Your Liver Transplant
AT EMORY UNIVERSITY HOSPITAL
A Journey for Life
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The most important information you may ever read

Now that you are considering a liver transplant, your success as a transplant recipient may depend on your understanding of what to expect before, during and after your transplant. The purpose of this book is to provide you and your family with that information. Please read each section carefully. Feel free to jot down notes in the margins and ask questions about anything you do not understand or concerns you might have.

Liver transplantation is considered when conventional medication or surgery cannot improve the function of your failing liver. Transplantation offers many people the chance to survive and return to a normal, productive lifestyle.

The Emory liver transplant team seeks to thoroughly educate every candidate about transplantation. Pre- and post-transplant management can be difficult and demanding. You and your family must completely understand the risks, limitations and benefits of transplantation before you can make an informed decision concerning this procedure.

It is important to understand that a liver transplant does not “cure” your liver disease. You will need daily medication and rigorous follow-up by the transplant team for the rest of your life.

The Emory liver transplant team is committed to helping you if you are committed to the demands and requirements of transplantation. Your attitude regarding pre-transplant care, surgery, recovery and your participation in your care will play a vital role in the ultimate success of your liver transplant.
Why you may need a liver transplant

THE HEALTHY LIVER

The liver is the largest solid organ in the body, weighing about three (3) pounds in the adult. It is located primarily on the right side of the body between the diaphragm and the bottom of the rib cage. The blood vessels that carry blood to the liver are the large portal vein and the smaller hepatic artery. The blood vessels that carry blood away from the liver are the hepatic veins.

The liver performs several important functions, a few of which are:

• Metabolism (breakdown) of nutrients from food for use by the body.
• Manufacture of proteins necessary for blood clotting and restoring body protein, which your body continually breaks down.
• Metabolism of drugs and hormones.
• Manufacture of a protein called albumin, which helps the body keep blood volume and blood pressure normal.
• Manufacture of bile, which helps the body digest fats.

All of these important liver functions are decreased or lost when the liver is irreversibly damaged from disease. Just as you cannot live without your other vital organs, you cannot live without your liver. Your liver is a vital organ, necessary to sustain life.

THE FAILING LIVER

Cirrhosis is a chronic, progressive disease in which the functions of the liver are gradually lost as normal liver tissue is replaced by scar tissue. Common causes of cirrhosis in the adult are chronic hepatitis, sclerosing cholangitis, primary biliary cirrhosis, hepatic vein thrombosis, chronic alcohol abuse, and cryptogenic or unknown causes.

Damage to the liver occurs from a virus, a poison, or disease. As part of the healing process, scar tissue forms and replaces normal liver cells and tissue. As liver function is gradually lost, some or all of these signs of liver disease may appear:

• Jaundice (yellow coloring of the skin and eyes)
• Itching
• Dark, tea-colored urine
• Clay-colored stools
• Weight loss and muscle wasting
• Tendency to bruise and bleed easily
• Ascites (fluid in the abdomen)
• Night blindness
• Decreased energy and fatigue
• Mental confusion which may progress to coma
• Vomiting blood or passing blood in the stools
• Edema

Cirrhosis is ultimately a terminal condition. Although there are treatments that may slow down damage to the liver, the liver will eventually fail to respond to these treatments. When this occurs, liver transplantation may be indicated.

TYPES OF LIVER TRANSPLANTS
Whole liver transplantation is the most common procedure where the entire donor liver is placed in the recipient.

Split liver transplantation is when the liver tissue, blood vessels and biliary structures are divided to obtain feasible grafts for use in two patients. The advantage for this procedure is that two recipients in urgent need of a liver graft can be successfully transplanted. It can also be safely used for an elective procedure. The portion of the liver used for each recipient is determined by the size and shape of the donor organ and the respective weights of the recipients.

WHAT ARE THE RISKS?
Liver transplantation has been a life-saving surgery for many individuals. Currently, the survival at 5 years after transplant is about 70-85%. Success is largely due to advances in drug therapy. Long-term survivors of liver transplantation can lead active and productive lives. However, there are significant risks associated with the surgery and the chronic use of immunosuppressive drugs. A member of the liver transplant team will discuss them with you individually.

HISTORY OF LIVER TRANSPLANTATION
The first human liver transplant was performed in 1963 by Dr. Thomas E. Starzl. Since then, more than 25,000 liver transplants have been performed worldwide. Improved techniques and the development of the anti-rejection drug Cyclosporine have made liver transplantation a treatment of choice for many patients with end-stage liver disease.

Emory University Hospital has a long and honored tradition of treating patients with end-stage liver disease and portal hypertension. More than two decades ago, the hospital’s Chief of Surgery,
Dr. W. Dean Warren pioneered several major surgical techniques still being used in medical centers today. Emory Hospital performed its first liver transplant in 1987. Today, Emory performs over 100 adult and pediatric liver transplants each year. Surgical director Dr. Thomas Heffron is a pioneer in living related donation for children and adults. Dr. Andrei Stieber has over 18 years experience and a special interest in new surgical techniques and teaching. For nearly two decades Emory University Hospital and Children’s Healthcare of Atlanta at Egleston on the Emory campus have been the only hospitals in the state performing liver transplantation.
Your transplant evaluation

The Emory team is comprised of liver transplant surgeons, transplant hepatologists, and a team of gastroenterologists, anesthesiologists, pathologists, radiologists, psychiatrists, chaplains, nurses, social workers and pharmacists who are all experienced in treating patients with advanced liver disease. This group is well qualified to perform the sophisticated, life-saving procedures involved in liver transplantation and to provide the care required after surgery.

Before you can be considered a candidate for liver transplantation, a thorough evaluation of your physical and emotional status must be done on an outpatient basis. Your nurse coordinator and schedulers will arrange this for you. The purpose of this evaluation is to determine just how damaged your liver is and whether liver transplantation is the best treatment option for you. During the evaluation, you and your family may have many questions about the evaluation and what to expect when it is over. Various members of the liver transplant team will be available to answer your questions.

TESTS

We will draw blood to determine your blood type and how well your organs are working. A urine test tells us if your kidneys are working well and if you are using illicit drugs. Many different tests will be done during the evaluation to determine how damaged your liver is and to determine if there are other physical problems, such as with your heart, kidneys or lungs, which might rule out liver transplant. The following tests and procedures MAY be done:

- Chest X-ray
- Electrocardiogram (EKG)
- CT scan/MRI scan
- Doppler ultrasound (looks at blood flow through the vessels to your liver)
- HIV test (Human Immunodeficiency Virus)
- Dobutamine Stress Echocardiogram or “stress test” (looks at blood flow through the heart and the valves of your heart).
- Liver biopsy (a needle is inserted though your side into your liver to take a very small sample of your liver to help diagnose your disease; medication to numb the area will be given before the biopsy is taken).
- Endoscope (a tube is inserted through your mouth into your stomach to look for bleeding or into your colon to assess for bleeding or cancer potential).
- Pulmonary function tests (special breathing tests to check your lungs).
• Additional tests or procedures may be ordered by consulting physicians.

Upon completion of the evaluation, your case will be discussed by all team members at the Liver Transplant Selection Committee Meeting. The liver transplant team will then decide if liver transplantation is the best treatment option for you. If it is, liver transplantation will be discussed with you in more detail.

MEETING THE TEAM
It is important that you meet all the members of the liver transplant team. Each brings special knowledge that will help you during all phases of the transplant process.

These are some of the people you will meet during the evaluation:

Physicians
Numerous physicians will be involved in your care. Emory University Hospital is a teaching hospital. Therefore, in addition to your attending transplant physicians, you will be meeting resident physicians and consulting physicians from many different services. Multiple specialty physicians may participate in your evaluation, including transplant surgeons, transplant hepatologists (medical liver specialists), gastroenterologists, psychiatrists, hematologists (blood specialists), cardiologists (heart specialists), nephrologists (kidney specialists), pulmonologists (lung specialists), anesthesiologists, and experts in the field of infectious diseases.

Liver Transplant Coordinators
The liver transplant coordinators are registered nurses (RNs) who provide education regarding the transplant and are case managers for patients before and after transplantation.

Psychiatry
The psychiatry staff consists of a clinical nurse specialist and a physician who assess the mental health of patients. They will provide and/or help arrange any treatment therapies as needed.

Pharmacists
The pharmacists are specially trained in transplant care and provide a wide array of information about medications including drug interactions and side effects. The pharmacy staff is an excellent source of drug information.
**Dieticians**
Representatives of Food and Nutrition Services will explain any food restrictions, answer questions about your diet, and help you make healthy food choices.

**Social Workers**
Clinical social workers will assist you regarding family concerns and will provide you with some guidance on services available to you.

**Financial Counselors**
Hospital staff members who will work with you to explain your insurance benefits and assist you with any financial issues. The financial coordinator will help you understand the cost of transplantation and your insurance benefits (see next section).

Because this time is stressful, we encourage you to write down your questions so they are all answered before the transplant.

**FINANCIAL CONSIDERATIONS**
The following information regarding the financial costs associated with liver transplantation will help you begin financial planning for transplant. This is a task that your Transplant Financial Coordinator will be happy to help you with.

To begin, you will need to know how much your insurance company will pay for both the liver transplant and for medications after transplant. It is unlikely that one single source will cover these costs. Often it is necessary to draw on savings accounts, investments, federal and private assistance options and fund-raising. Your financial coordinator is available to answer questions about insurance coverage and to assist you in identifying financial resources available to you.

Please obtain a copy of your health insurance policy, including benefits for liver transplant care and related deductibles and co-payment amounts. If you are covered by Medicare, refer to the current Medicare handbook for deductibles and co-payment amounts.

**During your Evaluation**
Most insurance companies require a review of your evaluation results to see if you meet their criteria to pay for a liver transplant. You will be asked to sign a consent form authorizing Emory to release certain medical information from your evaluation to your insurance company.

If you are a candidate for a liver transplant, the Emory Liver Transplant program will work with you in obtaining insurance approval from your insurance company. If your insurance carrier denies authorization of benefits, the liver transplant program will be happy to write a formal appeal for you. However, please be advised that gaining insurance approval for transplant is ultimately your responsibility.
Liver transplant costs
The cost of a transplant varies from patient to patient based on how sick the patient is before transplant. Here are some of the charges you can expect:

- Hospital charges relating to the liver transplant admission (the day of admission to the day of discharge) range from $68,951 to $347,541. The average hospital charge for transplant admission is $144,362.
- Physician charges from the date of transplant, including 90 days of follow-up care, average $48,067.
- Annual outpatient immunosuppressant medications following transplantation cost between $10,000 - $15,000/year.

Billing
Authorization by your insurance company for medical services provided by Emory does not guarantee full payment of all charges. You will be responsible for the following:

- All deductibles, co-payments and non-covered services as outlined in your health plan.
- Any balance between charges and what your insurance carrier pays as “usual and customary charges.” Ask your insurer for a copy of their usual and customary charges and an explanation of how these charges are derived.

You will receive separate billing statements for Emory Hospital (inpatient and outpatient hospital services) and The Emory Clinic (inpatient and outpatient doctors’ fees and medical services provided in The Emory Clinic buildings).

