After your liver transplant

Patient information

Corewell Health™

We will help improve your quality of life.

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Problems or concerns

After 4:30 p.m. Monday-Friday, weekends and holidays, please call **248.551.1010**. Ask the operator to page the transplant physician on call.

Section 1

Introduction

Congratulations on receiving your liver transplant. Liver transplant is a treatment, not a cure for your liver disease. Taking care of yourself and your transplant requires a lifetime commitment from you. This booklet is designed to help you with that commitment.

The transplant team includes nurses, doctors, dietitians, a pharmacist, financial coordinators, a transplant psychologist and social workers. You also are expected to be an active part of the transplant team. As part of the transplant team, you will need to:

- Communicate with your transplant team regularly.
- Take your medications as prescribed.
- Take antirejection medications for life.
- Keep your schedule of clinic visits and lab tests.
- Check your weight, temperature and blood pressure as ordered.
- Maintain a healthy lifestyle (for example: a healthy diet, no drinking alcohol and no smoking).

We expect that you will have many questions after your transplant. Your transplant nurse will be your main contact with the transplant team. Our registered nurses specialize in transplantation. They will be able to answer most of your questions. When necessary, your transplant nurse will talk with other team members to get your questions answered.

Section 2

Medications

You will be on many different medications after your transplant. These include antirejection medications (also known as immunosuppressants), antibiotics, antivirals and antifungals. You may also need to take other medications based on your individual case. For example, you may need medication to lower your blood pressure or blood sugar.

This section will list some of the medications you will be taking and their side effects. Talk to your transplant doctor, nurse or pharmacist if you have questions about:

- When and how to take your medications.
- What to do if you forget a dose.
- Where to get your medications.
- How to get medications if you don't have enough money to afford them.

It is very important to take all medications exactly as directed. Sudden changes in dosages may lead to serious complications. You must follow the directions for your medications and write down changes that are made by the physician. This is vital to the success of your liver transplant.

Before you are discharged from the hospital, you will meet with a transplant pharmacist to learn about your medications and how to take them. It is important to know:

- The medication names (including the generic names).
- The purpose of each medication.
- The medication dosages (strength).
- When and how to take each medication.
- The most common possible side effects of each medication.

Follow these rules after your liver transplant:

- Keep a record of all medications you take (including the dose and how frequently you take it). You should always carry a list of all your current medications with you.
- Take all your medications exactly as directed.
- Report any side effects to your transplant nurse, doctor or pharmacist.
- Do not take any over-the-counter medications, vitamins or herbal remedies without asking your transplant doctor first.
- Some medications interact with immunosuppressants and could harm your transplanted liver. If you are prescribed a medication by a doctor other than your transplant doctor, check with your transplant team to make sure that it is okay to take.
- Call your pharmacy for refills at least one week before you are due to run out of your medication.
- Make sure you will have enough medication with you if you will be away from home.
- Store your medications in a cool, dry place away from direct sunlight.
- Notify your transplant team immediately if you are unable to take your medications by mouth because you are sick or have nausea or vomiting.
- Ask for prescriptions for medication refills at your clinic visits.
- If you miss a dose of your medication, call your transplant nurse coordinator or physician for advice. Do not double the dose of your medication unless instructed to do so.
- Don’t cut, crush or chew a medication unless instructed to do so.

> The most important thing to remember is to take the right dose of your medication at the right time.

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Immunosuppressants

The following is a list of antirejection (immunosuppressant) medications that you may be taking. You will take these medications for as long as your liver transplant is working. These medications help to prevent rejection.

The most common medications that liver transplant patients receive are Prograf (tacrolimus) and Deltasone (prednisone). However, based on your individual case, you may be on a combination of two or three different immunosuppressant medications.

Transplant medications

Brand name	Generic name
Prograf	Tacrolimus
CellCept (or an alternate medication: **Myfortic**)	Mycophenolate mofetil/mycophenolic acid
Deltasone	Prednisone

Your medication schedule

- Before you go home, a transplant pharmacist will give you a medication chart that will help you keep track of your medications.
- Always keep this sheet with your records and bring it with you to all your transplant clinic visits.
- During the first few months after transplant, there will be frequent medication changes. Please update your medication sheet using a pencil so changes can be made easily.
- More information about your medications and possible side effects are on the following pages.
- Remember, while we list many possible side effects of your medications, you may experience only a few of them or you may not have any. If you notice bothersome side effects, tell your transplant nurse or doctor during your clinic visit. If a side effect becomes worse and you believe that you cannot wait for your next appointment to tell the transplant team, please call your transplant nurse.

Do not change the dose or stop taking these medications until you have talked to your transplant doctor or nurse. Stopping these medications on your own may cause a rejection episode.

