

# Liver Transplant

Surgery Guidebook



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# AdventHealth Transplant Institute

At the AdventHealth Transplant Institute, you can find comfort knowing that you will receive the best care from a professional staff dedicated to your overall health and happiness. That's because here, you're not just a patient. You are a member of our family.

## Transforming Lives for Over 40 Years

The AdventHealth Transplant Institute, a not-for-profit organization, has transformed lives for more than 40 years through personalized care of those awaiting the gift of life. Established in 1973, our program offers transplantation services, patient and professional education and dedication to those in need of lifesaving organ transplants.

### Transplantation:

#### Is it right for me?

There are many good reasons to choose transplantation. When making a decision, consider everything you hope to achieve through a liver transplant.

- Make a list of benefits and risks.
- Talk to other transplant recipients to enhance understanding.
- Read all materials shared with you by your transplant coordinator.

#### Ask yourself:

- Can I stick to a daily drug therapy routine?
- Am I willing to follow nutrition and exercise advice?
- Do I have a support system of family and friends to help me through stressful times?



AdventHealth is recognized by *U.S. News & World Report* as one of America's best hospitals in 7 types of care.



# Your Transplant Team

Health care professionals dedicated to improving lives through transplantation form the liver transplant team. Their knowledge, experience and team approach help people like you achieve the goal of better health and wellbeing. They identify needs specific to each patient, knowing every transplant experience is unique.

## **Transplant Coordinator**

Upon your initial visit, you will meet with a transplant coordinator and a registered nurse with special training in transplantation. The transplant coordinator's assistant schedules all tests and consults during the pre-evaluation phase. These individuals will be your main partners in transplant education, explaining every step along the way.

## **Medical Director of Liver Transplant Services**

As well as overseeing all aspects of patient care, the medical director of liver transplant services also manages research and medical-related issues within the program.

## **Transplant Physician/Hepatologist**

The transplant physician or hepatologist specializes in the treatment of liver disease and transplantation. This individual provides pre- and post-transplant care at the hospital and transplant clinic. The hepatologist will request testing, oversee treatment and adjust medications as necessary.

## **Transplant Surgeon**

The transplant surgeon performs the operation. You will work together to identify any possible complications that may affect your recovery. The surgeon is involved in the evaluation process as well as post-transplant care.

## **Transplant Nurse Practitioner**

The nurse practitioner assists the surgeon with your care during hospitalization. This individual will provide you with detailed information, making sure you have available resources for post-transplant education.

## **Social Worker**

A clinical social worker will meet with you to complete an evaluation of your support system, your resources, any barriers to transplant and your ability to follow the treatment plan. He/she will guide you in planning for your transplant and will also discuss with you and your support system the possible emotional, financial and physical stressors associated with transplant. The clinical social worker will offer resource referrals for fundraising, counseling, support groups and other services that can help during the pre-and post-transplant phase.

## **Financial Coordinator**

Your coordinator can provide specific information regarding the costs of transplantation. You will meet with the financial coordinator to assess financial needs, identify options and create a plan that works best for you and your family. It's essential that you communicate any changes in insurance to your financial coordinator.

## **Floor Nurse/Intensive Care Nurse**

While in the hospital, the floor nurse will be your main caregiver. He or she will see you daily to ensure your progress continues and needs are met.

## **Dietitian**

An AdventHealth registered dietitian will meet with you to develop a healthy meal plan. The dietitian will provide you with nutrition recommendations designed to keep you healthy before and after surgery.

## **Pharmacist**

Your post-surgery care will require a daily program of immunosuppressive drug therapy. The pharmacist is an authority on these medications and can answer questions about your doctor's instructions for taking them. Never alter the dosage schedule unless specifically told to do so by your doctor or transplant coordinator.

## **Pharmacy Technician**

The pharmacy technician will be available to contact your pharmacy for refills on your medication, obtain prior authorizations for medications if required and assist with financial grants for medications.

# Understanding Liver Function and Failure

The liver is one of the largest and most complex organs in the body. It helps to (1) process carbohydrates and proteins, turning them into energy and protein building blocks required for normal activity and growth, (2) digest fat through bile secretion, (3) produce proteins essential for the normal clotting of blood, and (4) break down toxic substances, including drugs and alcohol.

Various types of viruses, autoimmune and metabolic diseases, toxins and drugs, among others, may lead to liver failure.

## Signs of Liver Failure

- Yellow eyes (jaundice)
- Fatigue
- Tea-colored urine
- Gray or clay-colored bowel movements
- Itching (pruritis)
- Excess fluid build-up in the abdomen (ascites)
- Confusion, forgetfulness (encephalopathy)
- Restlessness
- Vomiting of blood

The following tests are also used to evaluate liver function.

- Medical evaluation – hepatologist
- Gastrointestinal evaluation – gastroenterologist
- Surgical evaluation – liver transplant surgeon
- Cardiac evaluation – cardiologist
- Gynecological exam (for women) – OB/GYN or PCP

Additional testing may be required.

## GET EVALUATED

A pre-transplant evaluation is performed to determine if transplantation is an appropriate form of treatment. Tests include:

- **Blood tests** – determines blood type. Screens for diseases such as hepatitis, HIV (AIDS), prostate cancer, venereal disease, Epstein Barr, cytomegalovirus and chicken pox
- **Urinalysis** – identifies urinary tract infections
- **CT scan/MRI** – detects cancer and evaluates overall area
- **Chest X-ray** – detects lung problems, infections or signs of heart failure
- **Electrocardiogram (EKG or ECG) and cardiac stress test** – evaluates heart function
- **Gastrointestinal evaluation (upper endoscopy/colonoscopy)** – detects esophageal and colonic varices
- **Comprehensive Cardiac Evaluation**

## REVIEW

- There are many causes of liver failure, including various types of viruses, autoimmune and metabolic diseases, toxins and drugs.
- End-stage liver disease is treated through transplantation.
- A pre-transplant evaluation helps your transplant team determine if liver transplantation is a good option for you.



