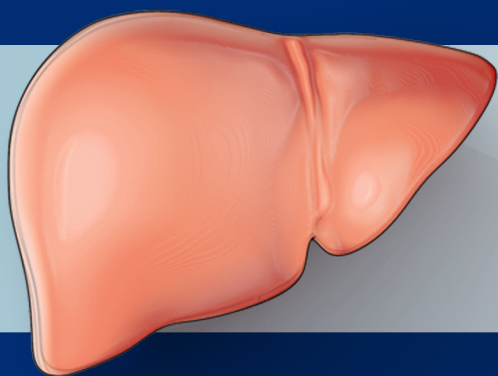


# Emory Liver Transplant Program

*Journey to Transplantation*



**BEFORE YOUR TRANSPLANT**

**EMORY**  
TRANSPLANT CENTER

Making a difference in the lives  
of our patients and our community.

# WELCOME TO EMORY TRANSPLANT

We are happy to have you and look forward to participating in your care. If you have any questions, please ask any member of your Emory Transplant Team.

## Meet Your Transplant Team

My Liver Specialist: \_\_\_\_\_

RN Transplant Coordinator: \_\_\_\_\_

LPN Transplant Coordinator: \_\_\_\_\_

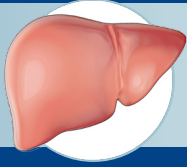
Transplant Secretaries: \_\_\_\_\_

Transplant Social Workers: \_\_\_\_\_



Questions? Here's that one perfect number:

**855-366-7989**



# Understanding the Transplant Process

☎ 1-855-EMORYTX (366-7989)  
🌐 [emoryhealthcare.org/transplant-liver](http://emoryhealthcare.org/transplant-liver)  
🏠 Clinic B, 6th Floor, Suite 6400

Welcome to the Emory Transplant Center. Over the next couple of days, different members of the Transplant Team will evaluate you and determine if a liver transplant is a good option for you. During this time, you and your family may have questions about the evaluation and what to expect when it is over. We are here to answer your questions.

If you have any questions about the process, please ask your nurse coordinator.

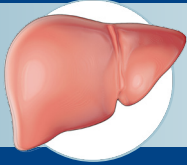


## Meet Your Team

A team of doctors and specialists will educate you and evaluate you over the next couple of days. The **purpose of the evaluation is to see how damaged your kidney is and to help the team decide whether kidney transplantation is the best option for you.** There are several steps in the process. The first stage involves meeting with the transplant team. They will perform medical tests and give you information on financial, nutritional, social and emotional issues.



- **Physicians** -surgical and medical physicians from different specialties
- **Pharmacist** - clinicians who provide information on medications including drug interactions and side effects
- **Financial Coordinators** - team member who will explain your insurance benefits and help you understand the cost of transplant
- **Liver Transplant Coordinators** - nurses who give education on transplant and help guide you throughout the process
- **Dietitian** - team member who will explain food restrictions, answer your questions about diet, and help you make healthy choices
- **Chaplain** -interfaith transplant chaplain can help you and your family deal with conflicting emotions and difficult spiritual questions
- **Psychiatry** - providers and physicians who evaluate the mental and emotional health of patients
- **Social Workers** - clinicians who will help you with your social support and developing a plan of care



# Understanding the Transplant Process

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## Your Evaluation

The evaluation is essential to your transplant experience. It will include a series of medical tests, imaging tests, and consultations with our trained team members. You are expected to show up to all the scheduled appointments. After the evaluation, your case will be discussed by the team and a decision will be reached. **For more information on the evaluation and the decision-making process, please refer to the Transplant Coordinator Guide.**



## After the Evaluation

If you meet the medical, surgical, psycho-social, and financial criteria, you will be approved for listing on the waiting list. The next step, if needed, will be to get approval from your insurance company. Our financial coordinator will supply your insurance company with the information they need.

Once you have financial approval, you will need to get one more blood test and your name will be added to the waiting list. Your time on the waiting list will be determined by your MELD score. To find out more about the MELD score, please refer to the Transplant Coordinator Guide.



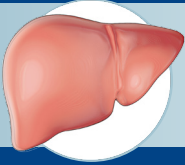
## On the Waiting List

When you are on the waiting list, you will need to give us reliable phone numbers so that you can be reached. **Make sure the number is up-to-date and that your voice-mail is setup.** You do not want to miss the call! Be sure to let us know if your number changes.

While waiting for the transplant make sure you **continue to take care of yourself.** This means that you should continue to see your doctor. Make sure you continue to take your medications. You will be asked to attend a support group session for continued education and support. Remember, the healthier you are before transplant, the more successful your transplant will be!



When you are on the waiting list, you need to remain in close contact with your transplant team. Let your nurse coordinator know of any changes in your health.