Prograf (tacrolimus)	
Purpose	Tacrolimus helps prevent transplant rejection by reducing the number of blood cells that are part of the rejection process. You will take this medication for the rest of your life. In some cases, because of side effects, patients must take an alternative medication, such as cyclosporine. If this is the case, you will be educated about this new medication.
Dosing	The capsules come in the following sizes: 0.5 mg, 1 mg and 5 mg The medication is taken twice a day, 12 hours apart, to keep the medication at an even level in your blood.
Monitoring	Your dose of tacrolimus will be based on your weight, the level of medication in your blood and any side effects that you may have. **On the day of your scheduled lab draw or clinic visit, do not take your morning dose of tacrolimus until your labs have been drawn.** **Bring your dose of medication to the clinic with you to take as soon as your blood has been drawn.** Your blood should be drawn about 12 hours from your previous evening dose.
Precautions	Tacrolimus may interact with some commonly used prescription medications (such as certain antibiotics), over the counter medications and herbal products. Always check with your transplant physician or nurse coordinator before starting a new medication. Do not use any pain medication besides Tylenol unless instructed by your physician. You may take up to 2 grams (2000 mg) of Tylenol in a 24 hour period. Medications like Motrin, Advil and Naprosyn should be avoided as they may increase bleeding and/or put stress on your kidneys when taken in combination with tacrolimus. Some fruits may alter the way that your body absorbs tacrolimus. These include grapefruit and pomegranate in any form (fresh or canned fruit and any juices made with pomegranate or grapefruit). Some examples of juices that include grapefruit are Squirt, Fresca, Sunny Delight, Sundrop and Five Alive. Any immunosuppressant medication will lower your body's defenses against cancer. Skin cancer is the most common cancer which may occur. Tacrolimus may increase your risk for developing certain cancers that affect the lymph nodes. See the section of this booklet titled "Cancer Precautions" for more information. Missing a dose of tacrolimus may allow your body to recognize the new organ and cause a rejection episode. Call your transplant doctor or nurse coordinator for further direction if you miss a dose or if you take too much tacrolimus.
Possible common side effects	• Headache. • Lowered resistance to infection. • Tingling, numbness or tremor in your hands or feet. • High blood sugar, high blood pressure, high cholesterol and/or high potassium levels. • Changes in kidney function. • Hair thinning or hair loss (usually temporary). • Nausea, vomiting or diarrhea (if you are unable to keep fluids and/or your medication down, go to the emergency department at Corewell Health for treatment).

CellCept (mycophenolate mofetil) or Myfortic (mycophenolic acid)	
Purpose	This medication (you will be given one or the other) works by reducing the number of blood cells that are part of the rejection process. Mycophenolic acid is enteric coated and is absorbed differently by the body.
Dosing	The medication is taken twice a day, 12 hours apart, to keep the medication at an even level in your blood. CellCept comes in 250 mg capsules and 500 mg tablets. Myfortic comes in 180 mg and 360 mg tablets. You will likely be on this medication for the rest of your life.
Monitoring	Your blood work will be monitored for side effects such as low white blood cell counts, red cell counts and/or platelet counts (which may increase the potential for infection or bleeding). **On the day of your scheduled lab draw or clinic visit, do not take your morning dose of CellCept until your labs have been drawn.** **Bring your dose of medication to the clinic with you to take as soon as your blood has been drawn.**
Precautions	Do not open or crush the capsules/tablets. If your skin meets contents from a capsule/ tablet, wash the area with soap and water immediately. You should not take CellCept and Myfortic at the same time. They are not interchangeable. Mycophenolate mofetil (and mycophenolic acid) may decrease the effectiveness of birth control pills. Mycophenolate mofetil (and mycophenolic acid) has the potential to harm a developing fetus. This medication must be stopped (by a physician) before attempting to become pregnant. If you are planning to conceive a child, discuss this with your transplant doctor first.
Possible common side effects	• Lowered resistance to infection. • Nausea, vomiting. • Diarrhea (if you are unable to keep fluids and/or your medication down, go to the emergency department at Corewell Health for treatment). Notify your transplant physician or nurse coordinator if you are having four or more watery stools in a day. • Slow wound healing.

Some of these side effects may go away with time or with a dose adjustment by the physician. The above is not a complete list of all possible side effects. Discuss bothersome side effects with your transplant physician and/or your nurse coordinator.

Deltasone (prednisone)		
Purpose	Prednisone helps prevent rejection by reducing inflammation and antibody production.	
Dosing	You will be prescribed 5 mg and/or 10 mg tablets. Right after transplant, you will be taking several prednisone pills together once a day in the morning. You will be given a schedule which decreases the dose to 5 mg over several months. Many patients will be off prednisone completely at the end of three months. However, patients with certain diagnoses may have to take prednisone for the rest of their lives.	
Precautions	Do not stop taking prednisone abruptly. It must be gradually decreased. Do not take prednisone on an empty stomach as it may cause stomach irritation and/or ulcers. Report bright red or black stools or vomiting blood. At higher doses, prednisone may increase your appetite. To help prevent weight gain, follow the instructions that the transplant dietitian provides. Prednisone is a steroid and can cause water retention (swelling in the legs, feet, or abdomen). Follow a low-salt diet, as instructed by the dietitian. Tell your transplant physician or nurse coordinator if you gain two pounds overnight or five pounds in a week. Prednisone can cause high blood sugar. If you have diabetes, your insulin dose may have to be adjusted. Monitor your blood sugar four times a day. Mood swings are common with prednisone. You may feel angry, sad, irritable, anxious or energetic. This effect usually improves as the prednisone dose decreases.	
Precautions (not a known diabetic)	If you do not have diabetes, watch for signs of high blood sugar: • Increased thirst. • Increased urine output. • Headache or blurred vision. • Feeling more tired than usual. If your blood sugar remains high, you may require medication for diabetes.	
Possible common side effects	• Lowered resistance to infection. • Increased blood pressure. • High cholesterol. • Acne. • Insomnia/sleep disruption. • “Moon face” (fatty deposits in the face). • Blurred vision.	• Cataracts or glaucoma. • Brittle bones. • Joint pain. • Muscle weakness. • Increased risk of skin cancer. • Delayed wound healing.

Some of these side effects may go away with time or with a dose adjustment by the physician. The above is not a complete list of all possible side effects. Discuss bothersome side effects with your transplant physician and/or your nurse coordinator.