## Compatibility

Liver transplantation is made possible through the generosity of donors. The blood type of the potential donor and patient awaiting transplantation must be compatible.

Do not be concerned with the age, race or gender of your donor. Your transplant does not mean you will share the donor's characteristics. You can be sure the donated liver will be tested for disease and given lovingly in the hopes of bringing good health and happiness to you, its new owner.

## Caring for Yourself While Awaiting Transplantation

If it is determined that you are a good candidate for transplantation, your name and patient information will be added to the national transplant waiting list.\* The amount of time you spend on the list is dependent upon blood type and the severity of illness. You must also be blood group compatible.

Waiting for a transplant can be very stressful for both you and your family. It is natural to experience several emotions at this time. Sometimes talking with a friend, clinical social worker or religious counselor is all you need to put your mind at ease. Don't turn your back on those who care about you the most. Keep doing activities that bring joy to your life.

Family and friends may also feel anxious during this time. While you are waiting for your transplant, talk to your family about the help you will need after surgery. Make sure someone is available to drive you to your appointments. You may even want to check with your place of worship, as they may offer this type of support to their members.

You'll also want to practice good nutrition and exercise during your pre-transplant care. Your transplant team can offer guidance.

*\*To ensure that your medical information remains current, you will likely require blood tests throughout the waiting period.*



## Organ Allocation

A list of all patients in need of organ transplantation is kept by the Organ Procurement and Transplantation Network (OPTN). This list is a tool used by all U.S. transplant centers and organ donor programs. The OPTN, a nonprofit organization, operates under the government's Health Resources and Services Administration to manage the national transplant waiting list.

Although you may hear your transplant team refer to a Florida list or a local list, they are both part of the same national list. The local list is the one kept by your transplant center.

All patients are listed according to OPTN rules. Allocation is based on organ compatibility, medical urgency and transportation time between the donor's hospital and liver patient's transplant center. The transportation time is important because little time can pass before organs become unsuitable for transplantation.

Once a compatible donor is located, you will be notified by the transplant team. Make sure your coordinator knows how to reach you. Once you receive the call, you will receive instructions from the coordinator on call. Remain calm and listen to all instructions given.

### STAY IN TOUCH

- It is critical that you can be reached quickly, 24 hours a day.
- You should give your transplant coordinator a list of telephone numbers where you can be reached, including your cell phone. This list should also include the numbers for family and close friends.
- Keep your transplant coordinator informed of travel plans, as well as any illnesses and hospitalization.
- Notify the financial coordinator in advance of any insurance changes so a helpful plan can be developed.

### REVIEW

- Many tests using blood samples are used to identify compatibility.
- Make sure your transplant coordinator can easily reach you.
- Always be ready for a quick trip to the hospital that could come at any time, day or night.
- Make a list of things you'd like to have in the hospital to make your stay as comfortable as possible.
- To ensure that your medical information remains current, you will likely require blood tests throughout the waiting period.

# Transplant Surgery

## Preparation

Before surgery, you will be asked not to eat or drink anything. Once you have been admitted, you will meet with the anesthesia team. At this time, you will receive necessary pre-operative medications and/or blood for transfusion. Patients suffering from liver disease usually have poor clotting factors. As a result, transfusions become necessary for surgery. Typically, patients receive eight to 12 units of blood during the operation.

Prior to transplantation, you will also be attached to monitors, allowing the team to observe heart and lung function.

An intra-arterial catheter and several intravenous lines will be placed to administer medications and monitor your condition throughout the operation. Once the lines are in place and preparation has been completed, you will be taken to the operating room and given general anesthesia.

After sleep is induced, an airway tube will be utilized to assist breathing. Typically, the tube is removed once the operation has concluded or you begin breathing well without assistance. It will cause a sore throat, and this discomfort may last for a few days. If breathing does not resume right away, you may be placed on a ventilator.

## Surgery

During the transplant, the surgeon will make incisions to insert tubing that will bypass blood from the lower body past the liver. The diaphragm is somewhat manipulated beforehand to allow proper visualization of the area. Some patients may experience numbness on the right side of the diaphragm temporarily.

During the operation, the surgeon will remove your entire liver from the blood vessels as well as other structures that keep it in place. The gall bladder is also removed to prevent attacks after surgery.

The healthy liver is then connected to the vessels and bile duct (a small tube that transports bile to the intestines). Three tubes will be used for draining purposes.



## Aftercare

Post-transplant care first begins with a team of health care professionals dedicated to making you feel as comfortable as possible. You will remain in the recovery room shortly before getting transferred to the intensive care unit (ICU), where you may stay one to two days, depending on your progress. The intravenous lines remain to track fluid volume. In addition, you will have a nasogastric (NG) tube inserted through your nose into your stomach. This is placed before surgery while under anesthesia. It prevents secretions from filling up in the stomach. You are watched very closely during this time and should not feel alarmed but reassured that you are receiving the best care.