# Understanding Your Transplant Evaluation

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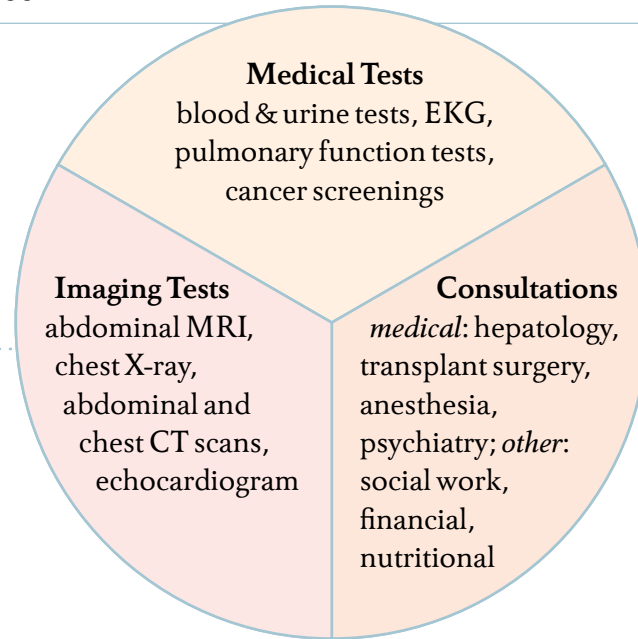
## Your Evaluation Process

### Step 1

A team of doctors and specialists will meet with you and perform some medical tests. They will also meet with you to discuss financial, nutritional, social and emotional issues. These **tests and consultations** will let the team know if a transplant is the best option for you.

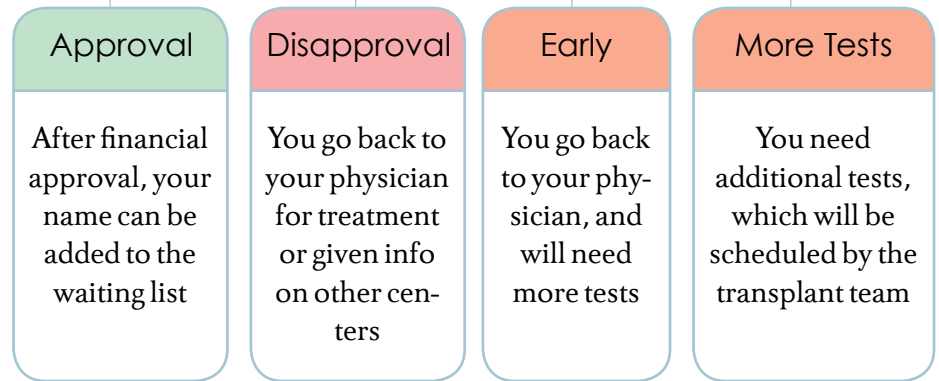
### Step 2

After the evaluation, your case will be presented at the **Liver Selection Committee Meeting**. The physicians and the rest of the transplant team with at clinic will discuss your case. A **decision** will be made and we will let you know the outcome by phone and letter.



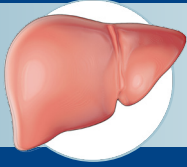
### Committee Meeting

Possible Decisions:



Financial approval from your insurance company.

There are many factors that affect the decision for your transplant. One of them is the **MELD** score. MELD is a scoring system that stands for Model for End-Stage Liver Disease. It ranges from 6 to 40. This score is **calculated using different values from your lab tests and is used to evaluate your priority for transplant**. Ask your transplant coordinator how you can calculate your MELD score. It is used by the United Network for Organ Sharing (UNOS), which is a national agency that regulates transplantation.



# Understanding Your Transplant Evaluation

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Once you are approved by the transplant team and have financial approval from your insurance company, a transplant nurse coordinator will call you and you will need to get your blood drawn. This will give you an updated MELD score. Your priority for transplant is based on this score.



## After the Evaluation

If you meet the medical, psycho-social, and financial criteria, you will be approved for listing on the waiting list. The next step will be to get approval from your insurance company. Our financial coordinator will supply your insurance company with the information they need. Then, the insurance company will make a decision.

Once you have financial approval, you will need to get one more blood test and your name will be added to the waiting list. Your time on the waiting list will be determined by your MELD score.



## On the Waiting List

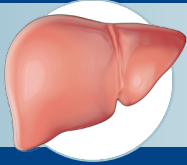
When you are on the waiting list, you will need to give us reliable phone numbers so that you can be reached. **Make sure the number is up-to-date and that your voice-mail is setup.** You do not want to miss the call! Be sure to let us know if your number changes.

While waiting for the transplant make sure you **continue to take care of yourself.** This means that you should continue to see your doctor. Make sure you continue to take your medications. You will be asked to attend a support group session for continued education and support. Remember, the healthier you are before transplant, the more successful your transplant will be!



If you have any questions, please ask your nurse coordinator.

Notes: \_\_\_\_\_  
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## Public Health Service (PHS) Increased Risk Donor Organs

### Increased Risk Information

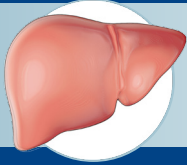
Nearly 25% of organ donors are at increased risk for spreading infections such as hepatitis or HIV. According to the U.S. Public Health Service guidelines, a donor is of increased risk if:

- a medical/social history cannot be obtained, or
- he or she has kidney disease and needed chronic dialysis in the year before death, or has taken human clotting factor for clotting disorders, or
- he or she did certain behaviors before death, such as:
  - used IV drugs, or
  - spent time in jail for longer than 72 hours, or
  - had sex for money/drugs or sex with someone who did drugs within the last 12 months
- the donor is a man who has had sex with other men in the past five years.

All donors are tested for hepatitis B, hepatitis C, and HIV prior to organ offers. There is a very small chance that the donor has HIV or hepatitis, even with negative test results. In some cases, the test results are positive. Those organs may be transplanted depending on the wait listed patient's test results and primary disease.