Other medications

Right after your transplant, you will take several additional medications. Bactrim, Valcyte (or Acyclovir) and Nystatin are used to help protect your body from infection. Proton pump inhibitors are used to prevent stomach upset and ulcers.

Bactrim (sulfamethoxazole/trimethoprim)		
Purpose	Bactrim is an antibiotic. It is used to prevent a specific type of upper respiratory infection (pneumocystis carinii). It also helps to prevent bacterial urinary tract infections.	
Dosing	Take this medication at night with at least eight ounces of water. Bactrim may cause crystals to form in your urine. Drinking water will help to prevent them from forming. You will take this medication for three to 12 months after your transplant.	
Monitoring	Your labs will be monitored to look for certain possible serious side effects, such as decreased white blood cell count and platelets or kidney dysfunction.	
Precautions	Do not take this medication if you are allergic to sulfa medications. Bactrim may cause an allergic reaction. Stop the medication and seek help immediately if you experience a severe skin reaction (rash with hives or severe itching) or other signs of an allergic reaction such as difficulty breathing or swelling in your mouth or throat.	
Possible common side effects	• Sensitivity to sunlight. • Nausea, vomiting and/or diarrhea.	
Valcyte (valganciclovir) or Acyclovir		
Purpose	Valganciclovir is an antiviral medication that is used to prevent CMV (cytomegalovirus). You may receive acyclovir rather than valganciclovir, depending on the CMV test results of you and of the organ donor.	
Dosing	This medication is usually taken twice a day. You will take this medication for three to six months after your transplant.	
Monitoring	Your blood work will be monitored as valganciclovir may cause a decrease in your red or white blood cell counts and/or platelets (which may increase the potential for infection or bleeding).	
Precautions	Do not break or crush the tablets. If your skin comes in contact with contents from a tablet, wash the area with soap and water immediately.	
Possible common side effects	• Nausea, vomiting or diarrhea. • Headache.	• Change in kidney function. • Decreased white blood cells or platelets.

Some of these side effects may go away with time or with a dose adjustment by the physician. The above is not a complete list of all possible side effects. Discuss bothersome side effects with your transplant physician and/or your nurse coordinator.

Mycostatin (nystatin)	
Purpose	Nystatin is an anti-fungal medication used to prevent fungal infections in the mouth. This infection, called thrush, may happen because the immunosuppressants decrease the “normal” bacteria in the mouth that keep the fungus from overgrowing. Thrush is identified by a white coating on the tongue and inner cheeks.
Dosing	Nystatin comes as a liquid. Swish the prescribed amount around your mouth for 30 seconds and then swallow it. It is taken four times a day (after meals and at bedtime).
Notes	• Do not eat or drink anything for 30 minutes after taking a dose of nystatin. • It works by coating the inside of the mouth and throat. • This medication is taken for three months after transplant.
Possible common side effects	Side effects are rare but may include mild nausea, vomiting, diarrhea and/or stomach pain.

Prilosec (omeprazole) or Protonix (pantoprazole)	
Purpose	Pantoprazole belongs to to a class of medications called proton pump inhibitors. Proton pump inhibitors help prevent stomach and duodenal ulcers by reducing the amount of acid in your stomach.
Dosing	Take one to two capsules once or twice daily (as instructed by your transplant physician). You will take this medication for three to six months after your transplant.
Possible common side effects	Side effects are rare but may include abdominal pain, constipation or diarrhea.

Some of these side effects may go away with time or with a dose adjustment by the physician. The above is not a complete list of all possible side effects. Discuss bothersome side effects with your transplant physician and/or your nurse coordinator.

Section 3

Caring for yourself after surgery

Incision care

- Clean your incision by showering daily.
- You may not take a bath or swim until your incision is completely healed. This is usually about six weeks after your surgery.
- Call your doctor if you notice redness, swelling, or drainage from your incision.
- Your staples/sutures will be removed in the transplant clinic about three weeks after your surgery.

Driving

- You may usually begin driving four weeks after your transplant. Your transplant physician will give you clearance.
- You must have someone who can drive you to your doctor appointments and lab draw appointments until you are cleared to drive.
- Seat belts are recommended.

Exercise

- For the first month, avoid bending, stretching or lifting more than 10 pounds.
- As you move around more, your strength and endurance will improve. Each person's recovery is different.
- Some transplant recipients will require either inpatient or outpatient physical therapy to regain strength and mobility.
- Exercising with weights, jogging and other sports should only be started after first talking with your transplant surgeon.

Benefits of exercise include:

- Weight control.
- Reduced stress.
- Improved sleep.
- Better digestion.
- Increased energy.
- Better glucose (blood sugar) control.

Avoid

- Contact sports.
- Horseback riding.
- Motorcycling.
- Snowmobiling.
- Any sport in which you may receive blows or strains to the liver or abdomen.

Sexual activity

- After one month, you may resume sexual activities at your discretion.
- Noticing changes in your sexual response is common among transplant patients. Changes may be due to the surgical procedure or the disease process which originally caused your liver failure.
- Changes in your medication may also affect your sexual response. Discuss questions or concerns with your doctor.
- Women of childbearing age should discuss birth control with their doctor and/or gynecologist.
- Transplant recipients can catch infections easily due to a lowered immune system. Follow safe sexual health practices to reduce the risk of sexually transmitted diseases such as chlamydia, gonorrhea, syphilis, human immunodeficiency syndrome (HIV) or hepatitis.
- Tell your physician about genital rashes, sores, unusual discharge, or yeast infections immediately.
- Women on antirejection medications are more likely to get urinary tract infections than men. Emptying your bladder before and after sexual activity helps get rid of bacteria and reduces this risk.