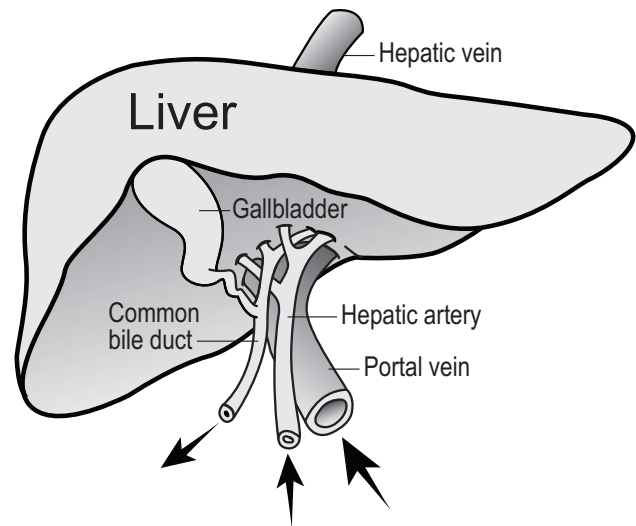
Normally, patients notice a change right away, as their energy, appetite and concentration increase. Discomfort from the incision should improve within a few weeks.

Patients in stable condition are soon moved to the transplant floor, where they will receive ongoing care. You will be asked to cough and deep breathe frequently to ensure the lungs are clear and pneumonia is not developing. This is a risk after many types of surgery.

Vital signs, fluid volume, and weight are measured regularly to determine if the liver is working well. Daily blood tests will also take place. Other exams may become part of the treatment, if necessary.

It is highly recommended that you limit the amount of visitors to reduce the risk of infection. In addition, flowers, plants, fruit baskets, raw fish and other meat, tap water and loose ice in your drinks should be avoided.

Before you are released from the hospital, the transplant team will provide information on follow-up appointments. On average, patients are seen twice a week for the first few weeks following discharge.



Post-transplant tests and procedures are common, as they assist the transplant team with monitoring liver function and overall health as well as detecting side effects to medications. For information about these tests, please speak with your transplant coordinator.

## FOLLOW UP

- Before you go home, your physician will determine how often you'll need to be seen in the transplant clinic.
- A liver transplant database tracks our patients' progress after transplantation. As your transplant center, we also must report this information to OPTN.
- If you move out of the area, please share your new address, phone number and the name of your new physician.

# Rejection and Other Complications

Surgical complications don't happen frequently, but they must be fully understood by anyone considering a liver transplant. Clotting, bleeding or rupturing of blood vessels, primary non-function and the need for immediate re-transplantation are surgical emergencies.

A small setback after transplantation is possible and should not cause alarm. Education will help you understand what is happening to your body and allow you to take steps to prevent or correct problems that might develop.

The most talked-about complication is rejection. Rejection means your body's immune system is trying to harm the transplanted organ. The immune system's job is to destroy foreign objects, such as bacteria and viruses that invade your body. Without daily use of special drugs to alter your immune system, your body will attack the new liver. The goal with immunosuppressive drug therapy is to prevent rejection without eliminating your ability to fight other infections.

## Organ Rejection

There are different types of rejection: acute or chronic. Acute rejection can happen any time after transplantation, but fortunately, it can usually be stopped if caught early. It's important that you become very familiar with the signs of rejection and report them immediately to your transplant physician or coordinator.

Another defense is your post-transplant clinical care. Lab tests during visits may catch subtle signs you might miss or medication might mask.

Treatment options for acute rejection include adjusting the amounts of immunosuppressive drugs, ordering an ultrasound and possibly performing a biopsy of your liver.

Chronic rejection occurs months or years after transplantation. Liver function slowly gets worse, at which point you may consider another transplant, if treatment isn't successful.

## Hepatitis C Recurrence

For patients who are infected with Hepatitis C prior to receiving a liver transplant, the recurrence of Hepatitis C is almost universal. It will be determined by your hepatologist when a liver biopsy will be performed. This will be done prior to beginning treatment to combat Hepatitis C with the antiviral medications available.

## Infections

Infections are a common complication in liver transplantation. Immunosuppressive medication decreases your ability to fight them. As a result, infections can occur and spread much more quickly.

You will be most at risk immediately following your transplant, while receiving larger doses of drug therapy. Avoid people with measles, mumps, flu, chicken pox, shingles or other infections.

### SIGNS OF ORGAN REJECTION

**Tenderness:** Pain or swelling in the area of your new liver should be reported to your transplant team.

**Fever:** A temperature above 100° F should be immediately reported. Fever is most often a sign that the body's immune system is in battle. Your transplant team must be kept informed in order to build a strong defense.

**Swelling:** Sudden weight gain indicates fluid retention. Keep a daily record of your weight. Look for swollen hands or feet, as well as eyelids, and report these signs immediately.

**Flu-like symptoms:** Symptoms may include muscle aches, joint discomfort and chills. While these could be from the flu, they could also be signs that rejection is occurring. Always report these symptoms to your transplant team.

**Other signs:** You should report any signs of jaundice (yellow-colored skin or eyes) and dark, tea-colored urine. If necessary, a liver biopsy may be performed to detect possible rejection.

Do not remodel your home during the first few months as well since mold spores can disperse into the air, infecting the lungs.

Washing your hands regularly and taking your medications as prescribed are good ways to decrease the possibility of infection.

## Potential Infections

### Cytomegalovirus (CMV)

CMV is a member of the human herpes virus family, which also includes herpes simplex virus types 1 and 2, and Epstein-Barr virus. Many people carry antibodies for CMV, but only 10 percent will develop CMV disease. Symptoms include low-grade fever, body aches and fatigue. Abdominal pain, loss of appetite and diarrhea may show CMV involvement in the stomach and intestines.