All Emory Clinic charges will be billed on one account with a specific account number. However, you will have several different accounts with Emory Hospital. The first nine numbers on every hospital account will always be the same; only the last four (4) numbers will change. Your accounts will include:

- Inpatient admissions (different accounts for each admission).
- Specimen accounts (a separate account for lab specimens drawn outside of Emory University Hospital including those specimens drawn at The Emory Clinic buildings).
- Recurring accounts (outpatient follow-up visits). This account is referred to either as an outpatient recurring or transplant recurring account. Recurring accounts will remain open for three to six months. Any outpatient hospital charges during that period will be placed on that account. On recurring accounts, the hospital bills your insurance company once a month.

MORE ABOUT OUR FEES
Our fees reflect the fact that the physicians and transplant team members are specialists in this area and bring to your case training, expertise, and experience of the highest level.

YOU WILL RECEIVE SEPARATE BILLS FROM:
- Emory Hospital for inpatient and outpatient hospital services
- Emory Clinic for doctors’ fees and medical services

PAYMENT ARRANGEMENTS
Emory University Hospital and The Emory Clinic provide services to you with the expectation that you will make the payment in full, not your insurer.

If you will not be able to pay the balance on your account in full, the hospital and clinic business offices will be happy to work with you to set up payment arrangements.

To arrange a payment plan, please call the financial coordinator at 404-712-4601.
SAMPLE QUESTIONS TO ASK YOUR INSURANCE COMPANY:

1. Do I have benefits for liver transplantation?

2. What is my transplant maximum benefit? Is there a specific maximum for liver transplantation?

3. What is my lifetime maximum benefit? How much have I used toward that maximum?

4. What is my annual maximum benefit? How much have I used toward this maximum?

5. Is organ acquisition covered? If yes, is there any limitation on how much my insurance will pay?

6. Is living donor coverage provided, and if so, is there a limitation on how much my insurance will pay?

7. Does my insurance plan have “Centers of Excellence” for transplant services? If yes, is Emory University Hospital an approved transplant center? For PPOs-is Emory University Hospital in-network or out-of-network?

8. Is there a different billing address from the address listed on my insurance card that transplant claims must be sent to? (Note: If there is a different transplant claims address, please be sure that each time you come to Emory for transplant services, you tell the insurance registration representative the correct address.)

9. What are my deductibles, co-payments and out-of-pocket expenses? How much have I paid this year toward my deductible and out-of-pocket expenses?

10. What are considered reasonable and customary charges? How much am I likely to pay?

11. Do I need to obtain authorization/pre-certification for outpatient office visits and medical services?

12. Are outpatient prescription drugs covered, specifically immunosuppressant medications? How much is my responsibility for paying for outpatient prescription drugs? Is there a mail-order pharmacy that I may use that provides a higher level of benefit?
13. Is there a specific nurse case manager that will coordinate my transplant care? If yes, what is his/her name and telephone number?

14. Do I have any transportation or lodging benefits? Are ambulance or air ambulance services covered?

15. Am I in a pre-existing period of coverage so that treatment for my condition is not covered? If yes, what conditions need to be met to pass the preexisting period?

Waiting for your transplant

THE WAITING LIST

If liver transplantation is the best treatment option for you and you agree to it, there will be a period of waiting for a compatible donor liver to become available. This may be a difficult time for you and your family. We will be available to assist you in coping, if necessary, during this time.

YOUR STATUS ON THE LIST

Your name will be added to a list of other patients waiting for a liver transplant. The United Network for Organ Sharing (UNOS) is the national agency that regulates organ transplantation. LifeLink of Georgia, Inc., the organ recovery agency for this area, will coordinate efforts to locate a donor for you. Your priority for transplant is based on a UNOS MELD score that takes into consideration your bilirubin, prothrombin time (INR), and creatinine levels to stage your priority. It is critical that you have labs done when requested and ensure that they are sent to us or your score may be dropped to lower levels by UNOS. Generally, as your MELD score increases, you “move up on the list.” However, if your score gets too high, you may be too sick for a transplant.

FINDING A DONOR

There is absolutely no way to predict when a donor will become available. The wait, depending on your UNOS priority score, could be a few hours to several months or even years. Organ donors are people who have suffered brain death, usually as a result of trauma or brain hemorrhages. The next of kin of the brain-dead patient must give consent for the patient to be an organ donor. After transplantation, many families often ask questions about the age of the donor and how the donor died. The transplant team cannot give out any information to you about the donor nor do we give any information about you or your family to the donor family. The donor family has been promised that this information will be kept confidential.

We do encourage you to write a letter to the donor families at some point following your surgery. Please do not reveal your identity. If you choose to write a letter, a transplant coordinator will send it to LifeLink of Georgia who will then forward it to the donor family.
When a compatible donor is found, you will be notified by a member of the liver transplant team. At that time, you will be given instructions about coming to the hospital for your transplant. We advise you not to bring any valuables with you, such as jewelry, money, expensive clothing or small appliances.

Every effort will be made to find a donor liver quickly. The wait for a donor organ depends on your MELD score, blood type, body size and critical nature of your disease. To find a donor match for you, we look at three things:

• You and the donor must have compatible blood types.
• You and the donor must be close to the same weight.
• You must not have antibodies that are incompatible with the donor.

LIVING DONATION

The option of receiving a portion of a liver from a friend or relative is possible at Emory University Hospital. If you are interested, please call 404-727-3599.

YOUR BEEPER

Once you are listed for transplant, you will need to purchase and carry a beeper at all times so that we can easily reach you when a donor liver becomes available. A cell phone is not adequate as it is not as reliable. We need you to have access to a direct telephone line to be able to reach you regarding any medical issues. It is your responsibility to notify the transplant coordinator when you have obtained a beeper and to keep them informed of any times that you may be out of town. Test your beeper daily. Notify your coordinator of any number changes.

AIR TRANSPORTATION

Time is very crucial when a donor organ becomes available, and we need you to arrive at the hospital as quickly and safely as possible. If you live more than a four-hour drive from Atlanta, you may need to fly to Atlanta for your transplant. A coordinator will provide the names of local air ambulance companies. However, it will be your responsibility to set up air transportation with a special air ambulance service that is available 24 hours each day if you live outside the four-hour travel range.
DEALING WITH STRESS

Anxiety is normal. Everyone has a different experience with transplantation. You may encounter personal, physical, psychological, spiritual and financial stresses during each phase of liver transplantation.

During the transplant evaluation, waiting for the transplant and after the transplant, you may feel discouraged, afraid, anxious, sad or depressed. It is normal to worry that you might die before an organ becomes available. Members of your family may also experience emotional distress related to your illness and worry about the risk of death before transplantation.

There is a weekly support group available for patients and families/friends. This group meets on Tuesdays from 9am to 10am and is located in the outpatient transplant clinic conference room. Being with other patients and families who are waiting for liver transplant can help decrease the sense of isolation that some people feel while waiting. Whenever you are scheduled to return to the transplant clinic for an appointment on a Tuesday, plan to come to the group. Attending the group will not delay your appointment time with the doctor.

Post-transplant life can be a challenge, too, even if you are highly motivated and well-adjusted. Minor complications are likely for most recipients and may require treatment and hospital stays that interfere with your daily life. As a transplant recipient, you will also be recovering from surgery and taking new medications that may cause extremes in your emotions. These feelings should go away in six to eight weeks after the transplant. If they do not, please let your transplant coordinator know.

Many transplant candidates report that keeping a positive attitude about the situation helps. Other helpful coping strategies during the waiting period include getting involved in activities and seeking support from others. Simply talking with someone may help put your feelings into perspective and relieve stress and anxiety. Check with your social worker for the time and place of support group meetings. Our support group welcomes people waiting for transplant, as well as those who have had a transplant. We encourage family members to participate as well. Another program that may be able to help is the Mentor Project. You can find out more information about the Mentor Project later in this book.

While you can expect these brief periods of discouragement, they should not affect your usual daily activities. If these feelings occur frequently (for longer than a week or two) or begin to interfere with your daily activities, talk with your doctor or coordinator.

Our goal as the transplant team is to help you openly explore and discuss your feelings at any time during the transplant process. Please do not hesitate to call us.
HEALTH MAINTENANCE

Continue your general medical care with your primary and referring physicians. Your first follow-up appointment is scheduled eight weeks after you are listed. We will perform follow-up scans of your liver every three to four months to rule out development of new problems. If you have known malignant tumors in your liver, we will scan your liver every 3 months or as directed by our hepatologist. We will perform a heart test (echocardiogram with Doppler studies) yearly while you are listed for routine follow-up. Your MELD score will be provided by your coordinator. It is important that you and your local doctor forward any labs to Emory as soon as possible (office visits, hospitalizations) so we can upgrade your status as appropriate.
Going to the hospital

THE PHONE CALL
When a donor liver becomes available, a transplant coordinator will phone you at home first. If we cannot get in touch with you at home, then we will page you. It is important that you call us back within thirty minutes.

We will tell you that we have a potential donor and then ask how you have been feeling physically. If you have a fever, vomiting or diarrhea, we may not be able to do the transplant. The most important thing you can do while waiting for a transplant is to seek treatment quickly if you become ill, so that you will be ready at any time should a donor liver become available.

The first call you get does not always mean the transplant will occur. We will tell you that we have a potential donor. The surgeon examines each donor organ and may find that the organ is not strong and healthy. If the donor organ is not functioning well, we will not do the transplant. This does not happen often, but it is a possibility.

LEAVING FOR THE HOSPITAL
You need to come directly to Emory as soon as you have finished talking with the coordinator. If you have difficulty driving to the hospital, please call the coordinator and we will try to help you get there safely. We would not want you to lose a chance for a new liver because your car broke down. If you have arranged to fly, you will need to contact the air ambulance service immediately for departure and arrival times and then tell your coordinator. We can then anticipate when you will arrive at Emory.

ARRIVING AT THE HOSPITAL
When you arrive at Emory Hospital, please drive to the valet entrance on Clifton Road, then go directly to Admissions located on the second (2ND) floor of the hospital. Sign in under the surgeon’s name. The admissions personnel will direct you to your room where you will be prepared for surgery. This time will be very hectic. Several final procedures such as blood tests, chest X-ray and an EKG may need to be done. A transplant surgeon and an anesthesiologist will also talk with you, and you must sign a Consent for Surgical Operation.

THE LIVER TRANSPLANT SURGERY
On the same day or the next morning, you will be taken to the operating room. There, the anesthesiologist will insert intravenous needles for administration of medications and blood and for taking
blood samples. Medications will be given to make you fall asleep. A catheter will be inserted into your bladder and will drain your urine, and a tube that goes into your lungs will be attached to a respirator to breathe for you during surgery and for a short period of time afterwards. The transplant surgeons will make a Y-shaped incision in your abdomen to remove your liver and replace it with your new one. Three small tubes known as Jackson Pratt (JP) drains will come out of your incision to drain fluid from around your new liver. They will remain in place until the drainage stops. A tube called a T-tube may be placed in your bile duct. This tube comes out of your body, usually on the right side, and drains bile into a bag. The T-tube usually is disconnected from the bag and capped off in five to seven days. The capped off tube will stay in place for approximately three to six months after your transplant. A nasogastric (NG) tube will be placed through your nose and into your stomach to keep it from filling with air until normal bowel functions return.

