

LIVER CIRRHOSIS

An Information Booklet for Patients

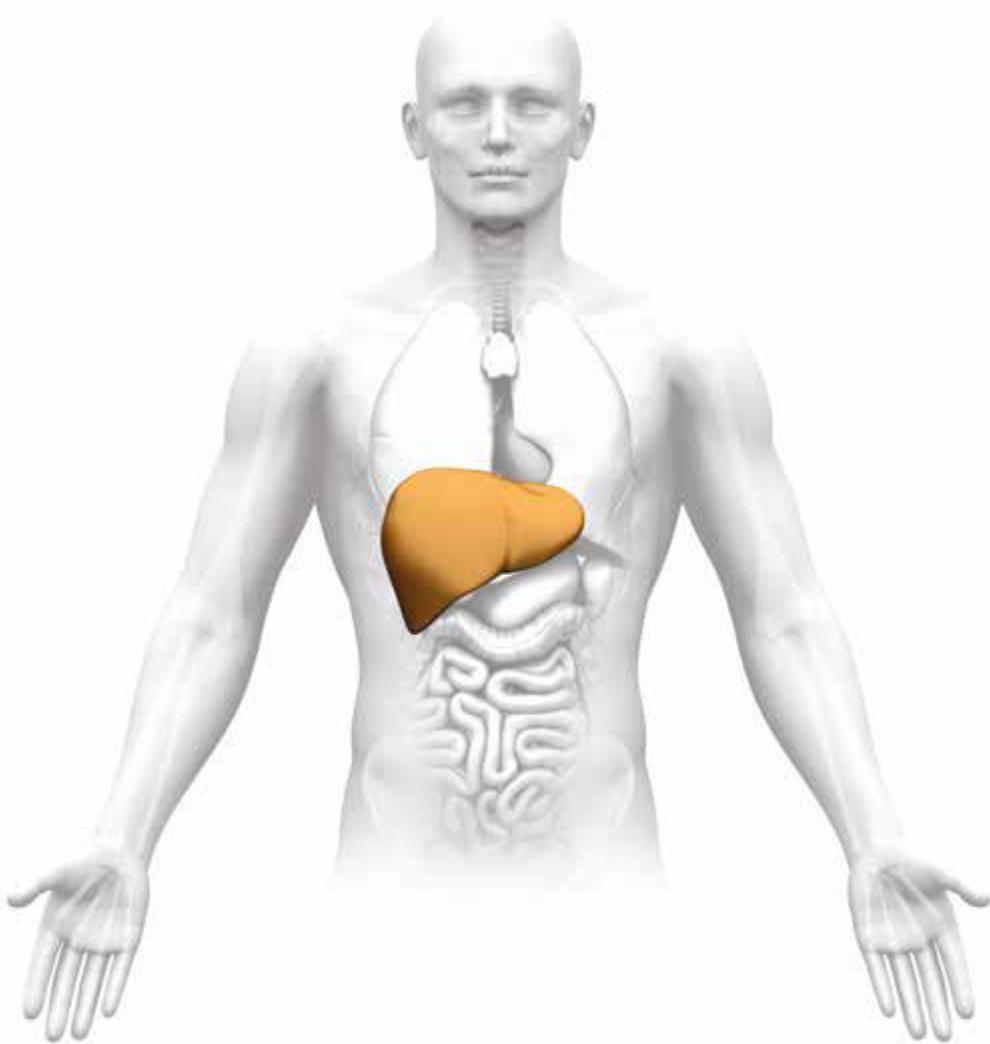


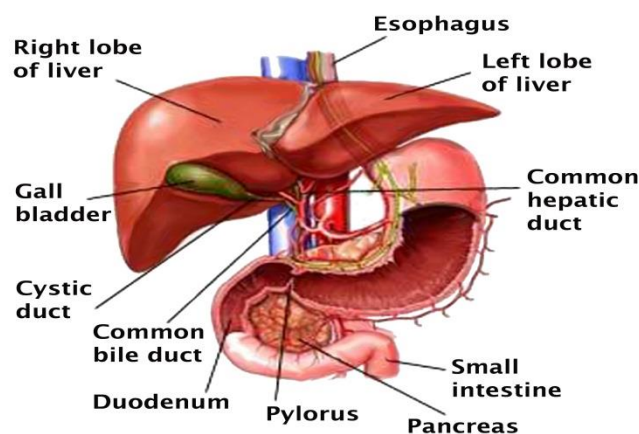
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INTRODUCTION

This booklet has been put together to provide you with information about liver cirrhosis, what it is and how it will affect your life. It is also intended to provide you with useful information about how to look after yourself and your liver once the diagnosis has been made.

It is intended as supplementary information for you and is not a replacement for talking with your liver specialist, nurse specialist or GP about your diagnosis.

THE HEALTHY LIVER



The liver is a large organ sitting to the upper right side of the abdomen. The liver is an extremely important organ in the body that has many functions which are essential for life and growth. These include:

- Taking the carbohydrate, protein and fat from food and turning these into energy for the body.
- Filtering alcohol and other toxic substances and excreting these from the body
- Helping to activate medications so that they work properly and then breaking them down and removing them from the body.

WHAT IS LIVER CIRRHOSIS?

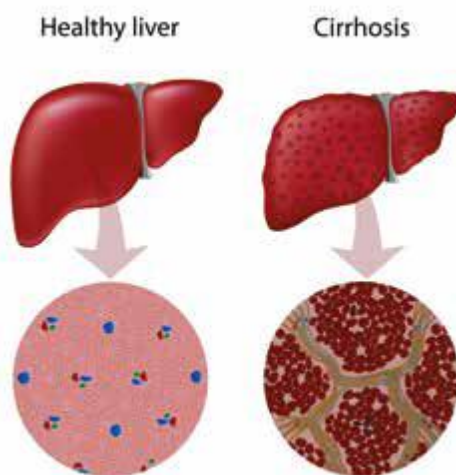
Liver cirrhosis is a medical term used to describe a condition where the liver contains a large amount of scar (fibrosis) tissue. Scar tissue forms from ongoing injury to the liver, usually from a chronic viral infection such as chronic hepatitis B and chronic hepatitis C. It can also be caused from alcohol or too much fat in the liver – see causes of liver cirrhosis on page 4 for more causes and details.

The scarring process is a slow process and usually takes between 20 and 40 years for cirrhosis to develop. The damage can begin slowly, often with no outward symptoms or signs to indicate the gradual progression of scarring to the cells and resulting loss of liver functions.

Liver cirrhosis itself also has several stages. In the early stages there are still enough healthy liver cells to perform the functions of the liver. This is called **Compensated Cirrhosis**. However, if the scarring is allowed to continue, more of the cells are lost and the liver is no longer able to fulfill its important functions. This is called **Decompensated Cirrhosis**. Eventually the liver can become so scarred and shrunken that without a liver transplant the result is death. Cirrhosis of the liver also increases the risk of a cancer developing in the liver.

Fortunately cirrhosis can be diagnosed before the onset of these symptoms through blood tests, FibroScan or through liver biopsy. Cirrhosis is sometimes discovered incidentally during routine imaging (especially CT scan of abdomen) or during an abdominal surgery.

Comparison of a healthy and a liver with cirrhosis



WHAT ARE THE SYMPTOMS OF CIRRHOSIS?

In patients with compensated cirrhosis, there are no specific symptoms although people commonly complain of being lethargic and easily fatigued. They may notice poor sleeping at night, reduced appetite and lack of libido. In women, periods usually stop.

As cirrhosis progresses the scar tissue reduces the blood flow through the liver, causing increase in pressure in the veins which may cause bleeding in the gullet and stomach. Specific symptoms which develop in the later stages of cirrhosis include jaundice, weight loss, swelling of legs and abdomen, confusion and bleeding into the bowel. These topics are covered in more detail later on pages 11 – 16.

WHAT CAUSES LIVER CIRRHOSIS?

Cirrhosis is the end-stage of many types of liver disease, the most common being chronic viral hepatitis due to either hepatitis B virus (HBV) or hepatitis C virus (HCV) infections, alcohol abuse, and fatty liver (from obesity or diabetes). Cirrhosis may also be caused by conditions where your own immune system damages the liver, such as autoimmune hepatitis, Primary Biliary Cholangitis and Primary Sclerosing Cholangitis. And in rare cases, cirrhosis may be caused by long-term exposure to some medicines or environmental toxins. In about 10% of cases of cirrhosis, no underlying cause can be found. These cases are called “cryptogenic cirrhosis”.

Knowing the underlying cause of your cirrhosis is the very first step in caring for your liver because the different causes of cirrhosis need different kinds of treatment. This will be discussed in more detail with your liver specialist or nurse, who will prescribe the medications and actions appropriate to your diagnosis.

TAKING LONGER TERM CARE OF YOUR LIVER

The liver has an amazing ability to repair itself and regrow after it has been damaged. Once the cause has been diagnosed, and in some cases cured, a liver-friendly lifestyle will contribute enormously to maintaining the health of the liver cells, halting, slowing and possibly even reversing the spread of the cirrhosis in the liver. It is important to maintain this lifestyle even if the outward signs of liver disease have disappeared in order to guard against any progression to decompensated cirrhosis.

THINGS YOU CAN DO TO LOOK AFTER YOURSELF AND YOUR LIVER

Lifestyle factors are very important for anyone with chronic liver disease.

1. AVOID ALCOHOL



Alcohol is a liver toxin and can increase the rate of scarring in your liver. If you already have cirrhosis or severe fibrosis, **STOP** all alcohol. If you have mild or no fibrosis, reduce your alcohol intake to a maximum of 2 standard drinks per day for women, 3 per day for men and make sure you have at least two alcohol free days each week.

2. REDUCE CANNABIS



Cannabis contains THC which can also increase the rate of scarring in your liver. If you have chronic liver disease and you use cannabis you should try to reduce your cannabis intake to maximum of 1 joint per day or equivalent.

3. DRINK COFFEE!



Drinking coffee (including decaffeinated) each day may help protect the liver from developing cirrhosis, help prevent liver cancer and may slow the progression of liver disease. It is recommended that you drink at least 2 cups but no more than 4 cups per day.

<https://www.britishlivertrust.org.uk/liver-information/diet-and-liver-disease/coffee-and-the-liver/>

4. MAINTAIN A HEALTHY DIET AND LIFE-STYLE



Eating a healthy, balanced diet and regular exercise are important for maintaining strength and achieving a healthy body weight.

When you are in the early stages of liver disease you can follow the Ministry of Health 'Healthy eating, active living' guidelines for adults (<https://www.health.govt.nz/your-health/healthy-living/food-and-physical-activity/healthy-eating>):

- Eat from the four food groups:
 - Plenty of vegetables and fruit
 - Grain foods – mostly wholegrain and those naturally high in fibre
 - Some milk and milk products, mostly low and reduced fat
 - Some legumes, nuts, seeds, fish, other seafood, eggs or poultry, or red meat with the fat removed
- Choose and/or prepare foods:
 - With unsaturated fats instead of saturated fats
 - That are low in salt (sodium); if using salt, choose iodised salt
 - With little or no added sugar
 - That are mostly 'whole' or less processed
- Drink mainly plain water – aim for 8-10 cups per day
- Sit less and move more – be as active as possible

As your liver disease progresses you may experience symptoms such as loss of appetite, nausea, low energy levels, fluid retention in the legs or around the abdomen (ascites) which require a more specialised diet. This is likely to include a high intake of protein rich foods such as meat/chicken/fish/eggs/dairy/meat alternatives, increased energy dense foods and restrictions on fluid and salt intake (see malnutrition section on pages 15 - 16 for more information).

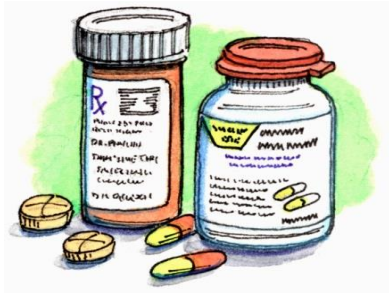
It is important to talk to your Doctor before making any dietary changes as they may refer you to a Dietitian for personalised dietary advice.

5. ATTEND REGULAR CLINIC AND ULTRASOUND APPOINTMENTS



You need to be constantly checking how things are going with your liver, catching and treating any changes that might occur as soon as possible. Because you can't always see the outward signs of change to your liver, your regular blood tests, clinic appointments and scans are crucial.

6. TAKE MEDICATIONS AS PRESCRIBED



Keeping to your medication schedule is another central feature of liver care. Medication will be prescribed to reduce the effects of the cirrhosis, preventing it from worsening and providing the best conditions for liver repair or regeneration. **Take your medications as prescribed** and don't stop taking them without talking to your doctor or nurse first. There will be reason for what you take and when, and if you are uncertain, just ask. Also ask your family doctor, nurse or liver specialist first before starting any new medication.

7. VACCINATIONS



Consider vaccination against hepatitis A and B if not already protected. An annual flu vaccine is also recommended and is available for free from your GP for people with chronic medical conditions, including liver cirrhosis.

Simply by addressing these lifestyle factors, you can reduce your risk of ever developing cirrhosis by more than 90%. Even if you already have cirrhosis, these lifestyle changes will help reduce your risk of developing life-threatening complications.

RELATED ISSUES

DOES LIVER CIRRHOSIS MEAN LIVER CANCER?

NO.

Having cirrhosis of the liver does not mean you have cancer of the liver. However, having cirrhosis of the liver does **increase the risk** of developing cancer in the liver (about 5%), and you will need to be screened for this every six months. This screening involves a blood test and a liver scan (most likely an ultrasound) and a clinic appointment. The screening needs to continue even if your cirrhosis has stabilised and even if the tests shows a negative result every time.



Just like cirrhosis of the liver, liver cancer is often silent until it is too late. This six-monthly screening will significantly increase your chances, should you develop a liver cancer, of it being detected at an early and very treatable stage.

DECOMPENSATED CIRRHOSIS - SIGNS OF LIVER FAILURE AND HOW TO MANAGE THEM

When the remaining healthy liver cells become too overwhelmed you may progress to ***decompensated cirrhosis***. Decompensated cirrhosis is very serious and has many potential complications, leading to a significant decline in health and eventually **liver failure**.

PORTAL HYPERTENSION

As cirrhosis progresses and more healthy liver cells are replaced with scarring the liver becomes very hardened and lumpy, making it very hard for blood to flow freely. This causes a buildup of pressure in the veins attached to the liver.

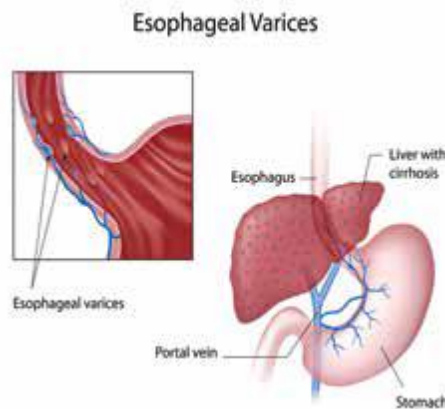


Imagine a hose full of water that has been kinked at one end. The water builds up and flows back towards the tap. In a similar way the pressure builds up in the portal vein, which is responsible for bringing blood to the liver. Pressure increased in the portal vein is called *portal hypertension*.

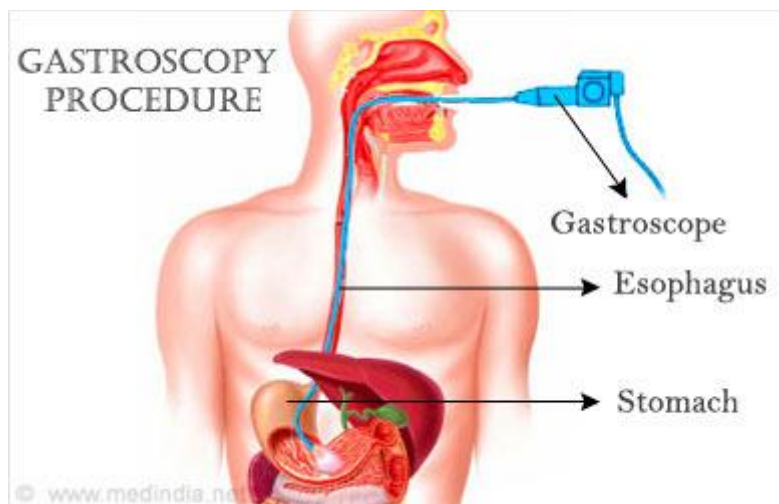
The increased pressure causes back-flow to the spleen causing an increase in size to the spleen (splenomegaly – big spleen). A larger spleen will hold onto most of the platelets which normally circulate in the blood and help with clotting, and you might bleed or bruise more easily. Signs that you may have developed portal hypertension will be picked up on your ultrasound and through your blood test results.

OESOPHAGEAL VARICES

Portal hypertension can also lead to *oesophageal varices* (like varicose veins in the gut), where some of the blood vessels in your oesophagus and gut become swollen and at risk of bleeding.



Oesophageal varices can be detected by a **gastroscopy**, which involves placing a camera on a special tube down your throat. (Sedation can be given to help with the discomfort of the procedure.) If the oesophageal varices are small all you might need is a special medication called a betablocker to bring down your pulse rate and blood pressure. If the oesophageal varices are larger they might be treated by banding, which can be done during the gastroscopy procedure. A gastroscopy might need to be repeated every 1- 3 years.



If left untreated there is a risk of the blood vessels bursting. ***This is an emergency. If you start vomiting blood call an ambulance, or if your stools become black and tarry, go to your nearest emergency room for treatment immediately.***

ABDOMINAL ASCITES

High pressure in the veins and low protein levels in the blood can also cause a buildup of fluid in the belly, called *abdominal ascites*. The belly will become swollen and you will notice a sudden weight gain from the extra fluid. You will probably feel quite uncomfortable and your appetite may be reduced because you will always feel full. Breathing can also become difficult if the huge belly squashes the lungs or if the ascites leaks through the diaphragm around the bottom of the lungs.



The fluid itself is not dangerous but an infection in the fluid can be life threatening. ***If you suddenly experience tummy pain and/or have a temperature you should go immediately to your nearest emergency room as you will need antibiotics.***

Ascites can be managed in part by a low-salt high-protein diet. A dietitian can help with specialized advice. You might also be prescribed diuretic medication (water pills) to help shift the extra fluid back into your blood stream so that you can pass it out by urine. If that doesn't work some people need to come in and have the fluid drained off at the hospital by placing a small needle into the belly. This procedure is called *paracentesis*.

The best guide to whether you are responding to this treatment is what happens to your body weight. We recommend that you have a reliable bathroom scales and check your weight frequently – at least once a week first thing in the morning after you have been to the toilet. You can record your weight each week on page 19.

ENCEPHALOPATHY



Encephalopathy means mental confusion. Bacteria in your intestine produce toxins such as ammonia that need to be filtered out of your bloodstream by the liver. When the liver can't manage to do this properly the toxins can enter the brain causing confusion and disorientation. This can be very dangerous.

The early stages of encephalopathy might be daytime drowsiness or nighttime insomnia (unable to sleep). Loved ones might also notice a change in your mood, concentration, long and short term memory or ability to perform simple mathematical and spelling operations. You might notice a tremor in your hands when you hold them out straight. Tell your doctor if any of these things are happening to you!

Lactulose (a liquid containing special type of sugar that causes you to move your bowels) is an effective medication that taken regularly will help prevent the buildup of bacteria-causing toxins (see instructions on bottle or follow your health consultants advice). As a prevention for encephalopathy, the amount you take can be adjusted so that you are having at least 2-3 loose bowel motions per day. If the early stages of encephalopathy have already begun to occur, slightly higher doses of lactulose will help reverse the condition by increasing bowel motions. Because these toxins are produced by bacteria in the intestine they can build up if you become constipated, dehydrated or if you start any medication which affects the brain. NEVER start any sleeping tablets or pain killers without discussing with your liver specialist, GP or nurse.

Natural laxatives such as kiwifruit might help you move your bowels but it does not have the same effect as lactulose. Medication called **Rifaximin** might also be prescribed to help reduce the bacteria in the intestines. Your doctor or liver nurse might also prescribe an enema in some cases.

Check with your doctor before using commercially available laxatives.

Encephalopathy can be very serious. If your loved ones or companions notice that you are very confused or very sleepy you should be taken ***you should go or be taken immediately to your nearest emergency room for treatment.***

JAUNDICE



Jaundice is yellowing of the skin and whites of the eyes. It is caused by a buildup of bilirubin, a substance usually filtered out of the blood by the liver. If you notice jaundice for the first time it may be a sign that your liver may be getting worse or you could have an infection. You should see your doctor immediately if this happens.

MALNUTRITION AND LIVER DISEASE



Malnutrition is very common in liver disease. In the early stages it has been shown to be present in around 20% of patients and as liver function declines it becomes much more common. Studies have shown 60-95% of people with End Stage Liver Disease will be malnourished. It is important to remember that malnutrition is not based on weight and you can be overweight and still malnourished. Loss of muscle mass is common in malnutrition. The buildup of fluid around the abdomen (ascites) can mask weight loss/muscle loss.

There are many factors causing malnutrition in patients with cirrhosis.

- Your body is working harder than it would if you had a healthy liver which means you have high requirements of energy and protein (protein requirements can be up to twice as high).
- Your appetite may be reduced due to abdominal pain, ascites and nausea therefore you eat poorly.
- The cirrhotic liver has a limited ability to store energy from food like a healthy liver would therefore your body will breakdown your muscle mass for energy. This will occur overnight in a person with cirrhosis, without cirrhosis it would take 3 days of starvation for your body to do this. This can result in loss of weight, and, more importantly, loss of muscle mass. This leads to weakness and fatigue

It is important that if you are experiencing these symptoms you talk with your doctor and get a referral to see a dietitian who will give individualized dietary advice.

Some nutrition pointers:

- Eat regular meals plus in-between snacks
- Include protein rich food at each meal e.g. eggs, meat, chicken, fish, dairy products, tofu
- Ensure you have a snack before bedtime (this is a good time to have your supplement drink)
- Take your supplements as prescribed by a dietitian or doctor
- Limit your salt intake, particularly if you have oedema or ascites as this can make fluid accumulation worse.

Your doctor may recommend you take a dietary supplement such as **FORTISIP** or **ENSURE** to help keep up with your nutritional requirements these can be obtained on prescription from your doctor or dietitian and are partially or fully subsidised.

LIVER TRANSPLANTATION

If your liver does continue to deteriorate or if you develop liver cancer you may need to be considered for a liver transplant. Liver transplant is when you undergo an operation to replace your diseased liver with a healthy new one, usually from a deceased donor. You would need to undergo an assessment process to make sure this is a safe and suitable choice for you. If it is and you want to receive a liver transplant you would need to be put on a waiting list until a suitable liver becomes available. Liver Transplantation is very successful with 90% of people experiencing very good health at one year post transplant.

If you have reached this stage this option will be discussed with you in more detail and you will be referred to the New Zealand Liver Transplant Unit for assessment and extensive education around this.

YOUR MEDICATION LIST

Medication Name and Dose	To Be Taken	Indication (What It's For)
e.g. Spironolactone 100mg	Once a day	Reduce fluid build up

WEIGHT CHART

Date	Weight	Date	Weight	Date	Weight

APPOINTMENT SCHEDULES

Date	Time	Type (Clinic/Ultrasound/Endoscopy)	Location

USEFUL WEBSITES

NZ Hepatitis Foundation: www.hepfoundation.org.nz

NZ Liver Unit www.nzliver.org

Australian Liver Foundation www.liver.org.au

British Liver Trust – Pioneering Liver Health

<https://www.britishlivertrust.org.uk/liver-information/diet-and-liver-disease/coffee-and-the-liver/>

Ministry of Health ‘Healthy eating, active living’ guidelines for adults

(<https://www.health.govt.nz/your-health/healthy-living/food-and-physical-activity/healthy-eating>):

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November 2017