CMV is serious and can result in pneumonia or even liver rejection. Fortunately, CMV is usually treatable. You will be watched closely for CMV infection, and screenings of both the donor's and your antibodies will be completed prior to transplantation. You will be placed on prophylactic treatment for CMV for a minimum of three months.

### Herpes

Transplant patients may also experience herpes simplex (cold sores) and varicella (shingles). Many people have already been exposed to the herpes virus, even through chicken pox. Antiviral medication will be prescribed to help prevent these. If you believe you may have been exposed to the infection, contact your transplant coordinator.

### Pneumocystis Jirovecii Pneumonia (PCP)

PCP, a fungal lung infection, is a rare infection. Septra or Dapsone, an antibacterial medication, may be used to prevent this infection.

## SIGNS OF INFECTION

**Fever:** A temperature above 100° F is cause for concern.

**Persistent cough:** A nagging cough may be a sign of lung infection.

**Frequent or burning urination:** An increase in urination or need to urinate immediately after using the bathroom could be a sign of urinary tract infection.

**Skin wounds:** Watch for drainage from cuts or wounds, since those are also signs of infection.

**Mouth sores:** Watch your mouth for white areas or ulcerations. Call your transplant team if they occur.

**Vomiting:** If you vomit within one hour of taking your medications, retake. Call your transplant team for direction.

## Blood Pressure

High blood pressure may show a change in liver function, or it can be a side effect of a particular medication. It may also be caused by too much salt in your diet. Your transplant team will show you how to monitor your blood pressure at home.

Blood pressure is recorded as two numbers. The top number is the systolic blood pressure, and it is a measurement of the force of contraction of the heart muscle as blood is pumped out of the chambers. The bottom number is the diastolic blood pressure. This measures the force of the heart muscle as it relaxes and fills with blood. Normal blood pressures range between 110/70 to 140/90.

Tracking your blood pressure is important, and so is reporting any change to your transplant team.

## REVIEW

- Small setbacks are normal in post-transplant care.
- Learn the signs of rejection, and report them immediately to your transplant coordinator.
- Check-ups in the transplant clinic are important. Stay on track.
- Watch your blood pressure.

## Going Home

You did it. Now you're ready to start living your life free from the physical and dietary restrictions that go along with liver failure. Here are some basic instructions to guide you.

### Don't get lost in the crowd.

You shouldn't let fear of catching a cold or infection stop you from doing things you enjoy, but you should use common sense in choosing activities that support transplant success. This means avoiding large crowds and people who have colds or the flu. This is very important right after your transplant, when you are most at risk for infection.

### Dental Care Matters

Another step to preventing infection is daily dental hygiene. Brush your teeth with a soft-bristle toothbrush several times a day and remember to floss regularly. You'll not only prevent tooth or gum disease, but will also lower the risk of infection. All plans for dental work after your transplant, like cleanings or fillings, must be reported to your transplant team, who will prescribe an antibiotic beforehand to prevent infection.

### Physical Activity

Liver recipients are normal, healthy people. You can resume old activities or begin new ones. While recovering at home, you will need to get plenty of rest to promote healing. After all, transplantation is major surgery, and you'll want to stay away from strenuous activity for the first six weeks. Don't be too worried about damaging your liver. Simply follow the instructions provided by the transplant team upon leaving the hospital.



### Pets and Animal Contact

Pets can bring great joy to your life if you remember to follow a few simple rules. Restrict your family cat to the house. Cats that hunt or come in contact with other animals could pick up a dangerous infection called toxoplasmosis. They receive it by eating wild animals or uncooked meat. Keep the cat at home and feed only commercial cat food. Litter boxes should be changed frequently, and preferably by someone other than you.

A favorite pet bird should be examined for infection by your veterinarian. Again, have another family member clean and disinfect the perch and food dishes, as well as change cage liners.

#### LIMITING ACTIVITY

- Don't lift heavy things (10 pounds or more).
- Your physician will tell you when activities like driving, vacuuming or lawn mowing can be resumed.
- Do not participate in contact sports.

## Sun Exposure

It's understandable that you'll want to take advantage of Florida's sunny skies, especially now that you're feeling more energetic. However, you should never leave home without applying sunblock first. The medications needed for transplant success increase the risk of getting skin cancer.

You may also feel more sensitivity to sunburn. Therefore, be smart and limit your time under the sun, always apply sunblock (at least 25 SPF), and don't forget to protect your lips with sunscreen. Just as with any bodily change that may happen, always report a lesion or cold sore immediately to your physician.

## Smoking

Cigarette smoking greatly lowers oxygenation and tissue damage to major organs in the body, including your liver. Smoking also shrinks the vessels leading to your liver. Take good care of yourself by not smoking.

## Sex and Birth Control

A healthy sexual relationship is an important part of life, and it is something you should feel very comfortable talking about with members of your transplant team. You can engage in sexual activity as soon as you feel well enough, unless specifically directed otherwise by your physician.

You will not damage, bump or cause harm to your liver, so you and your partner can be close without fear of injury. Women should try not to become pregnant, especially during the first two years after their surgery. Also, the strain of carrying a child may be too difficult for your new liver to handle. Women of child-bearing age should use birth control. Select a method with help from your transplant team.

Both men and women will probably have an increase in sexual desire, just as their interest may increase for other pleasurable activities. Any questions or concerns should be shared with your physician or transplant coordinator.

## Support Groups

The New Life Transplant Group is a great resource, offering newsworthy information, social activities and opportunities for volunteer involvement. Meetings are held monthly. For more information, contact one of our social workers.

