LIVER CIRRHOSIS: A PATIENT RESOURCE GUIDE



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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:

- Preventing infections
- Removing bacteria and toxins from the blood
- Produce "juices" needed for digesting food and processing medications and hormones
- Making proteins that help the blood clot
- Storing vitamins, minerals, fats, and sugars for use by the body



What is liver cirrhosis?

When something attacks and damages the liver, liver cells are killed and scar tissue is formed. This scarring process is called fibrosis (pronounced "fi-bro-sis"), and it happens slowly over many years. When the whole liver is scarred, it shrinks and hardens. This is called cirrhosis. Any illness that affects the liver over a long period of time may lead to fibrosis and, eventually, cirrhosis. Heavy drinking and viruses (like hepatitis C or B) are common causes of cirrhosis. However, there are other causes as well. Cirrhosis may be caused by a buildup of fat in the liver of people who are overweight or have diabetes. Some people inherit genes that cause liver disease. Other causes include certain prescribed and over-the-counter medicines, environmental poisons, and autoimmune liver disease, a condition in which a person's own immune system attacks the liver as if it were a foreign body.

What happens when you have cirrhosis?

Cirrhosis causes the liver to become lumpy and stiff. This prevents blood from flowing through the liver easily and causes the build-up of pressure in the portal vein, the vein that brings blood to the liver. High pressure in the portal vein is called portal hypertension. To relieve this pressure, the blood goes around the portal vein, through other veins. Some of these veins, called varices, can be found in the pipe that carries food from your mouth to your stomach (the esophagus) or in your stomach itself.

Portal hypertension also causes blood to back up into another organ called the spleen. This causes the spleen to get bigger and destroy more platelets than usual. Platelets are blood cells that help in blood clotting. With cirrhosis, blood is blocked from entering the liver and toxic substances that the liver normally filters escapes into general blood circulation. Aside from the problems with liver blood flow, when cirrhosis is advanced, there aren't enough healthy liver cells to make good substances, such as albumin (a protein) and clotting factors that the liver normally makes. Another complication is Liver cancer, called hepatocellular carcinoma (HCC). This cancer can occur if some of the sick liver cells start to multiply out of control. Liver cancer, may occur in any stage of cirrhosis. There may be no signs of liver cancer until the cancer has grown very large and causes pain.

What are the symptoms of cirrhosis?

The early stage of cirrhosis is called compensated cirrhosis. At this stage you may have no symptoms at all. In fact, a person may live many years with cirrhosis without being aware that their liver is scarred. This is because the pressure in the portal vein is not yet too high and there are still enough healthy liver cells to keep up with the body's needs. But if nothing is done about the cause of cirrhosis (for example, if the person continues to drink alcohol, or if hepatitis or other causes of cirrhosis are not treated), the pressure in the portal vein gets higher and the few remaining healthy liver cells are not able to do all the work for the entire liver. At that point, you may notice symptoms like low energy, poor appetite, weight loss, or loss of muscle mass. As the disease progresses symptoms become more severe and may be life threatening.

Advanced cirrhosis is called decompensated cirrhosis. At this stage you can also develop the following serious problems:

- bleeding varices internal bleeding from large blood vessels in the esophagus
- ascites (pronounced "a-sigh-tees") a buildup of fluid in the belly,
- encephalopathy (pronounced "en-sef-a-lop-athee") confusion from the buildup of toxins in the blood
- Jaundice yellowing of the eyes and skin

Sometimes, if the damaging agent (such as alcohol) is removed, the liver can slowly heal. Other times, the only way to cure cirrhosis is to replace the sick liver with a healthy liver – this is called liver transplantation.

Treating the complications of decompensated cirrhosis

Preventing bleeding from Esophageal Varices

Backup of blood from the scarred liver may cause the veins in the wall of the esophagus to enlarge. The esophagus is the swallowing tube that connects the throat to the stomach. The pressure inside the enlarged veins, called esophageal varices, is higher than normal. The increased pressure can cause the veins to burst, leading to sudden and severe bleeding. Bleeding varices can be very serious, causing death if not treated immediately. Signs of bleeding varices include vomiting of large amounts of fresh blood or clots. People who have signs of bleeding varices should go to an emergency room immediately.