Pregnancy

- It is recommended to wait for at least one year after transplant to try to conceive or father a child.
- If you are a female who has been prescribed CellCept or Myfortic, it must be stopped by your physician before you attempt to conceive a child.
- During pregnancy you must be monitored closely by your doctor and an obstetrician who specializes in high-risk pregnancy.

Return to work/school

- Returning to work and/or school is encouraged. Talk to your doctor about resuming these activities.

Smoking

- Smoking is a major risk factor for heart disease and certain types of cancer. Therefore, you should not smoke after receiving your transplant.
- If you need help quitting, consult your transplant nurse or doctor.

Alcohol

- Alcohol is harmful to the liver and may interact with your medications. Alcohol includes beer, wine and liquor.
- Caring for your new liver includes avoiding anything that may damage it, so you must avoid alcohol consumption entirely.

Recreational or illegal drug use

- Do not use recreational or illegal drugs as they are harmful to your liver and other organs. They may also interfere with the action of the antirejection medications.
- Examples of recreational or illegal drugs include (but are not limited to): marijuana, methamphetamine, cocaine, LSD (“acid”).

Traveling

- We recommend that you do not travel for at least three months after your transplant while your body heals and adjusts to the new medications.
- Before traveling abroad, consult your doctor about vaccinations or preventive medications needed.

If you travel:

- Be sure to drink only spring or distilled bottled water without ice when traveling outside the United States. Also use bottled water to brush your teeth when outside of the United States.
- Remember to bring extra medications with you in case your trip is extended for any reason.
- When traveling by plane, store your medications in your carry-on luggage. Do not put your medications in bags to be checked onto the plane.
- Protect your medication from extreme temperatures.
- Consider purchasing supplemental health insurance when traveling outside the United States.
- If there is a change in your liver function, you may need treatment right away.
- Think about buying cancellation insurance when ordering airline tickets or making other travel plans.

Section 4

Diet

Your post-transplant diet should be low in sodium (salt) and saturated fats (low cholesterol). Before discharge, a dietitian will meet with you to discuss your individual diet needs and will provide you with education about safe food handling, to help avoid food-borne illnesses.

Weight gain is common after a liver transplant. This may be due to several factors. First, food may taste better now that you are feeling better. Second, prednisone may increase your appetite. To keep your weight in control, it is important to follow the guidelines given to you by your dietitian and to follow an exercise program.

People who have had a liver transplant are at a greater risk of developing injury to their kidneys. This is because of several factors. Before transplant, when your liver was failing, the blood flow to your kidneys was decreased. In addition, Prograf can cause harm to your kidneys over the long term. Dehydration can also contribute to kidney dysfunction. Drinking at least two quarts of fluid per day will help you avoid dehydration. Water is the best fluid for you to drink.

Signs of dehydration are:

- Thirst.
- Decreased weight.
- Increased pulse.
- Low blood pressure.
- Dizziness when standing.
- Decreased urine output.

Some causes of dehydration are:

- Fever.
- Not drinking enough fluids.
- Vomiting.
- Diuretics (water pills).
- Diarrhea.
- Sweating.

> Your medications may cause changes in your calcium, phosphorus, potassium or magnesium levels. Your doctor will monitor your blood levels and let you know if any changes in your diet are necessary.

Section 5

Monitoring yourself at home

When you are discharged from the hospital, it is your responsibility to update your transplant record book every day. Bring this record and your medication list to each clinic visit. Forms are in the back of this booklet.

Things to do each day and record in your transplant record:

- Take your temperature each morning and evening.
- Weigh yourself each morning before breakfast.
- Take your blood pressure morning and evening.
- If you have diabetes, check blood sugar (glucose) levels four times a day. Enter the levels into a log.
- Take your medications as ordered by your doctor.
- Note any changes, problems or questions to discuss with the transplant doctor, nurse or pharmacist at your next clinic visit.

When to call the transplant clinic

- If you notice edema (swelling of the ankles, legs or hands).
- If you feel tenderness or soreness over the incision.
- If your temperature is 100.5° F or greater.
- If you notice a change in your general sense of well-being (i.e., increased fatigue or decreased energy level).
- If you have diabetes: If your blood sugar levels are consistently above or below the recommended range made by your doctor.

If you have diabetes: An endocrinologist (a physician who specializes in diabetes) should manage your diabetes long-term as the immunosuppressant medication can make your blood sugar levels high.

> Do not hesitate to call the transplant clinic during office hours if you have any symptoms of rejection or infection. Prompt treatment is essential. Call the doctor after hours only if you need to receive immediate attention.

Section 6

Rejection episode

A rejection episode is the body's normal response to a new liver. The body doesn't recognize the liver as its own tissue and it tries to destroy the liver. However, a rejection episode doesn't necessarily mean that you will lose your transplant. You will be given antirejection medications (immunosuppressants) to lower the possibility of rejection.

Acute rejection usually occurs within the first six months after a transplant. It is not unusual to have an episode of acute rejection. Acute rejection usually can be reversed with prompt treatment.

Chronic rejection can occur after many months. It is different from an acute rejection. It is not reversible by treatment, but the process may be slowed down.

Signs and symptoms of a rejection episode:

- Fever of 100.5° F or higher.
- Tenderness or swelling in the abdomen.
- Flu-like symptoms (muscle aches, nausea, vomiting, fatigue).
- Increased blood pressure.
- Jaundice (yellow eyes or skin).
- Dark colored urine.
- Light colored stools.
- Elevated bilirubin and other liver function tests.