## REVIEW

- Steer clear of large crowds and people with colds or flu, as you are especially vulnerable to infections right after your surgery.
- Report all plans for dental work, even check-ups and cleanings, to your transplant team.
- Avoid strenuous activity for the first six weeks.
- Always wear sun protection.
- Birds and cat litter boxes carry a risk of infection. Keep the cat inside and have the bird checked by your veterinarian.
- The New Life Transplant Group is a great resource for you and your family.

## Life After Transplantation

Nutrition and exercise are important parts of your transplant aftercare and general wellbeing.

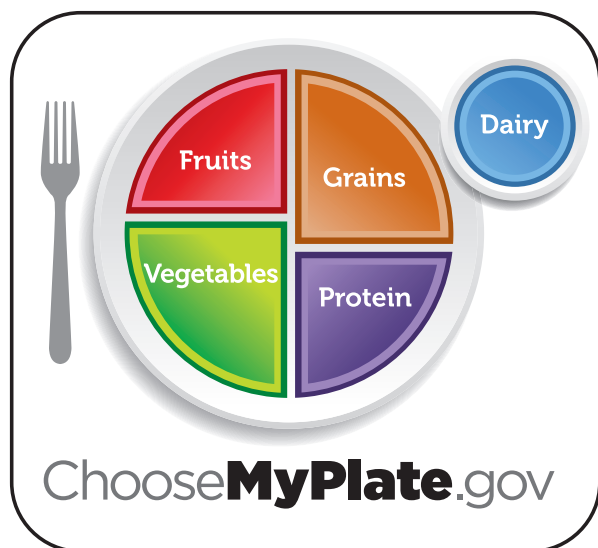
### Diet

Many foods you previously couldn't enjoy can now be included in a healthy meal plan. Most patients can begin a more "normal" diet within three to four days after surgery, if liver function allows it.

A post-transplant diet is usually higher in protein, with more lean meats and legumes to help muscle rebuild and cells repair. Prednisone,<sup>®</sup> one of the medications you may be taking, tends to decrease the amount of protein in your body, often weakening, even shrinking, leg and arm muscles.

Of course, you should always follow safe eating practices, such as thoroughly washing fruits and vegetables. Immunosuppressive medications will make you more vulnerable to food-borne illnesses.

- Soak all lettuce, spinach or other soil-grown leafy vegetables in salt water for about 15 minutes, and rinse well. This helps to prevent listeriosis, a disease related to meningitis.
- Use a separate cutting board for raw meats.
- Always remember to wash your hands often with an antibacterial cleanser during and after food preparation.



### Weight Gain

Weight gain is a common complaint among liver recipients. This can occur because food becomes more enjoyable; several dietary restrictions have been lifted; and certain medications, such as Prednisone, increase appetite. You'll need to limit extra calories, even if the medicine is causing you to feel really hungry.

Being overweight is not healthy. However, you can take control by making smart food choices. You will meet with the transplant dietitian before going home. The dietitian will help you develop a personal meal plan. Tips for making your own nutritious diet are provided at this time.

Plan your meals on a regular schedule. Never skip meals, as you may want high-calorie snacks later in the day. Pick colorful fruits, dark green vegetables and whole grains and pasta to enjoy. While protein is important to muscles, it should not be found in fatty meats. Try to choose lean meats, legumes and low-fat dairy products.

## Exercise

Regular exercise plays an important role in overall good health. For transplant patients, the benefits of exercise are even more important. When you return home after surgery, you should limit your physical activity as mentioned in the “Going Home” section of this guide. Once it is approved, exercise will be a great friend in helping you control your weight and manage stress.

Activities that best help your overall strength and endurance are walking, bicycling, swimming and aerobics. However, an exercise program should correlate with your medical condition and individual needs. The objective is to build your strength back slowly, working within your limits. Walking, for example, is a great exercise and is one that can begin while you’re still in the hospital.

Be patient with yourself. Results won’t happen overnight. Make a promise to exercise just five minutes a day, adding more minutes as you build strength. Pretty soon, you’ll be walking or bicycling for 30 minutes at a time, several times a week. Physical conditioning is a springboard to feeling good, and that spreads throughout everything you do.

## DIETARY PRECAUTIONS

- Try not to add extra salt to your diet, and use caution in eating salty foods such as ham, hot dogs, luncheon meats, and canned or processed foods. Too much sodium can lead to fluid retention, which causes shortness of breath and elevated blood pressure.
- Diabetics will still need to follow their diabetic diet.

## REVIEW

- Balanced nutrition and regular exercise are important to your wellbeing.
- Remember to thoroughly wash fruits and vegetables.
- Avoid salty and fatty foods.
- Diabetics will still need to follow their diabetic diet.
- Some of the medications you’ll take will cause you to feel hungry, even when you’ve had enough to eat. You can take control of the urge to eat unhealthy foods by making wise diet choices and maintaining an exercise routine.

# Medications

Sadly, the third major cause of transplant failure occurs when people don't follow their drug-therapy program. You will use a combination of medications to give you the best possible defense against organ rejection. Careful monitoring and adjusting of the dosage will be needed to develop a program that is best for you.

Be sure to follow your drug-therapy program exactly as instructed. Never skip a dose or change the amount unless told to do so by your transplant physician or coordinator. Ask your transplant coordinator how to handle missed doses.

Do not change your medications or take anything other than what was prescribed or approved by your transplant team. It's important to note that many over-the-counter medications can interact with your immunosuppressive drug therapy. This can be dangerous. Make sure you discuss this with your transplant team so you know which medications to avoid.