Your family will be asked to wait for you in the Intensive Care Unit (ICU) waiting area. We will make every effort to keep them informed of your progress. If your family chooses to wait somewhere other than the ICU waiting area, they should inform the ICU nursing staff of their location.

The surgery usually lasts from six to eight hours, but may take considerably longer in some patients. When the surgery is over, one of the surgeons will speak with your family. You will be taken directly to the ICU. Your family will be able to visit you for the first time about one hour after your arrival in the ICU. Each time your family members visit, they first will be asked to wash their hands at the sink inside your room. This is required of all visitors at all times. Handwashing is also required of all members of the liver transplant team. As you begin to recuperate and feel stronger, the tubes and catheters will be removed.

**WHAT HAPPENS AFTER SURGERY**

When you awaken in the ICU, the sights and sounds around you may be unfamiliar. Your recovery will be monitored and managed by highly skilled critical care nurses.

The tube in your lungs will remain in place to help you breathe deeply and prevent pneumonia until the anesthesia is completely out of your system. Because this tube passes through your vocal cords, you will not be able to talk while it is in, which will make communicating a challenge. The nurse will ask you “yes” and “no” questions and help you write messages on a notepad. When the tube is removed, you will be asked to do exercises, such as coughing and deep breathing, to keep your lungs clear.
You will have “squeezing devices” or sequential compression devices on your legs to promote the circulation of blood in your legs while you are on bedrest. This helps to prevent the formation of blood clots in your legs.

You will probably look different to your family the first time they visit you. You will be pale, possibly swollen and feel cool to their touch. This will improve after just a few hours in the intensive care unit. You will also still be sleepy and may not remember the first time your family visits.

A typical stay in the ICU is three to four days. Several times each day, various members of the transplant team will make rounds to monitor your progress. Please do not be alarmed at all of the attention you will be getting. This is normal and necessary for a safe recovery.

You will then be transferred to the surgical floor where our nurses and physical therapists will help you regain your strength, teach you how to care for yourself when you go home, and prepare you for discharge from the hospital. If all goes well, you can expect to spend five to seven days on the surgical floor before your discharge. During your recovery you will have both “good” and “not-so-good” days, but over time, you should get stronger and begin noticing differences in your body and abilities. Keep in mind that no two liver transplant patients recover at the same pace. You are an individual and comparing your progress with that of another transplant patient may only confuse and frustrate you.

As you move closer to the time you will leave the hospital, your activity level will be increased. You will be encouraged to walk daily. Eventually, you will be able to venture outside the hospital. You will also be expected to know how and when to take your medications.

**DEEP BREATHING AND COUGHING**

Deep breathing and coughing will help expand your lungs and remove lung secretions that have settled during your surgery. A respiratory therapist will show you how to use an incentive spirometer, a device that will help you take deep breaths. It is a good idea to take the incentive spirometer home with you to use the first four to six weeks after surgery.

Coughing may be painful, since you will have an incision. The nurse will teach you how to splint (decrease the pain by holding a pillow or your hands over your incision). Ask the nurse for pain medicine so you can breathe deeply and cough more easily and effectively.

**HOW TO USE THE INCENTIVE SPIROMETER:**

1. Assume a comfortable relaxed sitting position.
2. Attach one end of the tubing to the unit and one end to the mouthpiece.
3. Slide the pointer to your target volume as instructed by the respiratory therapist or nurse.
4. Hold the unit in an upright position.
5. Exhale normally, then place your lips tightly on the mouthpiece.
6. Breathe in slowly to raise the piston to the target volume.
7. Avoid raising your shoulders as you inhale.
8. Remove the mouthpiece and hold your breath for about five seconds until the piston falls to the baseline.
9. Slowly exhale through your mouth.
10. After each breath, cough and breathe deeply. Do not just clear your throat.
11. Relax and pace yourself in order to avoid excessive fatigue or dizziness.
12. Repeat steps 5-9 at least ten times.
EXERCISE AND ACTIVITY

You should begin to increase your physical activity soon after your surgery. If needed, Physical Therapy can be available for you. Once you are feeling better, generally the third or fourth day after surgery, you should begin walking in your room and the hallway. Each day increase the time and distance you walk. By the time you leave the hospital, you should be walking at least 30 minutes a day.
Possible complications after transplant

Many complications can occur after your transplant surgery. Most of these complications are minor, treatable and are no cause for alarm. Your transplant team will help you understand early warning signs, be available to discuss your care, and will recommend further treatment when necessary.

Some of the most common complications seen after liver transplant are: rejection, infection, or bile duct problems.

REJECTION

Rejection is a natural response of your body’s immune system. The immune system is the body’s defense against foreign invaders such as viruses, bacteria and even some types of cancers. This natural defense system will also treat a transplanted organ as foreign and try to reject or attack the new liver. The most common type is acute rejection. It is seen most frequently within 2 weeks after transplant, but is still common up to 1 year after transplant. Acute rejection is always possible, especially after changing some of your medications. Early rejections probably will not have any signs or symptoms. You may be told you have rejection after we see your lab work, which is the first indication for rejection. The diagnosis for acute rejection requires a liver biopsy. Later signs may include any of the symptoms listed here. Treatment for this generally requires a hospital stay of several days, where you will be given IV medications.

To prevent your body from rejecting your new liver, you will take medications called immunosuppressants, which will lower your immunity or defense against foreign agents. These medications, when taken on time and as prescribed, reduce the risk of severe rejection that can damage the liver. You will take these medications for the rest of your life.

You may feel good and have no symptoms, yet still be experiencing rejection. That is why we follow your progress so closely after transplant.

If you have any of the symptoms of possible rejection listed in the margins, call your transplant coordinator.

REJECTION WARNING SIGNS

If you have any of these symptoms, call the transplant team:
- Fever greater than 100 degrees Fahrenheit
- Swelling or tenderness over the new liver
- Flu-like feelings
- Clay-colored stools
- Dark, tea-colored urine
- Yellow skin or eyes (late signs)
INFECTION

As a liver transplant recipient, you will be more susceptible to infection because of immunosuppressant medications. The risk of infection from bacteria and viruses is greatest in the early period after transplant when dosages of medicines are at their highest. That’s why it is important to protect yourself from exposure to infections while in the hospital. Here’s how:

- Anyone entering your room must wash their hands.
- Avoid large crowds of people in the first month after transplant.
- Avoid people with colds or the flu.
- Carefully clean any cuts or scrapes that you receive with antibacterial soap (such as Safeguard or Dial) and water.
- Always call the transplant coordinator if you suspect an infection or develop a fever.
- Normal sore throats and ear infections can turn into bigger problems in transplant patients because your immune system is suppressed. Please notify the transplant coordinator of any signs of infection such as fever, shortness of breath, cough, sore throat, fatigue, headache or flu-like symptoms.
- You will need to take antibiotics prior to dental and oral work, as well as respiratory tract or esophageal procedures.

HYPERTENSION/HIGH BLOOD PRESSURE

Many transplant recipients take medications to control hypertension or high blood pressure since prednisone and cyclosporine, two of the medications used to limit rejection, can raise blood pressure. Blood pressure is recorded as a top (systolic) and bottom (diastolic) number. Normal blood pressures range from 100/70 to 130/80. After transplant you will take your own blood pressure regularly and keep a record in a daily log we give you. We will also provide blood pressure guidelines and will expect you to call us if your blood pressure goes above or below the guidelines. Untreated high blood pressure can eventually damage your heart and other organs.

POST-TRANSPLANT DIABETES

Some of the immunosuppressant medications that you take may increase the likelihood of you developing diabetes. Diabetes is an increased level of sugar in your blood. Signs of diabetes may include excessive thirst, frequent urination, blurred vision, drowsiness, or confusion. Notify the transplant team if you notice any of these signs.

In some cases, high blood sugar can be reduced and managed by weight loss, careful diet and exercise. However, you may need an oral diabetes drug or insulin injections. If you get diabetes, you will be given special teaching about how to deal with this problem.

INFECTION WARNING SIGNS

If you have any of these symptoms, call the transplant coordinator.
- Fever, chills, sore throat
- Nausea, vomiting, diarrhea
- Headache, sinus drainage
- Productive cough
- Wound redness, swelling, or pus
- Pain or burning with urination
- Enlarged neck glands or persistent running nose
- Pain in your head, chest, stomach, throat, or ears
CYTOMEGALOVIRUS (CMV)

Cytomegalovirus (CMV) is a very common virus. About 70% of adults have been exposed to CMV at some time. It usually causes a flu-like illness with fever, general body aches, and a decreased appetite which lasts two or three days. After exposure to the CMV virus, your body forms antibodies in your blood to protect you from future exposures to CMV. This is similar to what happens after you have chicken pox. We are able to do blood tests to check both the transplant recipient and donor for the presence of CMV antibodies.

Because of the immunosuppressant medications, you will be at risk for infection with CMV after transplant. During the first few months, while the immunosuppressant doses are highest and your immune system is especially weak, the CMV virus can “reactivate” or “wake up”. A CMV infection can range from flu-like symptoms to more serious infections involving your stomach and lungs (pneumonia).

If either you or your donor were positive for CMV antibodies you will be given antiviral medications for the first few months after transplant. As your doses of immunosuppressants are lowered over time, your risk of CMV will decrease as well and the medication will be stopped. If you develop an active CMV infection again, you will be treated with medications in the vein.

DISEASES FROM THE DONOR ORGAN

Donor organs are screened for various diseases in accordance with standards required by the United States Department of Health and Human Services – Centers for Disease Control and Prevention (CDC) and the United Network for Organ Sharing (UNOS). However, transplant recipients may be at risk of contracting certain diseases from the organ donor, such as various types of infectious diseases and cancers, which are not detected during the organ screening process.
Medications

After your transplant, you will have to take certain medicines for the rest of your life. These medicines are very important and must be taken exactly as prescribed and on time for the transplanted organ to work properly. Failure to do this may result in organ failure and death.

LEARNING ABOUT YOUR MEDICATIONS

While you are in the hospital recovering from your surgery, our pharmacists and nurses will teach you and at least one family member about all your medications. We will review with you the purpose, dosage and possible side effects of each medicine. To help you feel more comfortable taking these medications, we will ask you to begin administering your medications and keeping your own medication records in the hospital a few days before your discharge.

All transplant patients take immunosuppressants. The following pages explain what’s important to know about these medicines. You may be placed on medications other than these after transplant. Since immunosuppressants reduce your ability to fight infection, you will receive a preventative antibiotic. Many patients will require additional medication for their blood pressure. Other medications will be prescribed based on patients’ individual needs.

WHERE TO GET YOUR MEDICATIONS

Soon after your transplant surgery, the coordinator will ask you what pharmacy you will use to get your medications. You may use a pharmacy in your hometown or a mail-order pharmacy. Please try to plan ahead and make these arrangements before you get your transplant. You can contact your social worker for available medication assistance programs.

Prior to your discharge, a coordinator will call your pharmacy with your medicines. It is your responsibility at least one week in advance, to contact your pharmacy when you are about to run out of medications or to contact our office when you need new prescriptions, so that you will always have all of your medicines. Your prescription will usually be for a month’s supply along with eleven refills.