If you vomit blood or your stool turns black and tarry, you must go to the emergency room immediately. These are signs that varices may have begun to bleed, and this can be life threatening.

What can be done to prevent serious bleeding?

If you have liver disease that could cause varices to form, your doctor will usually recommend that you have an upper endoscopy test (EGD) to determine if varices are present and what their size is. Larger varices have a higher risk of breaking and bleeding, and if you have them your doctor will start treatment with medications called Beta Blockers. Beta blockers help reduce blood flow and pressure in varices.

If large varices are found or if they do bleed, doctors may apply rubber bands to the varices to block them. If the varices still bleed after treatment with medication and rubber bands, you may need a TIPS procedure (Transjugular Intrahepatic Portosystemic Shunt). With this procedure the doctor creates an internal tunnel in the liver that reduces blood flow and pressure in varices.



Managing ascites

Another problem caused by high pressure in the veins of the liver is ascites. Fluid leaks out into the belly and begins to fill it up. This can make the abdomen (belly) enlarge like a balloon filled with salt (sodium) and water. The legs can get swollen too. This can be very uncomfortable. Ascites may make it difficult to eat because there is less room for food. It can also be difficult to breath, especially when you are lying down. The most dangerous problem associated with ascites is infection, which can be life threatening.

To avoid formation of ascites it is critical to be on a low sodium diet (less than 2 grams a day).

If you have ascites and you suddenly get a fever or new belly pain, you must go to the emergency room immediately. These could be signs of a serious infection that can be life threatening.

Abdominal Anatomy

The abdominal cavity (the belly) contains the digestive organs such as the stomach, intestines and liver. Normally, the abdominal contents are moist, but contain no fluid. Ascites is a medical condition in which excess fluid begins to puddle within the abdominal cavity. This fluid is outside of the intestines and collects between the abdominal wall and the organs within.

Causes of Ascites

Liver disease is the most common cause of ascites. The word "cirrhosis" means "scar tissue," so this condition is often called "cirrhosis of the liver". This scar tissue changes the normally smooth liver surface to a lumpy surface that blocks the blood from exiting the liver. If the blood cannot flow freely, too much pressure builds up in the liver tissue. This is called portal hypertension. This condition causes the surface of the liver to "weep" fluid into the abdominal cavity. The fluid collects in the belly and causes ascites. The liver also sends signals to the kidney to "hold on" to salt, resulting in fluid retention in the legs or abdomen.



Symptoms

In mild cases, there are usually no symptoms. As more fluid collects, the abdomen swells. There may be a loss of appetite, frequent heartburn, fullness after eating, or abdominal pain. Eventually, there is swelling of the abdomen that looks similar to the later stages of pregnancy. This may cause back pain, changes in bowel function, and fatigue. During the day, gravity may carry some of the fluid down into the scrotum (the sac that hold the testicles) or legs causing swelling, (edema). Initially, the swelling may go down overnight. As the condition worsens, however, the swelling may spread up the leg and be present day and night. As more fluid builds up, it may spread up to the chest and cause difficulty breathing.

Treatment

Ascites is not actually a disease, but a symptom. The proper treatment depends upon the underlying cause. If infection, cancer, or heart failure is the cause, the treatment is directed appropriately to the underlying problem. However, in the majority of patients, ascites is a sign of advanced liver failure, or cirrhosis of the liver. The basis of treatment includes:

• Avoiding further liver damage

Patients who drink alcohol must stop all alcohol consumption.

• Low salt (sodium) diet

The buildup of ascitic fluid is not the result of too much water intake, but rather the body's inability to eliminate sodium (salt). For this reason, it is important to cut down on salt intake, not water intake.

Patients with edema and ascites are at very high risk of developing infections that, in turn, carry a very high risk of death. To avoid formation of edema and ascites, the most important factor is to avoid sodium in your diet!

• Diuretic therapy ("Water Pills")

These medications help the body get rid of extra sodium and water through the kidneys. Common medications include spironolactone (Aldactone®), and furosemide (Lasix®).

• Paracentesis (Tap)

Paracentesis is the draining of fluid out of the abdomen with a needle. This is done using local anesthetic (lidocaine). The drained fluid is sometime tested in the lab see what it contains. Tap provides a very quick relief of ascites symptoms, but it does not correct the underlying cause so the fluid eventually returns. You must follow strict sodium restriction and diuretic therapy in order to slow down the re-accumulation of fluid.

