



Cirrhosis Care Packet

Division of Gastroenterology and Hepatology

Welcome

Thank you for choosing the Massachusetts General Hospital Division of Gastroenterology Liver Center as part of your team to help manage your cirrhosis. We are hopeful that this packet provides valuable information for you as we move forward on this health care journey with you.

In addition to reading this packet, we strongly advise that you join the Mass General Brigham Patient Gateway, our secure online patient portal. It is a great tool for you to view labs, radiology reports, and provider notes as well as send a message to your doctor directly. If you have not already set up an account, visit the Patient Gateway website at:

patientgateway.massgeneralbrigham.org

Lastly, we hope that you contact your medical team with any questions or concerns regarding information in this packet. Please share this packet with loved ones to educate those around you. Caring for your liver disease is a team effort.

Important Telephone Numbers

Liver Center Appointments: 617-726-2426

Liver Center Triage Nurse: 617-726-5482

Gastroenterology Fax: 617-724-6832

Interventional Radiology: 617-643-4723, option 2

Blood Transfusion Service: 617-726-3622

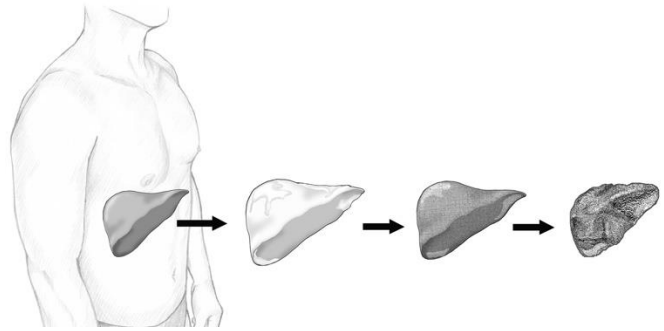
MGH Outpatient Pharmacy: 617-724-3100

MGH Main Line: 617-726-2000

Disclaimer: Please review this packet with your doctor as each patient is unique and requires personalized, specific recommendations. Therefore, not all of the recommendations listed may apply to you.

About the Liver and Cirrhosis

The liver is located on the upper right part of your stomach area, and it is partially covered by the rib cage. The liver is very important to your body, as it helps with a number of different functions such as removing toxins, making proteins, digestion of food, blood pressure regulation, and more. For this reason, when the liver is not functioning as well as it should be, it can affect a number of different organ systems.



The progression of liver damage from a healthy liver on the left to a cirrhotic liver on the right.

Image by: National Institute of Diabetes and Digestive and Kidney Diseases, National Institutes of Health

Cirrhosis develops when repeated injury occurs to the liver tissue, which then causes scar tissue to form. There are many factors that can lead to cirrhosis, including infection, obesity, diabetes, alcohol use, inflammation, and genetics. Because cirrhosis affects your liver function, our management plan at the Liver Center is to identify, limit, and manage any complications related to cirrhosis. This packet outlines a general care plan to help achieve this goal. We will work with you to develop an individualized care plan that works best for you.

Managing Cirrhosis Complications

This section discusses known complications of cirrhosis and how to manage them.

Complications may include:

- Fluid Buildup
- Infection
- Bleeding
- Hepatic Encephalopathy
- Liver Cancer (Hepatocellular Carcinoma)

Fluid Buildup

The liver is important in making sure your body does not hold extra fluid. When it is not working as well as it should be, you are at increased risk of fluid buildup. This fluid buildup can happen in the stomach area (ascites) and legs (edema).

Here are ways to lower your chances of fluid buildup:

1. Maintain a low sodium diet of less than 2 grams (2,000 milligrams) daily. Many foods have hidden salt in them. Salt contains sodium. A list of foods that tend to be high in sodium and tips on managing your sodium intake can be found on page 5.

2. Check your weight daily. If you don't own a scale, it would be helpful to get one. Monitoring your weight every day is one of the best ways for us to manage you from home. We've included a Daily Weight Tracker for you to log your weights on page 11.

- ⇒ If you gain more than 5 pounds within 3 days, please give our office a call. We may need to adjust your diuretics (water pills) or ask that you have labs drawn.
- ⇒ We also don't want you to lose weight too quickly. The weight loss goal of 0.5-1.0 pound daily. If you are losing more than that, please give us a call.

3. Take diuretics or "water pills." These medicines are important as they help remove the fluid from your body through urine. We typically prescribe spironolactone (Aldactone®) or furosemide (Lasix®).

