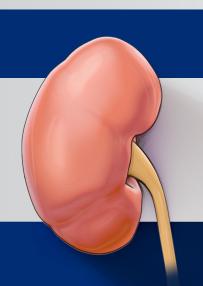
Emory Kidney Transplant Program

Journey to Transplantation



AFTER YOUR TRANSPLANT



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



Contacting the Transplant Team









How to get in touch with the Transplant Team

The Transplant Center is open Monday through Friday from 8 AM to 5 PM. Calls received after hours will be transferred to the Clinic Operator who will page the on-call clinician or physician.



1-855-EMORYTX (366-7989)

Call this number for:

- Appointments
- Nurse Practitioner/Transplant Coordinator
- Medication Refills

In case of emergency, call 911.

Fast Track: 404-686-5720 or 800-640-9293 Monday through Friday, 7am to 7pm Saturday, 8am to 4pm Call this line to register your insurance

Social Worker: 404-712-4366 Monday through Friday, 8am to 5pm Ask for the Kidney and Pancreas Social Worker.

information prior to a scheduled appointment.



Emory Transplant Center Website:

www.emoryhealthcare.org/transplant-kidney

Patient Portal Website:

www.emoryhealthcare.org/patient-portal

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Temperature of 100° F or greater	Feeling unusually tired
Blood Pressure greater that 170/100 for two readings in a row	Pain, tenderness or swelling in the area of the new kidney
Weight gain of more than 3 pounds in a day or 5-7 pounds in a week	Increased pain, redness, or pus-like drainage at the incision
Cough, shortness of breath, sore throat, chills	Persistent headache or flu-like symptoms
Nausea, vomiting, or stomach pain	Any unexplained rash, sores, or bruising
Diarrhea	Swelling of the hands, feet, or ankles
Decreased appetite	Unable to take medications for any reason
Blood in the urine or bowel movements, painful urination	Anything that concerns you about your health

You should call the Transplant Team if you experience any of these symptoms, or any time anything about your health changes, even if it is not related to your transplant.





Understanding Possible Complications After Transplant

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People who receive a transplant may develop complications after their surgery. Your nurse coordinator and transplant team will help you understand the warning signs of possible complications, discuss your care, and recommend further treatment when necessary. This handout will list and explain the different complications.

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



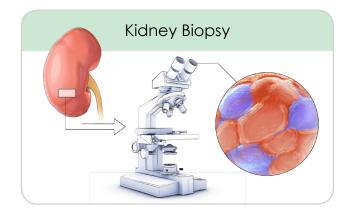
Rejection

Rejection occurs when your immune system recognizes the transplanted kidney as foreign and attacks it. You may feel good and have no symptoms, yet still be experiencing rejection. An increase in your serum creatinine or an increase in protein in your urine may be warnings of rejection. Most rejection episodes can be treated successfully with medication, especially if detected early.

The only way to know whether you have rejection is through a **kidney biopsy**. During a biopsy, some cells will be taken from your body and looked at under a microscope. This will be done by a transplant nephrologist in the Emory Clinic. After the biopsy, there is a 4 hour recovery. If you have a biopsy done, you will need a driver to take you to and from the clinic.

The biopsy will let the transplant team know:

- $\cdot \ How well your transplanted kidney is working$
- Find out if and why the kidney is working poorly





Infection

The immunosuppresant medicines you are taking decrease the risk of rejection; however, they also increase your risk of infection. The risk is highest during the first few weeks after your transplant.

Signs of infection include:

- · Fever, chills, sore throat
- · Nausea, vomiting, diarrhea
- · Wound redness, swelling, or pus
- · Pain or burning with urination

How to avoid infection:

- · Wash your hands frequently
- · Avoid contact with people who have infections like colds or the flu
- · Clean cuts and scrapes with soap and water
- Avoid sharing utensils or drinking from the same container





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Acute Tubular Necrosis

Acute tubular necrosis, or ATN, is the medical term for a transplanted kidney which is slow to function. This condition is sometimes called a 'sleepy kidney,' If this happens, you may need dialysis to give the kidney time to heal.



