlying liver disease:					
Please complete table with yes, no or N/A. If something has changed start a new column.					
Date of change:	/ /	/ /	/ /	/ /	/ /
Ascites present?					
On diuretics (water tablets)?					
Previous SBP?					
On prophylactic antibiotics?					
Known varices?					
Variceal screening offered?					
On Propranolol/Carvedilol?					
Previous encephalopathy?					
On Lactulose?					
On Rifaximin?					
Liver cancer screening considered?					
Patient education provided?					

For your own notes.....

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What is The Cirrhosis Self-management Toolkit?

You have been diagnosed with cirrhosis of the liver. The aim of this toolkit is to provide you with advice about the condition and some hints to help you optimise your treatment. Cirrhosis can lead to some important complications. These complications are outlined in this toolkit and can be effectively managed if they are identified early and treated appropriately. This document will give you an overview of what cirrhosis is and what complications can occur. It will also provide advice on how to manage some aspects of the condition yourself. Hopefully, this will help to avoid admissions to hospital and ultimately improve your quality of life.

Receiving a diagnosis of cirrhosis can be a worrying time and there may be a lot of information to take in. Your consultant, GP and nursing team are there to help and support you. Please make sure you ask any questions you may have about your condition.

For your own notes

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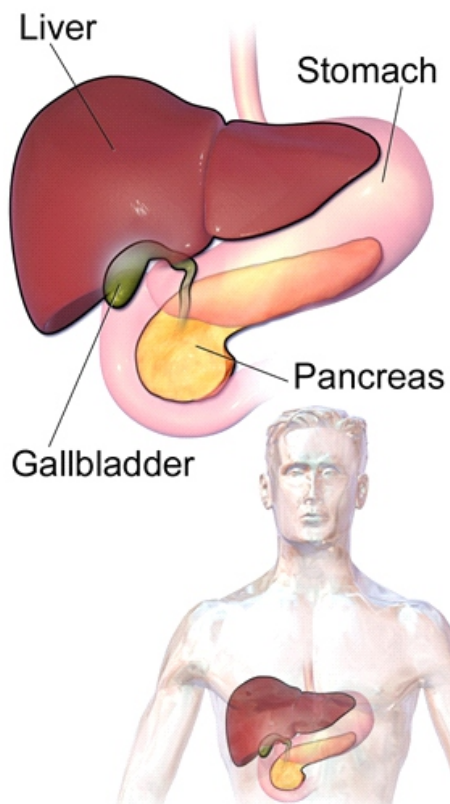
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What is the Liver?

The liver is the body's largest internal organ. It is an essential organ and the body cannot survive without it. The liver has many important functions including:

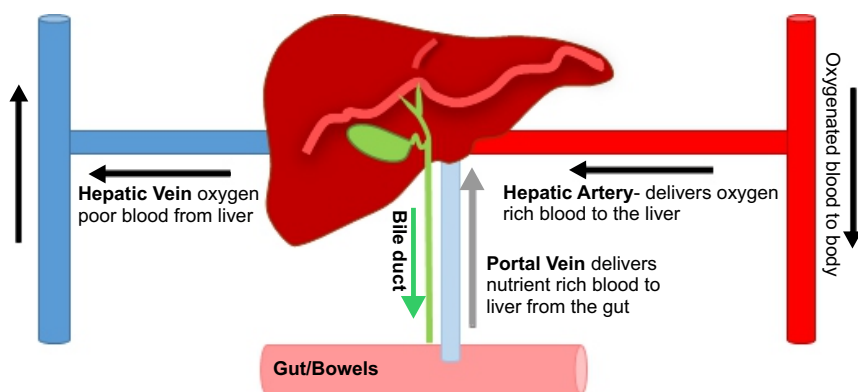
- Storing fats, sugars, vitamins, and minerals for use by the body
- Making bile to help with absorption of fat from food
- Processing medications and hormones
- Making proteins that help the blood clot
- Removing bacteria and toxins from the blood to reduce risk of infections.



What is Liver Cirrhosis?