4. Consider paracentesis. Fluid buildup in your stomach area (ascites) can make you feel "full" (distended) or short of breath when you lay down. Paracentesis is a procedure used to remove the fluid buildup.

- ⇒ If you experience any shortness of breath or increased distention, call the office. Your doctor may want to modify your diuretics, order an ultrasound, or recommend paracentesis.

Infection

Your liver is very important for your immune response. With cirrhosis, it increases your risk for all infections, including those outside of the liver. One type of infection that is unique to liver disease is spontaneous bacterial peritonitis (SBP), which is an infection of the fluid buildup in your stomach area (ascites).

Here are ways to prevent and monitor for infection:

- 1. Monitor for symptoms.** Call the office if you experience any fever, chills, stomach pain, night sweats, or changes in your thinking (less sharp, confused, sleepy).
- 2. Take your antibiotics as prescribed.** If you have had SBP in the past, you should be on an antibiotic to prevent a second infection in the future. We typically prescribe ciprofloxacin.
- 3. Make sure your vaccinations are up-to-date.** Vaccines include pneumococcal, influenza (injection form), hepatitis A, and hepatitis B.
- 4. Avoid foods with infection risk.** Raw seafood in particular can put you at higher risk for infection.

Bleeding

Cirrhosis increases your risk of bleeding and further complications. It can lead to the development of **esophageal varices**, which are enlarged blood vessels in your esophagus (connects your mouth to your stomach) caused by increased pressure in your liver. Varices can break open and cause life-threatening bleeding.

Here are ways to prevent or lower your risk of bleeding:

1. Get evaluated. Go to the Emergency Department to be evaluated if:

- ⇒ You vomit blood or your vomit looks like coffee grounds
- ⇒ You pass black stools that look like tar

These can be signs of bleeding varices which is life-threatening.

2. Take beta blocker medicines. Beta blocker medicines can help lower the pressure in your liver. We typically prescribe nadolol or propranolol.

3. Avoid nonsteroidal anti-inflammatory (NSAID) medicines. NSAIDs include aspirin, ibuprofen, naproxen (Aleve®), and celecoxib (Celebrex®). These medicines thin the blood and increase your risk of bleeding.

4. Get routine endoscopies. Make sure you have had an endoscopy and stay up-to-date on them by marking them in your calendar or putting a reminder in your phone.

Hepatic Encephalopathy

Hepatic encephalopathy is confusion caused by the liver not working properly. Encephalopathy is thought to be related to too much ammonia in the body. Its severity is variable. Some patients have increased fatigue or changes in their sleep pattern, while others may experience confusion or a coma.

Here are ways to lower your risk for and treat encephalopathy:

1. Take lactulose. Taking lactulose daily helps remove ammonia from the body through stool. Lactulose should produce 3-5 bowel movements daily. If you have more frequent or loose stools, call our office as we may adjust the dosage. It is important to educate people who help take care of you about encephalopathy, so that they can monitor symptoms as well.

2. Take rifaximin. This antibiotic decreases the number of ammonia-producing bacteria in your intestine.

3. Avoid medicines that can change your mental status. This includes narcotics, opioids, and sleep medicines. Please discuss with your hepatologist (liver doctor) before starting these medicines.

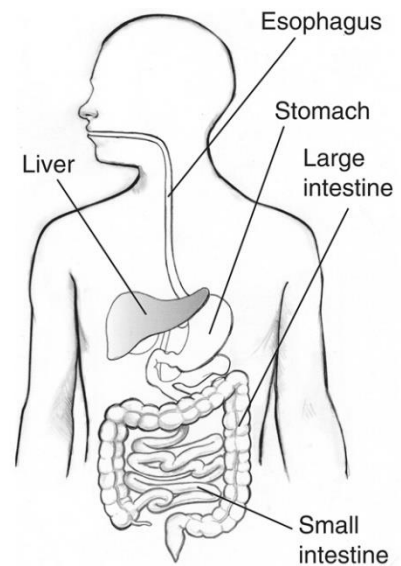


Image by: National Institute of Diabetes and Digestive and Kidney Diseases, National Institutes of Health

4. Monitor your mental status. If you or a family member find that you are confused, hard to wake up, or incoherent, it is important to go to the Emergency Department as it may be due to encephalopathy. If untreated, it can be life-threatening.