High Blood Pressure

Your blood pressure measures how much force your heart uses to pump blood to your body. Some immunosuppressants can raise blood pressure; therefore, some people must take additional medications to control their blood pressure. Notify the team if your blood pressure goes above 170/100 for two readings in a row.



Post-Transplant Diabetes

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



Blood pressure and diabetes can be managed and treated by healthy eating. Refer to the **Nutrition Guide** for some helpful tips!



Viral Infections

There are two common types of viruses that are checked for during your blood tests. These are the *Cytomegalovirus* (CMV) and the *Polyoma BK virus*. These are common viruses that people are exposed to.

The CMV virus causes flu-like symptoms, such as fever, body aches and decreased appetite. The immunosuppresant medicine you take gives you a higher risk of getting infected with CMV. If you or the donor has CMV antibodies, you will get antiviral medicine after transplant.

The BK virus has non-specific symptoms. Because of this, the lab tests and blood work will let your Transplant Team know if you have the virus.





Understanding Possible Complications After Transplant

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Lymphocele

A lymphocele (*lim-fo-seal*) is a collection of lymph fluid around the kidney. Signs and symptoms include swelling of the leg where the transplanted kidney is located or swelling over the kidney. If a large amount of fluid collects around the kidney it can cause unwanted pressure on the kidney and ureter. If this happens, the lymph fluid will need to be drained.

Notes:	





Your Guide to Staying Healthy After Your Transplant

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Now that you have had your transplant, we encourage you to resume your normal activities as much as possible. It is important to take care of yourself so that you and your kidney will remain healthy.

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



Your Daily Routine

Keeping a daily routine of checking vital signs and recording your weight is important. You should also develop a schedule for taking your medicines. By maintaining a plan you will be able to detect post-transplant problems early.

Use the **Daily Records** to help you keep track of your vital signs and weight. Ask your nurse coordinator for help in filling it out.

Your Daily Records					



Taking Care of the Wound

Your incision, or wound, is closed with stiches under the skin. The skin is then glued together. To take care of it, you should shower with soap and water.

- Do not use tub baths, go swimming until your incision as healed (usually 1 month).
- · Call if there is redness, pus, pain, or the skin edges open.



Your Medicines

You may be on numerous medications after the transplant. Your nurse coordinator and pharmacist will work with you to make sure you are comfortable taking all your medicines. Do not take any new medicines without checking with someone from the Transplant Team. For a list of approved over-the-counter medicines, refer to the **Medication Guide**.





Your Guide to Staying Healthy After Your Transplant

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Routine Medical Care

Routine medical care is important for early detection and treatment of disease. The transplant team is specialized in caring for the unique health needs of transplant patients; however, you should regularly see your primary care physician for regular check-ups.



Skin care:

- . Your medicines can cause changes in the skin and put you at a higher risk for skin cancer.
- . Use sunscreen (SPF above 30) anytime you go outside in the sun.
- . Wear a hat that will shade your face and neck.
- . You should see a dermatologist within the first year and then once a year afterwards. Get lesions (skin damage) checked by a physician.



Immunizations:

- . Do not get any immunizations for the first 3 months.
- . Do not ever get a live virus vaccine.
- . Get your flu shot every year.



Dental Care:

. Do not get routine dental work for $6\,months.$ After that you can go back to a regular schedule.



Nutrition, Exercise, and Activity

In order to heal properly and stay healthy, a good diet and exercise plan is very important. You should drink at least 64 ounces of water each day. Water is the best choice. If you do not drink, then you will be dehydrated and your creatinine levels will rise. For a full list of good fluids and foods, please refer to the Nutrition Guide.

- . You should walk 3 times a day. Start slowly and slowly build up.
- . Do not perform twisting exercises (such as golf or tennis) for the first 3 months.
- . Do not lift more than 20 pounds, until 6-8 weeks after your surgery.

Do not drive for the first 3-4 weeks. You must be off of your pain medications.

You may be around pets, but do not change litter boxes or get any new birds.