You may have some, all, or none of these symptoms if you experience rejection. It can be difficult to decide whether a patient is having a rejection episode.

An ultrasound of your liver transplant may be done to rule out other causes of increased liver blood tests, such as obstruction. In some cases when rejection is suspected, a biopsy of the transplant is done to be sure that the correct treatment is started.

Treating rejection:

When a rejection episode occurs, it is usually first treated with Solu-Medrol, a form of intravenous prednisone. Treatment is given as an outpatient once a day for three days.

After finishing the Solu-Medrol treatments, you will be required to increase your dose of prednisone. The prednisone dose will slowly be reduced over several weeks. Your labs will be monitored more frequently during a rejection episode.

In the rare case that the rejection episode continues, you may be treated with additional medication, based on your individual circumstance. This treatment may require being in the hospital for several days.

Even though most rejection episodes can be reversed, every rejection episode damages your transplanted liver. The best way to avoid a rejection episode is to take your antirejection medications as prescribed.

Section 7

Recurrence of disease

Diseases such as hepatitis B, hepatitis C, autoimmune hepatitis, hepatocellular carcinoma, primary biliary cirrhosis and primary sclerosing cholangitis may recur in your transplanted liver.

You will be monitored closely for signs of recurrence. There are strategies to help prevent this from happening; for example, medication to help prevent hepatitis B or hepatitis C from damaging your new liver.

Return to substance abuse, such as alcohol or nonprescribed medications, will damage the liver faster than it took prior to transplant. Our transplant team is here to help you with resources to maintain sobriety. Please don't hesitate to ask for assistance from the transplant social worker or psychologist.

Evaluation for a second liver transplant may be an option for you if your liver becomes damaged by recurrent disease.

However, if you do not make an effort to maintain sobriety, you may not be eligible for a second liver transplant at Corewell Health William Beaumont University Hospital.

Section 8

Avoiding infection

The medications you are taking to help your body maintain liver function and prevent rejection episodes will also lower your resistance to infections. An infection may also lead to a transplant rejection episode. The highest risk for developing infection is in the first six months after your transplant.

If you have signs or symptoms of infection, notify your transplant hepatologist or nurse as soon as possible, or go to the nearest emergency room if the symptoms are severe.

Some things you can do to protect yourself from infection include:

- For the first month after surgery, avoid crowded areas such as churches, shopping malls, movie theaters, etc.
- Wear a mask to the transplant clinic for the first four weeks after surgery.
- Continue to wear a mask in public places during flu season. Consult with the transplant team for current COVID-19 recommendations.
- Avoid contact with people who are obviously sick.
- Use good personal hygiene: Wash your hands frequently and shower daily (you may take tub baths after your incision has healed completely).
- Carry hand sanitizer with you and use it after contact with public items.
- Immediately wash cuts and scratches with soap and water and apply antiseptic ointment (such as Neosporin or Bacitracin).
- Brush your teeth at least twice a day and floss your teeth daily. Have dental check-ups every six months. Before treatment, inform your dentist about your transplant.
- Avoid areas that may contain dust containing fungus or mold, such as barns, construction sites, or old buildings undergoing renovation. This dust may contain aspergillus or histoplasma, which can cause serious infections. If you must be in this type of environment, wear a mask and gloves.
- Avoid undercooked meats or seafood. Your transplant dietitian will give you more information about how to avoid food borne illness.
- Avoid cleaning litter boxes, bird cages or reptile tanks.
  - A parasite which causes toxoplasmosis is often found in cat feces.
  - Birds may carry a bacteria which causes a lung infection called psittacosis.
  - Reptiles may carry salmonella, which can cause potentially dangerous stomach symptoms (severe nausea, vomiting and diarrhea).
- Flu vaccines are recommended each year.
- Pneumovax vaccines are recommended every five to seven years.

The following are some signs and symptoms of infection. Should one or more signs or symptoms occur, notify your doctor or nurse.

- Temperature of 101° F or higher.
- Chills.
- Joint pain.
- Increased pulse rate (greater than 100 beats per minute).
- Swelling.
- Decreased appetite.
- Fatigue (lasting for more than one or two days).
- Headache.
- Stiff neck.
- Swelling or drainage anywhere the skin is broken.
- Burning sensation when urinating.
- Sore throat and/or cough.
- Nausea, vomiting and diarrhea.
- Cloudy urine.
- A rash or other skin change.

Treatment:

Notify your transplant team if you have exposure to a communicable disease such as, but not limited to chicken pox, measles or tuberculosis.

Many infections can be treated and cured at home with prompt and proper use of antibiotics. Severe infections may require hospitalization.

It is important to know that antibiotics do not work against viral infections, such as colds. If you have cold symptoms, ask your transplant doctor or nurse for a list of over-the-counter symptom relief medications that you may take.

Cytomegalovirus (CMV)

Cytomegalovirus infects most of us at some time in our lives. Because it has some of the same symptoms as a flu virus, most people do not even realize that they have been infected. However, in immunosuppressed patients, CMV can be a serious complication. You will be given Valcyte (mentioned in the medication section) to help prevent CMV. CMV occurs most frequently during the first three months after transplant. You will also be monitored for this at your clinic visits.

Symptoms to watch for:

- Fever.
- Stomach pain.
- Fatigue.
- Night sweats.
- Cough.
- Loss of appetite.
- Muscle aches.
- Generally feeling like you have “the flu.”

Food safety

The following are just a few important food safety tips. The transplant dietitian will provide additional information.

At home:

- Wash hands and kitchen surfaces frequently while preparing food. Wash all fruits and vegetables before eating them.
- Don't use the same utensils or plates for cooked foods that were used to prepare raw foods such as meat, fish or eggs.
- Use a food thermometer to make sure that foods are cooked to the correct temperature (refer to FDA.gov for guidelines).
- Check "use by" dates and be sure to refrigerate foods within one hour of cooking.
- Do not drink unpasteurized products (e.g. apple cider).
- Do not eat raw meat or seafood (including sushi or raw shellfish).

When dining out:

Try to avoid buffets and salad bars. When ordering meat be sure to ask for "medium" or "well done." Sprouts (bean, alfalfa and others) are frequently contaminated. They are often used in wraps, so ask before ordering. Avoid eating eggs that have yolks that are not fully cooked.

Section 9

Immunizations/vaccinations

An important thing to remember is that transplant patients should never receive a "live" vaccine.

Examples of "live" vaccines include:

Oral polio vaccine

- Avoid contact with anyone who has received the oral polio vaccine for four to six weeks following the vaccination. It is possible to develop polio if exposed to any body fluids of the vaccinated person. The injectable form of the vaccine is not a "live" vaccine and is safe for transplant patients and their family members.

MMR (measles, mumps, rubella)

- Transplant patients should not receive this vaccination but there is no apparent risk if family members receive the vaccine.

Chickenpox

- Transplant patients should not receive the chickenpox vaccine.
- There is no apparent risk if family members receive the vaccine.
- Notify your doctor immediately if you have been exposed to chickenpox or shingles.

Rotavirus vaccine (usually given to infants at 2, 4 and 6 months of age)

- Avoid contact with anyone who has received the rotavirus vaccine for six weeks following the vaccination. It is possible to develop rotavirus if exposed to any body fluids of the vaccinated person.

Vaccinations safe for transplant patients	
Influenza	Recommended yearly in the fall.
Pneumovax	Booster given every five to seven years at the discretion of your doctor.
Tetanus and diphtheria	Booster shots are recommended every 10 years. If you are injured with a dirty object, a booster is recommended after five years.
COVID-19	The COVID-19 vaccine is most effective if given prior to transplant. Its effectiveness decreases after transplant due to the antirejection medications that you will be taking. However, it is still recommended after transplant if you did not receive a vaccine prior to transplant. The transplant clinic team members will keep you up to date with the most current recommendations.
Shingrix	A vaccination to prevent shingles. Recommended for patients over the age of 50.

Section 10

Cancer precautions

Suppression of the immune system may increase your chances of developing some forms of cancer.

We use the least amount of antirejection medication to avoid rejection of your transplant while trying to decrease your cancer risk. Close monitoring of the dosages of antirejection medications is important.

Skin cancer

The most common cancer seen in patients after transplant is skin cancer. Skin cancer is caused by being in the sun for too long or over too many years. More than 90% of all skin cancers are on parts of the body exposed to the sun. The face, neck, ears, forearms and hands are the most common locations of skin cancers.

When diagnosed and treated promptly, skin cancer has a high cure rate. If untreated, skin cancers enlarge, and in rare cases may lead to severe illness or death. Your hepatologist may refer you to a dermatologist to look for early cancers.

Look for these signs of skin cancer:

- Any new, small, shiny or fleshy nodules on exposed skin. They could be an early warning of a basal cell skin cancer.
- A red, scaly, flat patch or a nodule, which could be a sign of squamous cell carcinoma.
- A mole that changes in size or that has irregular borders.

Take precautions to decrease the risk of skin cancers:

- When outside, always apply sunscreen to all exposed body areas one hour before sun exposure.
- Reapply the sunscreen generously every two hours while in the sun.
- Sunscreens labeled with an SPF (sun protection factor) of 30 or greater provide the best protection.
- Limit outdoor activities between 10 a.m. and 2 p.m. in the summer months (11 a.m. and 3 p.m. daylight savings time). Play golf, tennis or swim (after clearance from your physician) in early morning or late afternoon.
- Wear light protective clothing to add protection to the back, shoulders, arms, chest and legs. Wear a wide brimmed hat to protect the face.
- Stay in the shade as much as possible.
- Avoid overexposure to the harmful rays of the sun on cloudy days. You still may become sunburned when the sky is full of clouds.
- Some drugs and cosmetics may increase the possibility of sunburn. Your doctor or pharmacist can advise you about medications that can cause problems in the sun.
- Avoid tanning booths. Tanning booths add more damage to what is received from natural sunlight. Tanning booth bulbs give off ultraviolet light and can cause sunburn, skin cancer and premature skin aging. A tan can give some protection against sunburn but skin damage continues even with a tan.

Other cancers

People with transplants may develop other types of cancers at a slightly higher rate than the general population. Promptly report any unusual bumps or lumps on your body to your dermatologist to make an early diagnosis of a tumor.

All female transplant patients should keep regular appointments (every year) with their gynecologist. They also should perform a monthly self-breast exam to monitor for lumps. Ask your nurse if you are unsure how to perform a self-breast exam.

> Your doctor will recommend other cancer screening tests, such as a colonoscopy or prostate exam or a mammogram. This will be determined by your age and risk factors.

Section 11

Social and emotional support

Significant improvement in health and quality of life often follow a transplant. However, the traumatic effects of anesthesia, surgery and steroid treatment may result in a variety of responses. They can include anxiety, confusion and irritability (particularly when steroids are at their highest level). These emotional responses vary in how often they occur, how intense they are and how long they last.