5. Check with your doctor if it is safe to operate motor vehicles. Encephalopathy impairs your thinking, which can make driving very dangerous. If you have had encephalopathy in the past, speak with your doctor to form a plan first. If your encephalopathy is not well controlled, you may not be allowed to drive or operate motor vehicles.

Liver Cancer (Hepatocellular Carcinoma)

Having cirrhosis increases your risk of developing hepatocellular carcinoma (HCC), a cancer that starts in the liver. For this reason, it is important to stay up-to-date and go to all your appointments. We will screen you for HCC every 6 months through lab tests and imaging tests such as abdominal ultrasounds, CT scans, or MRIs.

Lifestyle Changes

This section discusses ways to manage cirrhosis through diet and exercise.

Diet

Salt and sodium: We recommend that you maintain a low sodium diet of less than 2 grams (2,000 milligrams) daily. Many foods have hidden salt in them. Salt contains sodium.

Foods that tend to be high in sodium:

- Soups and stocks
- Deli meats
- Cured meats
- Instant pudding
- Canned vegetables
- Pizza
- Breads and rolls
- Frozen meals
- Pickled vegetables
- Jerky and dried meats
- Soy sauces and marinades

Alternatives to high sodium foods:

- Use salt-free spices to season foods
- Make your own soup and stock
- Use fresh meats over processed meats

There are apps available for your phone to help track salt intake including **Smart salt – Sodium tracker®** and **MyFitnessPal®**.

We can also refer you to a registered dietitian through the Department of Nutrition and Food Services at Mass General. A registered dietitian can work with you on your dietary needs in the management of cirrhosis.

Additional dietary considerations

Alcohol and raw seafood: It is important to avoid alcohol and raw seafood. We want to avoid any further damage to your liver, and avoiding alcohol is very important. Raw seafood and shellfish put you at a higher risk of ingesting harmful bacteria and parasites.

Fluid and protein: There is no need to change your fluid or protein intake. We also do not recommend protein supplements or shakes. Talk with your doctor if you need more protein.

Exercise

There is growing evidence that weight-based exercise improves health outcomes in patients with cirrhosis. As recommended by the American Heart Association, we suggest at least 150 minutes (2.5 hours) per week of moderate intensity aerobic activity.

Examples of moderate intensity aerobic activities include:

- Brisk walking
- Water aerobics
- Dancing
- Gardening
- Tennis
- Biking

To learn more about moderate intensity aerobic activities, visit the American Heart Association website at: heart.org/en/healthy-living/fitness/fitness-basics/aha-recs-for-physical-activity-in-adults

Your Medicines

New medicines: If your doctor starts you on a new medicine, be sure to let them know about your cirrhosis. We always want to make sure that the medicines you are on are safe for your liver. Some medicines require different dosing due to cirrhosis. Always talk with your hepatologist if you are unsure if a medicine is safe or not.

Prior authorizations: Some medicines require a prior authorization from your insurance. Let us know if that is the case, and our team can work with your insurance company on the process.

Rifaximin: Rifaximin is a medicine that may require an insurance prior authorization and can also be quite expensive. Here are some online resources that can help ease the out-of-pocket cost:

- Rifaximin Copay Card: xifaxan.copaysavingsprogram.com
- Bausch Health Patient Assistance Program: bauschhealthpap.com

Tylenol®: We often receive questions about how much Tylenol® you can take. We advise that with your history of cirrhosis that you take no more than 2 grams of Tylenol® per 24 hours for pain.

Outside Hospitalization

If you are hospitalized outside of the Mass General Brigham, please give our office a call. We will update the providers on your medical care and request a copy of your records upon discharge.

Glossary of Procedures and Tests

Ultrasound: Ultrasounds of the stomach area every 6 months are used to make sure that there aren't any new masses found on your liver. Ultrasounds work by using sound waves to create images. It is non-invasive and painless.

MRI (Magnetic Resonance Imaging): MRIs are used to monitor your liver yearly to make sure that there aren't any lesions found. They work by using a large magnet and radio waves to look inside your body. MRIs are non-invasive, painless, and used together with ultrasounds. Some people are unable to complete MRIs because of their big fear of enclosed spaces (claustrophobia). An alternative to the traditional tube MRI is an open MRI, which typically lowers anxiety. We can also prescribe a medicine to help with the anxiety if needed.

FibroScan®: A special non-invasive ultrasound machine that checks for scarring and fatty changes in your liver. It is performed in our clinic by appointment. The procedure uses a small ultrasound probe to measure stiffness of your liver, which is painless. You will be provided procedure instructions to review before the appointment.