Your Guide to Staying Healthy After Your Transplant

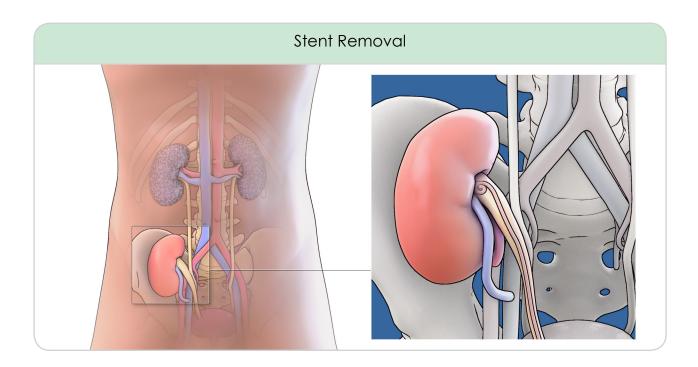
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Stent Removal

What is a ureteral stent?

Your donated kidney came with its own ureter, which is connected to your bladder. To allow this attachment site time to heal, a temporary stent was placed at this attachment site. A stent looks like a thin, hollow straw, which is curved at each end.



How is the stent removed?

About six weeks after your surgery, your stent will be removed by a procedure called a cystoscopy. This is a short procedure. This will be performed in the Urology Clinic by a urologist at Emory.

You will receive a letter from the department of urology with the date and time of your appointment.

Where is the Urology Clinic?

The clinic is located in the Emory Clinic Building B. You will need to go to the Endoscopy desk on the first floor.





Understanding Your Schedule After Transplant

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After transplant, you are beginning a new phase of your journey. Before you go home, your Transplant Team will meet with you and your family to let you know what you need to do to take care of yourself and your new kidney. As part of the support, your nurse coordinator will give you a schedule after transplant. **Your schedule will include both short-term and long-term steps**. This handout will give you an overview of these steps.

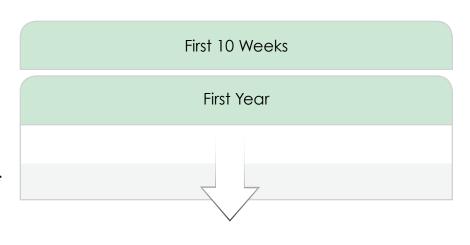
Be sure to call if anything about your health changes, even if it is not related to your transplant.



Your Schedule

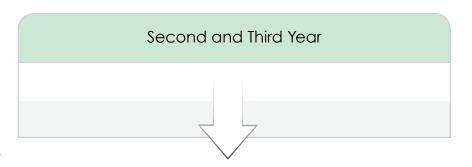
Short-Term Plan

The first year after transplant will be challenging, but rewarding. You will be coming to the clinic for lab tests and doctor's appointments, which will help the Transplant Team make sure you and your kidney are healthy. It is important that you develop routines for taking care of yourself too. As always, be sure to call if your health changes. We are here to help, and want to make sure you are doing well!



Long-Term Plan

After the first year, you will be coming to the Emory clinic less often and you will be able to see your local healthcare team more. During this time, it is important to maintain your health and continue taking your medicines. This will help you and your kidney stay healthy. As you get further along, the Transplant Team will help you setup the transition to your long-term healthcare team.







Understanding Your Schedule After Transplant

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Notes:

Going home after your transplant is very exciting. For the first few weeks though, you will be coming in often for follow-up appointments and lab tests. You will be able to ask questions and talk to your transplant team. Your nurse coordinator will give you a schedule for the first year. This handout will provide an overview of your treatment plan.

Be sure to call if anything about your health changes, even if it is not related to your transplant.



Your Schedule: First 10 Weeks

First 10 Weeks					
Week 1					
Week 2					
Week 3					
Week 4		9			
Week 5					
Week 6	△ Em	* Stent removed			
Week 7					
Week 8		En Doctor visit			
Week 9	<u>s</u>	Belatacept			
Week 10	₹	infusion			

Remember to plan ahead! Make sure you have a way to get to and from your appointments. Also, parking can become expensive. Let your transplant team know if there are any problems getting to your appointments.