If you would like help finding a mail-order pharmacy, please let the coordinator know. He or she can give you phone numbers to call. If you decide to use a mail-order pharmacy, it is your responsibility to call and initially set up the service, and then the coordinator will call in the prescriptions. Mail-order pharmacies use overnight delivery to send your medications once a month. After you contact them with any new medication dosages, the pharmacy

IMPORTANT:
Please bring your medications in their bottles with you to your first follow-up visit.

PLAN AHEAD:
Before you have your transplant, arrange for your medications with the pharmacy of your choice.

My home pharmacy is

Their phone number is

My Atlanta area pharmacy is

Their phone number is
asks us to verify the changed prescription. Mail-order pharmacies usually bill your insurance company directly.

Some of the medications that you will be on after transplant can, for some patients, cause mood changes or problems. This effect is usually related to high doses of some of the medicines and usually goes away when the dosages are lowered. Some of the side effects that may occur are: nervousness, irritability, depression, changes in sleep patterns, and mood swings. Some patients have very few mood side effects from the medications. Again, if these side effects occur, it is temporary.

**FREQUENTLY USED MEDICATIONS**

**Immunosuppressants**
You will take immunosuppressants for the rest of your life to protect your new liver from rejection. Immunosuppressants alter your immune system so that it can not reject your new liver. These medicines also make you more susceptible to illness and infections. All immunosuppressive drugs have side effects, but not all of the side effects occur in everyone.

**Tacrolimus (Prograf®)** – also known as FK 506, a very potent anti-rejection drug that comes in 1 mg and 5 mg capsules.

*Special instructions:*
- Must be taken every 12 hours.
- Must be taken one hour before eating or two hours after eating.
- Do not take with other medications.
- Notify your pharmacy several days before discharge so that this drug can be ordered for you.

*Possible side effects:*
- Increased risk of infection
- Damage to kidneys
- Increased potassium
- Increased blood pressure
- Increased blood sugar
- Nausea, vomiting and poor appetite
- Trembling hands and voice
- Thinning hair

**IMPORTANT:**

*Do NOT eat or drink ANYTHING after midnight except blood pressure medicine and water before having your blood drawn.*
*Do NOT take cyclosporine or Prograf® the morning before your blood draw.*

**TIPS FOR TAKING MEDICATIONS**
- **Know the medicines that you are taking and their side effects.**
- **Tell the transplant coordinator if you experience any side effects.**
- **Keep a record of medicines you are taking, including the frequency and dose.**
- **Talk to the transplant coordinator before adding, stopping or changing any medicine, including those prescribed by other physicians such as your local doctor.**
- **Keep medicines in a dry place, away from heat or light, and out of the reach of children.**
- **If you miss a dose, DO NOT double the dose; take the next dose as directed.**
- **If you miss two doses, notify the transplant coordinator.**
Cyclosporine (Neoral® or Sandimmune®) – a very potent anti-rejection drug that comes in 25 mg and 100 mg capsules.

Special Instructions:
• Must be taken every 12 hours.
• Do not store capsules out of foil wrappers.
• Do not store in refrigerator or leave in hot sun.
• The capsules have a funny smell. You may take your dose out of the foil and let the capsules stand for five minutes if the smell offends you.

Possible side effects:
• Increased risk of infection
• Damage to kidneys
• Increased blood pressure
• Headaches
• Trembling hands and voice
• Tingling of hands and feet
• Increased body hair
• Thickening of gums

Azathioprine (Imuran®) – an anti-rejection drug that is sometimes taken with Prograf® or cyclosporine. Comes in 50 mg tablet shaped like an “8”.

Special instructions:
• Watch for increased bruising or bleeding and report to the transplant team.

Possible side effects:
• Increased risk of infection
• May lower your white blood cell or platelet count
• Nightmares
• Nausea and vomiting

Mycophenolate Mofetil (CellCept® or MMF) – a very potent anti-rejection drug sometimes prescribed instead of Imuran®. Usual dose is 1000 mg a day.

Special instructions:
• Must be taken every 12 hours
• Notify your pharmacy several days before discharge so that this drug can be ordered for you.

Possible side effects:
• Nausea
• Diarrhea
• Leg cramps, weakness
• Headaches

Bring a list of your medications including their frequency and doses each time you see a health care professional.

Never take over-the-counter medications or herbal remedies unless you check first with the transplant coordinator to prevent possible dangerous interactions.

Do NOT take aspirin unless approved by the transplant coordinator as it affects blood-clotting rates. Use other medications such as Tylenol®.
Prednisone (Deltasone®) – A steroid drug that helps prevent and treat rejection. The dose will be slowly decreased over time and in some patients may be stopped completely after several years.

Special instructions:
• Take with food
• Monitor your weight weekly
• Have an annual eye exam
• Wait four to six months before changing your eyeglass prescription, because Prednisone can change your vision.

Possible side effects:
• Stomach irritation
• Increased appetite, weight gain
• Fat deposits
• Water retention and round, puffy face
• Cataracts
• Brittle bones
• Fragile skin with bruising and skin tears
• Night sweats and trouble sleeping
• Increased blood sugar
• Diabetes

ANTI-INFECTION DRUGS (PROPHYLAXIS)

Acyclovir (Zovirax®) – antiviral agent used to help prevent and treat herpes related infections such as fever blisters, shingles and cytomegalovirus (CMV).

Special instructions:
• Generally prescribed as 200mg capsules twice a day for the first six months after transplant.
• May be prescribed for longer than 6 months if you have had and active infection.

Possible side effects:
• Nausea and vomiting
• Diarrhea
• Headaches
Bactrim (Septra®, Sulfatrioxazole) – used to prevent a life-threatening pneumonia called pneumocystic carinii (PCP).

Special instructions:
• You will take Bactrim every Monday, Wednesday and Friday.
• If you are allergic to Sulfa drugs you will be prescribed Dapsone or Pentamidine.

Possible side effects: (uncommon):
• Skin rash
• Upset stomach

Clotrimazole troche (Mycellex®) – drug used to prevent and treat fungal infections of the mouth and gut.

Special instructions:
• Dissolve one troche slowly in the mouth 5 times daily for one month after transplant
• Do not chew or swallow it whole

Possible side effects:
• Bad or unusual taste in your mouth

Nystatin – drug used to prevent and treat fungal infections of the mouth and gut.

Special instructions:
• Nystatin is taken four times daily for one month after transplant.
• Shake liquid well before taking.
• Liquid should be swished in mouth for at least five seconds, then swallowed.

Possible side effects:
• Side effects are very rare.

Clotrimazole vaginal suppositories (Gyne-lotromin®) – drug used to prevent vaginal fungal infections in women

Special instructions:
• Unwrap suppository and insert into the vagina at bedtime every night for the first month after transplant rinse applicator with warm soapy water after each use

Possible side effects:
• increased vaginal discharge
• vaginal itching or burning
ANTI-HYPERTENSIVE DRUGS
Procardia®, Nifedipine, Clonidine, Labetalol, Normodyne, Trandate®, Capoten®, Captopril – used to control high blood pressure which is a common side effect of your immunosuppression.

Special instructions:
• If you have high blood pressure, you will be asked to obtain a blood pressure cuff and monitor your blood pressure regularly. Insurance will sometimes cover the expense. We will provide you with a letter of medical necessity should it be required.

Possible side effects:
• Dizziness or headache
• Flushing
• Ankle swelling
• Palpitations
• Impotence

OTHER DRUGS
Prevacid® (lansoprazole) – drug that decreases acid secretion in the stomach to treat and prevent ulcers

Special instructions:
• Take this medicine 30 minutes before breakfast every day

Possible side effects:
• Nausea
• Headache

Pepcid® (famotidine) – drug that decreased stomach acid secretion and is used to prevent and treat stomach ulcers

Special instructions:
• Initial dose is 20 mg twice a day
• The dose will be increased as your Prednisone dose is decreased.

Possible side effects (uncommon):
• Headache
• Dizziness

OVER-THE-COUNTER DRUGS
Many medications interfere with your immunosuppressive medications, so please call your transplant coordinator before taking any over-the-counter drugs.

STUDY MEDICATIONS
You may be asked to participate in a research study to evaluate a new drug to prevent rejection of your new liver. If you consent to be in a study, a research nurse will explain the study and the drug to you.
Going home from the hospital

Going home with a new organ is very exciting. However, it can also be overwhelming because of all the medications you must take and the risks involved with transplant. Before you go home, we will thoroughly review with you and your family what you need to do to keep your transplanted organ healthy.

The transplant coordinator, physical therapist, pharmacist and your nurses will begin preparing you for discharge the day you transfer from the intensive care unit to the surgery floor. It is very important that you and at least one family member understand the information provided here, so if you have any questions, please ask them.

As noted earlier in the Medications section, at this time you will learn about your medications, how to take them, how to keep your own medication records, and where to purchase medications.

MEDIC ALERT IDENTIFICATION
We request that you obtain a special Medic Alert bracelet or necklace. In case of a car accident or other type of emergency, this will alert health care professionals that you have had a transplant, as well as how to contact the transplant team. The identification bracelet or necklace costs a nominal fee. To enroll, call 1-800-432-5278.

DISCHARGE FROM THE HOSPITAL
You will be discharged to go home if you live in the Atlanta area. If you live more than 30 minutes from Emory, we will ask you to stay in Atlanta three weeks post-discharge so we can monitor your progress closely.

The Mason Guest House of Emory University offers private, low-cost lodging for organ transplant candidates, recipients and families. Individuals from out of town coming to a transplant evaluation or follow-up care may also stay at the Mason Guest House. (See section on Mason Guest House.)

WHEN TO CALL THE TRANSPLANT COORDINATOR
Call your transplant coordinator if you experience any of these symptoms:
• Temperature of 100° Fahrenheit or greater
• Blood pressure greater than 140/90 or less than 90/60
• Cough, shortness of breath, sore throat, chills, breathing fast or mucous production
• Nausea, stomach pain or decreased appetite that lasts more than 24 hours
• Diarrhea or vomiting
• Blood in the urine or bowel movements; painful urination
• Decrease in urine output
• Excessive fatigue
• Persistent headaches or flu-like symptoms
• Any unexplained rash
• Excessive swelling of the lower extremities
• Dizziness or “blackout” spells
• Other signs of infection: pus draining from incisions, sores in or around the mouth, painful sores on other areas of the body
• Skin blisters (shingles)
• Dark, tea-colored urine
• Clay-colored stools
• Yellow skin or eyes
• Anytime something “doesn’t feel right”

IMPORTANT PHONE NUMBERS

Liver Transplant Coordinator:
404-712-4981 or
1-888-295-8909

After hours call:
404-778-5000 and ask for the liver transplant physician on call.

Transplant Outpatient Services (2D)
404-712-5676

Mason Guest House
404-712-5100
Going for check-ups

After your transplant, all appointments at Emory will be scheduled in Transplant Outpatient Services, which is located on the second floor, D-wing of the hospital.

During this office visit, you will have a physical exam, review all of your medications, and ask questions about how you have been feeling. We will ask you specific questions about your vital signs, appetite, breathing, swelling of the feet, swollen gums and energy level and activities. This is a great opportunity for you to express any concerns or ask questions.