• Monitor Progress During treatment: it is important that your doctor monitors you closely with periodic measurements of body weight and blood tests. This is especially true in patients taking diuretics (which may cause reduced kidney function and changes in the blood levels of sodium and potassium). The best way you, the patient, can help the doctors manage your fluid problem is by recording your weight and dose of water pills (diuretics) you take every day. Use the attached log in the toolkit to record your weight and diuretic dose daily. In addition, keep track of dates when you have taps (paracentesis).

Managing Hepatic Encephalopathy

A poorly working liver may not be able to get rid of toxic substances like ammonia (which comes from the intestines), and it may allow these substances to go into the brain and cause confusion. Besides confusion, toxins in the brain cause changes in sleep, mood, concentration, and memory. If it gets really bad, these toxins can even cause a coma. These changes are all symptoms of hepatic encephalopathy. If you have encephalopathy, you may have problems driving, writing, calculating, and performing other activities of daily living. Signs of encephalopathy are difficulty sleeping at night with sleepiness during the day, trembling and hand "flapping". Encephalopathy may occur when you have an infection or when you have internal bleeding. It may also occur if you are constipated or take too many water pills or take tranquilizers or sleeping pills. Only an expert in liver diseases can diagnose Hepatic encephalopathy. Having elevated ammonia in the blood does not necessarily mean you have this diagnosis.

If you are not acting like yourself, if you are confused, or if you are very sleepy, you must be taken to the emergency room immediately. These symptoms could be a sign of a serious medical problem. Do not drive when you have these symptoms.

Effects of Hepatic Encephalopathy:

• Even low levels of hepatic encephalopathy may cause problems with safe driving. Patients, family member and doctors will discuss the issue of driving and decide if the patient is able to drive. If patients have any confusion they should not drive.

• Even when not confused, patients may have difficulty with normal sleeping cycles and may be more irritable, "cranky" and forgetful. They may have worsening handwriting and may not be able to complete simple arithmetic correctly. Family members need to supervise or take over financial calculations, bill paying, etc.

• Infections can bring on or worsen hepatic encephalopathy quickly. If patients rapidly become worse with confusion, the patient must be brought to an emergency room to evaluate them for infection, other blood problems or dehydration.

• Patients with cirrhosis and even early hepatic encephalopathy are very sensitive to drugs such as narcotic pain medications, valium-like drugs (benzodiazepines) and other sedating drugs. If a person with cirrhosis must take any of these drugs, she should take the lowest possible dose, and should be watched for increased confusion.

• Frequent small meals and taking live culture yogurt twice a day protects better against encephalopathy.

Treatment for hepatic encephalopathy consists of:

1. Lactulose syrup taken daily. Lactulose is an artificial sugar that cannot be digested by the stomach or intestines. It goes into the large bowel (colon). In the colon, it causes protein toxins to be held in the bowel (not absorbed in the body) and expelled in stool. Other laxatives will not do the same thing. Patients usually start with 2 or more tablespoons of lactulose syrup once or twice a day. The dose is gradually increased until the patient is having 3 loose stools a day. *Lactulose is one of the only medicines where it is up to the patient and family to adjust the dose.* Increase the dose if your stools are firm, if you are having fewer than 3 stools per day, or on days when you are more forgetful or confused. Decrease the dose if you are having more than 3 loose stools per day.

2. Antibiotics that work only in the intestine. These include rifaximin (Xifaxan[®]) and neomycin. These medications change the type of bacteria in the intestine to the kind that help get rid of toxins.

Managing Jaundice (yellowing of the eyes and skin) A liver that is working poorly cannot get rid of bilirubin, a substance that produces a yellowing of the eyes and skin, called jaundice. Too much alcohol and some medicines can also lead to jaundice. If you have cirrhosis and notice jaundice for the first time, it may be a sign of worsening of your liver function, an infection, or other new problems.

Living with Cirrhosis

Diet

It's a misconception that patients with encephalopathy/liver disease should restrict protein. Patients with cirrhosis should take a normal amount of protein, but they do better if they divide the protein between all the meals and snacks. To take a snack with protein at bedtime helps to prevent loss of muscle and helps to regain some of the muscle that has been lost.