Remember that as long as you have the transplanted organ, you will have to take immunosuppressant medications.

## What You Need to Know About Side Effects

Immunosuppressive drug therapy involves strong medications and has side effects. The number and type of side effects is unique to each person. Also, the higher the dosage you get, the more likely it is that you will experience a negative reaction. It is important to know the possible side effects so you can report them right away to your transplant physician or coordinator.

The following is a list of medications from which your physician will choose to help achieve a successful transplant. This is only an overview,

as your transplant team may prescribe other medications not listed.

## Immunosuppressive Medications

### PROGRAF® (TACROLIMUS)

Prograf is an immunosuppressant medication given to help prevent your body from rejecting the transplant. Prograf comes in capsule form of 0.5 mg, 1 mg and 5 mg. This medicine should be taken only as directed by your doctor. It is a good idea to take it the same time every day to keep a constant amount in your blood. We will monitor your Prograf levels throughout your lifetime.

#### SIDE EFFECTS

- Higher risk of infection
- Headaches
- Numbness or tingling in hands, feet or lips
- Nausea and vomiting
- Insomnia
- Itchy skin
- High blood sugar
- Tremors

### RAPAMUNE® (Sirolimus)

Rapamune is an immunosuppressive medication. It comes in 0.5 mg, 1 mg and 2 mg tablets and in liquid form.

#### SIDE EFFECTS

- Higher risk of infection
- Joint pain
- Decrease in red blood cells
- Diarrhea
- Rash or acne
- High blood pressure
- High cholesterol

## REVIEW

- Immunosuppressive drug therapy is a very important part of transplant success.
- Once you have your new liver, following a prescribed drug-therapy program will become your top priority. You will need to fully understand the purpose of these medications, the proper dosage and the possible side effects.

### **CELLCEPT® (Mycophenolate Mofetil)/ MYFORTIC® (Mycophenolic Acid)**

CellCept and Myfortic are immunosuppressive medications that greatly decrease the chance of rejection within the first six months after transplant. CellCept comes in 250 mg or 500 mg capsules and in liquid form. Myfortic comes in 180 mg or 360 mg tablets.

#### **SIDE EFFECTS**

- Higher risk of infection
- Diarrhea
- Leukopenia (decrease in white blood cells)
- Sepsis (infection in the blood)
- Abdominal pain and vomiting

### **PREDNISONE®**

Prednisone is a steroid hormone similar to one your body produces normally. It is given with other medications to prevent rejection. Prednisone comes in 1 mg, 2.5 mg, 5 mg, 10 mg or 20 mg tablets. We will reduce your dosage down to get to a maintenance dose.

#### **SIDE EFFECTS**

- Higher risk of infection
- Swelling of the face, hands or ankles caused by fluid retention
- Weight gain due to increased appetite or fluid retention
- Cataracts (decreases vision clarity) and vision changes (If you wear glasses, you may want to delay eye exams until Prednisone doses are lowered)
- Skin changes (acne, skin rashes, easy bruising, stretch marks, increased sensitivity to the sun)
- Muscle weakness
- Mood swings
- Night sweats
- Stomach ulcers
- Steroid-induced diabetes (patients with a family history of diabetes or who are borderline diabetic are most at risk)
- Bone and joint changes

### **TIPS FOR TAKING MEDICATION**

- Be sure you know what to take and how to take it.
- Keep a daily record.
- Report side effects.
- Consult your physician before taking any other drugs.
- Food can affect your medication absorption. Be consistent in taking your medications with or without food.

### **NEORAL® (CYCLOSPORINE)**

Cyclosporine is an immunosuppressant medication given to help prevent your body from rejecting the transplant. Cyclosporine comes in capsule form of 25 mg and 100 mg. This medicine should be taken only as directed by your doctor. It is a good idea to take it the same time every day to keep a constant amount in your blood. We will monitor your cyclosporine levels throughout your lifetime.

#### **SIDE EFFECTS**

- Higher risk of infection
- Headaches
- Gum overgrowth
- Nausea and vomiting
- Insomnia
- Numbness/tingling of hands and feet
- High blood sugar
- Tremors

# Medications

## Antibiotics

Since you will be vulnerable to various types of infection, it is not uncommon for your physician to prescribe a preventative dose of antibiotics.

### **SEPTRA® (Trimethoprim Sulfamethoxazole)**

This is used to prevent pneumocystis jirovecii pneumonia (PCP), and it is given in a single-strength dose.

#### **SIDE EFFECTS**

- Nausea
- Vomiting
- Rash
- Itching
- Decreased white blood cells

### **MYCELEX TROCHE® (Clotrimazole)**

This medication comes in the form of a white lozenge, which you let dissolve slowly in your mouth to prevent thrush.

#### **SIDE EFFECTS**

- Nausea
- Vomiting
- Abnormal liver function

### **VALCYTE® (Valganciclovir)**

Valcyte is an anti-viral medication used to prevent or treat cytomegalovirus (CMV) infection, and it is offered in 450 mg capsules and in liquid.

#### **SIDE EFFECTS**

- Fever
- Headache
- Diarrhea
- Decreased white blood cell count
- Decreased platelet count

## Anti-Ulcer Medications

Stomach ulcers may occur as a result of being placed on Prednisone. The transplant team may prescribe an anti-ulcer medication to minimize the problem. The type of medication, dose and duration will be determined by your transplant team.



## Diuretics

Diuretics, or water pills, help your body get rid of excess fluid (edema) by increasing urine volume. You may take one of several commonly prescribed diuretics, including Lasix, Bumex and Zaroxolyn.