Remember not to take any medications in the morning if you are having lab work done. Please bring all of your morning medicines with you to the hospital so that you can take them after the lab work. Also, remember to bring your complete list of all the medications you’re taking to all appointments for review.

ROUTINE BLOOD TESTS

We will check lab work with every clinic visit. Monitoring your blood through lab tests is one way that we can make sure that you are taking the right amount of medicines. **Do not take** your morning medication before coming for a scheduled visit because we will give you a special blood test to measure cyclosporine or Prograf® levels in your blood.

We have a special instruction form for laboratories outside Emory, which includes mailing a small sample of blood to Emory Hospital for your cyclosporine or Prograf® level. It explains what bloodwork to draw and how to report the results.

We also ask that you always call our office on the day that your blood is drawn so that we can check on the results. Within five days after the labs are drawn, a coordinator will call you with any medication changes and let you know when to have your blood checked again. If no change in medication is needed, the coordinator will mail a postcard stating when your next labs and clinic visit should be done. Remember to inform us of the name of your local lab and their phone number, if your lab work is not being done at Emory. If you have not received a call or postcard from a coordinator in two weeks after your labs are drawn, please call the office to check on your results.
ANNUAL EXAMS

Every year, around the anniversary of your transplant, you will have your annual exam. Cyclosporine and Prograf® can cause the formation of gallstones. We will periodically recommend a gall-bladder ultrasound to look for gallstones. If you develop gallstones, we will recommend surgery to have the gallbladder removed. If your gallbladder is not removed, a stone could possibly be released from the gallbladder and cause it to rupture. Since your immune system is suppressed, this could lead to a life-threatening infection.

COMMON LAB TESTS

AST/ALT
*Tells how the liver cells are working.*

ALK PHOS/GGT
*Tells how the bile ducts are working.*

Bilirubin
*Tells if the liver is working to clear the jaundice (yellow skin or eyes).*

Hematocrit
*A number that tells how many red cells are in the blood.*

PT/PTT
*Tells if the liver is working to make the blood cells.*

Platelet Count
*Tells if your body has enough cells to fight an infection.*

BUN/Creatinine
*Measures kidney function.*

Blood Sugar
*Tells how much sugar is in the blood.*

Cholesterol/Triglycerides
*Tells if you are eating a healthy diet or eating too many foods high in fat.*

Cyclosporine/Prograf
*Measures the level of medicine in your blood. It must be in the right range or your body will reject your liver. The blood should always be drawn before you take a dose.*
**Staying healthy**

Now that you have had your transplant, you can expect to have a relatively healthy life ahead of you. We encourage you to resume your normal activities as much as possible and take good care of yourself. Here are some suggestions:

**YOUR DAILY ROUTINE**

- If possible, take your cyclosporine or Prograf® first thing in the morning on an empty stomach an hour before breakfast. This allows your body to absorb the medicine better and in lower doses.
- Take your other medications with breakfast.
- Take your evening cyclosporine dose 12 hours after your morning dose and at least two hours after dinner.

**BATHING**

You may shower, but not tub bathe while your staples are in or while a T-tube is in. “Steri-strips” will come off in the shower. After your staples and T-tube are removed you may tub bathe.

**WOUND CARE**

Your wound may heal more slowly because of the steroid medication you are taking. Therefore do not lift anything over 10 pounds for 6 weeks. All your sutures and staples may be removed at 3 weeks as long as your incisions are healing. You do not need a dressing on the incisions unless they are open or draining, or it is more comfortable for you.

**T-TUBE CARE**

If you had a T-tube inserted during your transplant, it will stay in for 3 to 6 months. It is important to avoid the risk of infection while the T-tube remains in place. We ask that you not submerge it in water, so please avoid swimming, Jacuzzis, and tub baths. You may shower. If the T-tube leaks, or the skin around it becomes sore or reddened, call the transplant team.

**DRIVING**

You will not be allowed to drive for six weeks after your transplant. Your reaction time is decreased because of the surgery, anesthesia, medications and bed rest. It also takes about six weeks for your incision to heal properly. You may ride in a car during this time, but you must always wear a seatbelt.

**HELPFUL HINTS**

- Keep all clinic appointments.
- Never run out of medications.
- Report changes in vital signs listed in section called “When To Call the Transplant Coordinator.” Also report any symptoms of illness to your transplant coordinator.
- Never take cyclosporine before having blood drawn or before a biopsy.
- Never take over-the-counter drugs without checking with the transplant coordinator. They may interfere with your transplant medications.
- Never smoke.
- Avoid smoke-filled areas. Ask family members not to smoke.
- Avoid lifting heavy objects and strenuous physical work for at least six weeks after transplant.
EXERCISE AND ACTIVITY

Exercise helps counteract the weakening effects of your pre-transplant illness and offsets possible side effects of the immunosuppressive drugs you must take after transplant. Those side effects may include weight gain, water retention, high blood pressure, elevated cholesterol and blood sugar, and weakened bones. Regular activity also promotes confidence and a sense of well-being. Stop the exercise if you become dizzy, short of breath, nauseated, extremely tired or if you are sweating excessively. Avoid these activities during the first six to eight weeks after transplantation:

- Lifting more than 20 pounds
- Push or pull anything heavier than 10 lbs. (no vacuuming)
- Driving an automobile
- Push-ups, sit-ups, or pull-ups
- Use of a regular bicycle
- Football, karate, or other contact sports

Any time you are exercising, remember to warm up with stretching exercises and cool down by slow stretching and walking. Contact your transplant team if you have any questions about your exercise program or before beginning a more vigorous exercise program.

This scale can help you gauge the right intensity level of your activity. The numbers represent total number of heart beats in six seconds. You should not feel that you are working very hard or very, very hard when you exercise.

### Exertion Scale:

<table>
<thead>
<tr>
<th>6 Second Heart Rate</th>
<th>Exercise Intensity</th>
</tr>
</thead>
<tbody>
<tr>
<td>6</td>
<td>Very, very light</td>
</tr>
<tr>
<td>7</td>
<td>Very light</td>
</tr>
<tr>
<td>8</td>
<td>Fairly light</td>
</tr>
<tr>
<td>9</td>
<td>Somewhat hard exercise</td>
</tr>
<tr>
<td>10</td>
<td>Hard</td>
</tr>
<tr>
<td>11</td>
<td>Very hard</td>
</tr>
<tr>
<td>12</td>
<td>Very, very hard</td>
</tr>
</tbody>
</table>

*Modified from “Borg 20 Point Scale.”*
Limit your activity level to the warm-up or cool-down intensity if you have an infection, rejection, or fever. Contact your physical therapist if you have any questions about your exercise program.

SEXUAL ACTIVITY

After your transplant, your sex drive will probably return. Sexual activity may be resumed after discharge from the hospital. This will not harm your new liver. You may use any position that feels comfortable to you and does not put pressure on your incision. You may resume sexual intimacy once you feel ready. You should expect your sex life to be healthy and enjoyable. If problems develop, discuss this with your primary care physician or with the transplant team.

All sexually transmitted diseases are infections (which you are at increased risk for developing). It is always necessary to protect yourself. Hepatitis B is a sexually transmitted disease. If you have Hepatitis B, you should protect your partner.

PREGNANCY

Please talk to the transplant team if you are thinking about becoming pregnant. We can discuss pregnancy and birth control with you. Since there is little current data on transplant patients and pregnancy, advice on whether or not to become pregnant must be made on an individual basis.

SMOKING

If you smoked before your transplant, you were required to quit before being considered for a transplant. If past cravings return, please discuss this with your physician or transplant coordinator. Otherwise, avoid smoke-filled areas, and ask family members not to smoke.

CONSTIPATION

Constipation is a frequent problem after abdominal surgery. Use of pain medication increases the likelihood of this problem. You can avoid this by including fresh fruits and vegetables and bran in your diet, drinking plenty of fluids, and exercising regularly.

REMEMBER:

Practice safe sex, such as using a condom, as you will be more susceptible to sexually transmitted diseases.
PROTECTING YOURSELF FROM INFECTION

Tranplant patients are more at risk for infections due to the immunosuppressive medications prescribed. While it is important that you strive to lead a normal life, it is also important to make every effort to stay healthy. The single most effective way to avoid infection is with good handwashing. Additional helpful hints include:

• Avoiding close contact with individuals with upper respiratory infections.
• Avoid all raw meat.
• Drink only pasteurized milk.
• Cook all animal foods completely.
• Avoid foods made with raw eggs.
• Properly wash all fruit and vegetables using a scrub brush and chlorinated water.
• Never drink water from an open well or a river or lake.
• Notify your physician immediately (within 24-48 hrs) if you have never had/been exposed to chicken pox and you become exposed.
• Avoid pets with diarrhea.
• Wash hands thoroughly after handling pets.
• Keep litter boxes of cats indoors and do not feed cats raw or uncooked meat.
• Avoid cat bites and scratches. If they occur, clean immediately with soap and water.

RETURNING TO WORK

One of the goals of our transplant program is to help patients return to work when they are physically and emotionally ready. Returning to work can be as easy as returning to a previous job. However, you may not have worked for a long time, lack current job skills, or need to change occupations because of physical or other limitations. You may benefit from career counseling. We can refer you to the Georgia Transplant Foundation’s JobLink Program, and they can assist you in a number of ways. Please refer to the JobLink section of the handbook for further details.

TRAVEL TIPS

If you choose to travel long distances for an extended period of time after your transplant, please notify the transplant coordinator. We can tell you the location of the transplant center nearest your destination in case any problems should arise. If you plan to travel overseas, alert the transplant team. Some required vaccinations may be harmful to transplant recipients.
Always take your medications with you on the plane, in case your luggage is lost in flight. Also remember to bring extra medications in case you were to lose some of yours.

We suggest that you wear your Medic Alert bracelet or necklace and carry an ID card that identifies you as a transplant recipient. This identification should have the contact number of the transplant team. In case of emergency, it is also a good idea to carry a list of your current medications.

**ROUTINE MEDICAL CARE**

Routine medical care is important for early detection and treatment of disease. We recommend routine medical care not only because it makes good sense, but also because some of the medications transplant patients take can affect other body systems. All transplant patients should have an annual check-up by their local physician, including a complete history and head-to-toe physical exam. If you do not have a primary care physician (PCP), please choose one so that you will have access to care for your routine health needs after transplant.

**Immunizations**

Transplant recipients should not receive live vaccinations. This includes the measles, mumps and rubella (MMR) vaccine, the oral polio vaccine (OPV), varicella and smallpox vaccines. Please contact the transplant team if someone in your household is to be vaccinated. All transplant candidates will receive a one-time pneumococcal vaccine to protect against pneumonia. We recommend that all transplant patients and their family members receive a tetanus booster every 10 years.

**Dental Care**

Good mouth care is especially important because of some of the medications you are taking. Some transplant patients on cyclosporine experience problems with tender, swollen gums. To avoid tooth and gum problems, we recommend dental visits every six months and sometimes every three months. If problems do arise, you may need to see a periodontist (a dentist specializing in gum problems).

You will need to take one dose of antibiotics before any dental procedure, including cleanings, fillings or oral surgery. The transplant coordinator will provide you with a prescription for the appropriate antibiotic.