Liver Biopsy: A liver biopsy is the gold standard on grading your liver disease, and it can diagnose cancer. It is a procedure in which a needle is inserted into your liver and a small amount of tissue is removed. It is performed in the Interventional Radiology Department.

Before the procedure, please let your doctor know if you are on anticoagulation (blood thinner) medicine, as they may want you to stop taking it a few days before the procedure.

Before starting the procedure, you will be given sedative medicine through an IV to prevent pain and calm you. After the procedure, you may feel discomfort at the biopsy site. If you experience any fever, chills, worsening pain, or warmth at the site, please call Interventional Radiology as it could be signs of internal bleeding or infection.

Your liver biopsy is examined by a pathologist, and the report is sent to your doctor. The results typically return within 10-14 days. Sometimes, your biopsy is reviewed with the pathology team, which can take additional time.

Paracentesis: A procedure that drains ascites from your stomach area. It is done in the Interventional Radiology Department.

After the procedure, if you experience any fever, chills, or worsening pain, warmth, or drainage at the site, please call Interventional Radiology as it could be signs of infection or complications.

Upper Endoscopy (Esophagogastroduodenoscopy): A procedure that looks at your esophagus, stomach, and the first portion of your small intestine using a probe. The probe has a camera at the end, which allows the endoscopist to view the tissues and obtain biopsies.

The procedure can be performed at these two locations:

- MGH Main Campus: Charles River Plaza located at 165 Cambridge Street, Boston, MA
- MGH Danvers Campus: 102-104 Endicott St, Danvers, MA 01923

The procedure requires preparation beforehand, which you will receive instructions upon scheduling the appointment. These instructions are also located on our website under “Patient Resources” at: [massgeneral.org/medicine/gastroenterology/about/patient-resources](https://www.massgeneral.org/medicine/gastroenterology/about/patient-resources)

Before starting the procedure, you will be given IV sedation to prevent pain and calm you. After the procedure, you may feel discomfort, which will go away within a few days. If you vomit blood or your vomit looks like coffee grounds, please give the office a call or go to the Emergency Department.

TIPS (Transjugular Intrahepatic Portosystemic Shunt): The TIPS procedure is when a stent is placed through the jugular vein into the portal vein, to decrease the pressure gradient. You may need this procedure if you have uncontrolled ascites or esophageal varices. It is done in the Interventional Radiology Department.

Online Resources

- **Patient Gateway:** patientgateway.massgeneralbrigham.org
- **American Heart Association Recommendations for Physical Activity in Adults and Kids:** heart.org/en/healthy-living/fitness/fitness-basics/aha-recs-for-physical-activity-in-adults
- **Rifaximin Copay Card:** xifaxan.copaysavingsprogram.com
- **Bausch Health Patient Assistance Program:** bauschhealthpap.com
- **American Association for the Study of Liver Diseases:** aasld.org
- **American Liver Foundation:** liverfoundation.org
- **Mass General Substance Use Disorders Initiative, Addiction Medicine Resources:** massgeneral.org/substance-use-disorders-initiative

Rev. 1/2021

This document has been reviewed for plain language by the staff of the Maxwell & Eleanor Blum Patient and Family Learning Center

Appointment Organizer

Date/Time	Location	Provider Name	Follow-up Appointment

Medicine List

Medicine Name	Dosage (mg)	Frequency (daily, twice daily)	Start Date	Why am I on the medicine?

Daily Weight Tracker

Please call our office if you:

- Gain more than 5 pounds within 3 days
- Experience any symptoms of shortness of breath, abdominal swelling, or leg swelling

Date	Weight	Experiencing any shortness of breath, abdominal swelling, or leg swelling? (Y/N)

Daily Weight Tracker (continued)

Date	Weight	Experiencing any shortness of breath, abdominal swelling, or leg swelling? (Y/N)

Salt Intake Tracker

This tool will help you identify the sodium content in foods and note how your body responds it.

Download these apps on your smartphone to help track your sodium intake:

- Smart salt – Sodium tracker®
- MyFitnessPal®

Date	Meal (breakfast, lunch, snack, dinner)	Food	Sodium Content	Effect on the Body

Salt Intake Tracker (continued)

Date	Meal (breakfast, lunch, snack, dinner)	Food	Sodium Content	Effect on the Body