Understanding Your Schedule After Transplant

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Notes:

During the first year after your transplant, it is important to take good care of yourself. You will still be coming to the clinic often for lab visits and doctor's appointments. This will help to keep you and your new kidney healthy. This handout will provide an overview of your first-year treatment plan.

Be sure to call if anything about your health changes, even if it is not related to your transplant.



A Typical Schedule: First Year

The First Year					
Month 3		* Bone density scan to be scheduled			
Month 4					
Month 5					
Month 6					
Month 7					
Month 8					
Month 9					
Month 10		Lab visit Doctor visit			
Month 11		Belatacept			
Month 12		infusion			
Schedule a local dermatology visit within the first year.					

It is important to keep track
of your vital signs (weight,
blood pressure, temperature,
and blood sugar) at home.
Bring your records with you
when you come for your visits

Remember to plan ahead! Make sure you have a way to get to and from your appointments.





Understanding Your Schedule After Transplant

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After your first year post-transplant, it is important to maintain your health. If you keep a good routine of checking your vital signs and taking your medications, you will have a better chance of catching any problems early. Only some of your appointments will be at Emory; the rest you can have locally.

As you get further along, the Transplant Team will help you transition to your long-term healthcare team. We will work with you to set up a local nephrologist and infusion center.



A Typical Schedule: Second and Third Years

The	Second Year	
Month 13		
Month 14		
Month 15		
Month 16		
Month 17		
Month 18	₹ Em □	
Month 19		
Month 20		
Month 21		
Month 22		
Month 23		
Month 24	E P	

The Third Year				
Month 25	5			
Month 26	7			
Month 27	7			
Month 28	7			
Month 29	7			
Month 30	7	E P		
Month 31	3			
Month 32	3			
Month 33	3			
Month 34	3			
Month 35	3			
Month 36	3	E Y		

Routine medical care is important to avoid problems. Remember to schedule regular checkups with your primary care physician, local nephrologist, and other healthcare providers.







Medications After Transplant



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One of the most important aspects of your life after transplant is the medication routine that you must follow. You must take your transplant medicine to keep your new organ healthy. You will have to take medications called immunosuppressants or anti-rejection medications. These medicines prevent your body from rejecting your transplant and are very important. You will need to take them for as long as you have your transplanted organ.



About Your Medicines

You will be given different types of medicince after your transplant. These medicines will work together to keep you and your new organ healthy. You should learn why you are taking each medication and its side effects. Refer to your medication sheet to help you learn about your medications.

You should take only the medications on your medication sheet. All other medications taken before the transplant should be set aside or disposed of.



Where to Get Your Medicines

After your transplant surgery, your transplant coordinator will work with you to order your transplant medications before you are discharged home. Your transplant medications are very expensive. Their cost can be as high as \$5000 per month. You may be eligible for assistance programs if you qualify.

How to refill your medicines:

- Call for refills SEVEN days prior to running out.
- You should have refills on your medication that were delivered to the
 hospital. Call the number on the medicine bottle and tell them you
 need your next month's supply. They will set up delivery to your home.
- If you want to use a local pharmacy, need to use mail order, or need a new prescription, call the medication nurses at 1-855-366-7989.







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Tips for Taking Your Medications

- Take your medication exactly as prescribed every day. One of the main causes of transplant failure is missing doses of medications.
- If you do miss a dose and it is within 4 hours of the scheduled time, you can take the medications as soon you remember. If it is more than 4 hours after the scheduled time, skip the dose and take it at the next scheduled time. Do not double dose. If you miss more than 1 dose, call your transplant coordinator for instructions.
- Be consistent!!! Take medications at the same time and the same way each and every day.



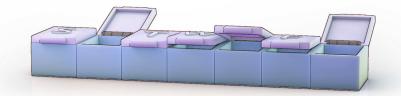
- Do not adjust your immunosuppression medications yourself. This could result in rejection and loss of your transplant.
- Notify the transplant team if you experience any side effects. Often we can take steps to limit any side-effects you may have.
- If you are sick or nauseated and cannot take your medications, call your transplant coordinator or physician immediately. You may need to be admitted to the hospital to receive your immunosuppression through the vein.
- Talk with the transplant team before starting or stopping any medications. Many drugs can interact and influence your immunosuppressants and your new transplanted organ.