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**IMMUNIZATION SCHEDULE**

- **Pneumonia Vaccine:** every 5 years
- **Flu shot:** annually
- **Tetanus booster:** every 10 years

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**CHECK-UP SCHEDULE**

- **Teeth:** dental exam every six months

  Ask the Transplant Team about antibiotics before having any dental exam.
Vision Screening
We recommend regular vision screening at least every two years or annually if you wear glasses or contacts. Prednisone and other medicines can cause changes in eyesight, including blurry vision, cataracts or glaucoma. Tell your ophthalmologist about your transplant history so he or she may specifically test for these conditions.

Healthy Skin
One of the complications frequently seen in transplant recipients is changes in the skin. You will be taking medications for the rest of your life and they will make your skin more sensitive. The most common skin problems after transplant are increased sensitivity to the sun, dry skin, and acne.

Dry, cracked skin can become a source of irritation. If dry skin is a problem, use a mild soap without perfume or deodorants. You may use a lotion or bath oil on your skin as needed.

Some patients are bothered by “breakouts” or acne after transplant. The best way to control acne is to keep your skin very clean. Gently wash your face and other areas where acne occurs at least daily with soap. Always use a fresh, clean washcloth. Do not rub or scrub, as this will increase the irritation. Pat your skin dry after washing. Do not touch your face or other breakout prone areas as this may spread or worsen the acne.

The ultraviolet rays from the sun, which are responsible for causing skin cancer, are present even in shady areas and on cloudy days. You should always protect your skin from exposure to these rays. After your transplant you are more likely to become sunburned, even if you have never had this problem before. Sunburn is dangerous for several reasons. It is painful and severe sunburn can lead to loss of body fluids and infection. Also, frequent exposure to the sun can lead to skin cancer.

Skin cancer is the most common cancer in the United States. The cause of skin cancer is well known. It is commonly caused by prolonged exposure to the sun, especially if it results in sunburn. Blistering plays a key role in beginning skin cancer. The majority of skin cancers occur on parts of the body not protected by clothing, such as the face, neck, forearms and back of hands. Most skin cancers are easily treatable if detected early enough. Avoid the use of tanning beds or sun lamps. Always wear sunscreen with SPF of 30 or higher on exposed skin (such as face, hands, ear, head if bald, arms, and neck) when going outside. Make it a habit to wear your sunscreen everyday. Wear a hat that shades your face when you are outside. Because your immune system will be suppressed, you may also be more likely to develop skin cancers.

If lesions develop or if you notice a change in a mole or freckle, you will need to see a dermatologist.
You may also be more prone to developing mouth sores and ulcers. Please let the transplant coordinator know if you notice any unusual lesions or ulcers on your skin or any sores or white patches in your mouth. Suspicious lesions should always be examined by a physician.

**Colorectal Screening**
Liver transplant patients are considered to be at risk for colorectal cancers, especially those with a history of Inflammatory Bowel Disease (IBD) and Primary Sclerosing Cholangitis (PSC). Most cancers occur within the first two years after transplantation. Therefore, regular screening is recommended at six months post transplant for all patients, then annually for patients with a history of IBD, PSC or a family history of colon cancer. Average risk patients should be screened every two to three years.

**FOR WOMEN ONLY:**

**Pap Smears**
Women taking transplant medications may be at increased risk of getting cervical cancer. Regular pap smears are an excellent method for early detection and treatment of cervical cancer. Because there are usually no physical signs of this problem, a Pap smear is the primary test for detecting cervical cancer. Cervical cancer is 100 percent curable if it is detected early enough.

The transplant team and the American Cancer Society recommend annual Pap smears and pelvic exams for all women over the age of 18. This should include a rectal exam to check for blood in the stool. Women who are or have been sexually active should have yearly exams regardless of age. A urinalysis also should be included in this yearly exam.

We also recommend good health practices such as prompt treatment of vaginal and cervical infections; limiting the number of sexual partners; using condoms to avoid sexually transmitted diseases; and reporting abnormal uterine bleeding, discharge, spotting, or painful intercourse.

**Breast Self Exam (BSE)**
As many as 95 percent of breast cancers are accidentally discovered. All women should perform regular exams 7-10 days after each menstrual period as a routine good health habit. We join the American Cancer Society in recommending that all women over
age 20 perform monthly breast self examinations. Your local physician or gynecologist should be able to instruct you in this practice. We also recommend breast exams by a physician every three years if you are between 20 and 39 years old and annually for women over the age of 40.

**Mammography**
A mammogram uses a very small, safe amount of radiation to detect masses or tumors in the breasts. The American Cancer Society recommends that all women age 40 and over have yearly mammograms. However, if you have a strong family history of breast cancer, follow the recommendation of your physician regarding frequency of testing.

**FOR MEN ONLY:**

**Testicular Exams**
Most testicular cancers are discovered by men themselves first. We do not know how to prevent testicular cancer, but if treated early enough, there is an excellent chance for its cure. The American Cancer Society recommends that all males over the age of 15 perform testicular self examinations monthly on a set date. Your local physician can instruct you on this practice.

**Prostate Exams**
All men should have a rectal exam yearly. During this exam, the prostate is examined to see if it is enlarged or infected and the stool is checked for blood. All male patients over the age of 50 also should get a special blood test called a prostate-specific antigen (PSA) to screen for prostate cancer. If anyone in your family has ever had prostate cancer, start having this blood test at age 45.
NUTRITION

Proper nutrition is necessary before and after your transplant. A balanced, low-fat diet will help you maintain a healthy body weight as well as reduce high blood cholesterol levels. A low-salt diet will help reduce fluid retention. You also may need to eliminate sugar in your diet to help control high blood sugar.

Our clinical dietitian will meet with you and your family to evaluate your diet and teach you about the right foods to eat to meet your special needs. While waiting for an organ and after your transplant, the dietitian will adjust your diet as necessary. Our dietitian is also available to answer any questions you or your family may have and to help with meal planning at home.

Before your transplant, it will be important for you to reach and maintain a healthy body weight and to eat a balanced diet to keep your strength up while waiting for your transplant. We will ask you to reduce the table salt and sodium in your prepared food to prevent your body from retaining too much fluid or water. Some patients have poor appetites and need special attention to ensure good nutrition. A healthy diet will improve your healing process after surgery.

After your transplant, it is very important to adopt a lifestyle that includes healthy eating habits and a regular exercise program. Your new diet is necessary to help prevent or manage side effects of transplant medications. It is designed to help you regain strength, aid in healing after surgery and most importantly, promote long term health.

Protein
The first month after your transplant you will need to eat more protein to prevent muscle breakdown caused by Prednisone. Protein supplies your body with the building blocks necessary to build and repair body tissue. Your diet should include adequate amounts of protein. Good sources of protein include: lean meats (chicken, turkey, fish, pork, beef), low fat milk and yogurt, low fat/low sodium cheese, eggs or low cholesterol egg substitutes, dried beans and peas, peanut butter, soy, nuts and seeds.

Once your Prednisone dose is decreased, you will need less protein to maintain your health.

Nutrition goal
___________ oz per day protein for the 1st month
___________ oz per day protein long term

(1 oz = 1 egg, 1/2 cup beans, 1/4 cup nuts, 2 tablespoons peanut butter)
Carbohydrates (sugars and starches)
Prednisone may cause high blood sugar (glucose) levels particularly in the first few months after transplant when the dosage is high. Your body may be unable to use carbohydrates properly at this time. If you have a strong family history of diabetes or if you are overweight, the likelihood of having high blood sugar is greater, especially during this time period. In some patients Prednisone can cause “steroid-induced diabetes”. If this occurs, the dietitian will educate you on a diet to help better control your blood glucose levels.

In order to prevent high blood sugar levels, it is important to limit concentrated sweets, such as sugar, desserts, candy, sweetened fruit juices, and other sweetened beverages (such as sweet tea, lemonade, punch and regular sodas). If your Prednisone dose is lowered, your blood sugar will be easier to manage. If you have diabetes at the time of transplant, continue to follow your diabetic diet.

Sodium
Prednisone and Cyclosporine/Neoral® can cause water and sodium retention resulting in quick weight gain and an increase in blood pressure. You should restrict your dietary intake of sodium to less than 4,000 mg per day.

The majority of the sodium in your diet comes from processed and “fast foods”. Because these foods contain large amounts of sodium, their use should be limited. You may use a small amount of salt (1/4 teaspoon per day) in cooking or at the table if your blood pressure is under control and you do not have edema (swelling). Buy foods with less than 200 mg of sodium per serving (see food label). Choose foods labeled “low sodium” and be suspicious of claims stating “lower in sodium”, as these can still be high in sodium. Read the labels!

Calcium
Prednisone may cause loss of calcium from your bones. To help prevent osteoporosis add at least 3 calcium rich low fat foods to your diet daily. You may need to take a calcium/vitamin D supplement to help prevent osteoporosis.

Fat and cholesterol
Prednisone, Cyclosporine/Neoral®, Prograf® and Rapamune® can result in elevated cholesterol and lipid (fat) levels in your blood.
The reason a low fat diet is so important is the dietary components known as cholesterol and fat can accumulate on the walls of your arteries (a process called arteriosclerosis). Arteriosclerosis can slow or stop the flow of blood to your heart, brain and legs. This can lead to heart attack and stroke. **Following a low cholesterol, low fat diet reduces your risk of developing heart disease.** In addition, it can help you maintain or achieve a desirable body weight after your transplant.

### LOW FAT/CHOLESTEROL AND LOW SODIUM FOOD LIST

**Milk/Dairy/Milk Alternate**

*Foods to choose:*
- Skim, 1/2%, 1% or evaporated skim milk
- Soy milk or soy yogurt
- Fat free or low fat: yogurt, sour cream, sherbert
- Low fat, low sodium cheese
- Low fat ice cream
- Lactose controlled milk/dairy products if needed

*Foods to limit:*
- Whole and 2%
- Buttermilk
- Eggnog
- Cream, Half & Half
- Regular cheeses, cottage cheese, sour cream and ice cream

**High Protein Foods**

*Foods to choose:*
- Egg whites, cholesterol free egg substitutes (Egg Beaters, Second Nature, Healthy Choice, Scramblers)
- Lean fresh or frozen meats: chicken, turkey, hen, fish, beef, tuna packed in water (and rinsed), pork tenderloin, London Broil
- Choose loin and round cuts
- Natural unsalted peanut butter, unsalted nuts/seeds
- *
- *Tofu, *dried beans and peas

*Foods to limit:*
- Egg yolks
- Processed, cured, salted, canned or smoked meats: ham, bacon, sausage, corned beef, salt pork, bologna, hot dogs, potted meat, sardines, anchovies
- Fried or breaded meat
- Regular peanut butter
- Salted nuts/seeds
**Vegetables**

*Foods to choose:*
- All fresh vegetables prepared without salt, smoked meats or butter/cream sauce
- “No added salt” frozen or canned vegetables
- Low sodium tomato or V8 juices
- *Broccoli, greens

*Foods to limit:*
- Vegetables prepared with salt, cured meats, butter, cheese or cream sauces
- Regular (salted) canned vegetables, tomato or V8 juice
- Pickles, olives

**Fruit**

*Foods to choose:*
- All fruit – fresh, frozen, canned, dried
- *Calcium fortified orange juice

*Foods to limit:*
- Fried fruit
- Fruit prepared in butter/cream

**Bread and Cereals**

*Foods to choose:*
- White, wheat, rye, Italian, pumpernickel and French bread
- Bagels, English muffins, grits, oatmeal, low fat muffins, rice
  pasta, dried beans, peas
- Unsalted soda and other crackers

*Foods to limit:*
- Croissants, biscuits, cornbread, sweet rolls, Danish, doughnuts
- Regular crackers (Ritz, Townhouse, Goldfish)
- Convenience rice, pasta and potato dishes (Hamburger Helper, Rice a Roni, Chef Boyardee)

**Fats**

*Foods to choose:*
- Canola, olive or peanut oils
- Diet tub margarine
- Low fat mayonnaise, sour cream or tartar sauce
- Unsalted nuts and seeds

*Foods to limit:*
- Butter, lard, bacon fat, salt pork
- Coconut, palm and palm kernel oils
- Regular salad dressing, sour cream or mayonnaise

*good source of calcium*
**Fluids**

It is important to drink plenty of fluids after a transplant to prevent dehydration. **You need at least eight (8 oz) glasses per day.** Any beverage that does not contain sugar, caffeine or alcohol counts towards your fluid intake.