#### **SIDE EFFECTS**

- Muscle weakness and leg cramps
- Dry mouth and headache
- Dizziness/weakness
- Constipation
- Low potassium levels
- Lower blood pressures

## PRECAUTIONS

- Be familiar with your medications. Know their name, dose and frequencies.
- Follow your doctor's instructions for taking them.
- Know all the possible side effects, and report those you may experience to your transplant coordinator.

## Glossary

**ACUTE** - Describing an experience that comes on rapidly, is sharp and lasts a short time, as in acute pain. Differs from chronic, which describes a long-lasting or frequently recurring experience.

**ADVERSE REACTION** - Side effect. Any unintended, abnormal reaction to medicine taken at normal doses.

**ANTIBIOTIC** - Medication that kills or limits the growth and multiplication of bacteria and other microorganisms. Most non-prescription antibiotics are applied topically.

**ANTIBODY** - A protein made by the body's immune system to fight infection and foreign substances. Your body produces antibodies in response to something foreign. Transplant recipients take immunosuppressive medication to prevent antibodies from attacking a new liver.

**BIOPSY** - Removal of cells from a newly transplanted liver to be closely examined for signs of rejection. A biopsy may be necessary if your liver doesn't work right after transplant. Biopsies are the best way to find out if there is rejection and to allow your doctor to treat the problem. The procedure is usually done by your hepatologist and may take place in a hospital room or in the X-ray department.

**CAPSULE** - Medicine-containing shell or gelatin or other material that can dissolve in the stomach, releasing the capsule's contents.

**CMV** - Cytomegalovirus, member of human herpes virus-causing disease.

**DECEASED DONOR** - An individual who died of reasons not related to liver failure or liver problems, and whose wish was to donate organs to help others awaiting the gift of life.

**DIASTOLIC** - The bottom of two blood pressure numbers that measures the force of the heart muscle at rest, when it expands and fills with blood.

**DOSAGE** - Information contained on product packaging or labels that tells how much medicine to take, when to take it and any special instructions.

**END-STAGE LIVER DISEASE** - Permanent damage to the liver treatable through liver transplantation.

**ENDOTRACHEAL TUBE** - An airway tube inserted through the mouth to help you breathe during surgery.

**EXPIRATION DATE** - The date prior to which the product can be expected to retain its full strength as stated on the label, according to the manufacturers. Products should be disposed of properly once they reach their expiration date.

**GLUCOSE** - A type of sugar found in the blood.

**IMMUNOSUPPRESSANT** - An agent capable of suppressing immune responses, commonly referred to as anti-rejection medication.

**INFECTION** - The condition in which the body is invaded by a pathogenic agent that multiplies and produces effects.

**INTRAVENOUS (IV)** - Literally into or within a vein. Also refers to fluids and medications that are injected into a vein through a needle or catheter.

**LAXATIVE** - Agent that promotes bowel movement by softening or increasing the bulk of the stool, lubricating the intestinal tract or stimulating muscle contraction of the intestine.

**REJECTION** - When the body tries to get rid of a transplanted liver by making antibodies to go on attack. Transplant recipients take immunosuppressive medication to prevent rejection from happening.

**SIDE EFFECT** - Unintended, but sometimes not unexpected, effect on the body apart from the principal and intended action of the medication.

**SYSTOLIC** - The top of the pressure number that measures the force of contraction of the heart muscle as blood is pumped out of the heart chambers.

# CREATION Health: Our Philosophy of Health and Wellness

CREATION Health is a whole-person lifestyle that helps people live a healthier, happier life, no matter what stage of life they might be in. Each letter of the word CREATION stands for one of the eight principles of health found in the Bible's creation story — Choice, Rest, Environment, Activity, Trust, Interpersonal relationships, Outlook and Nutrition. You can use this philosophy as a guide to personal fulfillment and recovery.

## Choice

Choice inspires personal fulfillment and well-being. Establishing control over your life through conscious decision-making leads to improved health and longevity. Choose the most important thing for you each day and share it with friends and loved ones

## Rest

Rest rejuvenates the body, mind and spirit, empowering you to function at your best. Proper sleep and relaxation can lower blood pressure and reduce stress. Rest is important to your recovery. Take time to relax. Listen to soothing music, read and meditate.

## Environment

Environment influences your overall health. Creating pleasant surroundings that energize the senses can lead to inner peace and happiness. Keep things around you that make you feel comfortable. Adjust lighting and temperature as needed.

## Activity

Activity strengthens the body, sharpens the mind and invigorates the spirit. Regular physical and mental exercise can greatly improve your quality of life. Maintain the level of activity that your health care team recommends. Puzzles, word searches and other games are a fun way to stimulate your mind.

## Trust

Trust promotes healing and security in your relationship with God or a higher power, family, friends and coworkers. Nurturing trust in all your relationships creates inner stability and confidence, which leads to wellness. Talk to your pastor, friends and family about your spiritual and emotional needs. Pray, read scripture or journal about your experiences.

## Interpersonal Relationships

Interpersonal relationships can spark health and healing. Social connection fortifies resolve and nourishes the body, mind and spirit. Stay connected through emails, blogs, letters and phone calls. Encourage friends and family to visit.

## Outlook

Outlook creates your reality. A positive attitude can strengthen the health of your body, mind and spiritual life. Begin a gratitude journal and write down what you are thankful for each day. Keep a list of how you are integrating CREATION Health principles into your life.