A transplant social worker and a transplant psychologist are available and encourage all transplant patients and family members to discuss:

- Emotional responses to the transplant.
- Adapting to changes in your body.
- Psychological acceptance of a body part from another individual.
- Coping with the uncertainties of the transplant experience.
- Developing strategies and resources for re-entry into roles within and outside the family.
- Vocational rehabilitation.
- Networking with other transplant patients and families.

The transplant social worker can also assist with:

- Arranging for transportation to clinic visits.
- Referral to social service programs.
- Anonymous contact with the family of your liver donor.

Section 12

Post-transplant financial concerns

Transplant medications are expensive, so it is important to have a financial plan for your medications and other transplant related expenses.

If physically possible, your goal after transplant is to return to work with a job that provides insurance coverage.

Investigate options for additional coverage such as becoming a dependent on a spouse's insurance policy. Even if your current coverage is excellent, you may choose to be a part of your spouse's insurance to maximize your coverage.

Consider fundraising. Depending on the amount of your coverage, you might need to raise your own funds to have money available for follow-up care and medications.

Remember, it is possible that your status may change. Whether you are no longer disabled, your company changes insurance plans, you change jobs (which in turn changes your insurance plan) or your benefits change as you retire, your coverage for transplant expenses may be altered. Stay knowledgeable about your current coverage and options to have the resources available to care for your new liver.

Don't change insurance plans without consulting the transplant financial representative.

If you have difficulty paying for your medications, the transplant financial representative can assist you with contacting the pharmaceutical company for medication assistance.

> Please refer to the "The Financial Handbook for Liver Transplant Patients" that you received at your transplant evaluation for more information. Your transplant financial representative is available to assist and counsel you during this life changing experience.

Section 13

Clinic visits

Outpatient follow-up care

You will be closely monitored by your transplant physicians and nurses for the first year after discharge.

At first, you will be scheduled for a physical exam and blood tests at least once a week. The number of times you visit will decrease over three months. During this phase of your post-transplant care, your immunosuppressant (antirejection) medications will be adjusted and your liver function closely monitored. You may need to come to the clinic more or less often, depending on the results of your blood tests/condition.

Your kidney function will also be monitored closely, as the antirejection medication may cause damage to your kidneys over time.

Follow these steps when visiting the transplant clinic:

1. Register with the receptionist.
2. The office team members will let you know when and where to have your blood drawn. Routine blood tests include CBC, liver function tests, electrolytes, magnesium, glucose (sugar) and your antirejection medication levels.
3. A post-transplant nurse coordinator will assess you. You will be weighed and your vital signs will be checked. You will be asked for a list of your medications (include any vitamins or supplements that you are taking). The transplant nurse will review your records from home (blood pressure, weight, etc.) and can answer many of your questions.
4. The transplant doctor will examine you and tell you about changes that need to be made in your medication or care. The doctor will answer any other questions you may have about your progress.
5. After you see the doctor, check out at the front desk and make an appointment for your next visit.

You may access your laboratory results in MyChart. Do not be concerned if your laboratory values are not in the “normal” range. We will call you when any of your labs are of concern.

See a primary care physician (family doctor) for common problems such as colds or flu or sprains. Your primary care physician will also be responsible for prescribing and refilling any medications that are not related to your transplant.

Long-term follow-up for liver transplant patients includes

- Monthly lab work.
- Office visits every one to three months depending on the stability of your condition and the length of time since your transplant.

Remember:

- **Do not take your morning dose of tacrolimus (Prograf) or cyclosporine (Neoral) on the day of your appointment.**
- **Bring your tacrolimus (Prograf) or cyclosporine (Neoral) with you so you can take it after your blood is drawn.**

Section 14

Confidentiality

All information obtained throughout your transplant journey will be kept as confidential as possible. However, we are required to provide certain identifiable information to members of state and federal agencies. Your medical information is sent securely to these agencies. In addition, your insurance provider may request copies of your medical records as part of authorization for testing.

Section 15

Definitions of terms

Acute rejection
Acute rejection can happen at any time after a transplant. During an acute rejection episode, the liver function tests rise. This usually can be treated by taking higher doses of immunosuppressive (antirejection) medications until the lab tests return to a baseline.

Antibody
An antibody is part of the immune system that helps the body fight infections and foreign substances.

Antigen
An antigen is the “marker” that stimulates the body to produce antibodies.

Antirejection medication
This medication helps prevent your immune system from rejecting the new liver. Also known as immunosuppressive medication.

Ascites
A buildup of fluid in the abdomen, usually associated with liver disease.

Bile
Thick, alkaline fluid that is secreted by the liver and stored in the gallbladder.

Bile duct
Any of the ducts (tube) that transport bile from the liver.

Bilirubin
A breakdown product of hemoglobin from blood cells, the results of which are used in the MELD calculations as a measure of the severity of liver disease.

Biopsy (of the liver)
A diagnostic test in which a small needle is inserted into the liver and tissueis removed for analysis. The tissue can show rejection, disease or toxicity from medications.

Blood typing
A blood test that indicates blood group. You can be O, A, B or AB. The recipient’s blood type needs to be compatible with the donor’s blood type to receive the liver transplant.

Chronic kidney disease
Occurs when the overall function of the kidneys declines to less than 10% of normal. When this happens, treatment, such as dialysis or a transplant, is needed to replace lost kidney function and support life.

Chronic liver disease
Chronic liver failure is permanent damage to the liver that cannot be corrected. It is treated by a transplant.

Chronic rejection
Chronic rejection can develop over months or even years. During this process, the total bilirubin slowly rises. There is no medication to reverse chronic rejection.