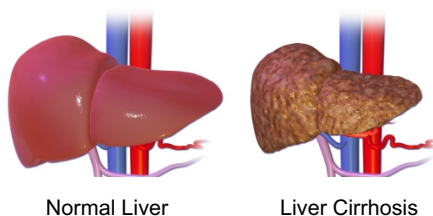
Cirrhosis is scarring of the liver caused by long-term liver damage. This scarring leads to loss of liver cells, which can result in reduced liver function. Any long-term condition or disease that affects the liver can cause cirrhosis. Some of the most common causes of cirrhosis are non-alcoholic fatty liver disease, alcohol-related liver disease, chronic viral hepatitis, autoimmune liver disease and some inherited liver diseases. Your doctor will have advised you about the underlying cause of your liver damage. Some treatments can help to stop more damage occurring to the liver and reduce the risk of developing complications of liver disease.

Cirrhosis causes the liver to become firm and knobbly because of a build-up of scarring in the liver. This can reduce blood flow through the liver, which in turn can cause a build-up of pressure in the portal vein. This is the main vein that takes blood from the intestines to the liver. High pressure in the portal vein is called **portal hypertension** and this causes many of the symptoms associated with cirrhosis.



Early Stages of Cirrhosis

At this stage you have cirrhosis but the liver may function normally and you may have no symptoms. In fact, a person may not be aware that they have liver cirrhosis. The pressures in the portal vein are higher than normal but still at a low enough level not to cause problems. This is known as compensated cirrhosis. If there is continuing liver damage then the pressure in the portal vein can rise and the liver may not be able to meet the body's demands. Many people with cirrhosis do not progress beyond early stage cirrhosis.



Progression of Liver Cirrhosis

If liver cirrhosis progresses some symptoms may be noticed including:

- Weight loss
- Loss of muscle mass
- Poor appetite
- Low energy and symptoms of fatigue or excessive tiredness.

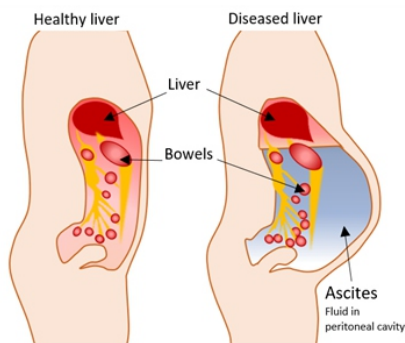
More advanced cirrhosis, which is known as decompensated cirrhosis can lead to other complications such as:

- **Ascites** - a build-up of fluid in the abdomen
- **Bleeding varices** - internal bleeding from blood vessels in the gullet (oesophagus) or stomach
- **Encephalopathy** - confusion from the build-up of toxins in the blood that can affect brain function.

The next section will go on to explain these complications further and discuss how to prevent and/or manage them.

Ascites

Ascites is fluid that has built up in the peritoneal cavity.



Ascites occurs due to high pressure in the portal vein and other veins around the liver. This causes fluid to leak out and build up in the peritoneal cavity within the abdomen.

This fluid is outside of the intestines and collects between the abdominal wall and the organs within the abdomen.

The liver also sends signals to the kidney to 'hold on' to salt, resulting in fluid and salt retention, which can cause swelling in the legs. The protein levels in the blood can also fall, allowing fluid to leak out of blood vessels more easily causing a build-up of fluid under the skin.

When ascites is severe it can make it difficult to eat due to pressure on the stomach. You may also notice that when you lie flat that it may be harder to breathe than normal.

Infection can also develop in ascitic fluid. This is called **Spontaneous Bacterial Peritonitis (SBP)** - see page 12. It is very important that this infection is treated quickly as it can be life threatening if not treated.

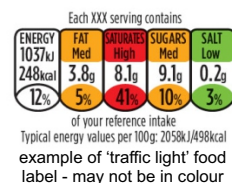
Treatments for Ascites

No added salt diet

Salt retention by the body in individuals with cirrhosis can contribute to the build-up of ascitic fluid. For this reason, it is important to reduce your salt intake. It is recommended that people with ascites do not add salt to their food and avoid foods that have large amounts of salt in them.



Most salt in a person's diet comes from processed foods, not from adding salt to food. Checking the traffic light labels on food packaging may help. Aim for low salt products.



Diuretic tablets (Water Pills) e.g. Spironolactone or Furosemide

Diuretic medication:

- Helps the body get rid of extra salt and water through the kidneys, the dose of these medications may be changed over time depending on your response to them
- Measurement of bodyweight every few days can be very helpful to assess the response to the water tablets (1kg change = 1 litre of fluid).

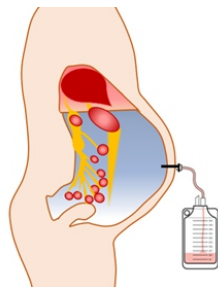
Blood tests are needed as these medications can affect your kidney function. Your consultant, GP, or nurse will monitor the level of salts (sodium and potassium) in the blood. Your doctor (GP or consultant) may increase or decrease the dose based on your kidney function, salt levels and your response to the medication.

It is important to take your diuretic tablets if they have been prescribed. They will help reduce your ascites.

Abdominal Paracentesis

Paracentesis (or ascitic drain) is the draining of fluid out of the abdomen through a small tube that is inserted into the abdomen. Usually diuretic medication has been trialled before proceeding to a drain.

- A local anaesthetic is given before the drain is placed
- The drain will be left in for a maximum of 6 hours
- Usually a maximum of 15 litres is drained
- You will be given albumin solution through a drip into your veins to maintain your blood pressure during the drainage and replace protein that is lost in the drained fluid.



A paracentesis provides quick relief of ascites symptoms, but it does not correct the underlying cause so the fluid may eventually return. By following a low salt diet and taking diuretic medication you will help to slow down the build-up of fluid again.

How to know when you need a paracentesis (ascitic drain) and who to contact.

If your ascites has built-up and your abdomen is very swollen and tense then you may need it draining (paracentesis).

The best way you can help the doctors manage your fluid problem is:

- Use the weight and diuretic dose diary starting on page 19 to record your weight and diuretic dose regularly
- When you have gained 10 kg (1kg = 1 litre of ascites) in weight or the skin on your abdomen is tense then arrange a paracentesis
- A record of when you last had a paracentesis can be found on page 23.

The contact number to arrange an appointment for a paracentesis is shown on the back cover. Please give a few days' notice so that we can book an appointment for you.

Spontaneous Bacterial Peritonitis (SBP)

SBP is when the ascitic fluid becomes infected. This can be life threatening so it is important to get treatment promptly. Patients with SBP may not have any symptoms but can have:

- **Fever**
- **Abdominal pain**
- **Worsening jaundice (yellowing of the eyes)**
- **Confusion due to hepatic encephalopathy**

SBP is treated with intravenous antibiotics and albumin infusions through a drip. You will require admission to hospital for this treatment as you will need close monitoring.

Preventing SBP infection recurrence

If you have been treated for SBP infection then you may be at risk of this again in the future. You might be prescribed a low dose antibiotic tablet to take every day to reduce the risk of future episodes of this infection.

SBP can be a serious infection. If you have ascites and develop a fever or new abdominal pain then you should go to A&E for an assessment without delay.

For your own notes

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Oesophageal Varices

Varices are swollen veins at the lower end of the gullet (oesophagus) or the upper part of the stomach (gastric).

They occur because blood that drains from the intestines cannot flow through the liver like normal. This results in this blood bypassing the liver and flowing through veins around the gullet and stomach. These veins are called **varices** and they are at risk of bleeding.

Bleeding varices can be life threatening if not treated urgently.

Signs of bleeding varices include:

- Vomiting fresh blood or clots
- Passing black and tarry stools (melaena)

People who have signs of bleeding varices should go to an A&E urgently.

Treatment for Oesophageal Varices

A procedure known as a gastroscopy is used to treat varices. This is a telescopic examination of the gullet, stomach and duodenum. The procedure involves passing a narrow flexible instrument (gastroscope) through the mouth to examine these areas. The varices can be treated by putting small elastic bands (banding) over them. A clot forms after a few days causing the varices to shrink, which reduces the risk of them bleeding again.

For your own notes

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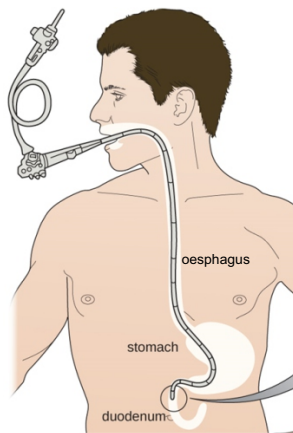
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Preventing Variceal Bleeding

When you receive a diagnosis of liver cirrhosis you may be offered a gastroscopy to see if you have varices. By identifying the varices early, your doctor can offer treatments to reduce the risk of them bleeding in the future. If they are medium or large in size your doctor may 'band' them or start you on beta-blocker tablets to reduce the risk of them bleeding.

If no oesophageal varices have been detected you may be offered regular surveillance gastroscopies every 2-3 years to see if varices develop.



Other Treatments to Prevent Bleeding

Medication

Beta blockers can reduce the blood pressure in the varices, which reduces the risk of them bleeding. Carvedilol or Propranolol are the most commonly prescribed beta-blockers in patients with cirrhosis because they reduce the pressure in the varices more effectively than other beta-blockers. You should take this medication every day. This medication may also reduce your overall blood pressure and can occasionally make you dizzy or lightheaded if your blood pressure goes too low. In this case the dose of the medicine may need to be reduced. If your blood pressure is too low before taking these medications then they may not be suitable for you.

For your own notes

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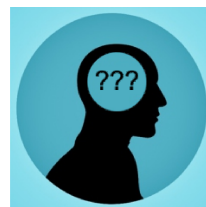
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Hepatic Encephalopathy

Hepatic encephalopathy occurs when toxins, which are normally removed by the liver, build up in the blood and affect the brain, causing confusion. A cirrhotic liver is not as good as a normal liver at removing toxins. The main toxin that builds up is ammonia. The ammonia comes from bacteria in the intestines.



These toxins can cause:

- Changes in sleep and mood
- Reduced concentration and memory
- Drowsiness and sleepiness
- In severe cases it can result in coma from which you can completely recover with treatment.

If you have hepatic encephalopathy, you may also have problems with:

- Driving (do not drive if you are suffering from encephalopathy)
- Writing
- Calculating
- Performing activities of daily living, such as cooking.

You may also have a hand tremor.

Things that increase your risk of encephalopathy:

- Infection
- Gastrointestinal bleeding (e.g. variceal bleeding)
- Constipation
- Some medications such as pain killers, sleeping pills and sedating drugs.

It is useful for your family and friends to be advised on what to do when you are suffering with encephalopathy, as you may not notice the symptoms yourself.

If you or your family and friends notice you becoming rapidly worse with confusion, then you should attend hospital or your GP as soon as possible (within a few hours) to find the cause (such as infection or constipation) so it can be treated.

Treating Hepatic Encephalopathy

Lactulose Syrup

Lactulose is a laxative made from an artificial sugar that cannot be digested by the stomach or intestines. It goes into the large bowel where it reduces the absorption of toxins from the bowel. Other laxatives are not as effective as lactulose for treating encephalopathy. Patients usually start with 2 or more tablespoons of lactulose syrup once or twice a day. The dose is gradually increased aiming for you to open your bowels with 2-3 soft stools a day.



How to manage your lactulose dose yourself.

You can increase the dose if:

- Your stools are firm
- If you are having fewer than 2 loose stools per day
- On days when you are more forgetful or confused
- You can decrease the dose if you are having more than 3 loose stools per day.

Rifaximin

Rifaximin is an antibiotic that works only in the intestine. It is usually prescribed if symptoms of encephalopathy remain despite lactulose treatment. It changes the type of bacteria in the intestine reducing the amount of toxin produced. This helps reduce your risk of having episodes of encephalopathy.

For your own notes.....

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Nutrition in Liver Disease

Nutrition is defined as the process of taking food into the body and absorbing the nutrients in those foods.

Nutrients are chemical compounds in food that are used by the body to function properly and maintain health. Examples include proteins, fats, carbohydrates, vitamins and minerals.

Given the vital role of nutrition in the liver, malnutrition can be common. Signs of malnutrition include; unexpected weight loss, loss of appetite and muscle wasting.

In cirrhosis, the liver may be unable to store as much energy as a normal healthy liver. The energy from the food you eat may only last for 2 hours, therefore if you are not having regular meals and snacks, the energy store disappears very quickly. If there are no energy stores available in the liver, the body will break down muscle to fuel the body. This results in muscle and weight loss.

Top nutrition tips:

The aim is to avoid prolonged periods of fasting to reduce muscle wasting and weight loss. You should try to:-

- **Eat regular meals containing carbohydrate**
 - Aim to have 3 meals a day. These may be smaller than you would normally manage. All meals should be based on a source of starchy carbohydrate, such as bread, potato, cereal, pasta, rice, noodles or couscous.
- **Eat snacks containing carbohydrate every 2–3 hours**
 - Suitable snacks suggestions include yoghurt, tea cake, scone, toast, cheese and crackers, chocolate bar, cake, or a small sandwich.
- **Have a bed time snack**
 - You should aim to have 50g carbohydrate, as less can reduce muscle loss overnight, examples of suitable snacks include:-
 - Bowl of cereal and banana
 - 2 slices of toast and jam and a glass of milk
 - Slice of fruit cake and glass of milk
 - 4 biscuits and a glass of milk
 - 2 crumpets and a banana.

What if I am finding it difficult to eat?

- Try to eat small but frequent meals
- Avoid skipping meals and snacks, however small, every little helps
- Avoid drinking with meals as this may fill you up and spoil your appetite
- A short walk or fresh air before a meal, may increase your appetite
- Prepare meals in advance when you have more energy and make extra for the freezer
- Consider ready meals; these can be just as nutritious (select the lower salt versions if you have ascites)
- Include convenience foods (such as tinned, dried or frozen foods) in your weekly shop as these will last longer.

How can I gain weight?

- Try to avoid filling yourself up with large servings of fruit, vegetables or salads as they do not provide much energy
- If you usually use low fat, low sugar 'diet' foods and drinks, switch to the non-diet options
- Add ingredients such as cream, cheese, butter, olive oil, cream cheese, milk powder and lentils to foods like soups, stews, curries, vegetables, potatoes
- Add honey, syrup and jams to porridge, milky puddings, or toast (avoid if you have diabetes)
- Fortify your usual milk by whisking 4 tablespoons of skimmed milk powder into 1 pint of milk
- Focus on nourishing drinks. These can include: full fat or semi skimmed milk, malted drinks, made with milk, smoothies, fruit juice and full sugar fizzy drinks
- Try making a nutritious homemade milkshake: these can be made up with a mixture of milk, honey, milkshake powder, yoghurt, ice cream, cream or pureed fruit
- Try to have a pudding after your main course or as an in-between meal snack
- Powdered nutritional supplements are available from chemists or supermarkets
- In some cases, prescribed oral nutritional supplements, such as Fortisip Compact Protein, Ensure Plus or Fortijuce may be required and be beneficial. Your doctor or Dietitian may advise.

Protein

When your liver is not working properly your body needs more protein. Protein is essential for building and repairing body tissues and keeping your muscles strong. Combining a good intake of protein with exercise is ideal for maintaining and building muscle and making you feel stronger.



Tips to improve your protein intake

- Good sources of protein include; meat, fish, eggs, soy, tofu, beans, pulses, nuts and seeds and dairy foods such as milk, yoghurt and cheese
- Milky drinks, such as hot chocolate or Ovaltine
- Milky puddings such as custard and rice pudding after or between meals.

Please note, if you have diabetes, consult with your Dietitian/health care provider as some of the above suggestions may not be suitable.

See the LIVERNORTH 'Nutrition Support in Liver Disease' booklet 14a for more detailed guidance on nutrition and liver disease.

For your own notes

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Surveillance for Liver Cancer

People with cirrhosis have an increased risk of developing liver cancer compared with those without cirrhosis. Individuals with cirrhosis are therefore offered regular liver scans to try to detect a cancer early when it is more likely to be cured with treatment.

Individuals with cirrhosis may be offered an ultrasound every 6 months. Some patients may need further scanning with Computerised Tomography (CT) or Magnetic Resonance Imaging (MRI).

Vaccination

The yearly influenza vaccination (flu jab) is recommended for patients with cirrhosis. Some patients with cirrhosis may be advised to have a vaccination for hepatitis A and B if they have not received these before.