*Good Fluid Choices:*
- Water, sodium free Seltzer water – flavored or plain
- Diet soft drinks
- Sugar free Country Time Lemonade or Crystal Light
- Sugar free Kool Aid
- Skim or 1% milk
- Apple, cranberry, and grape juices (limit to 4oz per meal)

**CONCLUSION**

Following the transplant’s team advice after transplantation is necessary to ensure the best outcome. In addition to taking your medications, it is also important to follow your new diet. As discussed previously, your new diet is designed to manage or decrease the risks associated with the side effects of your new medications.

The following guidelines are to be used immediately (for the first 6 weeks) after transplantation.
- High protein intake
- Limit concentrated sweets (if diabetic, follow diabetic diet guidelines)
- Moderate sodium restriction (less than 4,000 mg per day)
- Drink plenty of fluids, at least 8 glasses per day

**Long term after transplant**
- Low fat/low cholesterol
- Moderate sodium restriction (less than 4,000 mg per day)
RECIPE

Vegetable Soup
Serves 4; approximately 8 ounces per serving

1 tablespoon olive oil
1/2 cup chopped onions
1/2 cup diced celery
1/2 cup sliced carrots
1/2 teaspoon oregano
1/2 teaspoon thyme
2 cloves garlic, minced
4 cups low-sodium beef broth
Freshly ground black pepper to taste
1/2 cup cut fresh green beans
1/2 cup chopped fresh tomatoes

Place oil in a medium stockpot over medium heat. Add onions, celery, carrots, oregano, and thyme and sauté until soft, about 5 to 7 minutes. Add garlic and cook for another minute. Add beef broth, pepper and the rest of the vegetables. Simmer 30 to 45 minutes or until vegetables are soft.

Potato Salad
Serves 6

5 medium, red potatoes, cooked, peeled and diced
1/4 cup chopped celery with leaves
1/2 cup sliced radishes
2 green onions, diced
2 tablespoons mayonnaise
2 tablespoons plain nonfat yogurt
1 teaspoon dry mustard powder
1 tablespoon sugar
1/4 teaspoon turmeric
1/2 teaspoon celery seed (optional)
2 1/2 tablespoons white vinegar
3 tablespoons skim milk

Combine potatoes, celery, radishes and onions. In a separate bowl, mix together mayonnaise, yogurt, mustard powder, sugar, pepper, turmeric and celery seed. Add vinegar and milk and stir until mixed. Combine with potato mixture and stir well. Chill before serving.
**Reduced-Calorie Ranch Dressing**

Makes 1½ cups; serves 24; 1 tablespoon per serving

1 cup low-fat buttermilk  
1/2 cup plain low-fat yogurt  
1 tablespoon Dijon mustard  
2 tablespoons minced onion  
1 tablespoon fresh dill  
1 tablespoon chopped fresh parsley  
1/2 teaspoon garlic powder  
1/4 teaspoon freshly ground black pepper

In a jar with a tight-fitting lid, combine all ingredients. Shake well to blend. Refrigerate for at least 2 hours.

**Oven-Fried Fish**

*Serves 4*

Vegetable oil spray  
2 tablespoons acceptable margarine, melted  
1 tablespoon fresh lemon juice  
1/4 teaspoon freshly ground black pepper  
1/4 teaspoon paprika  
1/4 teaspoon basil  
1/8 teaspoon garlic powder  
1 pound fillet of flounder or other fish  
1/4 cup dry bread crumbs

Lightly spray a shallow baking dish with vegetable oil spray. Preheat oven to 475° F. Combine margarine, lemon juice, pepper, paprika, basil and garlic powder. Mix well. Dip fish in margarine-herb mixture and roll in bread crumbs. Arrange fish in a single layer in a baking dish. Spoon remaining margarine mixture over fish. Bake uncovered 15 minutes or until fish flakes easily with a fork. Do not overcook.

**Hash-Brown Potatoes**

*Serves 6*

1/4 cup acceptable vegetable oil  
1/4 teaspoon freshly ground black pepper  
1/8 teaspoon onion powder  
1/8 teaspoon garlic powder  
6 cups chopped or grated peeled potatoes  
1/4 teaspoon paprika

Heat oil, pepper and onion and garlic powders in a large, nonstick skillet over medium-high heat. Add potatoes and paprika. Cook until potatoes are crisp and browned, stirring frequently. Drain on paper towels and serve immediately.
**Spaghetti with Meat Sauce**

*Serves 6*

1 pound lean ground beef  
1 medium onion, chopped  
1 clove garlic, minced  
5 medium fresh tomatoes, peeled and chopped, or one 28-ounce can no-salt-added tomatoes, chopped  
1 6-ounce can no-salt-added tomato paste  
1/2 cup dry red table wine  
1/2 teaspoon oregano  
1/2 teaspoon basil  
1/2 teaspoon fennel seeds  
1/8 teaspoon freshly ground black pepper  
1 8-ounce package spaghetti

Brown ground beef in a large nonstick skillet. Pour off fat. Add remaining ingredients except spaghetti. Cover and simmer over low heat 1 1/2 hours, stirring occasionally. If sauce appears too thick, add water. Cook spaghetti according to package directions, omitting salt. Drain. Pour sauce over spaghetti and serve.

**Vegetable Medley**

*Serves 4*

1 tablespoon acceptable margarine  
2 medium yellow summer squash, diced  
1 medium zucchini, sliced  
1 medium yellow onion, diced  
3 medium fresh tomatoes, diced  
1/2 cup frozen corn  
1 clove garlic, minced  
1/2 teaspoon oregano  
1/2 teaspoon basil  
1/4 teaspoon freshly ground black pepper

In a large pan over medium heat, melt margarine. Add squash, zucchini and onion. Sauté 3 to 4 minutes. Add tomatoes, corn, garlic and seasonings and cook another 2 to 3 minutes. Serve immediately.
Apple Crisp

Serves 8

Vegetable oil spray
1 1/2 pounds (5 medium) apples, cored and sliced, unpeeled
2 tablespoons fresh lemon juice
1/4 teaspoon ground cinnamon
2/3 cup all-purpose flour
1/3 cup firmly packed brown sugar
1/3 cup uncooked oatmeal
1/3 cup acceptable margarine

Preheat oven to 375° F. Lightly spray a 2-quart casserole dish with vegetable oil spray. Arrange apples in prepared dish. Sprinkle with lemon juice and cinnamon. In a medium bowl, combine flour, brown sugar and oatmeal. Cut in margarine with a fork or pastry blender until mixture is crumbly. Spread over fruit. Bake 40 minutes or until apples are tender.
**Glossary**

**Acute Hepatic Failure (AHF)** – process of sudden dramatic decline in liver function. This may result from a variety of causes: drug reactions, alcohol/drug overdose, acute hepatitis A,B,C, or some unknown reason.

**Anesthesia:** medicine given by injection or mouth that causes partial or complete loss of feeling for a period of time, usually during surgery.

**Antirejection medicine:** (See immunosuppressants.)

**Antibiotics:** drugs taken to prevent infections and kill bacteria.

**Antihypertensive:** medicine that prevents or controls high blood pressure.

**Aspirin:** pain reliever taken by mouth; also helps to prevent blood clot formation.

**Ascites:** an abnormal accumulation of fluid in the abdominal cavity.

**Autoimmune hepatitis (AIH):** chronic and progressive condition in which the patient’s own immune systems attacks the liver causing inflammation and liver failure. The condition is chronic and progressive.

**Azathioprine:** immunosuppressive drug used mainly to prevent the body from rejecting an organ or tissue transplant. (See Imuran®.)

**Breast self exam:** monthly check of the breasts for lumps or tumors that could be cancerous.

**Cancer:** disease in which abnormal cells multiply out of control and disrupt normal cell or organ function.

**Cardiac catheterization:** a procedure in which a small tube is guided through a vein or an artery into the right or left side of the heart to check the function of the heart and the coronary arteries.

**Cardiologist:** doctor who studies and treats diseases of the heart.
Cataract: thickening of the eye lens in one or both eyes that impairs vision and often leads to blindness.

Catheter: tube, generally small and flexible, inserted into the body, to infuse medications, monitor organ function and drain fluid.

CellCept®: immunosuppressant drug used mainly to prevent the body from rejecting an organ or tissue transplant. (see also mycophenolate mofetil.)

Cervical cancer: cancer of the cervix.

Chemotherapy: the use of drugs to destroy cancer cells.

Cholesterol: fat substance found in animal meats, dairy products and produced by the liver; a high level of cholesterol in the blood is a risk factor for developing heart disease. Blood cholesterol can be elevated by cyclosporine.

Clinical nutritionist: specialist in selecting foods that repair or maintain the body.

Cytomegalovirus (CMV): a very common virus that usually causes a flu-like illness with fever, general body aches, and a decreased appetite which lasts two or three days.

Congenital: existing at birth.

Cyclosporine: drug that helps keep the body from rejecting a transplanted organ. Brand names include Neoral® and Gengraf®.

Dermatology: study and treatment of skin.

Diabetes: the body’s inability to control the amount of insulin or blood sugar it produces for energy.

Diastolic blood pressure: bottom number of the blood pressure reading that shows the amount of resistance in the blood vessels that the heart has to overcome.

Diuretic: medication that assists the kidneys in ridding the body of excess fluid.

Donor: person who gives an organ to be used in another person.
Echocardiogram: diagnostic test that uses reflected sound wave images to see the heart and provides information regarding the structure and function of the heart.

Edema: swelling of body tissue caused by fluid leaking from blood vessels.

Endotracheal tube: long tube used to provide an airway into the lungs. This tube is generally connected to a breathing machine.

ERCP: GI procedure used to visualize the biliary ducts from the “inside out”. Endoscopist places the tube down the patient’s throat and approaches bile duct from common duct

Fluid retention: condition in which the body stores excess fluid.

Foley catheter: tube inserted into the bladder to drain urine.

Gallbladder: organ that stores bile.

