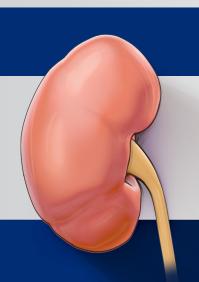
Emory Kidney Transplant Program

Journey to Transplantation



BEFORE YOUR TRANSPLANT



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



Understanding the Transplant Process

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- moryhealthcare.org/transplant-kidney
- (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 kidney 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
- Physician Assistant/Nurse Practitioner providers of the transplant team who may obtain your medical history, perform your physical exam and supervise your transplant evaluation under the supervision of a licensed physician
- 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
- Pre Transplant Coordinators nurses who give education on transplant and help guide you before your transplant
- 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
- Waitlist Transplant Coordinators nurses who give education on transplant and help guide you as you wait for your transplant
- Social Workers clinicians who will discuss your recovery needs after transplant and encourage you to make a plan to meet those needs





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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 Evaluation 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, your name will be added to the waiting list. If there are any changes to your insurance during this time, let your financial coordinator know. For more information on the waitlist, please refer to the Transplant Evaluation Guide.



Transplant Options

Kidneys for transplant come from two sources: living donors and deceased donors.

Living Donor

Kidneys come from family members, spouses, or friends, who are at least 18 years of age.

With a living donor, the long-term success is better. The wait time is also lower. As soon as you and your donor are approved, the transplant can take place.

Deceased Donor

Kidneys come from people who have died and donated their organs for transplant.

The waitlist for a deceased donor kidney is much longer, usually 4-5 years, and increasing with time.

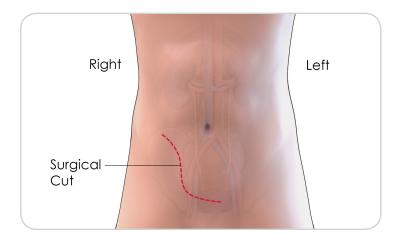


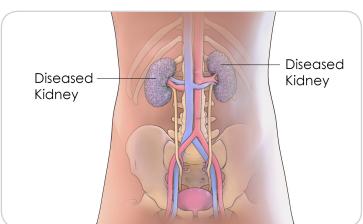


Understanding Your Transplant

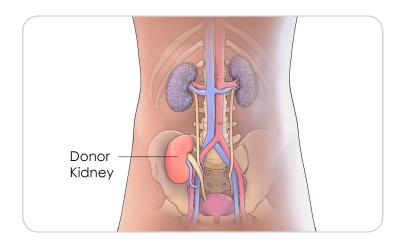
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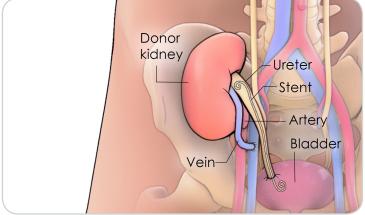
Before Transplant





After Transplant









Questions/Notes

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Your Evaluation Process

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
Become an active member of the team. Stay in touch with your coordinator. Collect and share your prior medical history with your care team.

After the evaluation, your case will be presented at the Kidney 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.

Medical Tests blood & urine tests, EKG, cancer screenings

Imaging Tests abdominal imaging, chest X-ray, and cardiac testing Consultations medical: transplant nephrology, transplant surgery, cardiology, other: social work, financial, nutritional

Possible Decisions:

Approval

After financial approval, your name can be added to the waiting list

Disapproval

You go back to your physician for treatment or given info on other centers

More Tests

You need additional tests, which will be scheduled by the transplant team and then will be approved or disapproved

Financial approval from your insurance company.

Committee Meeting





Understanding Your Transplant Evaluation



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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, your name will be added to the waiting list. If there are any changes to your insurance during this time, let your financial coordinator know.



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. If you receive a message from us, you need to call back within 1 hour or we will move to the next person on the list. 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. Remember, the healthier you are before transplant, the more successful your transplant will be!



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

Keep Us Informed

While waiting be sure to inform the waitlist team with any changes in your:

- · Health status
- · Dialysis clinic information
- · Changes in the way you do dialysis
- Phone numbers or address changes
- · Any changes in your insurance information





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:











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:

- $\cdot In surance employer group coverage, COBRA, individual policy \\$
- · Medicare/Medicaid
- Fundraising and community support
- Personal Savings
- Friends and family

Keep Us Informed

You need to let your transplant financial coordinator know if your insurance coverage changes.





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. It is important to **work with your insurance provider to understand your benefits and costs after transplant**. Here are some sample questions to ask:

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

Are outpatient prescription drugs covered, specifically tacrolimus, mycophenolate, and valganciclovir? What is the cost of monthly belatacept infusions that will be given in transplant clinic? 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 Foundation** (for Georgia residents only) 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	
List any new dr	Patient Name: Health Coverage: rug-related expenses you will have in the first six months post-	
Insurance Pi	remiums for Drug Coverage Secondary, supplement or part D: Other	pay after transplant to keep drug
Prog Progr Cellcept (1	se (OUt-Of-pocket) graf (tacrolimus) 5mg capsule, 1 capsule twice a day raf (tacrolimus) 1mg capsule, 4 capsules twice a day mycophenolate) 500mg tablet, 2 tablets twice a day Valcyte (valganciclovir) 450mg tablet, 1 tablet daily Nulojix (belatacept) 750mg infusion, monthly Other	your cost. If you have drug coverage other than Medicare, please contac your insurance company to confirm any co-payments, co-insurance or deductible amounts. If you have
Total Insurar	nce Premiums and Drug Expense	Remember, this is only an estimate of the first six months of new drug-related expenses you will have post-transplant.