Low sodium (salt)

A low salt diet is important for patients with liver disease, particularly those with leg swelling or ascites (fluid in the abdomen). The more salt you eat, the more fluid buildup you will experience.

Medications (over-the-counter and prescribed by other doctors)

• Patients with cirrhosis must avoid pain medications called "non-steroidal anti-inflammatories (NSAIDS)". These include over-the-counter medications such as ibuprofen (Motrin[®], Advil[®]), naprosyn (Aleve[®]), as well as some prescription medications. Ask your doctor if any of your medications are NSAIDS.

• For mild to moderate aches and pains, it is safe to use Tylenol[®] (acetaminophen) at doses of 2,000 mg/day or less (no more than 6 regular strength or no more than 4 extra strength each day AND no more than 20 regular strength or no more than 15 extra strength each week). Some cold medicines and prescription pain medicines contain acetaminophen, so read the labels and make sure you don't take too much by mistake.

• Most other prescription medications are safe for the liver. You are not at increased risk of side effects just because you have cirrhosis. In particular, statins such as Lipitor[®] and Zocor[®] can be used for treating cholesterol in patients with liver disease. You will require the same monitoring like other patients without liver disease.

- Discontinue/avoid any alcohol including beer, cooking wine, non-alcoholic beers.
- Avoid herbal supplements

Exercise

Encourage physical activity as tolerated: a combination of aerobic and resistive exercises to maintain muscle mass, achieve weight loss (if overweight/obese) and tackle fatigue (break fatigue – lack of physical activity – fatigue cycle), one of the most common symptom of cirrhosis/chronic liver disease. Aim for about 30-45 mins of exercise 5 days per week.

Surgery

• Surgery can be quite risky in patients with cirrhosis. If you are considering having any type of surgery, please be sure to ask your hepatologist (liver specialist) if this is safe for you. If there are any concerns, please ask your surgeon to talk to your hepatologist.

Hospital stays

• It is very important for us to keep track of any hospital stays you have. Please call our office if you are admitted to an outside hospital, and call again once you are discharged.

Screening for liver cancer

• People with cirrhosis are at increased risk for liver cancer – the risk is about 1 in 100 per year (each year, out of 100 patients with cirrhosis, one will develop liver cancer). All patients with cirrhosis should have an ultrasound every 6 months.

• Although these tests are not perfect, they can often detect the tumor when it is small, before people develop symptoms. If the ultrasound shows some abnormality, the next step is MRI or CT scan. Since MRI and CT scans have gotten so good, in many cases a biopsy is not needed to make the diagnosis.

Vaccination

• If you have never been vaccinated against hepatitis A or B, we will check to see if you are immune (already have protection). If not, we will recommend vaccination, which can be arranged to be done near your home. The schedule is 2 to 3 shots depending which vaccine is needed.

• The yearly influenza vaccination (flu shot) is also recommended. It is important that you receive the inactivated vaccine (injection), not the live form (nasal drop).

• Pneumonia vaccine (Pneumovax 23 and Prevnar 13) are also important

Leg Cramps

Leg cramps are very common in patients with cirrhosis. They are frequently due to decreased amounts of minerals in the body, such as calcium, magnesium and zinc. If you have leg cramps, we would prefer that you take these kinds of mineral supplements and avoid taking medication like quinine. Quinine can cause a further drop in your platelet count and place you at a higher risk of bleeding.

NUTRITION AND LIVER DISEASE

• Cirrhotic patients have limited capability to store nutrients in the liver. For that reason, you need to eat very frequently in order to prevent using your own muscle mass as a source of nutrition for vital organs; we recommend you eat at least three meals a day and three to four snacks between meals. Patients who are overweight should be careful to eat low-calorie meals and low-calorie snacks. Patients who are under-nourished should have high-calorie meals and snack. Bedtime snacks are especially important. Patients with malnutrition and/or loss of muscle mass can improve their nutrition and muscle mass by drinking two cans of Ensure-Plus, or Boost-Plus at bedtime, or in cases of being overweight or having diabetes; 2 cans of Glucerna or Boost Glucose-Control at bedtime, or 1 can of Boost VHC at bedtime.