Gallstones: stones that form when the bile has too much cholesterol.

Glaucoma: eye disease in which increased pressure on the eyeball damages the optic nerve and eventually can lead to blindness.

Heart monitor: a device that records and displays information about the heart, including condition and number beats.

Hepatitis A Virus (HAV): virus that attacks the liver, usually transmitted through sea food contamination; vaccination against available.

Hepatitis B Virus (HBV): virus that attacks the liver, obtained through sex with someone who is infected, blood transfusions, IV, sharing tattoos; may be vaccinated against prior to infection

Hepatitis C Virus (HCV): virus that attacks the liver, obtained through blood transfusions, needle sharing, tattoos; not thought to be sexually transmitted; no vaccine available;

Hepatocellular carcinoma (HCC): liver cancer; may be contraindication for transplant if tumor is too large or numerous

Idiopathic: arising from an unknown or obscure cause.
Immune system: your body’s natural defense system against foreign invaders such as viruses, bacteria, some types of cancers, and sometimes transplanted organs or tissue.

Immunization: giving antibodies or other agents to protect against disease.

Immunosuppressants: drugs that help treat or prevent the immune system from rejecting an organ or tissue transplant.

Immunosuppression: process of preventing the body’s immune system from rejecting an organ or tissue transplant.

Imuran®: immunosuppressive drug used mainly to prevent the body from rejecting an organ or tissue transplant.

Infection: condition in which the body is invaded by a disease-causing micro-organism.

Intravenous (IV): a catheter (small tube) inserted into a vein so that fluid, blood or medicine can be received.

Jaundice: yellow/green/gray coloration of skin; usually corresponds to increasing serum bilirubin; may or may not be accompanied by pruritus.

Lab draw: process of taking blood or urine for laboratory analysis.

Laboratory (lab): place where blood and specimens are studied and identified.

Laxative: food or chemical substance that acts as a stool softener.

Lesion: injury or wound to skin or tissue.

LifeLink: organization which matches organs and tissues with potential recipients.

Liver biopsy: a small sample of liver is extracted with a needle placed either through the abdominal wall and into the liver or through the jugular vein down into the liver.

Mammography: screening process for early detection of breast cancer.
Medic Alert: nonprofit organization that provides a bracelet or necklace with your personal medical information which can be used by medical personnel in case you have a car accident or other type of emergency.

Mg: milligram, dosage used commonly in medications.

Mycophenolate mofetil: generic trade name for the drug CellCept®. (See CellCept®.)

Mycostatin®: trade name for the drug Nystatin. (See Nystatin.)

Mylanta: common over-the-counter drug used to relieve upset stomach.

Neoral®: (See cyclosporine.)

Non alcoholic steatohepatitis: liver disease that is characterized by increased deposition of fat in the liver, eventually inhibits ability of liver to function.

Norvasc®: drug used to prevent heart spasms and lower blood pressure.

Nystatin: antifungal agent used to prevent infections.

Ophthalmologist: physician who studies and treats the eye.

Orthotopic liver transplant (OLT: old diseased liver is removed & new liver from other source replaced in same location.

Osteoporosis: condition where the body loses bone mass; this can lead to bone fractures and disk breakdown in the spine.

Pap smear: test in which cells from the vagina and cervix are collected then analyzed to detect cancer.

Pathologist: specialist who diagnoses abnormal changes in tissue removed during an operation.

Pneumococcal: bacterial microorganism which causes pneumonia.

Pneumonia: infection of the lungs.

Post-transplant: after transplantation.
**Pravachol:** drug that lowers cholesterol.

**Prednisone:** medication used to limit rejection of a transplanted organ or tissue.

**Pre–transplant:** before transplantation.

**Primary Biliary cirrhosis (PBC):** a chronic disease that causes a progressive destruction of bile ducts in the liver.

**Primary Sclerosing Cholangitis (PSC):**

**Prograf®:** (See tacrolimus.)

**Prostate:** gland around the neck of the bladder and urethra in males that secretes ejaculatory fluid.

**Prostate-specific antigen (PSA):** special blood test recommended for men over the age of 50 to screen for prostate cancer.

**Psychiatric clinical nurse specialist:** nurse specially trained to help you and your family deal with behavioral and mental issues such as stress, anxiety, depression and addiction.

**Psychiatrist:** physician who diagnoses and treats mental disorders.

**Ranitidine:** (See Zantac®.)

**Rectal:** lower part of the colon or large intestine.

**Rejection:** condition in which recipient’s body rejects tissue or organ transferred from a donor.

**Sclerosing Cholangitis:** a disease in which the bile ducts become narrowed from inflammation and scarring.

**Split Liver:** a whole liver is split between two persons usually an adult and child.

**Status:** patient’s current condition.

**Systolic blood pressure:** amount of force used by the heart to eject blood out of the heart; “systolic” refers to the top number read as part of blood pressure.
**T-tube:** a tube placed in the bile duct that allows bile to drain into a bag outside the body.

**Tacrolimus:** drug the helps keep the body from rejecting a transplanted organ. Brand name is Prograf®.

**Testicular:** Relating to the male reproductive glands that produce reproductive cells and the hormone testosterone.

**Tetanus:** infectious disease that causes painful muscle contractions; also known as lockjaw.

**Transplant coordinator:** specially trained, registered nurse who coordinates care for patients before and after transplantation.

**Transplant surgeon:** highly trained doctor who performs the transplant operation.

**Transplantation:** transfer of living tissue or organs from one person to another.

**Ultrasound:** device that uses ultrasonic waves to outline the shape of various tissues and organs of the body.

**UNOS:** United Network for Organ Sharing, a national agency that maintains a national computerized transplant waiting list and helps locate donor organs.

**Vaccination:** injection that builds your body’s resistance to an infection.

**Ventilator:** mechanical device which controls and monitors flow of air to the lungs.

**Vital signs:** temperature, pulse, respiration and blood pressure.

**Zantac®:** drug used to treat stomach problems like peptic ulcers and heartburn.
Mason Guest House

The Mason House is a private retreat that offers low cost housing for organ transplant candidates, recipients, living donors and families. Guests who book one of the 15 bedrooms, each with a private bath, will find a comfortable bed-and-breakfast environment. In addition, a two bedroom suite is available with it's own kitchen, living area and private entrance. Several bedroom and bathrooms are wheelchair accessible. Continental breakfast is provided, but guests may cook their own meals. Other amenities include laundry facilities, TV’s in the gathering rooms, private phones, a VCR, stereo and a computer. The Mason House is a home-away-from-home, created to make transplant candidates, recipients and their families feel far away from a hospital environment, yet close enough to feel secure should they need medical assistance. Please call 404-712-5110 for reservations.

THE MENTOR PROJECT

What is the Mentor Project?

The Mentor Project provides one-on-one contact between people living successfully with a transplant and people who are new to the world of transplantation. The project pairs a “veteran” organ transplant recipient, primary caregiver or living donor with someone who is waiting for a transplant, a recent transplant recipient, family members of a transplant recipient or a living kidney or liver donor. Through these connections, even the smallest questions get answered, experiences are shared, and support is provided to both patients and families.

Who are mentors?

Mentors are organ recipients, parents or other supporting family members and living donors who are at least six months out from their transplant date or the transplant date of their loved one. Mentors attend a full day of training to learn how to draw on their personal experiences to address the needs of others that they mentor. Mentors are updated periodically on services and assistance available to transplant families within the transplant community, and the mentor network is an excellent connection to these resources.
How do I get a mentor?

If you live in Georgia, you can be referred to the Mentor Project by your social worker, transplant coordinator, clinical nurse specialist or physician. A mentor is never assigned without the consent of the potential mentee. Georgia residents may also call the Mentor Project and request a mentor directly.

For more information about the Mentor Project contact the Georgia Transplant Foundation at 1-866-(GATX411) or 770-457-3796.

JOBLINK

A career development and return-to-work program for transplant recipients in the state of Georgia

JobLink is an assistance program that helps Georgia transplant recipients and candidates return to the work environment. JobLink offers needed information and training in order for the transplant recipient to reach career goals.

The objective of JobLink is to provide transplant recipients and candidates a quick and successful re-entry into the work force. Skilled placement specialists evaluate work needs and provide both necessary skills training and access to the appropriate vocational and rehabilitation services.

JobLink offers access to the state’s vocational rehabilitative services and provides a comprehensive return-to-work program at no cost to you. The return-to-work program can be the link that completes the goal of transplantation in returning recipients to a productive lifestyle.

Services include:

- Career interest testing and development
- Assistance with Social Security issues
- Information on state vocational rehabilitation services
- Job skills training
- Resume development and interview techniques
- Job placement
- Early return-to-work programs
- Americans with Disabilities Act (ADA) awareness
- Post-placement intervention to ensure success
- Enrollment in Ticket to Work program

For more information, call 770-457-3796 or 1-866-428-9411. Your transplant social worker also will be happy to assist you with a referral.
TRANSPLANT CENTER AND EUH PHONE NUMBERS

Pre-transplant 404-712-7731 or 888-295-8907
Post-transplant 404-712-4981 or 888-295-8909
Pre-transplant fax 404-712-2769 or 404-712-5811
Post-transplant fax 404-712-5658
2D Outpatient Clinic 404-712-5676 or 888-727-9370
Fast Track Admissions 404-686-5270 or 800-640-9293
Mason Guest House 404-712-5110

HELPFUL RESOURCES AND WEB SITES
FOR THE LIVER TRANSPLANT PATIENT

Emory Transplant Center
www.transplant.emory.edu

Georgia Transplant Foundation
www.gatransplant.org
770-457-7396

LifeLink of Georgia
www.lifelinkfound.org
404-266-8884

National Transplant Foundation
www.transplants.org
1-800-489-3863

Transplant Recipients International Organization, Inc.
www.trioweb.org
1-800-874-6386

TransWeb
www.transweb.org
734-998-7314

United Network For Organ Sharing (UNOS)
www.unos.org
1-888-894-6361

Coalition on Donation
www.donatelifedr.net
American Liver Foundation
www.liverfoundation.org
1425 Pompton Avenue
Cedar Grove, NJ 07009
(201) 256-2550
(800) 223-0179

Substance Abuse & Mental Health Services Administration
www.samhsa.gov
(800)662-4357

The American Heart Association
www.heart.org
www.megaheart.com (ways to decrease fat and cholesterol in diet)
www.heartinfo.com (ways to decrease fat and cholesterol in diet)
www.tppp.net (general transplant info)
www.tppp.net/pdfs/diet_n_exercise/diet_n_exercise_esp.pdf
(Spanish material for diet and exercise)
www.tppp.net/pdfs/diet_n_exercise/diet_n_exercise_txt.pdf
(English material for diet and exercise)
www.transplantawareness.org/resources.html
(Nutrition following transplant info)

Cookbooks
• “501 Delicious Heart Healthy Recipes”
• “AHA Around the World Cookbook”
• “AHA Low Fat and Luscious Desserts”
• “AHA Low fat, Low Cholesterol Cookbook”
• “AHA Meals in Minutes Cookbook”
• “AHA Quick and Easy Cookbook”
• “George Foreman’s Big Book of Grilling, BBQ and Rotisserie”
• “The New AHA Cookbook” 6th edition
Notes