Cirrhosis
A chronic liver condition caused by widespread scarring of the liver and damage to cells which replaces normal, healthy liver tissue. Cirrhosis makes it hard for the liver to remove poisons (toxins) like alcohol and drugs from the blood. These toxins build up in the blood and may affect the brain.

Creatinine
Creatinine is a waste product of muscle breakdown. Creatinine level serves as a good indicator of kidney function.

Deceased donor
A person who has donated their organs after dying from a severe brain injury or cardiac death that will not affect future liver function. The deceased or family has generously offered organs and/or tissues to be transplanted.

Diastolic blood pressure
This is the bottom blood pressure number. It shows the force of the heart muscle at rest. This is when the heart expands and fills with blood.

Edema
Swelling caused by too much fluid trapped in the body's tissues.

Encephalopathy
Serious brain function abnormalities experienced by some patients with advanced liver disease (and other diseases). Symptoms most commonly include confusion, disorientation, insomnia and may progress to coma.

End-stage liver disease (ESLD)
Irreversible liver failure that requires transplantation as hepatic replacement therapy.

Fatty liver
Also known as non-metabolic steatohepatitis (MASH). A build-up of excess fat in liver cells.

Fulminant hepatic failure (FHF)
Acute liver failure with no pre-existing liver disease.

Gallbladder
Pear-shaped sac lying beneath the right lobe of the liver, in which bile is stored.

Glucose
Glucose is a type of sugar found in the blood.

Graft
Graft is another name for a transplanted liver.

Hemoglobin
Part of the red blood cells that carries oxygen to tissues in the body.

Hepatic
Having to do with, or referring to, the liver.

Hepatitis
A viral infection or non-specific inflammation of the liver that can lead to liver failure.

Hepatitis A
An inflammation of the liver caused by the hepatitis A virus (HAV). Hepatitis A is transmitted when fecal matter from someone who has the disease is ingested, either directly or via food or water contaminated with the fecal matter.

Hepatitis B
An inflammation of the liver caused by the hepatitis B virus (HBV). Hepatitis B is transmitted through blood and infected bodily fluids. It is spread through unprotected sex; through sharing razors or toothbrushes with an infected person; through living in a household with an infected person; from an infected mother to her newborn child at birth; via unsterilized needles, including tattoo or piercing needles; through sharing IV drug needles; and through human bites.

Hepatitis C
An inflammation of the liver caused by the hepatitis C virus (HCV). HCV is transmitted primarily through direct exposure to infected blood through an opening in the skin or mucous membrane. The hepatitis C virus infects the liver, causing inflammation that results in damage to liver tissue.

Hepatologist
A specialist who is an expert in the diagnosis and treatment of liver diseases.

Hypertension
Hypertension is another word for high blood pressure.

Immune system
Organs and cells that work to defend the body against infection.

Immunosuppressive medication
Medication that helps prevent the recipient's immune system from rejecting the new liver. Also known as antirejection medication.

Intravenous (IV)
Into or within a vein. It also refers to fluids and medications that are injected into a vein through a needle or catheter.

Jaundice
A symptom of liver disorders. Jaundice causes the skin and the whites of the eyes to turn yellow.

Kidney
One of the two bean-shaped organs located beside the spine, just above the waist. They remove waste and balance fluids in the body by producing urine.

Liver
The largest organ in the body, made up of a spongy mass of wedge-shaped lobes. The liver secretes bile, which aids in digestion, helps process proteins, carbohydrates and fats, and stores substances like vitamins. It also removes wastes from the blood. A living donor can give part of their liver, after which the liver will regenerate itself in both the donor and recipient.

Liver enzymes
Liver enzymes are substances produced by the liver. When the liver is injured, these enzyme levels can be higher than normal.

Model for end-stage liver disease (MELD)
The scoring system used to measure the illness severity in liver transplant candidates was implemented in February 2002. This system prioritizes the allocation of livers to adult patients waiting for a liver transplant. MELD is a numerical scale used for adult liver transplant candidates. The range is from six (less ill) to 40 (gravely ill). The individual score determines how urgently a patient needs a liver transplant within the next three months. The number is calculated using the most recent results of five laboratory tests:

- Bilirubin, which measures how effectively the liver excretes bile.
- INR, which measures the liver's ability to make blood clotting factors.
- Creatinine, which measures kidney function – impaired kidney function is often associated with severe liver disease rejection.
- Sodium, which when at low levels, can be an indicator of severe liver dysfunction.
- Albumin.

Platelets
Blood cells that help prevent bleeding and help the blood to clot when needed.

Rejection
The way your body responds to a "foreign object," such as a transplanted liver. Rejection can be acute or chronic.

Split liver
A split liver transplant occurs when the donor liver is divided into segments and then transplanted. These segments may be transplanted into more than one recipient or a segment could be transplanted into a child for whom an entire adult liver would be too large.

Steroid
A medication used to help prevent rejection of the transplanted liver.

Systolic blood pressure
Systolic is the top blood pressure number. It measures the force of the heart muscle as blood is pumped out of the heart chambers (contractions).

Thrush
A yeast infection in the mouth or throat that causes white patches to form.

Transplant
Transplantation is transferring organs or tissues from a donor to a recipient.

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Temperature before dinner							
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Blood pressure morning							
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Blood sugar readings (if applicable)							

Things to mention to my transplant team:

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Corewell Health William Beaumont University Hospital Transplant Center

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248.551.1010 Phone
800.253.5592 Toll free

Hours: Monday-Friday, 8 a.m. to 4:30 p.m.

corewellhealth.org

Corewell Health™