## Nutrition

Nutrition is the fuel that drives you. Small changes to your diet can produce profound improvements to your overall health. Follow your diet plan to feel better and more energized.

# Our Health Equity Promise

## Patient Protection and Affordable Care Act: Section 1557

AdventHealth complies with applicable federal civil rights laws and does not discriminate on the basis of race, color, national origin, age, disability or sex. This facility does not exclude people or treat them differently because of race, color, national origin, age, disability or sex.

AdventHealth provides free aid and services to people with disabilities to communicate effectively with us, such as:

- Qualified sign language interpreters
- Written information in other formats (large print, audio, accessible electronic formats, other formats)

AdventHealth provides free language services to people whose primary language is not English, such as:

- Qualified interpreters
- Information written in other languages

### If you need these services, please call 407-303-5600 x1106707.

If you believe that this facility has failed to provide these services or discriminated in another way on the basis of race, color, national origin, age, disability or sex, you can file a grievance or request that someone assist you with filing a grievance at 407-200-1324 or [fh.risk.management@adventhealth.com](mailto:fh.risk.management@adventhealth.com).

You can also file a civil rights complaint with the U.S. Department of Health and Human Services, Office for Civil Rights, electronically, through the Office for Civil Rights Complaint Portal, available at [ocrportal.hhs.gov/ocr/portal/lobby.jsf](http://ocrportal.hhs.gov/ocr/portal/lobby.jsf), or by mail or phone at:

**U.S. Department of Health and Human Services**  
200 Independence Avenue, SW  
Room 509F, HHH Building Washington, D.C. 20201  
1-800-368-1019, 800-537-7697 (TDD)

Complaint forms are available at [hhs.gov/ocr/office/file/index.html](http://hhs.gov/ocr/office/file/index.html).

## The statements below direct people whose primary language is not English to translation assistance.

**ATENCIÓN:** si habla español, tiene a su disposición servicios gratuitos de asistencia lingüística. Llame al número siguiente.

**CHÚ Ý:** Nếu bạn nói Tiếng Việt, có các dịch vụ hỗ trợ ngôn ngữ miễn phí dành cho bạn. Gọi theo số điện thoại dưới đây.

**注意:** 如果您使用中文, 您可以免费获得语言协助服务。请拨打下面电话号码。

**Atansyon:** Si ou pale kreyòl Ayisyen, gen sèvis asistans nan lang ou ki disponib gratis pou ou. Rele nimewo ki anba an.

**주의:** 한국어를 사용하시는 경우, 언어 지원 서비스를 무료로 이용하실 수 있습니다. 아래의 번호로 전화하십시오.

**UWAGA:** Jeżeli mówisz po polsku, możesz skorzystać z bezpłatnej pomocy językowej. Zadzwoń pod numer podany poniżej.

ملحوظة: إذا كنت لا تتحدث اللغة الإنجليزية فإن خدمات الترجمة متوفرة لك مجاناً. الرجاء الإتصال بالرقم أدناه:

**ATTENTION:** Si vous parlez français, des services d'aide linguistique vous sont proposés gratuitement. Appelez le numéro ci-dessous.

**PAUNAWA:** Kung nagsasalita ka ng Tagalog, maaari kang gumamit ng mga serbisyo ng tulong sa wika nang walang bayad. Tawagan ang numero sa ibaba.

**ВНИМАНИЕ!** Если вы говорите на русском языке, то вам доступны бесплатные услуги перевода. Для этого позвоните по нижеуказанному номеру.

**ACHTUNG:** Wenn Sie Deutsch sprechen, stehen Ihnen kostenlos sprachliche Hilfsdienstleistungen zur Verfügung. Rufen Sie die untere Nummer an.

**सुचना:** जो तमने गुजराती बोवता हो, तो निःशुल्क भाषा सहाय सेवाओं तमारा माटे उपलब्ध छै. नीचे-नंबर पर फोन करो.

**ATENÇÃO:** Se você fala português, disponibilizamos serviços linguísticos gratuitos. Ligue para o número abaixo.

**ध्यान दें:** यदि आप हिंदी बोलते हैं तो आपके लिए मुफ्त में भाषा सहायता सेवाएँ उपलब्ध हैं। नीचे लिखे नम्बर पर सम्पर्क करें।

اگر شما فارسی زبان هستید، خدمات کمکی زبان بطور مجانی در دسترس شما قرار دارد. تو شماره زیر زنگ بزنید.

توجه فرمائیں۔ اگر آپ اردو بولتے/بولتی ہیں تو آپ کے لئے لسانی خدمات مفت میسر ہیں۔ ذیل میں دئیے گئے نمبر پر کال کریں۔

**注意:** 日本語でお話になりたい場合には、無料の通訳サービスをご利用いただけます。下記の番号にお電話してください。

**ໄປດຊາບ:** ຖ້າວ່າ ທ່ານເວົ້າພາສາ ລາວ, ການບໍລິການຊ່ວຍເຫຼືອ ດ້ານພາສາ, ໄດຍບໍ່ເສັຽຄ່າ, ແມ່ນມີພ້ອມໃຫ້ທ່ານ. ກະລຸນາໃຫ້ນຳເບີຊ່ອງລູກ

**LUS CEEB TOOM:** Yog tias koj hais lus Hmoob, cov kev pab txog lus, muaj kev pab dawb rau koj. Hu tus xojtooj hauv qab no.

**ATTENZIONE:** Se parlate italiano, sono disponibili dei servizi di assistenza linguistica gratuiti. Chiamare il numero sotto indicato.

**407-303-5600 ☎ 407-303-3025**







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