Preventing Further Damage to Your Liver

It is important to try to avoid things that can damage your liver, for example:

- People with cirrhosis are advised not to drink alcohol at all. If you need support to help you to stop drinking alcohol please talk to your doctor (GP or Consultant)
- Avoiding medications that can cause liver damage. These include non-steroidal anti-inflammatory drugs (NSAIDs), such as ibuprofen.



You should also try to:

- Keep to a healthy weight
- Eat a healthy, balanced diet. Malnutrition is common in people with cirrhosis
- Take regular exercise.

For your own notes

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Support for Patients with Liver Disease

Receiving a diagnosis of cirrhosis can be a worrying time and there may seem to be a lot of information to take in. Your consultant, GP and nursing team are there to help and support you. Do ask them if you have any questions about your condition.

LIVERnORTH can also provide support for you and your family. A registered charity, LIVERnORTH is a national liver patient support group and has numerous resources:

- Free information leaflets on most types of liver disease
- Helplines provided by qualified listeners
- A website where people can find out about the group and download information leaflets
- Regularly meetings with guest lecturers (usually consultant clinicians) who give the latest facts about liver disease and its treatment
- Regular quarterly newsletters
- Accommodation at the Freeman Hospital, Newcastle (a 4 bed flat) for patients, their carers and families who find travel to and from the hospital difficult (the Freeman is a major Hepatology centre with patients attending from all parts of the UK and abroad).

For your own notes.....

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Weight and Diuretic Dose Diary
1kg of weight = 1 litre of fluid

Date	Weight (kg)	Diuretics	Doses

Date	Weight (kg)	Diuretics	Doses

Diary of Other Medication Prescribed

Medication Name	Dose	Frequency (e.g. 3 times per day)	Date dose changed:

Hospital Appointments Diary (outpatient clinics, day ward visits)

Date	Time	Location	To see

Paracentesis Dates (to be completed by the doctor)

Date	Side of abdomen	Amount drained	Any complication

Information Leaflets Available:

1. Liver Patient Support
2. Accommodation for patients & families
3. Autoimmune Hepatitis
4. Alcoholic Liver Disease
5. Look After Your Liver
6. Primary Biliary Cholangitis (PBC)
7. Coping With Stress
8. Primary Liver Cancer
9. You and Your Consultant
10. Primary Sclerosing Cholangitis (PSC)
11. NAFLD Lifestyle Guide
- 11a. Non Alcoholic Steatohepatitis
12. Liver Disease
13. Skin Care for Liver Patients
14. Diet and Liver Disease
- 14a. Nutrition in Liver Disease
15. Hepatitis C
16. Travel Insurance for Liver Patients
17. Hepatitis E
18. Fatigue in Liver Patients/A Patient's Journey
19. Understanding Healthcare Tests
20. Liver Cirrhosis Self Management Toolkit (this one)*
21. Exercise & Osteoporosis in Liver Patients
22. Hepatic Encephalopathy

* only from your doctor or healthcare professional

How to access our information leaflets:

1. ISSUU: <https://issuu.com/livernorth>

2. Download from our website:

(<http://www.livernorth.org.uk/pages/factsheet.htm>)

3. Collect from our display boards:

(Various Hospitals & Clinics)

4. Email us: info@livernorth.org.uk

5. Phone/FAX: 0191 3702961

6. Write to us:

Freepost LIVERNORTH

(no postage stamp necessary)

7. Facebook message us:

<https://www.facebook.com/livernorth/>

Useful Numbers:

Consultants:

Apply Avery laser/inkjet
label ref:7163/8163
to fill this space

Booking a Paracentesis:

Apply Avery laser/inkjet
label ref:7163/8163
to fill this space

LIVERNORTH Support

Receiving a diagnosis of cirrhosis can be a worrying time and you may have lots of questions about your diagnosis or want to talk to someone who has cirrhosis. The LIVERNORTH team are there to provide help and support for patients with liver disease. Feel free to contact them directly on their helpline.

LIVERNORTH

freepost LIVERNORTH

Tel & helpline: 0191 3702961

Info@livernorth.org.uk

www.livernorth.org.uk

Registered Charity Number 1087226

LIVERNORTH is a national liver patient support charity
and has provided this toolkit booklet free of charge.

We have no paid employees.

NIHR non-commercial Partner