- Ask the transplant team before taking herbal or alternative medications.
- Only take over-the counter medications listed on the over-the counter list. Never take aspirin, Motrin, Advil, ibuprofen, Aleve, or nonsteroidal anti-inflammatory drugs (NSAIDs) unless approved by your transplant physician.
- Bring a list of medications with current dose and frequency each time you see a health care professional.
- $\bullet \ Talk \ to \ the \ transplant \ team \ before \ you \ receive \ any \ immunizations \ / vaccinations.$



 Store your medications in a safe and dry place away from heat and light. Avoid storing medications in bathrooms and above sinks since moisture can harm medications. Keep medications out of reach of children.







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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)





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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.







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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.



Notes:		





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Your Guide for Heart-Healthy Eating

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		





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Your Guide for Heart-He	althy Eating
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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 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 Alcoholic beverages in excess		





Your Support and Resources After Transplant

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Following your transplant, your life will be significantly different. The impact of the changes can sometimes be overwhelming. This guide will discuss some of these transitions and provide resources for any questions you may have.

Your Emory social worker is available to assist you in understanding these changes. They can guide you to hospital and community resources that will provide you with financial and emotional support.



Financial Support

Some patients experience financial hardship following transplant. There are immediate costs, but also long-term costs involved in order to ensure your transplant journey is a successful one. 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 regarding your financial situation. Some examples of areas they can assist 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 should I do? I can't pay my insurance premium payment and I need assistance.	
My Medicare benefits are about to change. What can I do to help cover my expenses?	
The American Kidney Fund (AKF) will not continue to help pay for my health insurance premium following transplant. How can I manage this cost?	
I need help finding a job. Are there resources for career training or education?	
Are there community resources that may provide me with financial support?	
Call your social worker to discuss any questions you may have regarding financial concerns.	





Your Support and Resources After Transplant



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Emotional Support

The transplant journey can be stressful at times. While you may resume your normal lifestyle, there could be some challenges. It might be difficult for you and your loved ones to cope with the changes at times.

Your social worker can help you navigate through this process. They will provide you with supportive counseling and direct you to additional resources if needed. Some examples of areas they can assist you with are listed below.

Things to Discuss:

My caregivers and I need emotional support on how to cope and deal with life after transplant.

I feel depressed and anxious. Are there resources to address my emotional health?

Will I be able to connect with other transplant patients to receive support?

Hospital Resources



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

- . Transplant social worker
- . Transplant psychologist
- . Mental health social worker
- . Hospital chaplain

Helpful Resources

Georgia Transplant Foundation www.gatransplant.org

Medication Access Program www.mapuga.com

Needy Meds www.needymeds.com

Mason Guest House www.emoryhealthcare.org

Metro Atlanta United Way 211 online.unitedwayatlanta.org





Your Support and Resources After Transplant

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Recovery Support

Following your transplant, you will **need to have a committed support system in place to assist you**. We encourage you to have conversations with trusted and reliable members of your support system to discuss the specific ways they need to be available for you. Your support team might include family members and friends.

If you are concerned about your current plan for post-transplant support, then consider how you might reach out to others who are members of groups you might be involved with. Examples of these groups include your religious institutions, sororities, fraternities, co-workers or neighbors.

You will not be able to drive for the first 3-4 weeks after transplant. You will need to have someone available to transport you to and from your appointments, so have a backup person as well! It is important to attend all of your appointments.

Parking



You will be requireed to cover the cost of your own parking. At this time, the valet costs \$8 and the parking desks can vary from \$5-\$12.

An alternative option might be to ride the Emory CLIFF shuttles. Check the Emory transportation website for schedules.

Lodging



There are several lodging options nearby. If you choose to reside at the Mason Guest Lodge, you must have someone stay with you.

Notes:		