If you are offered a PHS risk organ, the coordinator or transplant doctor will share with you the donor's PHS risk status. You will learn the donor's test results and the transplant doctor or one of his/her team will discuss the risks and benefits of accepting the organ. **In general, our doctors believe that the potential benefit of accepting a PHS increased risk organ is higher than the risk of getting an infection from a donor.** However, you, not the doctor, will make the final decision to accept or turn down the offer. If you decide not to accept the organ offer, it will not affect your status on the waitlist.

If you accept the organ, for safety purposes, certain blood tests will be performed during the first year of transplant. The tests are to monitor for HIV and hepatitis infections. Depending on the organ to be transplanted, you also may need to take medication to prevent or treat an infection, should one occur.



# Understanding the Cost of Your Transplant

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Getting a transplant is an expensive process and it is important to plan for the upcoming costs. Your **transplant financial coordinator is here to answer questions the about your costs and insurance coverage**. They will help you identify the resources that are available that can help you have a successful transplant.

This guide will help you understand the different costs and provide resources on how to plan. Please ask your financial coordinator if you have any questions or concerns.



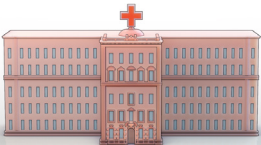
## Costs of Transplantation

Getting a transplant is **long-term commitment**. There are immediate costs, but also continuing costs needed to care for your transplant. Since your financial situation may change with time, it is important to plan ahead for all the costs and let your transplant team know if changes in your insurance coverage occur. Some of the different costs of transplant include:

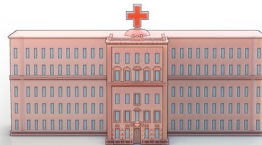
### Short-Term Costs

### Long-Term Costs

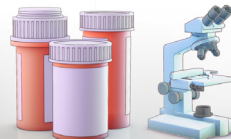
#### Hospital Charges



#### Clinic Charges



#### Medications/Labs



#### Parking/Transportation



## Payment Options

Since transplant is an expensive process, it is important to plan for the costs. It is unlikely that one single source will cover everything.

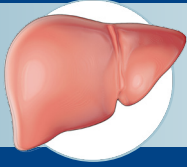
Options for payment include:

- . Insurance - employer group coverage, COBRA
- . Medicare/Medicaid - covers partial costs only
- . Outside Support and Fundraising - family, friends and community support
- . Personal Savings

### Keep Us Informed

You need to let your transplant financial coordinator know if your insurance coverage changes or if you have problems paying for your medicines.





# Understanding the Cost of Your Transplant

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Changes to your insurance coverage **can affect your ability to pay for medicine**. This will become vital to your transplant success! Use the Drug Expenses Worksheet to determine your cost of medicine. Remember that this will be an on-going cost.



## Insurance and Medicare

Many costs of transplant will be covered by your insurance company. Before your transplant, it is important to work with your insurance provider to understand your benefits. Here are some sample questions to ask:

### Be sure to consider:

What are my specific benefits for transplantation? What are my deductibles, co-payments, lifetime and annual maximum benefits for medical coverage and transplant?

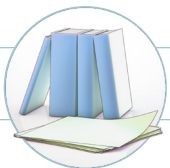
Are outpatient prescription drugs covered, specifically immunosuppressant medications (such as **Prograf**, **Cellcept**) and **Valcyte**? How much out-of-pocket expense will there be?

Are there transportation or lodging benefits during my transplant care?

Is there an approval process for transplant, outpatient office visits and medical services? If so, how long does this take once submitted?

Is organ acquisition and living donor coverage provided? If so, is there a limit?

Remember that even with Medicare and insurance, there will be out-of-pocket expenses.



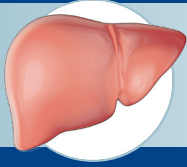
## Other Resources

There will be costs that are not covered by private insurance or Medicare. These include things such as parking, transportation, lodging, medication co-pays and deductibles.

If needed, there are resources that can help with fundraising. Outside resources such as the **Georgia Transplant Fund** and **HelpHOPELive** can help as well. It can be helpful to have a family member or friend coordinate this effort. Please ask your Transplant Financial Coordinator for more information.



Let us know if any changes to your insurance occur or if you have trouble paying for your medicines.



# Planning for Your Critical Drug Expenses

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This is a "**Drug Expense Worksheet**" for estimating your critical drug expenses for the first six months post-transplant. Please work with your Transplant Financial Coordinator to complete the worksheet. If your expenses estimate is over \$3,000 you will also need to complete the "**Drug Expense Plan**" stating how you plan to cover these expenses and submit to your Transplant Financial Coordinator for approval.



## Drug Expense Worksheet

Patient Name: \_\_\_\_\_ Date: \_\_\_\_\_

Health Coverage: \_\_\_\_\_

List any *new* drug-related expenses you will have in the *first six months* post-transplant:

### Insurance Premiums for Drug Coverage

Secondary, supplement or part D: \_\_\_\_\_

Other \_\_\_\_\_

Please include the cost of insurance premiums that you are not currently paying but expect to pay after transplant to keep drug coverage. This includes premiums for supplemental insurance that is currently being paid by the American Kidney Fund that they will no longer pay after transplant.

### Drug Expense (out-of-pocket)

Prograf (tacrolimus) 5mg, twice a day\* \_\_\_\_\_

Prograf (tacrolimus) 1mg, 4 pills, twice a day\* \_\_\_\_\_

Cellcept (Mycophenolate mofetil/MMF) 1,000mg, twice a day \_\_\_\_\_

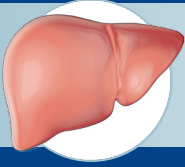
Valcyte (valganciclovir) 450mg, once a day (for 3 months) \_\_\_\_\_

Other \_\_\_\_\_

Please fill in your out-of-pocket cost for each of the medications listed. Contact your drug plan to find out your cost. If you have drug coverage other than Medicare, please contact your insurance company to confirm any co-payments, co-insurance or deductible amounts. If you have Medicare, examples are attached.

Total Insurance Premiums and Drug Expense \_\_\_\_\_

Remember, this is only an estimate of the new drug-related expenses you will have post-transplant.



# Planning for Your Critical Drug Expenses

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## Drug Expense Plan

Patient Name: \_\_\_\_\_ Date: \_\_\_\_\_

Health Coverage: \_\_\_\_\_

Transplant Financial Coordinator Name: \_\_\_\_\_

Phone: \_\_\_\_\_

Fax: \_\_\_\_\_

I know that I must tell my Financial Coordinator of any changes to my health plan coverage to avoid delays and expenses.

I know that I will need at least \$\_\_\_\_\_ to pay for six months of drugs and/or drug coverage post-transplant.

If this amount is over \$3,000, I must have a plan for meeting these expenses approved by my Transplant Financial Coordinator in order to be listed for transplant.

My plan is (please attach and supporting documentation):

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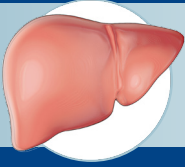
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Patient's Signature \_\_\_\_\_ Date \_\_\_\_\_

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Transplant Financial Coordinator's Signature \_\_\_\_\_ Date \_\_\_\_\_



# Your Emotional Health and Support During Transplant

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Going through a transplant will significantly affect your life. The impact of the changes can be overwhelming for both you and your loved ones. This guide will discuss some these changes and provide resources for the questions you may have.

Your **Emory social worker** is here to help you understand the changes and help you find ways to deal with the new situations that you face in your day-to-day life. They can guide you to community and hospital resources that **will give you information on financial, social, and emotional support.**



## Financial Support

Getting a transplant is an expensive process. There are immediate costs, but also long-term costs needed to care for your transplant. Since your financial situation may change with time, **it is important to plan ahead and let your transplant team know if any concerns arise.**

Ask your social worker if you have any concerns about your financial support. It is important to have a plan to pay for on-going expenses, such as medicine. Some examples of things they can help you with are listed below.

### Things to Discuss:

Notes: \_\_\_\_\_

- How am I going to pay for my medicine?
- My health insurance has changed or is ending. What do I do? I can't pay my insurance premium payment and I need help.
- I need help finding a job. Are there resources for vocational training or planning?
- Are there community resources that can give me financial support?

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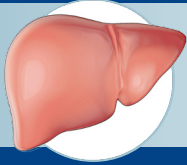


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Call your social worker to discuss any questions you may have about your insurance or any financial concerns.

Main: 404-712-4366



# Your Emotional Health and Support During Transplant

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## Social Support

Getting a transplant can be a stressful time. While you get back to your normal lifestyle, there will be some ups and downs. Your life has changed and it can be difficult for you and your loved ones to cope with the changes.

Your social worker can help you through these changes. They will provide you with counseling services and any additional resources that will help you feel better. Some examples of things they can help you with are listed below.

### Identify a Support Team:

It is helpful to have a reliable support team that can help you throughout the transplant process. Find people who can:

- Help you with everyday activities at home
- Take you to and from appointments
- Help you keep track of your medicines
- Provide financial help

### Helpful Hint

Talk to your team and ask for help. Here are some of the hospital resources available to help you:

- Transplant psychologist
- Hospital chaplain
- Mental health social worker

Notes: \_\_\_\_\_

\_\_\_\_\_

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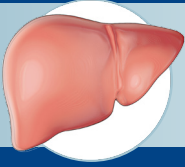
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# Your Emotional Health and Support During Transplant

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## Emotional Support

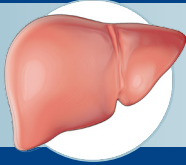
You will experience a lot of emotional ups and downs during your transplant journey. After the surgery is over, you will feel relieved, but remember that **your life will be different**. It will take time to get back to your normal life. You will be at a high risk for complications and keeping a positive outlook will impact your overall health and improve your chances of success.

Your social worker can help you find resources in your community to help with the whole process of transplantation. Meet people who are waiting for transplant and those who are living successfully with a transplant. Sharing your story or expressing your concerns can help make a difference for people who are going through similar experiences. Some helpful resources are:

Resources		
Emory Transplant Support Group	Meets 3 <sup>rd</sup> Monday of each month at 1pm	
Georgia Crisis and Access Line	<a href="http://www.myGCAL.com">www.myGCAL.com</a>	800-715-4225
Substance Abuse and Mental Health Services Administration	<a href="http://www.samhsa.gov">www.samhsa.gov</a>	877-726-4727

Notes: \_\_\_\_\_  
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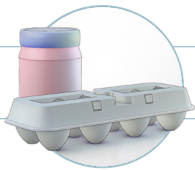


# Understanding Your Nutrition After Transplant

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After your transplant, it is important to have healthy eating habits and a regular exercise program. Your diet will manage or prevent side effects of your new medicine. Following these tips will help you heal properly from surgery and promote long-term health.

Your diet plan will depend on factors such as your blood pressure, weight, and other conditions. Your dietitian will help you with any questions you have about your diet. The following sections will cover the different areas of your diet.



## Protein

It is important for you to eat an adequate amount of protein. During the first month after transplant, you need extra protein to prevent muscle breakdown and to provide the building blocks to help you recover from surgery.

Your daily goal:      8 oz. for the first month

6 oz. per day long term

### Good Protein Sources




## Fluids

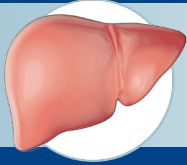
You need to drink plenty of fluids after your transplant to **prevent dehydration**. This means at least eight glasses per day (this is the same as 2 Emory cups).



**Water is the best choice.** Other good fluid choices are:

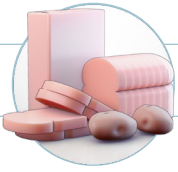
- Sodium-free seltzer water; flavored or plain
- Diet, caffeine-free soft drinks
- Sugar-free powdered lemonade, iced tea
- Sugar-free Kool-aid
- Skim or 1% milk
- Apple, cranberry and grape juice (4 oz. per meal)
- Decaffeinated coffee or tea (caffeine should be limited to 1-2 cups per day)





# Understanding Your Nutrition After Transplant

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## Carbohydrates (sugar and starches)

A side effect of some of your medicine is an increase in blood sugar levels. This can lead to diabetes. If an increase occurs, it is important to limit your sugar intake.

If you are already diabetic, please refer to the diabetic guidelines.

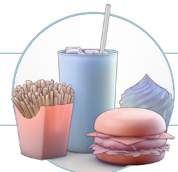
Foods to Avoid



## Sodium

Your medicine can cause swelling and give you high blood pressure. Your sodium intake should be limited to less than 2300 mg per day.

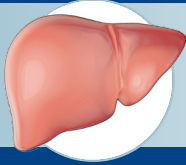
Fast food and packaged foods usually contain a lot of sodium. Avoid eating these types of food. Read labels and try to pick foods that are low in sodium (less than 140mg per serving).



## Fats and Cholesterol

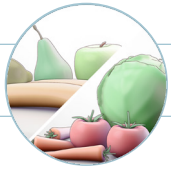
A low fat, low cholesterol diet is important because it can lower your risk of heart disease. It will help you keep a healthy body weight after your transplant.

Refer to the Heart Healthy Guide for some helpful tips.



# Understanding Your Nutrition After Transplant

☎ 1-855-EMORYTX (366-7989)  
🌐 [emoryhealthcare.org/transplant-liver](http://emoryhealthcare.org/transplant-liver)  
🏠 Clinic B, 6th Floor, Suite 6400

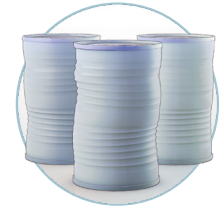


## Food Safety

After a transplant, you have a higher risk of infection, including food-borne illnesses. Since poor food handling causes most food-borne illnesses, you should follow these guidelines:

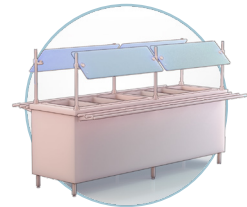
### Shopping for Food:

- Check expiration dates. Avoid products with a “SELL BY” or “BEST USED BY” date that has already passed.
- Avoid buying products with damaged packaging, such as dented cans.



### Eating Out:

- Order cooked foods and well-done meat and fish.
- Avoid eating raw oysters, fish, clams, sushi, and sashimi.
- Avoid eating from salad bars and buffets.



### At Home:

- Rinse fruits and vegetables before eating.
- Keep shelves, counter-tops, refrigerators, freezers, utensils, sponges, and towels clean.
- Do not use wooden cutting boards; use plastic boards instead because they are easier to clean.
- If you use a cutting board to cut meat, wash it with hot and soapy water and rinse before using again.
- Date and refrigerate leftovers right away, and only keep them for 48 hours. Heat leftovers before eating.



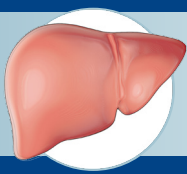
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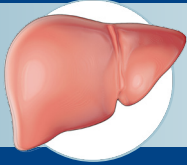


# Understanding Your Nutrition After Transplant

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## Your Guide for Heart-Healthy Eating

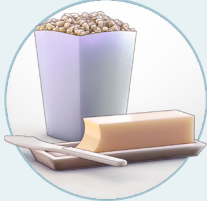




	Foods to Choose	Foods to Limit
Milk (3 cups/day) 	Skim, 1% milk Evaporated or powdered skim milk Low-fat or fat-free yogurt Chocolate milk with less than 1% fat Low-sodium buttermilk Fat-free cream or fat-free half and half	Whole or 2% milk and buttermilk Eggnog, malted milk Milkshakes Whole, chocolate or evaporated milk Sweetened, condensed milk Sour cream
Protein (4-6 oz/day) 	Lean, fresh or frozen meats Low sodium canned fish in water Natural peanut butter (no salt added) Low-fat or fat-free cheese Egg whites or egg substitutes Tofu, dried beans and peas Frozen dinner with less than 30% of calories from fat and 600mg sodium per serving	Fatty, cured, salted meats Regular canned tuna or salmon Fried or breaded meats Regular peanut butter or cheese More than 3 egg yolks/week Processed, convenience food Deli meats Fried or breaded meats
Fruits (2 or more servings/day) 	All fruits and fruit juices Calcium fortified orange juice	Fried fruits Fruit pie If diabetic, avoids syrups
Vegetables (3 or more servings/day) 	Fresh vegetables without salt Low sodium frozen or canned vegetables Low sodium tomato or vegetable juice	Vegetables with salt, bacon, or cream Fried or regular, canned vegetables Frozen vegetables in sauce Sauerkraut Pickles or vegetables in brine
Carbohydrates (6 or more servings/day) 	Pasta, rice, and potatoes Homemade cooked cereals Dried beans and peas Unsalted crackers, Melba toast Dry cereals Low sodium instant cooked cereals Calcium fortified products	Pasta/rice with butter, cream or fats Croissants and biscuits Sweet rolls, danish, donuts Quick breads Instant mixes or cooked cereals Salted crackers, pretzels, popcorn Self rising flour, regular baking soda



# Understanding Your Nutrition After Transplant

1-855-EMORYTX (366-7989)  
[emoryhealthcare.org/transplant-liver](http://emoryhealthcare.org/transplant-liver)  
 Clinic B, 6th Floor, Suite 6400

## Your Guide for Heart-Healthy Eating

	Foods to Choose	Foods to Limit
Fat (3-6 tsp/day) 	Margarine (no hydrogenated oils) Butter blended with canola/olive oil Low-sodium, low-fat salad dressing, mayonnaise, sour cream, gravy Unsalted nuts or seeds Vegetable oils (no palm or coconut oil)	Salted stick margarine or butter Regular salad dressing, sour cream, gravy Bacon fat, salt pork, lard Snack dips with cheese or buttermilk Salted nuts or seeds Chitterlings, olives
Sugar (limit if you have diabetes) 	Sugar, honey Pure maple syrup Jams or jellies Sugar substitutes	Blackstrap molasses Commercial pancake syrup Light and dark corn syrup
Snacks/Desserts (limit if you have diabetes) 	Fruit ice, sorbet, sherbet, flavored gelatin Fat-free frozen yogurt, pudding, ice cream Homemade bakery items with low-sodium and low-fat ingredients Jellybeans, marshmallows, hard candies Snack foods without hydrogenated oils	Desserts made with salt, baking powder baking soda and self-rising flour Desserts made with whole milk Instant pudding, gourmet frozen yogurt Commercial cake mixes Packaged peanut butter, snack foods with hydrogenated oils Coconut
Soups 	Low-sodium bouillon or broth Low-sodium, low-fat commercial soups Homemade soup without salt or high-fat	Regular bouillon or broth Regular commercial soup Reduced sodium or creamed soups Instant soup mixes
Beverage 	Most beverages in moderation including water, soft drinks, juice, tea, or coffee	Commercially softened water Sport drinks No alcoholic beverages



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# 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)
- Decreased energy and fatigue
- Mental confusion which may progress to coma



# 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, financial coordinators and pharmacists who are all experienced in treating patients with advanced liver disease. This group is well qualified to perform the sophisticated, life-saving surgical 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. 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. A urine test tells us if your kidneys are working well and if you are using illicit drugs. The following tests and procedures MAY be done:

- Chest X-ray
- Electrocardiogram (EKG)
- CT scan/MRI scan of the abdomen
- Doppler ultrasound of the liver (looks at blood flow through the vessels to your liver)
- Dobutamine Stress Echocardiogram or “stress test” (looks at blood flow through the heart and the valves of your heart).
- Endoscopy/Colonoscopy (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.



My social worker is:

My financial coordinator is:

**FINANCIAL QUESTIONS?**

Call the financial coordinator at 1-855-366-7989.

**DISABILITY QUESTIONS?**

Call the social worker at 1-855-366-7989.

**REMEMBER:** Bring to your evaluation a copy of your benefits for liver transplantation, including deductible and co-payment amounts.

**Social Workers**

Clinical social workers play a vital role in assessing your psychological needs, social support, and developing a comprehensive post transplant plan of care. Your social worker will assist you throughout the phases of your transplant process from pre-liver transplant to post-liver transplant. The transplant social worker is also a viable resource in brokering community recourses, advocating for patient care needs, and providing supportive council and guidance. Your social worker also plays a significant role in the Liver Transplant Selection Committee in assessing if a liver transplant is the best treatment option for you.

**Financial Coordinators**

A financial coordinator will be assigned to you to help explain your insurance benefits and assist you with any financial issues. The financial coordinator will help you understand the cost of transplantation and your health 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**

**Financial Planning and Insurance Authorizations**

Planning for the costs associated with liver transplantation is an important way to minimize stress and remove barriers to a successful transplant. The following information will help you begin financial planning for transplant. Your transplant financial coordinator can help you.

**During your evaluation**

During your evaluation you will meet with your financial coordinator and discuss how you can plan financially for a successful transplant. You will need to know how much of the cost of the liver transplant and the medications you will need to take after transplant your insurance company will cover and how much you will have to pay out-of-pocket based on your plan. It is unlikely that one single source will cover these out-of-pocket costs. Often it is necessary to draw on savings accounts, investments, public and private assistance options and fundraising.

To get started, please contact your insurance company to ask them about your liver transplant benefits including deductibles, co-insurance and co-payment amounts (below are a list of questions that can help guide you). Your insurance company may also assign a case manager specifically to your case to facilitate authorizations and follow your care throughout the process. If you are covered by Medicare, refer to the current Medicare handbook for deductibles, co-insurance and co-payment amounts. Please bring this information in with you to discuss with your financial coordinator.



Most insurance companies require a review of your evaluation results to see if you meet their criteria to pay for a liver transplant. 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 to be listed for transplant.

**Emory Healthcare bills**

The Emory Transplant Center on Emory University Hospital’s campus (ie. the main clinic on Clifton Rd), on Emory Saint Joseph’s campus, and on Candler Hospital’s campus in Savannah, Ga, are all hospital-based clinics and are billed to insurance companies as “outpatient hospital services.”

You will receive separate bills from the Emory Clinic and Emory Hospitals.

If you have questions about a statement received, the best place to start is to call the phone number on the top of the statement. If you would like to sit down with someone to review your account or make a payment, there are representatives from both the Emory Clinic and Emory Hospital available to meet with in person.

For reference, the main phone numbers for the billing departments are:

Emory Clinic Billing Customer Service: 404-778-7310

Emory University Hospital Billing Customer Service: 404-686-7041

If you aren’t able to resolve your issue directly with the respective billing office, please call the Emory Transplant Center at 1-855-366-7989 and ask to speak with the Transplant Billing Coordinator.





Every effort will be made to find a donor quickly. The wait for a donor 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.

### **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. It will be your responsibility to set up air transportation with a special air ambulance if necessary. Please talk to your coordinator to set up a transportation plan.

### **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 are support groups available to you and your family that we can provide for you.

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.

*Liver transplantation puts great demands and stress on recipients and their families. Call on the transplant team to help.*

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. If you have known malignant tumors in your liver, we will scan your liver every 3 months or as directed by our team. 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 soon as possible.

A vertical column of horizontal lines for writing, starting with a thick black header bar at the top. The lines are evenly spaced and extend from the top of the page down to just above the footer.

# Going to the hospital

## THE PHONE CALL

When a donor liver becomes available, a transplant coordinator will call you. Please ensure we have at least two working numbers listed for you. Also, please make sure that your mailbox is not full. 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 go 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 University 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.

*Do not have anything to eat or drink except sips of water with your routine medicines after we call you for transplant.*

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 an incision in your abdomen to remove your liver and replace it with your new one. 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 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. Hand washing 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 bed rest. This helps to prevent the formation of blood clots in your legs.

**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.

You will probably look different to your family: you will be pale, possibly swollen and will 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 one 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.

**EXERCISE AND ACTIVITY**

You should begin to increase your physical activity soon after your surgery. A physical therapist will be available to 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.



**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*

**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 anti-bacterial 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.
- The transplant center does not have a requirement for antibiotic prophylaxis before dental and oral procedures; these medications may be given at the discretion of your treating provider.

**HYPERTENSION/HIGH BLOOD PRESSURE**

Many transplant recipients take medications to control hypertension or high blood pressure since prednisone and Prograf, 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. We will 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.

## **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), eyes, and nervous system.

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 US Department of Health and Human Services, the US Public Health Service, 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.



**IMPORTANT:**

**Do NOT take cyclosporine or Prograf the morning before your blood draw.**

**You can take these medications the night before like you normally do and then take them again AFTER your blood draw.**

**TIPS FOR TAKING**

**MEDICATIONS:**

- *Know the medicines that you are taking.*
- *Tell the transplant coordinator if you experience any unusual 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 two doses, notify the transplant coordinator.*
- *Bring a list of your medications including their frequency and doses each time you see a health care professional.*
- *No grapefruit or pomegranate juices.*

# 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 caregiver about all your medications. We will review with you the purpose, dosage and possible side effects of each medicine.

All transplant patients take immunosuppressants. The following pages explain what's important to know about these medicines. You may also be placed on additional medications for a brief period of time other than these after transplant as a precaution to fight common viral illnesses. 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

For the first month after your transplant surgery, we will utilize a specialty pharmacy to deliver your first month supply of medications to your inpatient room prior to discharge. After this time you may continue to use the specialty pharmacy, use a pharmacy in your hometown or use a mail-order pharmacy to obtain your medications. Please try to plan ahead and make arrangements before transplant.

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.

If you would like help finding a pharmacy, please let the coordinator know. He or she can give you phone numbers to call. If you need help with the cost of medications, you can contact your social worker for available resources.

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

## 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 to reduce the risk of rejecting 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, anti-rejection drug that comes in 0.5 mg, 1 mg, and 5 mg capsules.

*Special instructions:*

- Must be taken every 12 hours.
- Take after blood is drawn on lab days.
- Avoid grapefruit and pomegranate

*Common side effects:*

- Shakiness, headache
- Kidney damage
- High blood pressure, high blood sugar, high cholesterol

**Cyclosporine (Neoral or Sandimmune®)** – an anti-rejection drug that comes in 25 mg, 50 mg, and 100 mg capsules.

*Special Instructions:*

- Must be taken every 12 hours.
- Take after blood is drawn on lab days.
- Avoid grapefruit and pomegranate.

*Common side effects:*

- Kidney damage
- Acne, hair growth in unwanted areas, gum problems

**Mycophenolate Mofetil (CellCept® or MMF)** – an anti-rejection drug that is taken along with another immunosuppression medication.

*Special instructions:*

- Must be taken every 12 hours

*Common side effects:*

- Diarrhea
- Low white blood cell count (increased risk infection)

**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.

*Special instructions:*

- Take with food
- Taken once a day

*Common side effects:*

- Stomach upset
- High blood sugars, high blood pressure, high cholesterol

**Everolimus (Zortress), Sirolimus (Rapamune)** – anti-rejection medications that some patients with renal dysfunction or some types of cancers may take

*Special instructions:*

- Take after blood is drawn on lab days
- Avoid grapefruit and pomegranate

*Common side effects:*

- Delayed wound healing
- Mouth ulcers
- Rash

### **Anti-Infection Drugs (prophylaxis)**

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

*Special instructions:*

- Generally prescribed for the first three months after transplant.

**Bactrim (Septra®, Sulfatrioxazole, sulfamethoxazole/trimethoprim), Mepron (Atovaquone), Pentamidine, and Dapsone** – used to prevent a life-threatening pneumonia called pneumocystis (PCP).

*Special instructions:*

- If you are allergic to Sulfa drugs you will be prescribed Mepron, inhaled Pentamidine or Dapsone.
- Taken for six months.

**Nystatin** – drug used to prevent and treat fungal infections of the mouth (thrush).

*Special instructions:*

- Nystatin is taken four times daily for three months after transplant.
- Shake liquid well before taking.
- Do not eat or drink for at least 15 minutes after using.



## Other Helpful Information

### MASON GUEST HOUSE

The Mason House is a private retreat that offers low cost housing for organ transplant candidates, recipients 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 wheel- chair 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-to-one contact between people living successfully with a transplant and people who are new or adjusting to the world of transplantation. The Mentor Project has trained mentors (recipients, living donors, spouses, parents of pediatric recipients, and other family members) who have a desire to help support others through the transplant process. All organ groups, living donors, and each Georgia transplant center are represented in The Mentor Project. Mentors provide hope and encouragement, share their personal experiences, and most importantly, they're good listeners. They offer support on an as-needed basis from a simple phone call to a hospital visit to personal meetings. Unlike a support group, in a mentoring relationship real life experiences are shared and even the smallest questions get answered privately and confidentially.

#### 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 or are a client at a Georgia transplant center, you can be referred to the Mentor Project by your social worker, transplant coordinator, transplant clinic professional or physician, or you can simply request a mentor

by contacting GTF directly. Mentors and mentees are matched by common experiences and situations. For example, transplant center, type of organ, and if possible, age, location, and medical history are all considered when selecting your mentor. All information you share or discuss with a mentor is confidential. Mention to a member of your transplant team that you'd like to talk with a mentor. Or, contact GTF directly by completing the "I would like to request a mentor" online form or calling the office at 770-457-3796 or toll free at 1-866-428-9411.

## **JUMPSTART**

Since health care benefits are an important factor in post-transplant health, the Georgia Transplant Foundation (GTF) makes it a priority to support clients in finding permanent positions with medical insurance benefits. In an effort to achieve that goal, GTF is pleased to offer JumpStart. JumpStart helps organ transplant candidates, recipients, and their families accomplish career goals through its accredited employment services, strategic partnerships and educational resources.

### **JumpStart services**

Services available through JumpStart include referrals to career development services; one-on-one coaching; educational resources and training; and financial evaluation. JumpStart also offers assistance in identifying career options, job readiness for the interview workshops, and defining job search techniques. Other informational resources are also available.

While JumpStart is not a placement service, it does provide clients with the tools necessary to prepare them for employment. All services are customized for the organ transplant community and are tailored to meet the specific needs and career level of each client.

### **Strategic partnerships**

JumpStart partners with the Georgia Vocational Rehabilitation Agency and works with community resources that provide information about health insurance, Social Security benefits, government assistance and legal needs. The program also offers clients referrals to short-term educational and training resources in areas like computer skills, customer service and income tax preparation."

For more information, call The Georgia Transplant Foundation at 770-457-3796 or 1-866-428-9411. Your transplant social worker also will be happy to assist you with a referral.

**EMORY TRANSPLANT CENTER PHONE NUMBERS**

Pre-transplant .....1-855-366-7989  
Post-transplant.....1-855-366-7989  
Post-transplant fax ..... 404-712-5658  
Pre-transplant fax..... 404-778-6875  
Referral fax..... 404-712-2769  
B6400 Outpatient Clinic .....1-855-366-7989  
Fast Track Admissions ..... 404-686-5270 or 800-640-9293  
Mason Guest House..... 404-712-5110

**HELPFUL RESOURCES AND WEB SITES**

**Emory Transplant Center**

emoryhealthcare.org/transplant  
1-855-366-7989

**Georgia Transplant Foundation**

gatransplant.org  
770-457-7396

**Help Hope Live**

helphopelive.org  
800-642-8399

**Children’s Organ Transplant Association** (also help adults with certain genetic diseases)

cota.org  
800-366-2682

**Transplant Living** (patient education site from UNOS)

transplantliving.org

**LifeLink of Georgia**

lifelinkfound.org  
770-225-5465

**National Foundation for Transplants**

transplants.org  
1-800-489-3863

**Transplant Recipients International Organization, Inc.**

trioweb.org

1-800-874-6386

**TransWeb**

transweb.org

734-936-4000

**United Network For Organ Sharing (UNOS)**

unos.org

1-888-894-6361

**American Liver Foundation**

liverfoundation.org

1-800- 465-4837

**American Organ Transplant Association**

aotaonline.org

713-344-2402

**Substance Abuse & Mental Health Services Administration**

samhsa.gov

1-877-726-4727

**The American Heart Association**

americanheart.org

megaheart.com (ways to decrease fat and cholesterol in diet)

heartinfo.com (ways to decrease fat and cholesterol in diet)

**Air Charity Network (patient travel assistance)**

aircharitynetwork.org

**Angel Flight**

angelflightsoars.org

**Mercy Medical**

mercymedical.org

**National Patient Travel Center**

patienttravel.org





# Notes

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