• Cirrhotic patients are at increased risk of acquiring food-borne infections: we recommend that all foods that you eat from animal organs should be fully cooked. This is especially true for seafood and poultry. Raw seafood, especially shellfish, should not be eaten. Only pasteurized milk and juices should be consumed. Vegetables should be well washed before being eaten.

• Patients with cirrhosis require normal amounts of protein but may poorly tolerate excessive amounts. We recommend that your protein intake be around 1.2 to 1.5 gm per kilogram of body weight but divided into meals taken throughout the day and not eaten in a single sitting. Cirrhotics generally have to take in at least 60 grams of protein per day to maintain nitrogen balance and muscle mass. Protein can be taken in the form of animal sources (beef, pork, fish/seafood, poultry, eggs and milk) and from vegetable sources, such as beans and lentils.

Dietary sodium intake is usually restricted to less than 2000 mg per day (less than 1 teaspoon per day). Most salt in a person's diet comes from processed foods, not from the salt shaker. It is important that you avoid all processed foods and cured meats, such as: ham, bologna, bacon, pickles, potato chips, corn chips, and other salty snacks. Milk and cheese should be used only in moderation because they have large amounts of sodium. Canned soups and bouillon cubes should be avoided. Whole meals should be prepared from scratch and not purchased from restaurants because no restaurant would be able to cook meals using less than 2,000 mg of sodium a day (and still stay in business).

Diet

Coffee: There is evidence that drinking coffee decreases the risk of liver cancer (HCC) in patients with cirrhosis. This is true for both decaffeinated coffee and coffee with caffeine. It is suggested to drink 4 cups of coffee a day, black (without cream or sugar).

High protein diet: At least 60-80 gms of protein daily (SEE PROTEIN DIET SUGGESTIONS ON THE BACK PAGE)

It's a misconception that patients with encephalopathy/liver disease should restrict protein. Snack supplements in between meals and at bedtime

Low sodium (low salt)

A low salt diet is important for patients with liver disease, particularly those with leg swelling or ascites (fluid in the abdomen). The more salt you eat, the more fluid buildup you will experience.

How do I watch a low salt diet?

Read the label on all your foods, and try to eat less than 2,000 mg of sodium per day. High salt foods include: all foods in restaurants or fast food places, most canned food, foods from the deli, pickles, tomato juice, chips and crackers. Also, if you have a well with a water softener, this adds lots of salt to the water.

How can I make food taste good without salt?

Use "Mrs. Dash" or other spices. Avoid "salt substitutes" because they contain too much potassium. Unfortunately, "sea salt" has just as much sodium as regular salt. Use natural spices like pepper, garlic, ginger, herbs, hot pepper, etc.

What about sugar and fat?

These will not harm the liver when eaten in moderation. However, you may need to watch these if you have diabetes, heart disease, or high cholesterol.

What if I am told my "sodium level" is too low?

This is usually a result of too much water in the body. **This does not mean that you should eat more salt!** See below about fluid restriction.

Do I need to limit fluid intake?

Drinking lots of fluid will not make your ascites or leg swelling worse; only salt will do that. Most patients with cirrhosis do not need to limit fluid intake, unless your sodium level is less than 130 mmol/L. Ask your hepatologist (U of L liver specialist) whether you need to watch your fluid intake.