Planning for Your Critical Drug Expenses



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Drug Expense Plan Date: Patient Name: 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): Patient's Signature Date

Date



Transplant Financial Coordinator's Signature



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?	
· What are my plans for managing my other transplant related costs (clinic copays, gas, parking, meals) while I am	
at the hospital?	





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

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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	
Georgia Crisis and Access Line	www.myGCAL.com	800-715-4225
Substance Abuse and Mental Health Services Administration	www.samhsa.gov	877-726-4727
Georgia Transplant Foundation Mentor Program	www.gatransplant.org	770-457-3796 or 866-428-9411

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

Your diet plan will depend on factors such as your blood pressure, weight, blood sugar and blood fats level as well as other conditions you may have. Your dietitian will help you with any questions you have about your diet. The following sections cover different diet instructions that you may need to follow as part of your nutrition regimen. Your dietitian will be able to instruct you on which of these instructions you need to follow as well as answer any questions you may have about your diet.



Protein

It is important for you to eat an adequate amount of high quality protein every day. Your protein needs depend on your height & weight as well as other factors such as your nutrition status.

During the **first month after transplant**, you need to pay special attention to eating a high protein diet to prevent muscle breakdown and to provide the building blocks to help you heal from surgery.

In the long term, you'll need to reduce your protein intake to a more moderate amount to maintain health and wellness.

Recommended protein sources

- · Lean meat/poultry/fish
- · Low fat & fat-free dairy products
- · Nuts & nut butters
- · Cooked dried beans



Fluids

You need to drink plenty of fluids after your transplant to **prevent dehydration**. For most people, this means drinking at least eight 8 oz. glasses per day. Your Emory cup holds 4 cups of fluid. (I measuring cup= 8 oz.)



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

- · Non-fat or 1% milk
- · Sodium-free seltzer water; flavored or plain
- · Diet and caffeine-free soft drinks
- · Sugar-free lemonade, iced tea lemonade/iced tea/fruit flavored drinks
- · Apple/ cranberry/grape juices in moderation
- · Mostly decaffeinated coffee or tea





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Carbohydrates (sugar and starches)

A side effect of some of your medicine is an increase in blood sugar levels, or even diabetes. If your blood sugar level is elevated, it is important to limit your sugar intake and monitor your overall carbohydrate intake. Choose mostly whole grain products and other high fiber foods. If you already have diabetes, please refer to the diabetic diet guidelines.



Sodium

Your medicine can cause swelling and cause you to have high blood pressure. The American Heart Association 2013 "guidelines to manage high blood pressure" advises that sodium intake should be limited to no more than 2,400 mg per day. Choose mostly foods that are fresh, seasoned with little or no salty seasonings or if packaged, are low in sodium.



Fats and Cholesterol

Following a diet low in fat and cholesterol is important because it can help lower your risk of heart disease. It can also help you maintain your weight in a healthy range after your transplant. When eating out, look for the "American Heart Association Diet and Lifestyle Recommendations" logo on menus. This certifies that the meal contains less than 800 Mg Sodium and less than 26 Gm fat.



Phosphorus

Some people experience loss of phosphorus for a period of time after transplant. You may need to follow a high phosphorus diet.

Good sources includes: high protein foods (meat/ chicken/fish), dairy products, nuts, dried beans and whole grain products.

Potassium

Some people experience high potassium levels after transplant due to some of the medications. You may need to follow a low potassium diet. You may need to limit certain fruits and vegetables.

Calcium

Your steroid medication can lead to bone loss over time. You need to choose high calcium foods every day; otherwise your doctor may recommend a supplement. Practicing weight bearing exercises a few times a week can also help you maintain your bone density in order to reduce your risk of fractures.





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Food Safety

After transplant, your medications suppress your immune system; this means you have an increased risk of infection, including food-borne illnesses. Since poor food handling causes most food-borne illnesses, you need to follow food safety guidelines at home, when shopping for food and while eating out.

General tips:

- · Maintain a clean kitchen and cooking equipment
- Wash produce before eating; do not eat foods that are near or already "expired"
- · Stay away from products with damaged packaging
- Meat and fish should be well-done/ leftovers heated thoroughly;
- Stay away from raw fish/shellfish/sushi/osyters as well as salad bars and buffets







Helpful Resources

American Heart Association www.heart.org

Healthy Diet www.choosemyplate.gov

Food Safety www.fightbac.org

www.foodsafety.gov

American Association of Kidney Patients www.AAKP.org

National Kidney Foundation www.kidney.org

National Kidney Disease Education Program www.nkdep.nih.gov





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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 Low-fat almond, cashew, or soy milk	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)	High fiber and whole grain products 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	





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Your Guide for Heart-Healthy Eating			
	Foods to Choose	Foods to Limit	
Fat (3-6 tsp/day)	Margarine (no hydrogenated oils) Butter blended with canolalolive 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 with minimal salt and fat	Regular bouillon or broth Regular commercial soup Reduced sodium or creamed soups Instant soup mixes	
Beverage	Most beverages including water, soft drinks, juice, tea, or coffee	Commercially softened water Sport drinks Alcoholic beverages	





Questions/Notes

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