GOOD CHOICES	AVOID	
Meats and Meat Alternatives:	• Processed meats (bacon, sausage, pepperoni, hot dogs, ham,	
• Fresh beef, pork, veal, lamb, poultry, fish	luncheon/deli meats, corned beef, anchovies, sardines, caviar)	
• Eggs	• Meat alternatives/vegetarian entrees	
• Dried beans, peas, lentils	• Dried meat, smoked fish	
• Unsalted nuts, unsalted peanut butter	• Salted nuts, salted peanut butter	
	Microwave/frozen meals	
Milk, Yogurt, Cheeses:	Buttermilk, malted milk	
• Milk or vogurt	Processed cocoa	
• Frozen vogurt, ice cream	• Processed cheese	
• Natural Swiss cheese	• Bleu feta and other salty cheeses	
• Low-sodium cheeses	• Regular cottage cheese	
• Low-sodium cottage cheeses	6 6	
Breads, Cereal, Rice, and Pasta:	• Breads, rolls, breadsticks made with garlic/onion salt, or	
• Bread, rolls, breadsticks without salt or cheese	cheese	
• Plain taco shells, tortillas	• Stuffing mixes	
• Pasta, barley, rice cooked without salt	• Pasta or rice with seasoning packets	
• Unsalted cooked cereal	• Instant hot cereals, ready-toeat cereals	
• Low-sodium crackers	• Salted crackers	
• Homemade soup with low-sodium ingredients	• Regular canned or dry soups, broths, bouillons	
	• Baking mixes such as cakes, pancakes, waffle or muffins	
Vegetables:	• Canned vegetables, vegetable juices	
• Fresh/frozen vegetables without salt added	• Pre-made spaghetti/tomato sauces	
Homemade tomato sauces	• Instant mashed potatoes, boxed	
	• Sauerkraut, olives, pickled vegetables	
Snacks:	• Potato chips, corn chips, taco chips	
• Fresh fruits and vegetables	• Regular popcorn	
• Unsalted popcorn	• Regular pretzels • Regular nuts	
• Unsalted pretzels	• Other salty snack foods	
• Unsalted nuts	5	
• Unsalted crackers		
Beverages:	• Gatorade	
• Water, fruit juices	• Powerade	
• Milk	• Vegetable juices (V-8)	
• Coffee, decaf coffee, teas	• Instant cocoa mixes	
• Cocoa made with milk	• Instant cappuccino mixes	
• Soda with no sodium (limit 24 oz or less per day)		
Desserts:	Instant pudding or other prepackaged dessert mix	
• Gelatin desserts	• Whipped topping	
 Homemade tapioca or rice pudding 	• Frozen pies	
• Custard made with milk	• Minced meat pies	
• Hard candy		
• Homemade cake, cookies, pie, sherbet, ice cream (limit to 1		
serving or less per day)		
Fats and Oils (use sparingly):	Salted spices (garlic and onion salts, etc)	
• Vegetable oil and mayonnaise	• Soy sauce, tartar sauce, teriyaki sauce	
• Unsalted butter or margarine	• Salsa, Worcestershire sauce, bouillon	
• Unsalted or low-sodium salad dressing	• Sweet & sour sauces, steak and BBQ sauce	
• Low-sodium cream, non-dairy creamers	• Monosodium glutamate (MSG)	
• Unsalted nuts	• Ketchup, relish, seasoning/coating mix, meat tenderizers,	
• Avocado	flavored vinegar	
Seasoning and Condiments: • Herbs and spices without salt	Salad dressings containing sodium	
(Mrs. Dash) • Lemon • Fresh garlic, onion • Fresh horseradish •	• Bacon and bacon fat	
Low-sodium ketchup, low-sodium hot sauce • Low-sodium	• Gravy made with mixes or bouillon	
chin sauce	• Snack dips made with processed cheese or instant soup mixes	
	• Avoid "sait substitute" as this contains high levels of	

HIGH PROTEIN DIET:

Foods to include and exclude

Choosing the right foods when eating a high-protein diet is important for maximum effectiveness.

Below are some excellent protein choices that could be suitable for a variety of dietary plans:

- eggs
- leaner cuts of beef
- chicken breasts
- turkey breasts (dark meat)
- beans, such as garbanzo beans or black beans
- shrimp
- nuts and seeds, such as pumpkin seeds, peanuts, and almonds
- fish, including salmon, flounder, and haddock
- sprouted grain bread, such as Ezekiel bread
- whey or plant protein shakes
- lentils
- <u>quinoa</u>
- chickpeas
- oats
- dairy products, such as Greek yogurt, cow's milk, or cheese
- vegetables, including Brussels sprouts and broccoli

People with necessary dietary restrictions should also continue to exclude unsuitable foods. For example, a person who has <u>lactose intolerance</u> should not use milk products to increase their protein intake.

Foods to AVOID

A person should generally also avoid the following foods as part of the high-protein diet:

- products that contain refined sugar, such as candy, baked goods, and sodas
- highly processed foods
- foods that manufacturers market as "diet" products, as they often contain excessive amounts of artificial sweetener



"I'm writing you a prescription: Be happy and feel great 3 times a day."

*some of the above material has been taken from the University of Michigan's health system website.

WEIGHT LOG

Weight:	Diuretic (water pill) dose:	Date: