

Caring for Yourself and Your Transplant



“Transplantation is an extraordinary journey that tests the limits of one’s strength and courage. In addition to commitment and faith, it requires strong mental and physical preparation as well as endurance. But you already know that. If you can endure transplantation, you can conquer anything that you set your mind to. The tough part is over. Now it’s time to let your body heal so your inner radiance and spirit shines through again. Wishing you well as you continue on your own transplant journey.”

-Diane Carnevale, artist and kidney transplant recipient (October 2018)

Caring for Yourself and Your Transplant

Introduction

Having a transplant procedure is a unique experience for each person, their family, and friends. You will likely have many questions and experience many different feelings as you return to daily life after your transplant. We turned to our staff and former patients to get their thoughts on what information would be most helpful to our patients. There is a lot of information to take in, so we have created sections that will help you find the answers you need easily. The Transplant Team will help you review different sections over time as you recover in the hospital and later in outpatient visits.

In the first part of the binder, you will find explanations of common concerns that arise when you leave the hospital. Medications and lab work are an important part of your follow-up transplant care; you can find information on both topics in multiple sections of this binder. Later sections focus on your day-to-day life in the year(s) following your transplant. The final sections of the binder provide more details on definitions you may not have understood or recalled. Finally, you will find worksheets that will help you keep track of how you are doing so the Transplant Team can best manage your care.

We hope you will find these materials useful as you move through your transplant journey. Please do not hesitate to reach out to the team if you are in doubt or feel you may need more resources to help you recover.

Sincerely,

Your MGH Transplant Team

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WHAT TO EXPECT AFTER YOUR TRANSPLANT

What to Expect After Your Transplant

During Your Hospital Stay

After Transplant surgery, you can expect to be in the hospital for 2-5 days. A lot of this depends on how you were feeling before your surgery. In general, you can expect to go home once you are awake and alert, eating well, moving around without difficulty and your pain is well controlled. Sometimes, patients are advised to go to a rehabilitation setting before they go home to get more supervision with self-care activities and special medications if needed.

Members of the Transplant Team

During your hospital stay, you will meet many different people who can help you manage different parts of your care after surgery.

Your **Transplant Surgeon and/or Physician** are also referred to as the attending physician or MD, who will oversee all aspects of your care and surgical procedure. There are also **Transplant Surgery Fellows** who are fully credentialed surgeons who are now pursuing specific training in Transplant Surgery, as well as **Surgical Residents** who are graduates of medical school who are enrolled in the 5-year surgical training program at MGH.



You will also meet our **Nurse Practitioners (NP)** and **Physician Assistants (PA)**, who have advanced education and certification to practice medicine in collaboration with the surgical staff.

There will be many members of the nursing staff available to care for you and your family during this time. Most of the time, you will see **Registered Nurses** who have special training in the care of transplant patients and are prepared to provide your 24-hour care with the goal of progressing your activity so you can care for yourself at home. **Patient Care Associates (PCA's)** are staff who are trained and certified to carry out various aspects of patient care under the supervision of an RN. A **Nursing Director** provides administrative oversight on the patient care unit and assures appropriate staffing and resources during your hospital stay. A **Clinical Nurse Specialist (CNS)** is an advanced practice nurse with specialized knowledge of the issues related to transplantation and provides clinical oversight to coordinate and manage the transitions across healthcare settings. These individuals often work together with other departments and hospital administration as the need arises.

Preparing for Discharge

Every effort is made to arrange for discharge from the hospital as soon as possible. Patients often recover better at home, where they can get back to routine activities of daily living with limited exposure to any infections that might be present in the hospital

environment. The Transplant team arranges for careful and frequent follow-up after discharge, in-person or virtual (phone or video) clinic visits. Several other team members are also available to help you prepare and arrange for the needs you will have at home.



Medications are a critical part of your care after discharge. You will learn a lot about your medications from your nurses when they are giving you medications each day. A **pharmacist** will meet with you before you go home to explain in more detail how you can manage your medications at home.

Transplant patients often need resources after their hospital stay. **Case Managers** are registered nurses who evaluate and coordinate the planning for care you may have after discharge. They work closely with **Social Workers** to identify available resources in your community and how the expenses for these services might be covered. This could include services at home on an outpatient basis or in a skilled nursing/rehabilitation facility. If you require more time to get your strength back and progress your activity, you will meet with **Physical Therapists (PTs)** and **Occupational Therapists (OTs)** for their recommendations. **Dietitians** are also available to help you with food choices if you are advised to stay on a special diet. Spiritual resources for religious affiliations are available through the MGH **Chaplains** Service.

Life after a transplant can get complicated without a safe plan of care after you leave the hospital. We will want to be sure that the following plans are in place before you are discharged:

- Transportation: We advise patients that they should not drive for 2-6 weeks. This will depend on how you are progressing after surgery and whether you are taking pain medication. It is important that you not only have a ride home at the time of discharge, but you must also be sure you have a way to get outpatient visits and lab tests needed during follow-up. The Transplant team will advise you when it is safe for you to start driving.
- Prescriptions: Taking medications is a critical part of the lifelong plan for caring for your new organ. Before you leave the hospital, we will confirm your prescription drug coverage (insurance) for your new medications, including any co-pays and how you can manage this expense. We will have a pharmacy deliver your 1st month of medications to the Transplant Unit (Blake 6).
- Daily Activities: Your activity will be limited, and you may tire easily in the early weeks after transplant. Be sure to think about who will be able to help you with things such as food shopping, housework, errands, and meal preparation. You should not lift more than ten (10) pounds for the first 2 months or until cleared by your physician.



Who to Call and When?

For any life-threatening emergencies at any time, call 911!



From the day of discharge until your 1st clinic appointment, you should call Blake 6 at (617) 724-8610 with any questions or concerns.

After your 1st clinic appointment, you should call the Transplant Clinic at (617) 726-5277 with any questions or concerns. Before 8AM or after 4PM, you will be directed to the answering service. For urgent issues, please ask them to page the on-call Transplant Resident.

If you experience any of the signs and symptoms below, we want you to call the transplant team as soon as possible:

| | |
|-----------------|---|
| Kidney | Fever greater than 100.4 Abdominal pain Decreased urine output Swelling of the legs or ankles Unintentional weight gain (e.g., 5 lbs in a week) Severe diarrhea Nausea and/or vomiting preventing you from taking medications Bloody urine |
| Liver | Fever greater than 100.4 Increase in abdominal size Abdominal pain Swelling of the legs or ankles Dark urine Pale stools Yellow skin Severe diarrhea Nausea and/or vomiting preventing you from taking medications |
| Pancreas | Fever greater than 100.4 Blood sugars higher than 200 for more than 24 hours Blood sugars lower than 80 for more than 24 hours. Severe diarrhea Nausea and/or vomiting preventing you from taking medications |

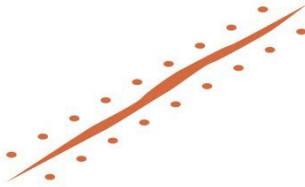
If you get admitted to another outside hospital, please have a family member contact the Transplant Clinic as soon as possible.

What to watch for at Home

We also encourage you to take every precaution to prevent infections and watch for any early signs that an infection is brewing. Pay particular attention to incision care and other possible risks of infection.



Incision Care



Making sure your incision heals after surgery is important. Look at your incision every day to make sure there is no fluid, redness, or new openings. If any of these things happen, contact the Transplant Clinic. Bruising around your incision is common and will improve with time.

Change the dressings every day if you see fluid from your wound. If your incision is dry or sealed, you do not need dressing. This fluid should be clear, but if it is foul smelling, discolored, or cloudy contact the Transplant Clinic.

If you have drains or tubes the nurse will teach you how to care for them at home and practice with you before you leave.

After showering, gently pat the incision dry. On days that you do not shower, clean the skin around the incision with gentle soap and pat dry. Do not sit in water (jacuzzi tub, swimming pool, bathtub) for 6-8 weeks after transplant or until informed by the team. Avoid lakes, ponds, oceans, or any other body of water until your incision has healed completely. Do not put any creams or lotions on the incision.

Preventing Infections



Taking every precaution to prevent any type of infection is important after a transplant. The recent COVID-19 crisis has made these measures even more important. This new virus has raised many new questions for which there are not clear answers at this time. In general, you should always stay away from people who are obviously sick and notify your Post-Transplant Coordinator if you're feeling unwell.

Daily Hygiene

- Wash your hands with soap and water before you eat and after you go to the bathroom.

Shower or bathe regularly. Wash your incision but don't scrub it in the first month after transplant. Do not submerge in water, such as baths or pools for 6-8 weeks or until informed by the team. Do not use lotions or powders on your incision.

- Clean cuts and scrapes with soap and water and apply an antiseptic and a bandage.

COVID-19

COVID is an important concern for all but especially for transplant patients given their increased risk for any infection. There is new information emerging about this virus every day. You will find the best and most up to date advice on the CDC website [coronavirus.gov](https://www.cdc.gov/coronavirus), which also includes information about coronavirus vaccines. You may receive the vaccine once you are 3 months post-transplant. If you have any specific questions, please be sure to reach out to your team.



Other Do's and Don'ts to reduce your risk of infection

DO

- Brush and floss teeth daily.
- Keep fingernails and toenails clean and trimmed. For hard-to-manage or ingrown toenails, see a podiatrist.
- Wear a surgical mask when you are in areas with lots of dust, dirt, or infectious agents in the air. .
- Eat only thoroughly cooked foods

DO NOT

- Go near places where there is extensive construction, dust and/or dirt in the air.
- Garden or dig in dirt without gloves or mow the lawn for six to eight weeks after your transplant. This could cause a serious infection.
- Under any circumstances, expose yourself to cigarette smoke, either firsthand or secondhand.

SPECIAL SITUATIONS

PETS

Pets are an important part of many transplant patients' lives. Adult, healthy, vaccinated dogs, cats (if able to avoid the litter box), and fish are all safe for transplant patients. Unfortunately, certain pets carry different germs that can cause serious illness in people with a weakened immune system. Even baby animals can carry a risk for bacteria because of the small scratches and biting that they frequently do when they are young.



Special Tips

Avoid certain pets with high potential to cause infections such as birds, reptiles, or rodents. Exposure to farm animals should also be avoided.

Get help cleaning up after your pets—transplant patients should never clean out barns or stalls, fish tanks, or cages for animals. Transplant patients should also avoid cleaning the litter box.

Bringing a pet to the vet: sick pets (like sick people) can spread disease to transplant patients. Also, transplant patients should avoid being in the room if a vet wants to give a live vaccine.

As always, washing your hands regularly after touching your pets will reduce the risk of infections for transplant patients.



DEALING WITH BUGS

There are many diseases that people can get from different bugs in the environment. Mosquitoes and ticks can cause a serious illness for transplant patients. Both can be found in heavily wooded areas and in tall grass. Mosquitoes are often found around standing water, while ticks are commonly spotted on family pets.

Special Tips

Do your best to wear long sleeves and long pants. If you can reduce the amount of skin

showing, there are fewer places for ticks and mosquitoes to bite you! For example, tucking your pants into your socks can help

Eliminate standing water from yards and potted plants to prevent breeding places for mosquitoes. Avoid areas of tall grass or heavily wooded areas with lots of mosquitoes or ticks.

Use Repellents: Patients should use mosquito and tick repellents that are at least 20% DEET. If you are going to be spending lots of time outside or in an area with lots of mosquitoes or ticks, you can also use permethrin on your clothing to prevent bites from ticks and mosquitoes.

AVOID ILLNESS FROM CONTAMINATED WATER

People can become sick from contact with germs found in oceans, lakes, rivers, small ponds, or other contaminated water sources. Swallowing contaminated water is most common source of contact, but some germs enter the body through cuts in the skin. While pools and other man-made swimming sites can be safe because of the careful monitoring of the water, it is important to pay attention for any potential contamination (think about dirty diaper in the pool)

Special Tips

It may be difficult to avoid swallowing some small amounts of water is difficult when swimming. You should avoid going totally underwater to reduce your risk of swallowing.

Protect Skin Wounds:

- If you have an open wound on your skin (feet, legs, hands, arms etc.) you should avoid recreational water sources as this can be a major route of transmission of the germs.
- If you are exposed to recreational water sources, you should protect open wounds with a watertight dressing like a Tegaderm.
- If a wound is exposed, wash it out with soap and water and monitor your skin for other signs of infection.

MEDICATIONS

Medication Guide for Kidney, Pancreas, and Liver Transplant Patients

New medications will be a critical part of your life after a transplant. You will take two types of medications to keep you healthy after your transplant. The first group of medications are called “immunosuppressants” or “anti-rejection” medications. You will have to take medications to prevent rejection for the rest of your life or as long as your transplanted organ is in your body. These medications can increase your risk of developing infections. You will also need to take medications to prevent serious infection for a period after your transplant. There is a more detailed description of the medications you may be taking in the appendix of this binder.

It is important to take these medications as ordered; you should never change or skip a dose of your medication without consulting the Transplant Team. During your recovery, the nurse and pharmacist will continue to teach you and your family members about these new medicines and how you can stay on schedule with them in your daily life. A medication card will be provided at the time of discharge and will be reviewed at each visit to help you track your medications. Please be sure to ask if you have any questions!

In this section, you will find some general tips about how to manage your medications.

Immunosuppressive Medications: Prescribed by Transplant Clinic

The Transplant Clinic Providers will manage and refill all immunosuppressive (anti-rejection) medications for as long as that transplant remains in place. If another physician or healthcare provider suggests a change in your immunosuppressive medications, please notify the MGH Transplant Clinic.

Below is a table that lists the commonly used immunosuppressive medications:

| Anti-Rejection Medication | Other Names | Dosing Frequency |
|----------------------------------|----------------------------|---|
| Tacrolimus | Prograf® | Twice a day, 12 hours apart |
| | Astagraf® * Envarsus® * | Once a day, 24 hours apart |
| Cyclosporine, modified | Neoral® Gengraf® | Twice a day, 12 hours apart |
| Cyclosporine | Sandimmune® | |
| Belatacept* | Nulojix® | Every 2 weeks at first, then once a month (every 28 days) |
| Mycophenolate mofetil (MMF) | CellCept® | Twice or Three times a day |
| Mycophenolate sodium | Myfortic® | Twice or Three times a day |
| Sirolimus | Rapamune® | Once a day |
| Everolimus | Zortress® | Twice a day |
| Azathioprine | Imuran® | Once or Twice a day |
| Prednisone | Steroids | Once a day |

*Generic unavailable

Refills: Immunosuppressive medication refills **must** be requested at least 5-7 business days before they are needed.

Emergency Supplies: If you are completely out of immunosuppressive medications, you should notify the Transplant Clinic so that we can help arrange an emergency supply.

Generic immunosuppressive Drugs: MGH's Transplant Clinic permits patients to take generic immunosuppressive medications.

Moving? If you move out of the area or are no longer able to attend visits at Transplant Clinic, responsibility for refilling your immunosuppressive medications will need to be transferred to another transplant center or physician. Please discuss this with your physician or post-transplant nurse coordinator.

Medications to Prevent Infections: Prescribed by Transplant Clinic



Most transplant recipient must take anti-bacterial and anti-viral medications for 3-12 months after transplant to prevent bacterial and viral infections. The Transplant Clinic Providers will manage and refill these medications. **If another physician or healthcare provider suggests a change in one of these medications, please notify the Transplant Team.**

Below is a table that lists the commonly used medications to prevent infections:

| Medication Name(s) | Indication | Treatment Time |
|---|---------------------------------|----------------|
| Valcyte® Valganciclovir | Prevents viral infection(s) | 3-6 months |
| Famvir® Famciclovir | Prevents viral infection(s) | 3 months |
| Bactrim® Sulfamethoxazole/trimethoprim | Prevents bacterial infection(s) | 6-12 months |
| Mepron® Atovaquone | Prevents bacterial infection(s) | 6-12 months |

Pain Medications: Prescribed by Transplant Clinic

You may take pain medicine if you have pain that stops you from sleeping or doing light activities like watching TV or reading.

- Prescription pain medication: You may be prescribed narcotic pain medication after being discharged from the hospital after transplant. You should not operate any vehicle or machinery while taking any prescribed narcotic medications.

- Massachusetts Law states that no more than a 7-day supply of narcotic pain medications can be provided on first-time opiate prescriptions. Refills of these medications need to be obtained from your primary care doctor (PCP).
- Narcotic pain medicine can cause your stomach to feel upset or can make you constipated (not able to go to the bathroom). Take narcotic pain medicine with food to help avoid stomach upset. If you are constipated, take an over-the-counter mild laxative like Senokot® (Senna), Dulcolax® (Bisacodyl), or Miralax® (Polyethylene Glycol). Follow the package directions. Do not drink alcohol. This includes beer, wine, and liquor.
- Over-the-Counter pain medications: Do not take over-the-counter medicines like Motrin®, Advil® (Ibuprofen), or Aleve® (Naproxen) as these can hurt your kidney when taken in combination with your antirejection medications.
 - You can take Tylenol® (acetaminophen) for pain, but you must limit the total dose:
 - i. If you have a liver transplant, you should take no more than 2,000 mg in 24 hours
 - ii. If you have a kidney transplant, you should take no more than 3000mg in 24 hours.
 - For other discomforts, you can refer to the list below for options. Be sure to check with the team before using any over the counter medications including dietary or herbal supplements including herbal teas. Many of these products can affect immunosuppression levels.

Over-the-Counter Medications

- Some over-the-counter medications are safe for transplant patients and others are not. Medications that contain “non-steroidal anti-inflammatory drugs” such as ibuprofen, naproxen and high dose aspirin are **NOT** safe. Some medications to treat upset stomach or constipation can interfere with the absorption of your immunosuppressive medications.
- A list of acceptable and unacceptable medications is presented in the appendix of the binder. This list does not include all available options, please call or message your transplant coordinator/transplant pharmacist if you have questions about using over the counter products.

Acceptable for Most Patients

Aches and Pains



Cough/Sore Throat



Congestion/Allergy



Heartburn



Diarrhea/Constipation



Only brand name products are pictured. Store brand or generic formulations are available and may look differently than shown. If you ever have any questions regarding the safety of over the counter medication please speak with your pharmacist or transplant coordinator.



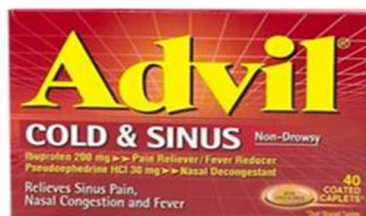
Unacceptable for Most Patients



Aches and Pains



Cold/Flu/Congestion/Allergy



If you have UNCONTROLLED HIGH BLOOD PRESSURE, please check with your physician before taking Sudafed and Aleve-D

Heartburn



May use TUMS, MYLANTA, and MAALOX two (2) hours before or four (4) hours after transplant medications, but **DO NOT take at the same time

Diarrhea/Constipation



May use PHILLIPS 2 hours before or 4 hours after transplant medications, **DO NOT take at the same time.

May take IMODIUM with for 1 day for non-bloody diarrhea, and if diarrhea last longer than 1 days contact your physician.



Only brand name products are pictured. Store brand or generic formulations are available and may look differently than shown. If you ever have any questions regarding the safety of over the counter medication please speak with your pharmacist or transplant coordinator.



Other Medications: Prescribed by Primary Care Physician or Other Specialist

Your primary care physician and/or other providers caring for you should prescribe and refill your non-immunosuppressive medications, such as:

- Antibiotics to treat bronchitis, sinusitis, or other short-term infection.
- Blood pressure pills
- Diabetes pills, insulin, insulin needles, glucometer supplies including test strips
- Asthma inhalers
- Chronic pain medications such as oxycodone
- Anti-depressant medications such as sertraline (Zoloft®)
- Anti-anxiety medications such as lorazepam (Ativan®)
- Sleeping medications such as zolpidem (Ambien®)
- Thyroid replacement such as levothyroxine (Synthroid®)
- Erectile dysfunction medications such as sildenafil (Viagra®)
- Blood thinners such as warfarin (Coumadin®) and clopidogrel (Plavix®) except if specifically prescribed to treat your transplant.
- Cholesterol lowering “statin” drugs
- Bisphosphonates for osteoporosis such as denosumab, alendronate and risedronate

Medications Previously Prescribed by Transplant Clinic

If your pharmacy contacts us to refill a non-immunosuppressive medication that we had prescribed in the past but is not managed by your transplant provider, we will ask your pharmacy to contact your primary care physician or other specialist to fill this prescription.

New Medications Prescribed for an Urgent Problem

A Physician or Nurse Practitioner at MGH Transplant Clinic may initiate a new medication (other than immunosuppressive medications) to treat an urgent problem. For example, if we discover during your clinic visit that your blood pressure, cholesterol, or blood sugar are significantly elevated, or you have an infection requiring an antibiotic, we may prescribe a new medication or increase the dose of an existing medications.

We require that at your earliest convenience you transition management for this medication to your primary care physician, diabetes doctor, or kidney or liver specialist, whose practices are optimized to manage such medications.

Interactions Between Immunosuppressive and Other Medications

Many prescription medications and herbal supplements can interfere with transplant immunosuppressive medications, lowering or raising their effect and putting you at risk for rejection or for over-suppression of your immune system.



We recommend:

- Before starting a new medication or supplement, remind the prescribing physician or nurse practitioner and your pharmacist that you are a transplant patient on immunosuppressive medications. Ask them to confirm that the new medication will not interact with your transplant immunosuppression and let your Transplant team know about the new medication.
- Avoiding herbal medications and supplements.
- The following is a list of commonly prescribed medications (*listed by generic name, not Brand or Trade name*) that transplant patients **should not take** without checking with Transplant Clinic:
 - Allopurinol
 - Carbamazepine
 - Clarithromycin
 - Clotrimazole Troche
 - Diltiazem
 - Erythromycin
 - Fluconazole
 - Itraconazole
 - Ketoconazole
 - Modafanil
 - Phenytoin
 - Phenobarbital
 - Posaconazole
 - Primidone
 - Rifampin
 - Trimethoprim-Sulfamethoxazole DS (double strength) twice daily
(Single strength taken once daily is safe after transplant)
 - Verapamil
 - Voriconazole
 - **Paxlovid (nirmatrelvir/ritonavir)**

NOTE: There may be other medications that should be avoided. You should check any new medications prescribed with this list or contact a member of your transplant team.

Herbals & Dietary Supplements

If you took herbal medications/dietary supplements prior to transplant, you should review these with your transplant coordinator and transplant pharmacist post-transplant. Many herbal products & dietary supplements can affect immunosuppressant levels and the immune system resulting in an increased risk for rejection or side effects. The use of herbal supplements and herbal teas should be avoided. Herbal products that are known to cause problems in transplant patients include St. John's Wort, ginseng, turmeric and echinacea.

Marijuana (CBD and Medicinal Marijuana)

Although medical and recreational marijuana is now legal in several states including Massachusetts, there are many concerns about the safety of marijuana/cannabis use after transplant and its potential impact on your transplant.

FIRST AND FOREMOST: Smoking marijuana can increase your risk of severe mold/fungus infections in the lungs. We recommend that you avoid smoking either medical or recreational marijuana after transplant.

If you choose to smoke marijuana, we recommend that you heat it to destroy any mold spores by baking the marijuana in the oven at 300 degrees for 15 minutes or in the microwave for ten or more seconds. The exact time needed to kill the fungus varies depending on multiple factors and is not guaranteed to be fully effective. Baking before eating marijuana (as in pot brownies and cakes) may also be helpful in reducing your risk of fungal infection.

Marijuana/cannabis is made up of two major compounds, THC and CBD. A **SECOND CONCERN** is that one of the components of marijuana/cannabis (CBD) can impact the levels of the antirejection medication which may negatively affect your kidney transplant. Ingestion of marijuana edibles and gummies likely have a lower risk of infection, however there is the potential for marijuana/cannabis to affect your antirejection drug levels. It is impossible to predict how much of an impact a certain ingestion will have on your drug level.

Products that contain THC only may be safer as it has not been shown to affect antirejection drug levels. Topical CBD or THC products, such as creams or ointments, are likely safe to use after transplant.

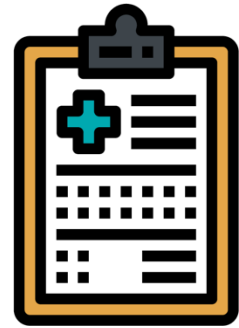
Please discuss with your transplant team before considering ingestion or use of any form of marijuana/cannabis. Potential transplant recipients should also be aware that insurance companies may refuse coverage for organ transplant if patients are documented to be actively using illegal drugs including marijuana.

Tips About Your Medicines

Taking medications is a critical part of your treatment after a transplant. Take some time to learn the names of your drugs and know how much to take, when to take them, how to take them and deal with important side effects. The next section describes common medications in detail.

Carry a list of your medicines and their doses with you at all times.

Be sure to bring your transplant medication list to **every visit** with any doctor and anytime you are admitted to the hospital.



We know it is not easy to manage a complex medication regimen. Here are some key tips that can help you stay on track:

- Never skip or change your medication dose unless instructed by your Transplant Coordinator or another Transplant provider.
- Never stop taking any of your medications. Contact your Transplant Coordinator immediately if you are worried about paying for your medicines or if there is a change in your insurance coverage.
- Never change the specific type of immunosuppressant medication you are taking without checking with your transplant team – they are not all the same!
- Keep medications in a cool, dry place away from heat or light. Refrigerate only if the directions say to do so.
- Keep all medications in a convenient place but out of reach of children.
- Get into a routine. Take your medications at the same time each day.
- Use tools to help organize your medicines, such as a pillbox that has individual compartments labeled with the days of the week.
- Many people now use smartphone or tablet applications to help remember their medications.
 - Install your pharmacy's app to assist with refills
 - Set an alarm on your phone or an appointment in your calendar to remind you to take your medications.
 - Keep an updated list of medications on your phone or tablet.
 - Use apps to help organize your medications and help remind you to take them. Two helpful apps for transplant patients are "Transplant Hero" and "Medisafe"
- Capsules and time release tablets should be swallowed whole and never crushed, chewed, or opened

- If you vomit after taking your medications, you should not retake your medicines. Call your Transplant Coordinator to get advice on how to handle your vomiting and the next steps on your medications.

Keep track of how much medicine you have left. Don't ever run out.

- Always ask your pharmacist how many refills you have left.
- Do not keep outdated medications. Check the expiration dates on your transplant medicines and discard those that are out of date periodically.
- Remember to take your medications with you if you go on vacation or travel. Let us know when you travel outside the United States. When traveling, carry medications separately and do not check them with your luggage.
- Know the name of a nearby pharmacy or hospital if you plan to be away from home.
- Mark your calendar so you remember to reorder your medications ahead of time.
- Try to buy all your medicines from the same pharmacy.
- Always ask your pharmacist or Transplant Coordinator if the pills look different or are a different size or color from what you are used to taking.

Food/Beverage Interactions



Do not eat grapefruits, grapefruit juice or soda (Fresca), pomegranate, starfruit or pomelo or fruit juice blends that contain these fruits. All these fruits can increase the levels of certain immunosuppressants in your blood to a potentially toxic level.

Managing Side Effects

Side effects can occur with any drug, even over-the-counter medications. Some are mild, others can be more severe. Mild reactions may resolve on their own, however, if they persist, contact your physician. Side effects for each medication are listed below. You should contact your transplant coordinator or physician immediately if you experience any of the major reactions listed below.

Financial Considerations after transplant

The medications you will need after your transplant can be very expensive. It is important to keep your prescription insurance active to help pay for your transplant medications. If you must change insurance, you should make sure that your transplant medications will be covered with your new insurance. Reach out to your transplant team prior to making a change in your insurance to make sure your new plan will cover your medications.



Even with insurance, transplant medications can be very expensive. If you have difficulty affording your medications, there are several ways that your transplant team can help. We never want you to change the dose of your medications or avoid filling your medications because you can't afford them. Missing doses of your

medication or taking lower doses of your medications can lead to rejection or infection after your transplant.

You should call your transplant team if you find that you can't afford your medications. There are several tools available that can be used to help pay for your medications. Below you will find some helpful tools that can be used if you find it difficult to pay for your medications.

Co-pay cards

- Can only be used with medications that do not have generics available (Massachusetts resident only)
- Can only be used with commercial drug plans (Caremark, Blue Cross, etc)

Free -drug vouchers

- Typically, only one time use for a 30-day supply
- Accessible online on drug company websites (Veloxis and Novartis)

Patient assistance programs

- Programs vary depending on medication
- Eligibility varies with different programs and is often determined based on coverage provided, co-pay, insurance type and income

Discount programs

- Websites such as GoodRx offer discount coupons that can be used in place of insurance or in the setting of no insurance coverage. Phone app also available.

Foundations

- Foundations that provide assistance to transplant patients in need.
 - HealthWell, American Kidney Fund, American Transplant Foundation, Good days®
- The Massachusetts Organ Transplant Fund may provide financial reimbursement for qualifying expenses

Medicare Extra Help

- Federal program to help with co-pays on Medicare Part D drugs

State specific prescription drug discount programs

- Income based programs that provide addition help for those who do not qualify for Medicare Extra help

Massachusetts Health Safety Net Program

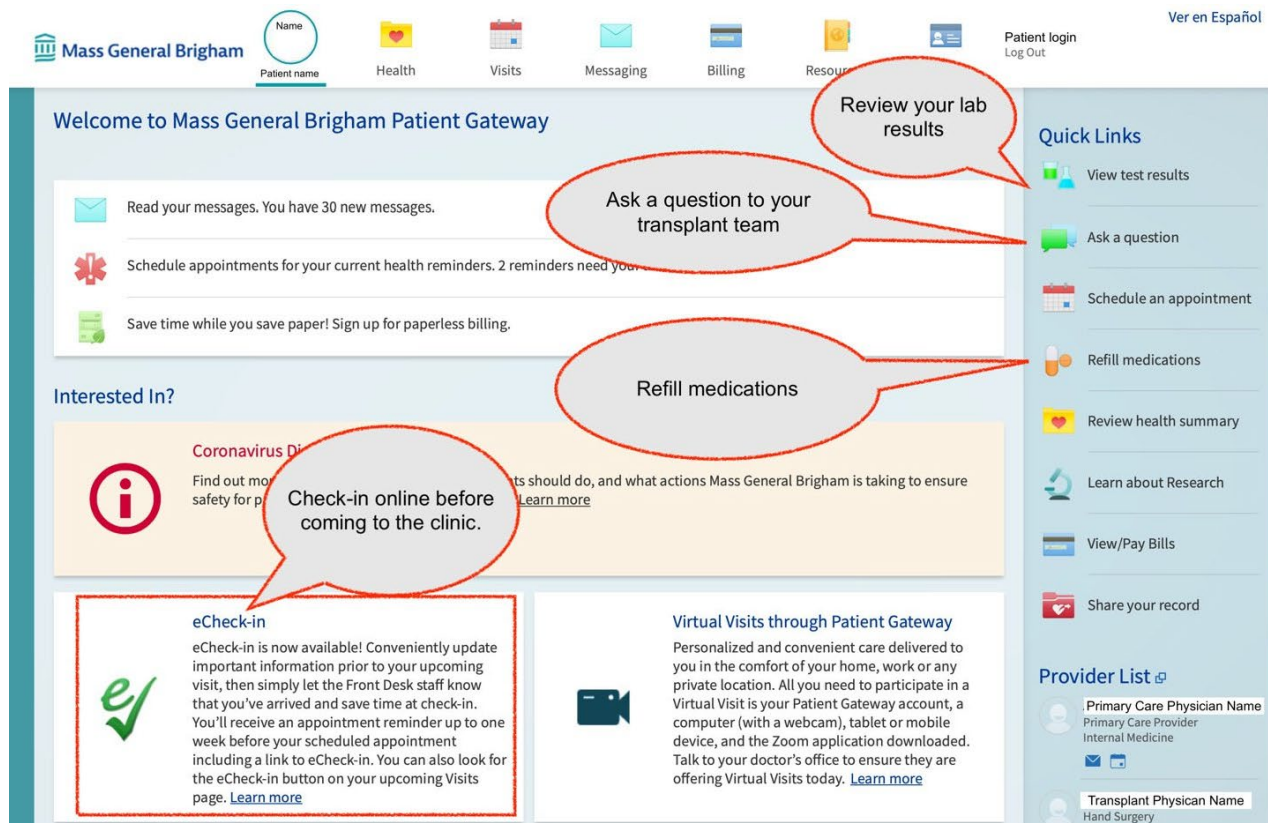
- Discount drug program available at MGH Outpatient Pharmacy for those who do not qualify for MassHealth

If you have any questions, please reach out to your specific transplant financial coordinator, whose business card you should have received during your transplant evaluation.

FOLLOW UP PLANS

Prior to Your First Clinic Visit

Patient Gateway (or My Chart) is your online resource that allows you to view your test results, refill medications, review visits' schedule, ask question to your provider and review your medical visit documentation. This will be an essential tool in your post-transplant medical care.



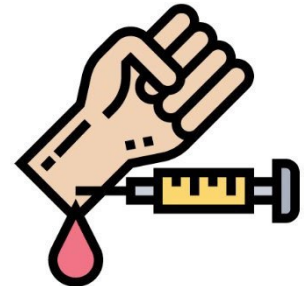
On the Day of Your First Clinic Visit

The Transplant Clinic is located at 165 Cambridge Street on the 3rd Floor. This area is also called Charles River Plaza and our building is next to Whole Foods grocery store. Parking is very limited in the plaza, so it is best to go to the underground parking garage that can be accessed on Cambridge St, next to Flour Bakery and Cafe. In the outpatient area, you will continue to be followed by many members of the Transplant Team. These visits will be in person, or virtual (video or phone conference) visits performed through the Gateway Patient Portal with the Transplant Team in the Transplant Clinic. The **Transplant Nurse Coordinators** have a special role in helping you to manage the



various aspects of your care. They are your first point of contact when questions arise and have access to the resources you may need. You will meet them in the clinic at your first visit after your discharge.

You should NOT take your morning dose of cyclosporine, tacrolimus, sirolimus, or everolimus until AFTER your blood is drawn, either at the clinic or your local lab. Bring the medication with you so that you can take it after your blood is drawn. Remember that your blood should be taken approximately 12 hours after your evening dose of cyclosporine, everolimus, or twice daily tacrolimus. The blood draw should be 24 hours after once daily tacrolimus or sirolimus.



After you have checked in and had your blood drawn, a medical assistant will collect your vital signs. Your Transplant Nurse Coordinator will talk with you about how to care for yourself and check on your post operative progress. They will go over important information related to your ongoing post-transplant care. **Please bring this binder to your clinic visits so we can update your medication list and look at your self-monitoring logs (vital signs, urine output, blood sugar) located in the back of the binder.** You will then meet with one of your doctors who will examine you and check on how your new transplant is working.

During your first few visits to the clinic, you will also meet with some other Transplant team members including the:

- **Pharmacists** who will review your medications in detail. Bring your medication card and pill box to all your appointments so that any changes may be recorded on your card and adjusted in your pill box.
- **Social Worker** who will talk to you about how you are recovering and coping at home. They can help with any insurance issues, other support, or services you may need, or questions related to mental health.
- **Dietitian** who can speak with you about your diet after transplant.

Follow-up Plan of Care

There is much to get used to after your transplant, so your team has a fairly standard approach to follow-up. They will be watching out to be sure you are taking the right amount of medication and managing to take care of yourself. This will mean having regular clinical visits, lab work, and additional instruction. Sometimes patients and their families find they need more support than anticipated. We can help avoid complications when we hear and see these needs early.

Your transplant team will want you to monitor certain things when you go home. This could include your blood pressure, heart rate, temperature, and/or blood sugar. If so,

enter the information on the worksheets provided in the back of this binder. Bring this information to each visit to help your doctors and nurses plan for the next steps in your care.

Early after transplantation, patients require frequent clinic visits and labs tests in the first year, when the risk of rejection is highest. You should plan to spend 3-5 hours at the clinic during your first few visits. The frequency of your clinic appointments and lab tests will be reduced over time.

The risk of rejection never goes away. Frequent follow up during the first year after transplant is critical. In the first 6 weeks, you will be scheduled for twice weekly blood checks at a lab near your home or at MGH. You will have clinic visits (in person or virtual) to see the transplant team about once a week for the first few weeks. The need for lab and clinic visits will likely decrease over time based on how well you are doing, especially after the first year.



It is also important to work closely with your local primary care providers (including your Primary Care Physician, local nephrologist and/or hepatologist, and endocrinologist) to help you with non-transplant care, and as you transition to less frequent visits and lab checks.

Lab Tests



Routine blood tests are critical for monitoring the health of your transplanted organ. We need your help making sure that your labs tests results are drawn properly and are available promptly for review. *Organ transplants may suffer unnecessary damage if the correct lab tests are not ordered, if the tests aren't drawn or performed, or if the tests results are not reviewed and acted upon.*

The MGH transplant clinic will review the result of labs tests ordered by our physicians. We urge you also to review the results yourself using the 'Patient Gateway' website. The transplant clinic does not routinely call patients with the results of their tests but will call if the results require additional testing or a change in therapy (*if you want to know the results, you must sign up for 'Patient Gateway'*). A list of the different lab tests you may need drawn is described in the appendix.

Patients have three options when choosing where to get lab tests drawn:

1. MGH, or another Partners Healthcare facility (see list of sites below): Results of tests drawn in these locations automatically become a part of your MGH medical record usually within a few hours after they are drawn. *For certain tests such as "HLA Antibody Screening," patients must come to the MGH Main Campus lab (Wang 2).* PHS (Public Health Service) labs (Hepatitis B, C and HIV screening) must be drawn at the transplant clinic between day 28 and 56 after transplant.

2. Quest Diagnostic lab: MGH has entered into an agreement with Quest so that lab tests drawn at Quest facilities within the United States automatically become a part of the MGH patient care record, typically within 24 hours after they are drawn. In addition, Quest has the capability of performing the drug level tests we require (e.g., tacrolimus levels) and virus screening (BK virus, CMV, etc.)

3. Another outside hospital or facility (least preferred)

In this case, test results must be faxed to MGH. A transplant clinic staff person will manually enter your results into your MGH medical record. This process typically takes several days to a week. *Note that some outside labs are unable to perform certain transplant related tests in which case important information may be delayed or may never reach transplant clinic staff. For this reason, we advise you to only use MGH affiliated or Quest labs.*

Keep your blood test appointment please!

Your blood tests will be scheduled for a specific day. **It is very important that you get your blood tests drawn on specific days.** You can see your expected lab test dates as scheduled appointments in Patient Gateway. This does not mean we have scheduled an appointment for you at your local lab- you must do so if that is required. Talk to your transplant coordinator about whether your labs can be drawn close to home or at MGH. If you receive a phone call saying your blood test results were not received, you must return the phone call!

Remember, on mornings that you are getting lab tests, DO NOT take your morning tacrolimus(Prograf®, Astagraf® or Envarsus®)/, cyclosporine(Neoral®, Gengraf® or Sandimmune®), sirolimus (Rapamune®), or everolimus (Zortress®) dose until AFTER

Preferred Outside Lab Locations

Partners Healthcare Labs Location

**MGH Main Campus
Wang ACC2**
55 Fruit Street
Boston, MA
Phone: 617-726-3215

MGH Back Bay Health Center
388 Commonwealth Ave.
Boston, MA
Phone: 617-267-7171

MGH/ BWH Foxborough
20 Patriot Place, 1st Floor
Foxborough, MA
Phone: 508-718-4006

MGH Chelsea Health Center
151 Everett Ave, 1st Floor
Chelsea, MA
Phone: 617-889-8555

MGH/ North Shore Center
104 Endicott Street, Suite LL01
Danvers, MA
Phone: 978-882-6199

MGH Revere Health Center
300 Ocean Avenue, 1st Floor
Revere, MA
Phone: 781-485-6192

MGH Waltham
40 Second Ave, 4th Floor
Waltham, MA
Phone: 781-487-6280

Brigham & Woman's Hospital
45 Francis St.
Boston, MA
Phone: 617-732-5974

Faulkner Hospital
1153 Centre Street
Jamaica Plain, MA
Phone: 617-983-7000

Newton-Wellesley Hospital
2014 Washington Street
Newton, MA
Phone: 617-243-6309

North End Waterfront Health
332 Hanover Street
Boston, MA
Phone: 617-643-8000

NSMC Salem Hospital
81 Highland Ave
Salem, MA
Phone: 978-741-1200

Cooley Dickinson Hospital
30 Locust Street (Rte 9)
Northampton, MA
Phone: 413-582-2000

Martha's Vineyard Hospital
1 Hospital Road
Oak Bluffs, MA
Phone: 508-693-0410

Wentworth-Douglass
789 Central Ave
Dover, NH
Phone: 603-742-5252

Other Community Labs

Hawthorne Medical (*Must have Hawthorne Medical PCP*)

Call for location or visit website
www.hawthornmed.com
Phone: 508-996-3991

Quest Diagnostics

Call for location or visit website
www.questdiagnostics.com
Phone: 866-697-8378

CARING FOR YOURSELF AFTER TRANSPLANT

Caring for Yourself After Transplant

In this section, we will address some of the common and most frequent concerns that come up after an organ transplant:

- **Graft or Organ Rejection**
- **Infections**
- **Cancer**

Other health conditions may arise as a result of medications you need to take or some condition you had before your transplant. Your team will be monitoring you carefully and adjusting your medicines as needed. If you have any other concerns about your health or transplant, discuss them with your transplant team.

Graft or Organ Rejection

What is Rejection?

Rejection occurs when your immune system attacks your new organ, which is a natural response. Your immune system is "programmed" to fight foreign invaders in your body such as viruses, bacteria, and, unfortunately, your new organ. Rejection doesn't mean the organ is lost, just showing evidence of this attack, and this is almost always reversible with more medication when detected in a timely manner. That is why rejection is described as an "episode".

How can I prevent Organ Rejection?

Antirejection medications weaken the immune system. Therefore, the best way to prevent rejection is to take all medicines in the way your doctor prescribed them - the right amount, at the right times. Don't miss a single dose. The Transplant Team can help you with tips to help you remember your medicines. If you have problems getting your medications or if you miss more than one dose, contact a member of your transplant team right away. It is also important to keep your clinic and blood test appointments because there may be signs of rejection before you notice any symptoms of rejection.

What to Do if Rejection Occurs

Rejection can usually be reversed if it is recognized and treated early. Some patients feel ill with aches or fevers or other symptoms (as in the table below), yet most do not have symptoms, only lab tests showing it. A piece of tissue ("biopsy") may be obtained to determine if a rejection episode has occurred. This is done by examining the biopsy tissue under a microscope (pathology). Based on how the tissue looks, your transplant team will determine if and how to treat it.

| Organ | Some Warning Signs of Rejection |
|-----------------|---|
| Kidney | <ul style="list-style-type: none"> • Pain over the graft site • Fever • Flu-like illness such as chills, nausea, aches and pains, vomiting, tiredness • Little or decreased urine output • Weight gain or swelling of ankles or legs or feet • Protein in the urine • Development of antibodies to the kidney (this is a special test sometimes done after transplant) • Increasing creatinine • Bloody Urine • Sudden increase in blood pressure |
| Liver | <ul style="list-style-type: none"> • Fever • Flu-like illness such as chills, nausea, aches and pains, vomiting, tiredness • Itching • Yellowing of eyes or skin • Light-colored stools or darker colored urine (tea-colored) • Weight gain or swelling |
| Pancreas | <ul style="list-style-type: none"> • Abdominal pain or at surgical site • Fever • Increased blood or urine glucose (diabetes) • Swelling of the belly • Increased urination • Abnormal blood sugar or Hemoglobin A1c |

Vaccinations After Transplant

Vaccines offer important protections to prevent infections. After a transplant, you **should not get any vaccine that contains a live virus**. Vaccines that contain “live” virus, include:

- Chickenpox/varicella
- Mumps/measles/rubella
- Yellow fever
- Smallpox
- Intranasal Influenza (FluMist)
- BCG
- Oral polio (only given in foreign countries)
- Live oral typhoid Ty21a



- Rotavirus
- Anthrax

Talk to your doctor if someone in your house is going to receive a live virus vaccine if you have not already been vaccinated.

The routine vaccines recommended for all transplant patients are as follows:

- COVID- 19- stay up to date with boosters as per CDC guidelines
- Please wait 3 months after your transplant to receive any COVID-19 vaccines
- Seasonal Influenza (Flu) Vaccine (injection): receive yearly, beginning at least 3 months after transplant. Transplant patients must receive the flu shot, not the nasal mist. The ideal timing for a flu vaccination is October or November to best protect you over the high-risk flu season from late December through March.
- Pneumococcal Polysaccharide Vaccine (PCV20): every 5 years beginning no sooner than 6 months after transplant. If you received PVC13 and Pnuemovax before transplant you could also be considered up-to-date.
- TDaP: (tetanus, diphtheria, and pertussis/whooping cough): every 10 years beginning no sooner than 6 months after transplant.
- Shingrix (Recombinant Zoster): the new shingles vaccine is not live and can safely be given to transplant patients who are at least one-year post-transplant, if not given before transplant.
- Respiratory Syncytial Virus or RSV (Arexvy or Abrysvo): if you are 60 years or older *and* more than one-year post- transplant, you should receive. One dose provides protection against RSV disease for at least two winter seasons.

If you plan on traveling outside of the US, you will need to be seen in the MGH Travel and Immunization Clinic where they will review food/ water safety, what to do if you become ill, travel activity consideration and provide any vaccines necessary for infection protection. Please call their office to make an appointment @ 617-724-0082. Call or message the transplant clinic or MGH ID clinic if you have any additional questions about vaccine safety.

Dental Care

Good dental hygiene is very important after your transplant, please follow the guidelines below:

- Brush your teeth after each meal and at bedtime.
- Floss your teeth gently every day.
- Examine your mouth every day and call your doctor or nurse if you see sores, blisters, or white spots.



In addition to good dental hygiene, we advise you to visit your dentist every six months.

Make sure the dentist knows what anti-rejection medications you are taking before he or she does any dental work.

Please do not plan any routine dental work until six months after your transplant operation. Urgent dental work (for example, for a dental abscess) can be performed in the first 3-6 months post-transplant but the dentist should notify transplant team for guidance in case antibiotics are needed. Transplant patient do not generally require antibiotics when they visit the dentist for routine care unless they have a history of heart valve problems, or some other risk of infection related to the heart.

Skin and Hair Care

Transplant medications can cause changes to your skin, such as acne, warts and dryness. In addition, your hair may become thicker or thinner, depending on which anti-rejection medications you take. Be sure to mention any troubling symptoms to the team, and do not use any new medications without checking in with them first.

Skin Cancer Prevention

The use of anti-rejection medicines increases your risk of developing skin cancer by 20-fold. This is especially true if you are light skinned and have had a lot of sun exposure in your life. Some skin cancers can be avoided, so efforts should be made to prevent them. Some things you can do to prevent skin cancer include:

- Avoid spending long periods of time in the sun without the protection of sunscreen, a hat, long sleeves, long pants and sunglasses.
- Limit the time you spend in the sun, especially when the sun is most intense between 10:00 am and 2:00 pm.
- Wear sunscreen SPF 45 or higher. Be sure you reapply frequently especially after you go in the water or if you have been perspiring. Do not try to get a tan.
- Wear a wide-brimmed hat and gloves.
- See a dermatologist every year after your transplant.



Most skin cancers can be cured if detected early so it is very important to recognize the early signs of skin cancer and seek treatment if you notice anything unusual. You can follow the American Cancer Society's "ABCD" rule for checking your skin for possible cancer:

- Asymmetry: one side of the birthmark or mole is different from the other
- Border: the edges are ragged, notched, irregular or blur red
- Color: the color is not uniform and there may be shades of black or brown, with patches of red, white or blue
- Diameter: the spot is bigger than a pencil eraser (6 millimeters across) or is growing



All transplant patients should be seen by a dermatologist within the first year after transplant, and then on a regular schedule as recommended by the dermatologist. See a dermatologist immediately if you notice any of the above. The MGH High Risk Skin Cancer Clinic is available at 617-726-6097.

Other Health Screenings

You should be sure to follow the advice of your primary care physician for routine health screenings such as colonoscopy, mammography, prostate exams, and other lab tests. These recommended screenings apply to transplant recipients as well as the general public.

Annual screening for lung cancer with low-dose computed tomography is recommended in adults aged 55 to 80 years who have a 30 pack-year smoking history and currently smoke or have quit within the past 15 years.

Monthly breast self-exam is important for all women, and mammograms are advised at age 40 and then every year. Women should also have a Pap smear once a year and an annual gynecologic (GYN) examination. HPV viruses can cause cervical cancer and skin warts. These can occur more frequently after transplantation.

Men who are age 40 and older should have a physical every year, and it should include a screening for prostate cancer. A monthly testicular self-exam is also important. Be sure to contact your doctor if you see or feel any abnormal or unusual lumps.

Dealing with Your Emotions

Most transplant recipients look forward to their transplants as a chance to return to normal, everyday activities. Indeed, most transplant recipients experience great happiness as their new organ begins to work and have a great sense of physical and emotional well-being. Despite these good feelings, some people find the adjustment to their new organ more difficult than they had expected. Here are some of the common concerns we hear about and some suggestions about how you manage them best:

Getting back to normal

Keeping track of a whole new set of medications is not easy. The immunosuppressive drugs are so important, and it can be stressful if people feel they are having physical or emotional changes from the new medications they must take. Write down the feelings you are concerned about so you will remember to tell your team about them when you come for your visit. Do not hesitate to reach out to your team with these feelings early. Sometimes a small change in the dose of medication can make all the difference.

You may have concerns about how your transplant is affecting your family members and their adjustment to your new needs. The recovery process may seem too slow or too confusing. People who have been quite ill prior to their transplant will need more time for recovery. This can cause feelings of anxiety and depression because they feel they are not making progress. These feelings usually resolve as they see their health improving. At times,

patients may also find they are worrying about how other transplant patients they know are doing. *These concerns are quite normal.*

Life after transplantation will be different. This might affect your ability to deal with issues at home, at work, and at times, your ability to work with your transplant team. Getting back to normal routines can take up to one year after a transplant. Every family is unique in their needs and resources. Be sure to reach out to any member of your care team with your concerns so they can connect you to the resources available at MGH or in your community.

Concern for Donors

Living donors

Some transplant recipients have a liver segment or kidney donated by a living family member or friend. This may create different concerns for recipients than if there was an anonymous donor. Living donors will still need a period of recovery after surgery. On occasion, a living donor may have a complication after surgery. This could result in the “sick” family member who has the transplant being discharged from the hospital before the “well” donor. Although the health care expenses will be covered, other concerns may arise due to lost time at work and the need to shift family roles and responsibilities.

Donors will also have their own emotions after organ donation. The wonderful feeling of saving a life may wane. If there are surgical complications, recipients may feel guilty for causing these problems for another. On the other hand, as time goes on, the donor may be very watchful and invested in how the recipient is taking care of themselves. Talking openly about these feelings, without judgment, will be important to reduce unnecessary tension in relationships.

Deceased Donors

Transplant recipients often express feelings of curiosity and concern about the donor who provided their organ. Patients and families can give thought to what they feel they want to know and what they would like to do. Sometimes transplant recipients choose to write to their donor family to express gratitude although this is a personal choice.

Donor families also have different feelings about correspondence from transplant recipients. Many donor families do appreciate a card or personal note from the recipient(s) of their loved one's organs and/or tissues. It offers them some comfort and consolation. Some also like an opportunity to write and tell you about their loved one; others choose not to respond.

New England Donor Services (NEDS) has a process to support written correspondence between transplant recipients and donor families. If you choose to send a card or letter, NEDS will help manage this process in a sensitive and confidential manner for all parties involved. Recipients writing a card can remain anonymous or include any identifying information they wish. NEDS no longer restricts this. More details about this process can be found on the next page.

Writing to the Family of My Donor

Our Aftercare Services team supports donor families following their loved one's donation. We are also here to help YOU by facilitating communications and connections between transplant recipients and donor families.



The decision to correspond with your donor's family is a personal one. Donor families often welcome and appreciate communication. There are no wrong words; even a simple thank you can be greatly appreciated.

You may wish to keep identities anonymous and confidential. If you do choose to include your personal contact information within your card or letter, it will be forwarded along to the donor's family to use at their discretion.

"To a recipient I would say—don't worry about finding the right words. Our grief is real, no words you can write will make it worse - they can only make it better. Speak from your heart. We only wish to know that you are better, that your life has improved...those are the words that give us comfort."

— Mother of a donor

How do I begin?

We encourage you to write what you feel comfortable sharing about yourself and other family members. Here are some of our most commonly used phrases:

"Dear Donor Family"

"I offer my condolences for the loss of your loved one."

"I would like to offer my sincere gratitude for the gift of life."

"Please know I am forever grateful for the second chance this gift has given me."

How do I send my card or letter?

Correspondence can be sent to us to share with your donor's family via regular mail, email or online.

Regular Mail:

Place your card or letter in an unsealed envelope. On a separate sheet of paper that is used for internal purposes to connect you to the correct donor family, please write:

- Your full name and mailing address
- Transplant center
- Organ received
- Date of transplant

Then, mail your correspondence into our Waltham office.

Email:

Attach your correspondence and include all of the bullet points above within the body of your email to ac@neds.org

Online:

Visit caringconnectionseds.org/connect then follow the instructions to submit your correspondence online.

Will I hear back from my donor's family?

You may not hear back from your donor's family. Although they are often comforted by knowing how donation and transplantation has changed your life, they may not be ready to respond. When a donor family does make the decision to write, they tell us that writing to recipients and sharing their loved one's story helps them with their grief and healing.

What is your contact information?

New England Donor Services
60 First Avenue
Waltham, MA 02451
Attn: Aftercare Services

Phone: (781) 373-7945

Email: AC@neds.org

Web: www.caringconnectionseds.org

"I am glad I wrote so they will know that their loved one's gift is remembered, appreciated, and will be honored every day of my life. Each extra day I am able to spend with my family means the world to me."

— A grateful transplant recipient

If you would like further guidance about writing to donor families, please call Donor Family Services at New England Donor Services 1- 800-446-6362.

Available websites (check for other online communities)

- UNOS Transplant Living
- National Kidney Foundation
- American Liver Foundation

To assist you with writing to your donor family, MGH Transplant offers a donor writing table in our reception area with writing instructions, cards and a mailbox to deposit your correspondence. Please stop by and visit this table while you are in clinic.

General Health Management Tips

Here are some other things that you can do to stay healthy and manage any stress you experience during recovery.

- A well-balanced diet is also very important when you are feeling stressed ([see the Nutrition section](#)). Our levels of nutrients can be depleted when we are stressed which can cause us to be more vulnerable to infection.
- Move more. A good balance of activity and rest will also be helpful. Walking is especially important during the initial phase of your recovery. You may want to start an exercise program as you begin to feel stronger. Take time to talk with your team when you feel you are ready to start an exercise program. ([see the Activity section](#))
- Prioritize your sleep. Try to go to bed at consistent times every night (within 45 minutes is okay) and wake up around the same time every morning. Shut off all screens for at least an hour before bedtime.
- Manage stress: Consider different strategies for managing if you are start to feel overwhelmed by all the changes:
 - Deep breathing exercises: Many of us do not breathe take deep breaths when we are stressed. When we can slow ourselves down and take deep breaths, it helps us to activate a part of our nervous system that enhances relaxation. Try to have your exhale last twice as long as your inhale.
 - Meditation: Different smart-phone apps (including



HeadSpace, InsightTimer) include guided meditations that can be a great introduction for novices. If “meditation is not for” you, mindfully engaging in a quiet activity (e.g., walking, stretching, painting, knitting, prayer) can provide you with the benefits of relaxation.

- Take time to enjoy your small things: Think about the things you enjoy most. You may find you can spend more time enjoying nature, music or hobbies that might distract you while you are recovering.

Stay connected. Social distancing has become very important to reduce the spread of infection especially for Transplant patients. This physical distancing does not mean you have to disconnect from family members and friends. Virtual platforms (e.g., Skype, FaceTime, Zoom) can help you feel more connected and help reduce stress. Be aware that overusing these platforms and focusing on social media can also be stressful. A good balance will keep you from feeling isolated.

Sex and Sexuality

Any illness can be expected to affect sexual desire and function. Chronic disease and certain medications can affect the body, one's feelings of sexuality and interest in sexual relationships. After a successful organ transplant, this can change. Sexual activity is usually encouraged when you are feeling better. Typically, we recommend waiting about 4 weeks after your transplant before resuming sexual activity. If you are having any problems, feel free to discuss this with your team. Remember, you are not alone, and there are options available to help you and your partner.

Many viruses can be transmitted during sexual intercourse. Some of the viruses that are transmitted through sexual activity are: Cytomegalovirus (CMV), Human Immunodeficiency Virus (HIV), and Herpes Simplex Virus (HSV) and Human Papilloma Virus (HPV). There is now a vaccine against certain forms of HPV; discuss with your physician whether you should receive this immunization.

It is always important to remember to protect yourself against sexually transmitted diseases (STD). Transplant recipients are strongly encouraged to use condoms. Oral sex is discouraged if there is a chance of acquiring herpes, especially if the non-transplant partner has had herpes or "cold sores" previously.

Transplant recipients are at greater risk for infections because they are on immunosuppression medication. These infections can be treated easily with proper medication if recognized early. Be sure to let your transplant doctor know if you note any sores or ulcerations of the mouth, genital area, or anus.

Childbearing Concerns for Men & Women

Birth Control

Unless you are planning a pregnancy (see below), the transplant team recommends using a birth control method immediately after transplant because women may produce eggs two to six months after the transplant operation and before regular menstrual periods begin. Talk to your nurse or physician about the birth control that is right for you and your partner because it may be different from one woman to another.

If you are taking mycophenolate mofetil (Cellcept®) or mycophenolate sodium (Myfortic®) you should follow the guidance about contraception outlined below.

When taken during pregnancy, Cellcept® and Myfortic® can increase the risk of losing your baby within the first trimester. It can also increase the risk of birth defects. If you become pregnant while taking Cellcept® or Myfortic® do not stop taking your medication, call your doctor right away, they will have to change your Cellcept® or Myfortic® to a different medication.

Everolimus and Sirolimus cannot be safely used during pregnancy. If you are taking



these drugs, you must take steps to prevent pregnancy.

Important information for female patients of childbearing potential:

Women are considered to have childbearing potential if they have entered puberty, still have a uterus intact and have not entered menopause. Menopause should be confirmed by your doctor.

A pregnancy test will be done immediately before starting mycophenolate and repeated 8-10 days after the transplant. Pregnancy tests should also be repeated during routine follow-up visits with your PCP.

All patients who are of childbearing potential must use acceptable forms of birth control the entire time they are taking Cellcept® or Myfortic® as well as for 6 weeks after stopping. One of the following methods of birth control is advised.

1. The following methods can be used alone:
 - Intrauterine devices (IUDs)
 - Tubal sterilization (having your tubes tied)
 - Vasectomy of partner
2. A combination of hormone AND barrier methods can also be used. Consider choosing one method from each category:

| Hormone Method | | Barrier Method |
|---|--------------------|---|
| Estrogen & Progesterone | | <ul style="list-style-type: none"> ▪ Diaphragm with spermicide ▪ Cervical cap with spermicide |
| Estrogen and Progesterone <ul style="list-style-type: none"> ▪ Oral contraceptive pill ▪ Transdermal patch ▪ Vaginal ring Progesterone only <ul style="list-style-type: none"> ▪ Injection ▪ Implant | <u>PLUS</u> | <ul style="list-style-type: none"> ▪ Diaphragm with spermicide ▪ Cervical cap with spermicide ▪ Contraceptive sponge ▪ Male condom ▪ Female condom |

3. A combination of TWO barrier methods is also considered effective:

| First Barrier Method (choose one) | | Second Barrier Method (choose one) |
|---|--------------------|--|
| <ul style="list-style-type: none"> ▪ Diaphragm with spermicide ▪ Cervical cap with spermicide ▪ Contraceptive sponge | <u>PLUS</u> | <ul style="list-style-type: none"> ▪ Male condom ▪ Female condom |

If you are female and of childbearing potential, you will be given a booklet about the Mycophenolate REMs program before you leave the hospital. This booklet provides an overview of the REMs program and more details about your birth control options.

Thinking about having a baby?

Many kidney transplant recipients have successful pregnancies and healthy babies. Outcomes for the mother and the child are much better than they are for patients on dialysis who attempt pregnancy. However, the decision to have children is influenced by many factors, and together with your care team you can decide what is best for you. Prior to trying to become pregnant, discuss it with the transplant clinic and pharmacists so that your medication regimen can be adjusted to make sure it's what is safest for you and your baby. Each medication has specific risks to you and your baby that your pharmacist can go over with you. You should also consult with your OB/GYN provider to assure they can care for you during your pregnancy otherwise refer you to someone who can.



Pregnancy may be harmful to your transplant and to you if it occurs too soon after your surgery. Discuss a reasonable waiting time with your transplant physician. Men should wait until they are fully recovered from transplant surgery before fathering a child.

It is equally important for men to discuss the use of birth control measures with the transplant team since men may father children at any time. While some of the medications taken for immunosuppression may cause birth defects when used by the mother; it does not appear these medications are dangerous when they are used by the father and most transplant centers do not adjust immunosuppression in men who are trying to father a baby. It will be important to discuss this with your transplant team so that changes can be made if necessary.

If you discover that you are pregnant at any time after your transplant, please contact the transplant team as soon as possible.

The FDA has a labeling system that lets you know how safe a drug is during pregnancy and for your unborn child. Specific risks will be described in your medication package insert and include risks related to the following categories: Pregnancy (including Labor and Delivery; Lactation (including Nursing Mothers); Females and Males of Reproductive Potential. Please discuss these specific risks with your transplant providers

The Transplant Pregnancy Registry International (NTPR) is an ongoing research study focused on the effects of pregnancy on transplant recipients and the effect of immunosuppressive medications on fertility and pregnancy outcomes. Please visit their website @ <https://www.transplantpregnancyregistry.org/> to learn more or to participate in this study should you become pregnant or father a child.

NUTRITION

Healthy Eating for Organ Transplant Recipients

After transplant, healthy eating is important for healing and overall health. Eating a balanced diet and increasing your physical activity can help to maintain a healthy weight, keep your bones strong and lower your risk of developing heart disease, diabetes, or high blood pressure.

Additionally, the post-transplant diet is individualized; your team will discuss any specific modifications or recommendations with you. (For example, some transplant patients may need to restrict potassium).

What is a Healthy Diet?

- A healthy diet includes a variety of foods
- Includes regular intake of fruits, vegetables, whole grains and dairy products
- Includes lean meats, poultry, fish, beans, eggs, and nuts
- Is low in saturated fats, salt (sodium), and added sugars

Step #1: Balance your Plate and Reach a Healthy Weight

Following your transplant, you may notice an improved appetite and your diet may be less restricted, allowing you to eat many foods that were limited before. While that is good news, it is important not to overeat. Having a balanced plate will help satisfy hunger, control calorie intake and provide your body with required vitamins and minerals.

When planning your plate:

- Make half of your plate fruits and vegetables
- Incorporate more colorful fruits and vegetables – use red, orange, and dark green vegetables into your main and side dishes
- Choose whole grain breads, pastas and brown rice most often
- Enjoy more fish
- Eat more beans and lentils, which are a natural source of fiber and protein
- Keep meat and poultry servings lean and trimmed of fat
- Include dairy products such as milk or yogurt daily



Step #2: Watch your salt intake

A low sodium diet is healthy for everyone. Transplant patients who eat too much salt may experience fluid retention and increased blood pressure. Most foods contain salt so even if you never touch the saltshaker, you are at risk of eating too much salt.

To reduce your salt intake:

- Choose more fresh foods and unprocessed meals – cook more homemade meals “from scratch”
- Limit dining out – fast foods and restaurant meals often contain too much salt
- Reduce intake of processed foods such as cold cuts, sausages, pickles, hot dogs, packaged pasta, rice mixes, sauerkraut, canned or dry soups, soy sauce, bacon, and canned vegetables
- Avoid adding salt in cooking or at the table. Instead, try other seasonings like pepper, garlic and onion powder, fresh or dried cooking herbs, lemon, vinegar or other salt-free seasonings.
- Limit foods with visible salt such as chips or crackers
- Read food labels and select foods that have less than 140mg sodium per serving.

Step #3: Eat less sugar

Diabetes is more common in transplant patients than in the general population. You can reduce your risk of diabetes and control blood sugar levels by maintaining a healthy weight, eating a balanced diet, and keeping active. Dietary Guidelines for Americans (2015-2020) suggest that less than 10% of your daily calories should come from added sugar.

For example:

- Limit simple sugars— candy, sweetened beverages, and dessert
- Limit juices and choose fresh fruit instead
- Drink sugar-free beverages or water; avoid sweetened beverages such as soda, sweetened coffee or tea, lemonade, or sports drinks
- Choose whole grain breads, rice, and pasta rather than white or processed products.

Step #4: Choose healthy fats

The amount and type of fats should be controlled in your diet after transplant. This will help to lower the risk of heart disease, stroke, and other blood vessel problems.

- Reduce the amount of fat or oil you use and choose heart-healthy fats (e.g., olive oil)
- Healthy fats such as monounsaturated and polyunsaturated fats are “heart healthy” and help decrease levels of bad cholesterol and increase good cholesterol. Healthy fat sources include fish, nuts, seeds, olives, avocados, olive oil and canola oil.
- Limit consumption of saturated and trans-fat, which increase bad cholesterol. Saturated fat is found in high-fat animal products such as whole milk, full-fat cheese, and red meat. Trans fats are found in fried foods and processed foods such as cookies, donuts, and crackers
- Select lean meats, chicken and fish or beans, peas, nuts, or seeds
- Cook using low-fat methods such as baking, broiling, grilling, or steaming. Avoid frying foods.
- Choose fruit or low-fat dessert instead of high-fat-sweets
- Increase fiber in your diet by choosing whole fruits and vegetables and whole grain

Step #5: Keep your bones strong

Transplant patients, particularly kidney transplant recipients, are at increased risk of bone loss and fracture. Children with transplants need adequate calcium for bone growth.

- Include milk, yogurt, and cheese in your diet regularly.
- Choose leafy greens, beans, and nuts
- Check with your doctor about taking calcium and vitamin D supplements

Step #6: Avoid grapefruit, pomegranate, starfruit, and pomelo

If you take tacrolimus, cyclosporine, everolimus or sirolimus, you should avoid grapefruit, pomegranate, starfruit and pomelo and any juice blend, seltzers or sodas that contain these fruits (e.g., Fresca) as they may affect the way your transplant medicine works.

Step #7: Follow food safety guidelines

Anyone can get a food-borne illness (“food poisoning”) and transplant patients may be more at risk because of immunosuppressive medications. It is important to follow proper food safety guidelines.

- Wash your hands before handling food

- Avoid raw and undercooked meats, seafood (including raw fish like sushi, raw clams, and raw oysters), eggs, and unpasteurized dairy products
- Wash all fresh fruits and vegetables with cold running water before cooking, peeling, or eating. Fruits and vegetables do not need to be peeled if they are carefully washed.
- Keep cold foods cold and hot foods hot
- Avoid salad bars, buffets, and self-serve areas
- Thaw all foods in refrigerator or microwave
- Use a separate cutting board for raw meats, poultry, and seafood
- Avoid undercooked meats, raw sprouts, *unpasteurized* dairy (including cheese, milk, and yogurt), raw juice, raw eggs, foods from street vendors, and foods that are spoiled or moldy
- Cook beef, chicken, turkey, fish, seafood, and eggs until well done. Use a meat thermometer to confirm that a safe cooking temperature has been reached.
 - Poultry: heat to temperature = 165 degrees Fahrenheit
 - Beef, veal, pork, lamb = 145 degrees Fahrenheit
 - Ground meats or poultry = 165 degrees Fahrenheit
 - Casseroles, dishes containing eggs = 160 degrees Fahrenheit
 - Fish = 145 degrees Fahrenheit
 - Leftovers = 165 degrees Fahrenheit.
 - Shellfish= If still in the shell boil the shellfish until the shells open and for an additional 5 minutes. If the shellfish doesn't open, do not eat it. If already shucked, boil for at least 3 minutes, bake at 450F for 10 minutes, or broil for 3 minutes.
- All foods from restaurants should be made fresh to order. Hot foods should be served steaming hot and cold foods should be served cold.

Step #8: Treat Treats as Treats

Saving your favorite treat for a special occasion will make sticking to a healthy diet easier. Avoid letting dietary indulgences become part of your normal routine.

- For example: it is ok to have a small piece of cake at a birthday party but having cake every night after dinner for dessert will likely result in weight gain.

Consider what your nutrition goals are:

ACTIVITY

Post-Transplant Activities

After having surgery and being in the hospital, you may feel more tired than you expect when you go home. It may be helpful to give yourself more time and to spread your activities throughout the day during your recovery.

Here are some general tips for pacing your activity:

- Plan your day ahead of time. Decide which activities/tasks are the most important to you. Do these tasks first but spread them out throughout the day. Less important tasks can wait or be completed by someone else.
- Do not rush. Allow enough time for each activity to avoid becoming too tired.
- Stop activity before you are overtired. Schedule rest periods or naps to help recharge yourself.
- Ask family and friends to help with tasks or activities that may be too tiring for you. You may want to choose one person to organize help when others offer. It can take a lot of energy to think, plan, and respond when others are reaching out to you.
- Standing takes more energy than sitting. Use a shower chair and hand-held showerhead to bathe or sit at the counter to prepare meals.
- Do not lift anything greater than 10 pounds for 6-8 weeks after transplant.
- Store more frequently used items at chest height to avoid bending and stretching in the kitchen, bathroom, or bedroom.
- Work done with your arms takes more energy than work done with your legs. Let dishes soak in the sink instead of scrubbing.
- Use wheels to move things. For example, use a shopping cart for your groceries, put your laundry in a cart.
- Arrange your work schedule to take advantage of peak energy times. If possible, try to work from home to reduce fatigue.

There may be days when you feel better and are progressing but there will likely be other days when you feel tired. Managing your activity and building strength over time will be most helpful.

Exercise: Start slowly with a progressive walking program (see following “Exercise” section for details). Your nurse or physical therapist can give you guidance and answer any question you might have about this.

2 to 6 Months after Transplantation:

- Progress your exercise routine in consultation with your physical therapist and/or doctor. This should include stretching, light weightlifting, and aerobic activity.
- If you're returning to work, you should find out about their expectations for you and set realistic expectations for yourself. You may want to start part-time and gradually progress to a full-time schedule.
- Do daily self-exams by weighing yourself, taking your temperature, and checking your blood pressure. Call your transplant team if you notice major changes.

6 Months to a Year after Your Transplant:

- Exercise regularly to stay healthy, improve your quality of life, and increase bone strength. Exercise also helps keep your weight down, which is important for preventing other illnesses such as heart disease and diabetes. Controlling your weight after transplantation can be one of your most difficult jobs.
- If you find that you're having trouble coping with situations that can cause stress, anxiety, or depression (for example, changing jobs, moving, marriage, divorce, birth, death), call your transplant social worker for help.
- Continue doing daily self-exams by weighing yourself, taking your temperature, and checking your blood pressure if you have been instructed to do so. Call your transplant clinic for significant changes.
- You will need to resume regular dental and eye exams, pelvic or prostate exams, mammograms, and other routine health exams

Exercise and Physical Therapy

Benefits of Exercise and an Active Lifestyle

Patients who have been very sick or waiting for a transplant for a long time often have lost strength and endurance. Starting an exercise program will help to reverse these effects. Talk to your transplant team members about getting help with an exercise program or using new equipment. It may be helpful to see a physical therapist.



After your transplant you will be taking several medications to help prevent your body from 'rejecting' your new organ. Long-term use of many of these medications may result in an increased risk of developing other health related problems such as hypertension, weight gain, muscle weakness, osteoporosis, and diabetes.

Research has shown that a regular aerobic and strength training program can do the following:

- Improve your ability to sleep
- Contribute to better bone health
- Improve your fitness level
- Improve your cholesterol
- Help lower blood pressure
- Control blood sugar
- Help control weight
- Increase muscle mass
- Disease prevention
- Delay or reduce effects of arthritis
- Improve strength and flexibility
- May help increase concentration
- Reduce feeling of stress, anxiety, and depression
- Lead to living a longer and healthier life

There are five different parts of an exercise program, including:

1. Warm Up: 3-5 minutes of light activity to prepare your body for exercise

The warmup gradually increases your heart rate and body temperature. This helps protect your body from injury and prepares the muscles and joints for exercise. .

It is very important that all transplant recipients get into a regular exercise regimen!

2. Strength Training: Exercises that increase muscle strength

Increasing muscle strength has many potential benefits including:

- Decreasing risk of injury
- Decreasing pain from arthritis
- Combatting long-term side effects of transplant medications
- Increasing bone mass, which can delay onset of osteoporosis
- Decreasing body fat, which can lead to weight loss

We recommend doing a combination of upper body, lower body and trunk exercises (for example- lifting weights, using resistance bands). Do 2 sets of 8-12 repetitions of each exercise, every other day. Start with low weights and gradually increase the weight while maintaining correct lifting techniques. Please call your care team for guidance.

NOTE: Depending on the location of your incision, your physician may ask you to delay your strength training or stretching exercises until your incision has healed.

3. Aerobic Exercise: Exercise to improve overall cardio-respiratory fitness

Aerobic exercise can decrease the risk of cardiac disease and other chronic health conditions. It also increases your endurance, so you can return to your everyday activities. Examples are walking, cycling, running, dancing. Try to build up to 30 minutes a day, 5-7 times per week.

4. Cool Down: 3-5 minutes of slower activity to allow your body to return to rest

A cool down decreases risk of muscle soreness and tightness, likelihood of irregular heartbeat, chance of low blood pressure, and dizziness after exercise.

5. Stretching

It's best to stretch your arms and legs after exercising. Stretching can also improve posture. After surgery, stretch until you feel a pull, but it should not be painful at your incision.

Pace Yourself! It is important to pace yourself with exercise by monitoring how hard you are working. It is best to exercise at a moderate or medium level of intensity. This is important for all exercise, including an aerobic or strength training program. There are different ways that you can monitor this, and you can discuss these with the physical therapy team.

Stop your activity if you have any of these signs:

- Chest or arm pain
- Dizziness or lightheadedness
- Excessive sweating or breathlessness
- Palpitations or abnormal heart feelings

Staying with your Exercise Program

- Begin a new exercise program slowly to avoid injury
- Avoid extremes of temperature (hot or cold)
- Rest if you have pain or swelling (let your doctors know!)
- Consider exercising at the same time each day to establish a routine
- Wear comfortable clothes and supportive shoes
- Exercise with others to help motivate you
- Keep an exercise log and reward yourself when you reach your goals
- Vary your exercise program if you get bored
- Choose activities that you enjoy

How can I increase my daily activity level?

- Park further from the grocery store entrance
- Take an extra lap or two around the mall
- Clean your own house
- Rake the leaves or mow the lawn
- Take the stairs instead of the elevator
- Take a walk before you eat lunch
- Walk down the hall to speak with someone instead of using the phone
- Walk or bike when running local errands
- Plan active outings with your kids
- Walk the golf course instead of using a cart
- Dance regularly with your partner or alone
- Use a wearable activity device and try to walk 10,000 steps each day

Tips to Avoid Injury

- Listen to your body: stop if it hurts!
- Monitor your level of fatigue or exertion to avoid muscle soreness
- Start a new exercise program slowly
- Drink plenty of fluids while exercising and throughout the day (unless on fluid restrictions)
- Allow enough time to warm up and cool down
- Wear appropriate clothing for the activity and weather conditions
- If you are diabetic, ensure you monitor your sugars closely and have a snack on hand, if needed.

SPECIFIC MEDICATION INFORMATION

Tacrolimus

What is tacrolimus?

Tacrolimus is an immunosuppressant (anti-rejection medication).

Are there other names for tacrolimus?

Yes, Prograf, Astagraf XL® and Envarsus® are all different formulations of tacrolimus

How do I take tacrolimus?

Tacrolimus should be taken twice a day 12 hours apart. There are new long-acting versions of tacrolimus called Envarsus® and Astagraf XL®, these versions are taken once a day in the morning. You should take your tacrolimus at the same time each day with the same types of foods to maintain a steady blood level. The tacrolimus blood level (called a trough level) is monitored on a regular basis and your dose is changed if the levels are too high or too low. On days that you have scheduled blood work, it is important to remember to take your tacrolimus with you to the lab, so you can take it after your blood is drawn.

You will continue taking the same dose until someone calls you and tells you to change it. You will only receive a phone call if you need to change your tacrolimus dose. If you do not receive a phone call you should assume that your tacrolimus dose does not need to be changed.

You should not drink alcohol when taking Astagraf XL. It can increase your risk of side effects and affect your drug levels.

What do I do if I miss a dose of tacrolimus?

If you miss your dose of twice daily tacrolimus, do not take two doses of tacrolimus within 6 hours of each other. If you remember to take your dose and your next dose is due within 6 hours, take your missed dose immediately and push your evening dose back 6-8 hours after you take your late morning dose.

Example: If you normally take your tacrolimus at 8am and 8 pm, you remember at 4pm that you forgot your 8 am dose. You should take your 8 am dose at 4:00pm. You will now push your 8pm dose back to 10pm or a little later if possible. You will then resume your 8am / 8 pm schedule the next day. You want to remember to always keep at least 6-8hours between tacrolimus doses and not to skip a dose because you remember to take it too late.

If you miss your dose of Astagraf XL®, it should be taken as soon as possible, but no longer than 14 hours after your regularly scheduled time. If it is longer than 14 hours, the missed dose should be skipped and the next dose should be taken the following morning at your regularly scheduled time. Do not take 2 doses at the same time.

If you miss your dose of Envarsus XR®, it should be taken as soon as possible, but no longer than 15 hours after missing your dose. If the time after you miss your dose is more

than 15 hours, the missed dose should be skipped, and the next dose should be taken the following morning at your regularly scheduled time. Do not take 2 doses at the same time.

If you have questions about what to do if you miss a dose call your transplant coordinator.

Is tacrolimus available in a generic formulation or any other formulation that I should be aware of?

A generic formulation of tacrolimus is available. In addition, there are versions of tacrolimus called Astagraf XL[®] or Envarsus[®] which only need to be taken once a day. At this time Astagraf XL[®] or Envarsus[®] are not available in generic form.

If you notice that your tacrolimus looks different, call your transplant coordinator, we will want you have you blood levels checked 5-7 days after your pharmacy switches you to a different generic.

What kind of side effects could I have while taking tacrolimus?

Some people are by bothered by the following symptoms that they may feel while taking tacrolimus. If you are experiencing any of these symptoms, be sure to discuss this with your team members:

- Headache
- Tremors
- Hair loss
- Tingling in hands/feet
- Bone or joint pain
- Confusion

Immunosuppression can always increase risk of infection. Any signs or concerns about developing and infection such as fever, sore throat, and/or urgent or painful urination should be taken seriously. Your team will be on alert for any signs that the drug may affect your urine output and kidney function, any stomach pain, diarrhea, nausea and vomiting. They will also be watching to be sure there is no evidence of seizure activity or increases in blood sugar or blood pressure.

Cyclosporine

What is cyclosporine?

Cyclosporine is an immunosuppressant (anti-rejection medication).

Are there other names for cyclosporine?

Yes, Neoral, Gengraf or Sandimmune

How do I take cyclosporine?

Cyclosporine should be taken twice a day 12 hours apart. You should try to take it at the

same time each day with similar foods to maintain a steady blood level. Cyclosporine blood level (called a trough level) is monitored on a regular basis and your dose is changed if the levels are too high or too low. On days that you have scheduled blood work, it is important to remember to take your cyclosporine with you to the lab, so you can take it after your blood is drawn. The capsules should be swallowed whole and not opened, crushed or chewed. Sandimmune® liquid may be mixed with room temperature milk, chocolate milk or orange juice. Neoral® liquid may be mixed with room temperature orange or apple juice. Only mix your cyclosporine in a glass container, do not use Styrofoam or plastic. Never mix your cyclosporine with grapefruit juice. Stir well and drink at once. To make sure you get the full dose, rinse the glass with more liquid and drink that too.

There may be an odor when you open the capsule package. This is normal. Once cyclosporine capsules are removed from the packaging, they are only good for 7 days, for this reason we ask that you only fill your pill box for one week at a time.

You will continue taking the same dose until someone calls you and tells you to change it. You will only receive a phone call if you need to change your cyclosporine dose. If you do not receive a phone call you should assume that your cyclosporine dose does not need to be changed.

What do I do if I missed a dose of cyclosporine?

Do not take two doses of cyclosporine within 6 hours of each other. If you remember to take your dose and your next dose is due within 6 hours, take your missed dose immediately and push your evening dose back 6-8 hours after you take your late morning dose.

Example: If you normally take your cyclosporine at 8am and 8 pm, you remember at 4pm that you forgot your 8 am dose. You should take your 8 am dose at 4:00pm. You will now push your 8pm dose back to 10pm or a little later if possible. You will then resume your 8am / 8 pm schedule the next day. You want to remember to always keep at least 6-8hours between cyclosporine doses and not to skip a dose because you remember to take it too late.

If you have questions about what to do if you miss a dose, call your transplant coordinator.

Is cyclosporine available in a generic formulation or any other formulation that I should be aware of?

There are multiple types of cyclosporine available, you should always know which formulation you should be taking. The two different brand names of cyclosporine are Sandimmune® or and Neoral®. There are different generic options for Neoral®, one is called Gengraf® and the other is modified cyclosporine. Generic preparations of Neoral® are ok to take as long as your transplant doctor knows what formulation you are on and you do not change between formulations. It is not ok to take generic cyclosporine if you are supposed to take the generic modified cyclosporine. Always look at your cyclosporine box to ensure that the word “modified” is present if you were started on a “modified” product at the time of your transplant.

If you notice that your cyclosporine looks different, call your transplant coordinator-we will want you have your blood levels checked 5-7 days after your pharmacy switches you to a different generic.

What kind of side effects could I have while taking cyclosporine?

Some people are bothered by the following symptoms that they may feel while taking cyclosporine. If you are experiencing any of these symptoms, be sure to discuss this with your team members:

- Headache
- Tremors
- Hair growth
- Swelling in your gums or overgrowth of gums
- Tingling in hands/feet
- Bone or joint pain
- Confusion

Immunosuppression can always increase risk of infection. Any signs or concerns about developing and infection such as fever, sore throat, and/or urgent or painful urination should be taken seriously. Your team will be on alert for any signs that the drug may affect your urine output and kidney function, any stomach pain, diarrhea, nausea and vomiting. They will also be watching to be sure there is no evidence of seizure activity or increases in blood sugar or blood pressure.

Belatacept

What is belatacept?

Belatacept is an immunosuppressive (anti-rejection) medication. It is only approved for us in patients who have been exposed to Epstein-Barr virus, the virus that causes mononucleosis ("mono").

Are there other names for belatacept?

Yes, Nulojix®.

Is belatacept available in a generic formulation or any other formulation that I should be aware of?

There is no generic formulation of belatacept available.

How do I take belatacept?

Belatacept is injected into a vein. The infusion is given in a clinic or hospital setting and takes approximately 30 minutes to complete.

Belatacept can be started at the time of your transplant or at a later time if your doctor thinks your anti-rejection medication should be changed. Belatacept is given more frequently at a higher dose to start, then transitioned to monthly infusions. Your physician

or coordinator will discuss the schedule of the infusions with you.

What do I do if I miss a dose of belatacept?

There is a 3-day window around (before and after) the scheduled date to allow for missed doses.

The transplant clinic will schedule a separate infusion appointment for each of your doses. If you need to reschedule an infusion, please contact the transplant clinic.

What kind of side effects could I have while taking belatacept?

Some people are bothered by the following symptoms that they may feel while taking belatacept. If you are experiencing any of these symptoms, be sure to discuss this with your team members:

- Headache
- Loss of appetite
- Confusion

Immunosuppression can always increase risk of infection. Any signs or concerns about developing an infection such as fever, sore throat, and/or urgent or painful urination, should be taken seriously.

Mycophenolate Mofetil (MMF)

What is mycophenolate mofetil?

Mycophenolate mofetil is an immunosuppressant (anti-rejection medication).

Are there other names for mycophenolate mofetil?

Yes, Cellcept.

How do I take mycophenolate mofetil?

Mycophenolate mofetil should be taken at the same time each day to maintain a steady blood level. Most patients take it twice a day 12 hours apart. Your doctor may have you spread out your dosing to 3 or 4 times a day if you have trouble with nausea or diarrhea on a twice-a-day schedule. Do not make this change on your own or stop taking mycophenolate without first discussing it with your doctor.

We do not check a trough level for mycophenolate mofetil, so you may take this medication before you have your blood drawn.

What do I do if I miss a dose of mycophenolate mofetil?

If you miss a dose, you can take it as soon as you remember, just try to separate doses by at least 6 hours.

Is mycophenolate mofetil available in a generic formulation or any other formulation that I should be aware of?

Yes. If you receive a generic mycophenolate mofetil product that looks different than what you are already taking you should call your transplant coordinator.

There is another formulation of Mycophenolate called Mycophenolate sodium (Myfortic). Your pharmacy cannot give you Myfortic in place of your CellCept unless it is ordered specifically.

What kind of side effects could I have while taking mycophenolate mofetil?

Some people are bothered by the following symptoms that they may feel while taking mycophenolate mofetil. If you are experiencing any of these symptoms, be sure to discuss this with your team members:

- Nausea
- Vomiting
- Diarrhea
- Heartburn

Immunosuppression can always increase risk of infection. Any signs or concerns about developing an infection such as fever, sore throat, and/or urgent or painful urination should be taken seriously. Your team will be on alert for any signs that the drug may affect your blood counts.

Mycophenolate Sodium

What is mycophenolate sodium?

Mycophenolate sodium is an immunosuppressant (anti-rejection medication).

Are there other names for mycophenolate sodium?

Yes, Myfortic®.

How do I take mycophenolate sodium?

Mycophenolate sodium should be taken at the same time each day to maintain a steady blood level. Most patients take it twice a day 12 hours apart. Your doctor may have you spread out your dosing to 3 or 4 times a day if you have trouble with nausea or diarrhea on a twice-a-day schedule. Do not make this change on your own or stop taking mycophenolate without first discussing it with your doctor.

We do not check a trough level for mycophenolate sodium, so you may take this medication before you have your blood drawn.

What do I do if I miss a dose of mycophenolate sodium?

If you miss a dose, you can take it as soon as you remember, just try to separate doses by at least 6 hours.

Is mycophenolate sodium in a generic formulation or any other formulation that I should be aware of?

Yes. If you receive a generic mycophenolate sodium product that looks different than what you are already taking you should call your transplant coordinator.

There is another formulation of Mycophenolate called Mycophenolate Mofetil (Cellcept). Your pharmacy cannot give you Cellcept® in place of your Myfortic® unless it is ordered specifically.

What kind of side effects could I have while taking mycophenolate sodium?

Some people are bothered by the following symptoms that they may feel while taking mycophenolate sodium. If you are experiencing any of these symptoms, be sure to discuss this with your team members:

- Nausea
- Vomiting
- Diarrhea
- Heartburn

Immunosuppression can always increase risk of infection. Any signs or concerns about developing an infection such as fever, sore throat, and/or urgent or painful urination should be taken seriously. Your team will be on alert for any signs that the drug may affect your blood counts.

Sirolimus

What is sirolimus?

Sirolimus is an immunosuppressant (anti-rejection medication).

Are there other names for sirolimus?

Yes, Rapamune.

How do I take sirolimus?

Sirolimus should be taken at the same time each day to maintain a steady blood level. Most patients take it in the morning between 7 and 9 am. The sirolimus blood level (called a trough level) is monitored on a regular basis, and your dose will be changed if the levels are too high or too low.

On days that you have scheduled blood work, it is important to remember to take your sirolimus with you to the lab, so you can take it after your blood is drawn.

You will continue taking the same dose until someone calls you and tells you to change it. If you do not receive a phone call you should assume that your sirolimus dose does not need to be changed.

What do I do if I miss a dose of sirolimus?

Do not take two doses of sirolimus within 12 hours of each other.

Is sirolimus available in a generic formulation or any other formulation that I should be aware of?

There are a few available generic formulations of sirolimus available.

If you notice that your sirolimus looks different, call your transplant coordinator, we will want you have you blood levels checked 5-7 days after your pharmacy switches you to a different generic

What kind of side effects could I have while taking sirolimus?

Some people are by bothered by the following symptoms that they may feel while taking sirolimus. If you are experiencing any of these symptoms, be sure to discuss this with your team members:

- Pneumonia
- Mouth sores
- Rash
- Swelling
- Bone or joint pain
- Blood clots

Immunosuppression can always increase risk of infection. Any signs or concerns about developing and infection such as fever, sore throat, and/or urgent or painful urination should be taken seriously. Your team will be on alert for any signs that the drug may affect your blood counts.

Everolimus**What is everolimus?**

Everolimus is an immunosuppressant (anti-rejection medication).

Are there other names for everolimus?

Yes, Zortress.

How do I take everolimus?

Everolimus should be taken twice a day 12 hours apart. You should try to take it at the same time each day to maintain a steady blood level. The everolimus blood level (called a trough level) is monitored on a regular basis and your dose is changed if the levels are too high or too low. On days that you have scheduled blood work, it is important to remember to take your everolimus with you to the lab, so you can take it after your blood is drawn. Do not take two doses of everolimus within 6 hours of each other.

You will continue taking the same dose until someone calls you and tells you to change it. If you do not receive a phone call you should assume that your everolimus dose does not need to be changed.

What do I do if I miss a dose?

Do not take two doses of everolimus within 6 hours of each other. If you remember to take your dose and your next dose is due within 6 hours, take your missed dose immediately and push your evening dose back 6-8 hours after you take your late morning dose.

Is everolimus available in a generic formulation or any other formulation that I should be aware of?

Generic formulations of everolimus will be available in early 2020.

What kind of side effects could I have while taking everolimus?

Some people are bothered by the following symptoms that they may feel while taking sirolimus. If you are experiencing any of these symptoms, be sure to discuss this with your team members:

- Pneumonia
- Mouth sores
- Rash
- Swelling
- Bone or joint pain
- Blood clots

Immunosuppression can always increase risk of infection. Any signs or concerns about developing an infection such as fever, sore throat, and/or urgent or painful urination should be taken seriously. Your team will be on alert for any signs that the drug may affect your blood counts.

Azathioprine

What is azathioprine?

Azathioprine is an immunosuppressant (anti-rejection medication).

Are there other names for azathioprine?

Yes, Imuran.

How do I take azathioprine?

Azathioprine should be taken at the same time each day to remain a steady blood level. It may be taken once or twice a day depending on your dose.

We do not check a trough level for azathioprine, so you may take this medication before you have your blood drawn

What do I do if I miss a dose?

Do not take two doses of azathioprine within 6 hours of each other. If you remember to take your dose and your next dose is due within 6 hours, take your missed dose immediately and push your evening dose back 6-8 hours after you take your late morning dose.

Is azathioprine available in a generic formulation or any other formulation that I should be aware of?

Yes, it is unlikely that you will ever be prescribed brand name Imuran.

What kind of side effects could I have while taking azathioprine?

Most people are not bothered by side effects that they may feel while taking azathioprine.

Immunosuppression can always increase risk of infection. Any signs or concerns about developing an infection such as fever, sore throat, and/or urgent or painful urination should be taken seriously. Your team will be on alert for any signs that the drug may affect your blood counts.

Prednisone**What is prednisone?**

Prednisone is in the class of drugs known as immunosuppressants (anti-rejection medications).

Are there other names for prednisone?

Yes, Deltasone and steroids.

How do I take prednisone?

Prednisone is usually only taken once a day. It is best to take it with food because it can upset your stomach. It is also preferable to take your prednisone in the morning as it may cause difficulty sleeping if it is taken too late in the day.

We do not check a trough level for prednisone, so you may take this medication before you have your blood drawn

Is prednisone available in generic formulation or any other formulation that I should be aware of?

Yes, you will likely receive generic prednisone, not brand name Deltasone.

What kind of side effects could I have while taking prednisone?

Most side effects of prednisone are rare when the dose is <10 mg/day, which most transplant patients are taking within about 1 month of transplant. Some people may be more sensitive to the side effects of prednisone even at low doses. If you are experiencing any of these symptoms, be sure to discuss this with your team members:

- Swelling
- Elevated blood sugar
- Mood changes
- Changes in your vision
- Bone or joint pain

Immunosuppression can always increase risk of infection. Any signs or concerns about developing an infection such as fever, sore throat, and/or urgent or painful urination should be taken seriously. Your team will be on alert for any signs that the drug may affect your blood counts or vital signs.

SPECIFIC LAB TEST INFORMATION

Creatinine

The creatinine blood test is the single best blood test to gauge how well your kidney transplant is working. While a lower creatinine is associated with better kidney transplant function, a stable creatinine value is a sign your kidney is working well. Your creatinine will begin to fall after the transplant as your new kidney begins to work. If there is a major increase in your creatinine, or it stays high for a period, it may indicate a problem with the transplant kidney. In most cases, the creatinine improves and levels off within a few weeks or months after transplant.



- Possible causes of an elevation in creatinine include:
 - Dehydration
 - High levels of tacrolimus or cyclosporine levels
 - Low blood pressure
 - Blockade of kidney drainage
 - Allergic reaction to medication
 - Infection of the kidney
 - Kidney rejection among others

Keeping well hydrated is important to keep your kidney healthy and happy. We recommend you drink a minimum of 80 ounces of fluid (2 liters) per day, not including caffeine or alcohol. Discuss with your transplant nephrologist if you have been told you are on a fluid restriction.

To find about the cause of an elevated creatinine, your transplant team will examine you and assess your blood work, considering additional tests when necessary.

Liver Function Tests

Liver function tests (LFTs) are used to gauge how well your liver transplant is working.

The main LFTs we monitor are: ALT, AST, Alk Phos, and Bilirubin.

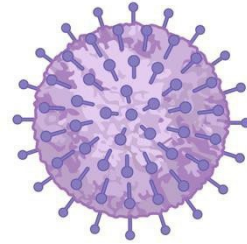
- A high ALT/AST could indicate that the liver is not working properly.
- Bilirubin (Total bilirubin and Direct bilirubin) is a waste product that is found in bile. A high bilirubin could indicate a problem with your liver.

Normal LFTs are associated with better liver transplant function. Your LFTs will begin to normalize after the transplant as your new liver begins to work. Once your baseline LFTs have been established, it is important to monitor it regularly for the life of your liver. A sudden increase on any given lab check above your baseline needs to be discussed immediately with the transplant clinic as it could be a sign of rejection or another problem with your transplant.

Epstein-Barr Virus (EBV) Monitoring

Background

Epstein-Barr Virus (EBV) is the virus that causes mononucleosis (“mono”), an infection that typically occurs in young people and includes fever, sore throat, and fatigue. On rare occasions, EBV affects the liver, lungs, or central nervous system.



If are not immune to EBV – that is, you have never been exposed, you may be at increased risk of getting the virus after transplant, particularly if the transplanted organ has the virus.

Epstein-Barr Virus After Kidney Transplant

After transplant, EBV can cause more serious disease than mononucleosis and can be associated with certain forms of lymphoma, which is why detecting it early is important. Mild EBV infection that doesn’t cause any symptoms at all.

Post-transplant lymphoproliferative disorder (PTLD) is a rare cancer of the lymphocytes that is caused by a virus. PTLD is related to immunosuppression and/or EBV, it can be treated by decreasing anti-rejection medications, taking anti-viral medications, surgical removal, or chemotherapy.

Preventing Epstein-Barr Virus Infection

You can prevent a new exposure to the Epstein-Barr virus with good hygiene and attention to handwashing. You should not share utensils with other people or drink from bottles or cans from which they have drunk.

There are no medications to prevent EBV infection, or to prevent the virus that may have come with your transplanted organ, from causing disease.

Monitoring for Epstein-Barr Virus Infection

Often low levels of the EBV appear in the blood prior to significant infection. In patients who have never had EBV but are at increased risk of getting it from the transplant organ, we monitor for EBV in the blood for six months after your transplant. Additional monitoring after six months may be indicated, as recommended by your transplant physician.

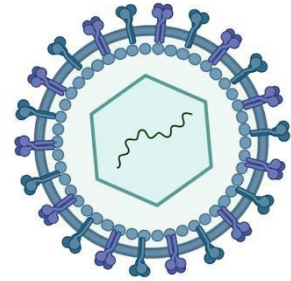
What if EBV is found in my blood on routine testing?

Your transplant physician and transplant coordinator will discuss the results with you and the plan to manage it. Most of the time, EBV can be successfully eradicated simply by reducing the dose and level of your immunosuppression. On occasion, the addition of other medications may be helpful.

Cytomegalovirus (CMV) Monitoring

Background

Cytomegalovirus (CMV) is a virus that causes symptoms like mononucleosis in patients with normal immune system. In transplant patients on immunosuppression, CMV infection can be asymptomatic or serious. Symptoms are non-specific and often include fatigue, stomach upset, or weakness. Symptoms typically come on slowly, usually not before 3 months after transplant. Blood tests may reveal inflammation of the liver, low white blood cell count, or other abnormalities.



You are at increased for CMV infection if blood tests show that you are not immune to the virus **and** you have received a donated organ with CMV.

Preventing CMV Infection

To prevent a CMV infection, most patients take Valcyte (valganciclovir) for three to six months after transplant. In patients who have trouble tolerating this medication, the transplant physician may recommend a strategy to monitor the blood for the virus every two weeks for approximately six months after the transplant.

After six months patients are still at risk for CMV infection, though this risk decreases over time. You will be monitored every 2 weeks between months 6-9 after transplantation.

Notify the transplant clinic if you have any symptoms that might be from CMV, such as fatigue or just 'not feeling well'.

Monitoring for CMV

After you finish six months of valganciclovir, you may need blood tests to detect low level CMV in your blood that is not yet causing any symptoms. Ask your transplant physician about this testing, particularly if you find that you aren't feeling as well as you did in the first six months after transplant.

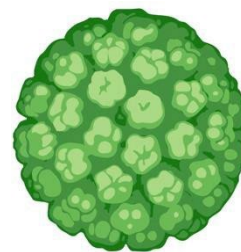
What if CMV is found in my blood?

CMV infection can almost always be treated. Low levels of CMV may come and go and the only intervention necessary may be additional monitoring. However, if more significant levels of CMV are detected in your blood, or if you have symptoms or evidence of CMV in your liver or other organs, you will need to be receive medications such as valganciclovir or even intravenous ganciclovir. Your immunosuppression may need to be adjusted to allow your immune system to fight the virus.

BK Virus Monitoring

Background

BK is a virus that most people are exposed to as children. In individuals with normal immune systems, the virus may cause mild cold symptoms or no symptoms at all.



In kidney transplant patients receiving immunosuppression to prevent rejection, the BK virus can reemerge in the transplant kidney and damage it. BK infection of a transplanted kidney can occur any time after transplant but is most common in the first two years. In transplant patients, BK virus almost never causes any symptoms. It is not contagious to family members.

Preventing BK Damage to your transplanted kidney

To help prevent BK from damaging your kidney transplant, your blood needs to be checked for the virus on a routine basis for two years following transplant. The BK blood test may also be checked if your creatinine (kidney blood test) rises above your baseline.

Monitoring for BK Virus

The level of BK virus in your blood will be checked every month for the first six months after transplant, then every two months beginning at month eight through month 24 (2 years).

Check the “Patient Gateway” website for BK virus blood test results. Ask the transplant clinic if you don’t see or understand the results. If you are following with your primary nephrologist at home, confirm that you are receiving the required BK virus monitoring. A result of <500 copies is considered a negative (normal) result.

What if BK virus is found in my blood?

Your transplant nephrologist and nurse will discuss the result with you and the plan to manage it. Most of the time, BK virus can be successfully eradicated by reducing the dose and level of your immunosuppression. On occasion, different medications are necessary.

Increased Risk Donor Monitoring

You were informed if risk factors were present in the organ donor prior to your transplant. Based on CDC recommendations (June 2020), donors are no longer labelled as “increased risk” if they had any risk criteria for hepatitis B, hepatitis C, or HIV infection. The reason is that CDC data showed that infections are rarely transmitted with a transplant from any donor, including those with ‘increased risk’ criteria. They recommended we screen all transplant recipients’ blood for Hepatitis B, C, and HIV after the transplant, using the schedule below, regardless of the donor’s risk criteria. These labs will be drawn in the transplant clinic between day 28 and 56 for kidney, pancreas, and liver transplant recipients. Liver recipients will need hepatitis B labs drawn again between month 11 and 13 and this set can be drawn at your local lab.

If you have any questions, please discuss them with your transplant physician.

| Test | Timing |
|---|---|
| HIV antibody/antigen | Check 4-8 weeks after transplant |
| Hepatitis B surface antigen, surface antibody, core antibody and viral load | Check 4-8 weeks after transplant AND Check 11-13 months after LIVER transplant |
| Hepatitis C antibody and viral load | Check 4-8 weeks after transplant |

Hepatitis C Monitoring

Hepatitis C is a common cause for needing a liver transplant. It is important to monitor your Hepatitis C levels after transplant. This is done with a blood test. The Transplant Clinic will closely follow this level and potentially refer you to a hepatologist or start Hepatitis C treatment if needed.

If you received an organ from a donor who had evidence of prior Hepatitis C, you will need monitoring for hepatitis C infection at regular intervals. Your transplant physician will discuss this with you.

Post-Transplant HCC Monitoring (Liver Transplant Only)

HCC (Hepatocellular Carcinoma) is a type of cancer that is typically found in the setting of liver disease and cirrhosis. With liver transplant, the tumor is removed and the damaged liver is replaced. The level of HCC monitoring will depend on the final pathology of the tumor. To be sure that the cancer does not recur, it is important to have imaging (CT scan or MRI) after transplant. It will be important for you to follow up with your oncologist routinely as well, who will arrange for any imaging you need done, and when it is needed.

GLOSSARY

Glossary

A

Acne: A common skin condition characterized by pimples (whiteheads) and blackheads.

Acquired immunodeficiency syndrome (AIDS): A disease caused by a virus, HIV, that attacks the immune system and causes a variety of effects, including increased risk of infection and cancer.

Acute: Rapid onset of a disease or severe condition that lasts for a short time.

Aerobic: The use of oxygen by the body during activity.

Alanine transaminase (ALT) and aspartate transaminase (AST): Enzymes present in the liver. Elevated levels of ALT and AST in the blood may indicate liver disease or, for liver transplant recipients, rejection.

Albumin: A protein that is produced by the liver and is often related to nutrition and health.

Alkaline phosphatase: A test to detect liver disease.

Alpha-fetoprotein: A blood test used to follow some cancers

Anemia: Having less than the normal number of red blood cells in the blood.

Antacid: A medication that reduces acid in the stomach.

Antibiotic: A drug that inhibits the growth of bacteria. Antibiotics may be used to prevent or treat infection.

Antibody: A substance in the blood that is part of the immune system. Antibodies fight infection but may also cause rejection.

Anti-rejection medications: Drugs that decrease the immune system's response to a transplant and help prevent organ rejection.

Anti-viral medication: A drug that attacks a virus in the body. Anti-viral medications may be used to prevent or treat viral infection.

Arteries: Tubes (blood vessels) that carry blood from the heart to the cells, tissues, and organs.

B

Bacteria: A microscopic living organism that can cause infections such as pneumonia.

Bile: A green fluid produced by the liver.

Bilirubin: A chemical compound in the blood, which can increase in the bloodstream if the liver or gallbladder is damaged.

Biopsy: Removal of a piece of tissue from a part of the body or from an organ to diagnose disease or rejection.

Bisphosphonate: A type of drug that reduces bone loss.

BK polyomavirus (BKV): A virus that can become active and cause kidney damage in individuals with weakened immune systems.

Blood pressure: The pressure exerted by blood and cells in the blood against the walls of the blood vessels, especially the arteries. High blood pressure is a risk factor for heart disease, stroke, and kidney failure.

Blood urea nitrogen (BUN): A blood test that indicates how well the kidneys are working. Prednisone (steroids), bleeding from the gut, and kidney failure can increase BUN.

Bone disease: A disease that affects the structure or strength of bones. This is a common problem in patients with kidney or liver disease, in older patients (especially women after menopause), and patients who require long-term therapy with steroids (prednisone).

Bronchitis: Inflammation of the bronchial tubes (small tubes in the lungs that carry air). It can be caused by viral or bacterial infections or by allergic reactions.

Bronchoscopy: A procedure that uses a special tube, called a bronchoscope, to look inside the lungs. It allows both examination and sampling of the lung tissue.

C

Calcitonin: A drug used to treat osteoporosis (thinning of bone), which is a form of bone disease.

Calorie: The amount of energy provided per unit of food.

Carbohydrates: A food source such as sugars and starches. They are a major source of energy in the diet.

Cardiac catheterization (angiogram): A procedure to diagnose heart disease during which a small tube (catheter) is inserted through a vein into a chamber or blood vessel of the heart. The catheter allows the measurement of pressures in the heart chambers or can be used to inject dye to allow pictures to be taken of the heart chambers or vessels supplying blood to the heart. It is also used to diagnose rejection among heart transplant recipients.

Cardiovascular disease: A structural or functional abnormality of the heart or of the blood vessels.

Catheter: A hollow flexible tube that, when inserted into the bladder, allows urine to flow out of the body. When inserted into a blood vessel, it can be used to administer fluids, measure pressures, or inject dye to evaluate the blood vessels.

Catheterization: Insertion of a catheter into a blood vessel or into a urinary bladder.

Cerebrovascular disease: Disease in the arteries of the brain or in the arteries supplying blood to the brain that reduces blood flow and can result in a stroke.

Chemotherapy: The treatment of cancer using specific drugs that destroy cancer cells.

Chest x-ray: An x-ray test used to detect lung or chest problems.

Child life specialist: A healthcare professional who provides activities to help children adjust to the hospital, prepare for a medical procedure, or cope with illness.

Cholesterol: A form of fat that, in large amounts, can increase the risk of heart and blood vessel disease.

Chronic: A disease or condition that persists for a long time.

Cirrhosis: Scarring of the liver. Scar is a type of tissue that replaces normal tissue that was injured by disease or inflammation. Cirrhosis of the liver permanently reduces liver function.

Clinical nurse specialist: A nurse who has advanced education (usually a master's degree in nursing).

Colonoscopy: A procedure to look inside the colon using a tube (colonoscope) that also allows biopsies (tissue samples) to be obtained.

Coronary angiogram: A test in which dye is injected into the arteries of the heart during cardiac catheterization to determine areas of blockage or narrowing of the arteries and the ability of the heart to pump. Also see cardiac catheterization.

Coronary artery disease: A narrowing or blockage in the vessels that supply blood to the heart.

Creatinine: A blood test used to measure kidney function. Creatinine levels increase during kidney failure.

Cushingoid: A change in the shape of the face to a rounder or fuller shape, often as a side effect of steroids.

Cytomegalovirus (CMV): One of a family of viruses (herpes viruses). CMV is a common cause of infection in persons with weakened immune systems or transplants.

D

Dermatologist: A doctor who specializes in the diagnosis and treatment of skin disorders.

Diabetes: A disease in which blood sugar is increased. Obesity and some anti-rejection medications are major risk factors for diabetes.

Diastolic blood pressure: The bottom number of a blood pressure measurement. It is the lowest pressure while the heart is at rest.

Drain: A tube that may be used to draw fluids from the body after surgery.

E

Echocardiogram: A test in which ultrasound is used to create pictures of the chambers and valves of the heart.

Electrocardiogram (ECG): A test that records the electrical activity of the heart in order to detect heart problems. Electrical leads are placed on the chest to check heart activity.

Endomyocardial biopsy (heart biopsy): Biopsy of a portion of the heart wall (right ventricle) to check for disease in the heart. It is also used to check for rejection in heart transplant recipients.

Epstein-Barr virus (EBV): A herpes virus that is associated with infectious mononucleosis and various types of cancer seen in a small number of transplant recipients. The most common type of cancer associated with EBV is PTLD (post-transplant lymphoproliferative disorder).

Exhalation: The act of breathing out.

F

Fatigue: Lack of energy.

Fertility: The ability to become pregnant.

Fracture: Broken bone.

Fungus: Organisms such as mold and yeast that can cause infection.

G

Gamma glutamyl transpeptidase (GGT): A test to detect liver disease.

Gastrointestinal system: A system of organs that digests food to extract energy and nutrients and eliminates the remains as waste. It includes the esophagus (the tube that connects your mouth to your stomach), stomach, intestines, liver, and pancreas.

Gingival hypertrophy: Enlarged or swollen gums that increase the risk for infection. It may be caused by some antirejection medications.

Glaucoma: An eye disease associated with abnormally high fluid pressure in the eye. Glaucoma can lead to loss of vision.

Glucose: The main sugar in the blood and a major source of energy. If the level of glucose in the blood is abnormally high, diabetes occurs.

Gout: Painful inflammation of the joints, especially of the feet and hands, and arthritic attacks resulting from deposits of uric acid crystals in the joints. Uric acid comes from eating too much red meat or from some medications. Some other forms of arthritis may have a similar appearance.

Guaiac: Test of a stool sample to detect small amounts of blood. Blood in the stool can be a sign of colon cancer or other problems.

H

Heart attack: A sudden decrease in blood flow to the heart due to coronary artery disease. It is often associated with severe chest pain and is often a life-threatening emergency.

Hemoglobin: Protein in red blood cells that carries oxygen from the lungs to the body's tissues.

Hepatitis B: A virus (HBV) that causes infection of the liver. In some people, hepatitis B resolves over time. However, in others it may progress and cause permanent liver

damage (scarring called cirrhosis). Patients with HBV have an increased risk for cancer of the liver.

Hepatitis C: A virus (HCV) that causes infection of the liver that may progress and cause permanent liver damage (scarring called cirrhosis). Patients with HCV have an increased risk for cancer of the liver.

Herpes simplex virus (HSV): The virus that causes cold sores or some sexually transmitted disease (genital sores).

Herpes viruses: A group of related diseases due to a family of viruses with similar structure. These viruses cause common diseases such as chickenpox and shingles (herpes varicella zoster virus), infectious mononucleosis (Epstein-Barr Virus or EBV), and cold sores or genital sores (herpes simplex virus or HSV). In transplant recipients, cytomegalovirus (CMV) is a herpes virus that can cause pneumonia and inflammation of the liver, pancreas, or gastrointestinal tract. Herpes is common in people with weakened immune systems. Antiviral medicines are available to treat some of these infections.

High blood fats (hyperlipidemia): An excessive amount of fat in the blood. Fats include cholesterol and triglycerides.

High blood pressure: See hypertension.

High blood sugar: See diabetes.

High cholesterol: An excessive amount of fat (lipids) in the blood, also called hyperlipidemia.

High-density lipoprotein (HDL): A combination of fats and proteins that carries cholesterol from body tissue to the liver where it can be eliminated. It is the "good" cholesterol.

Hirsutism: Excessive hair growth (often on the face) caused by some of the anti-rejection medications. It is also called hypertrichosis.

Hypertension: High blood pressure, or hypertension, is generally defined as a blood pressure reading greater than 130 mm Hg (systolic) over 80 mm Hg (diastolic) for adults. High blood pressure may increase your risk of stroke, heart attack, heart disease, or kidney disease.

I

Immune system: The system of white blood cells (e.g., lymphocytes) and proteins (antibodies) in the body that works to fight off infection and cancer. The immune system can damage a transplanted organ (rejection).

Immunosuppressive medications: Medications to decrease the function of the immune system and prevent graft rejection.

Infection: The presence of bacteria, virus, parasites, or fungus in parts of the body that usually do not have such organisms. Infection that causes injury to cells and tissues of the body may be called infectious disease. Commonly, infections in specific parts of the body may have names depending on the organ involved, such as pneumonia (lungs), hepatitis (liver), urinary tract infection (bladder, prostate, or kidney), peritonitis (abdomen), pancreatitis (pancreas), colitis (colon), or pyelonephritis (kidney).

Influenza: Influenza, also called the flu, is a viral infection that may be associated with muscle aches, headache, runny nose, cough, fever, tiredness, and feeling poorly (malaise).

Inhalation: The act of breathing in or "taking a breath."

Insulin: A hormone made by the pancreas that controls the level of sugar (glucose) in the blood. Insulin lowers the blood sugar. Diabetes is a disease that occurs when the pancreas does not make enough insulin or when the body responds poorly to insulin.

IV: An abbreviation for "intravenous" often referring to a small catheter for providing medications through a vein.

K

Kidney Problems: A disease or abnormality of the kidneys.

L

Laboratory (lab): A place where medical tests are performed.

Latency: The period of time when a virus remains "asleep" or not active.

Lipids: Lipids are fats, oils, and waxes in the body that store energy. They do not dissolve in water.

Liver disease: Liver disease includes hepatitis, cirrhosis, cysts, and cancer.

Low-density lipoprotein: A combination of fats and proteins that carries cholesterol in the blood. It is the "bad" cholesterol.

Lymph node: A gland that is the "home" to white blood cells when they are not in circulation. Clusters of lymph nodes are found in the underarms, groin, neck, chest, and abdomen.

Lymphocytes: A type of white blood cell involved in the immune system. There are 2 broad categories of lymphocytes: T cells and B cells. Lymphocytes play an important role in the body's defense against illness. They can also cause rejection of a transplanted organ.

Lymphoma: Cancer that develops from lymphocytes.

M

Malignancy: Cancer.

Mammogram: An x-ray image of the breast used to detect breast cancer.

Meningitis: An infection of the fluid that surrounds the spinal cord and the brain.

Metabolic system: A control system of the body that keeps the body's health in balance through the production of chemical substances.

Microorganism: A germ (such as bacteria or fungus) of microscopic size that can cause infection.

N

Nervous system: A network of nerves that controls actions and reactions of the body.

Nurse practitioner: A registered nurse with advanced education to provide health care, including many tasks usually done by a doctor, while under the supervision of a doctor.

Nutrient: A nourishing ingredient in food.

O

Obesity: Being highly overweight. Body mass index (BMI) is used to measure obesity and is based upon a person's height and weight. Obesity is defined as a BMI of over 30.

Occupational therapist: A healthcare professional who works with physically or mentally challenged patients to help them perform daily tasks at home and at work.

Organism: A life form, including bacteria or fungus.

Over-the-counter: Any medication that you can buy without a prescription.

P

Pap smear: A medical procedure that involves collecting a sample of cells from a woman's cervix (the end of the uterus that extends into the vagina) and examining them under a microscope. It is used to detect cervical cancer.

Pelvic exam: A medical exam of a woman's female organs (vulva, vagina, cervix, uterus, and ovaries).

Physical therapist: A professional who treats physical weakness or injury with exercise or other methods to help a patient gain better physical function.

Physician assistant: A healthcare professional trained to provide health care, including many tasks usually done by a doctor while under the supervision of a doctor.

Platelets: Small, flat cells in the blood that aid in clotting.

Pneumonia: An infection of one or both lungs that can be caused by a bacteria, virus, parasite, or fungus.

Precancerous: Not considered cancer but may lead to cancer.

Prostate-specific antigen (PSA): A blood test to screen for prostate cancer.

Proteinuria: An excess amount of protein in the urine that indicates kidney disease.

Psychiatrist: A medical doctor who diagnoses, evaluates, and treats mental and emotional disorders. Unlike a psychologist, a psychiatrist has a doctor's degree and can prescribe medication.

Psychologist: A healthcare professional who diagnoses, evaluates, and treats mental and emotional disorders. Unlike a psychiatrist, they usually do not prescribe medication but they can conduct psychological testing and provide individual and group counseling.

R

Radiation: High-energy rays used to image the body, diagnose disease, or treat cancer.

Rectal exam: Examination of the rectum through the anus.

Rejection: Injury to a transplanted organ caused by the immune system.

Renal: Related to the kidneys.

Respiratory system: The body system (including the lungs) involved in the intake and exchange of air. This is the main function of the lungs.

S

Saturated fat: A fat, most often from animal products, that is solid at room temperature. An excess of saturated fats in the diet can raise the amount of "bad" cholesterol in the bloodstream and cause heart disease or stroke.

Shingles: An infection caused by a herpes virus called varicella zoster virus (VZV); the virus that causes chicken pox. Normally, VZV will stay inactive in the nerves ("latency"), but may become active in older patients or those receiving immune suppressive medications. Shingles may appear as a skin rash (like a small area of chicken pox) or with pain in one area of the body.

Side effect: Any effect other than the intended effect of a drug.

Sigmoidoscopy: A procedure using a scope (like a colonoscopy) that allows the doctor to look at the inside of the large intestine from the rectum.

Spirometry – Pulmonary Function Testing (PFT): A measurement of the amount (volume) and speed (flow) of air that can be inhaled and exhaled. Spirometry is an important tool used for assessing lung disease.

Sputum: Cells and mucus coughed up from the lungs. Sputum is tested to diagnose infections of the lungs.

Steroids (corticosteroids): Anti-inflammatory medications often used to prevent or treat rejection.

Stool: Waste material from the bowel. It is also called bowel movement.

Stroke: A sudden loss of brain function caused by reduced supply of blood to part of the brain, characterized by loss of vision, weakness of a part of the body, loss of consciousness, slurred speech, or other symptoms. This is an emergency and requires immediate medical attention.

Systolic blood pressure: The pressure exerted by the blood against the walls of the arteries, especially during a heartbeat. It is the top number of a blood pressure measurement.

T

T cell: A type of white blood cell (lymphocyte) that plays a major role in transplant organ rejection and protection against viral infections.

Toxoplasmosis: A disease caused by a parasite. People can get this infection from eating raw or undercooked meat, or by contact with cat stool or cat litter. It is more common among organ transplant recipients.

Tremor: Shaking of the hands or other parts of the body.

Triglycerides: Fatty substance in the blood.

U

Urinalysis: An exam of the urine. An abnormal test could indicate infection or kidney disease.

Urinary tract: The organs of the body used to get rid of liquid waste. Urine is made in the kidneys and travels down tubes (called ureters) to the bladder and out from the bladder through a tube called the urethra.

Urinary tract infection: An infection of the urinary tract.

Urine: Liquid waste material from the kidney.

V

Vaccine: A substance, given to an individual, often by injection, to prevent infection by developing immunity.

Varicella zoster virus (VZV): A herpes virus that causes chicken pox and shingles.

Vein: A blood vessel that carries blood from cells, tissues, and organs back to the heart.

Vessels: Tubes in the body through which the blood circulates.

Viral infection: An infection caused by a virus.

Virus: A microorganism that causes infection and disease. Viruses invade the body and can grow if the immune system does not attack them or if medication is not used.

SELF-MONITORING TOOLS

Vital Signs Monitoring

[illegible]

Vital Signs Monitoring

[illegible]

Blood Sugar (BS) Monitoring

| Date | | Breakfast | Lunch | Supper | Bed | Comments |
|------|--------------|-----------|-------|--------|-----|----------|
| | BS | | | | | |
| | Insulin Dose | | | | | |
| | Insulin Type | | | | | |
| | BS | | | | | |
| | Insulin Dose | | | | | |
| | Insulin Type | | | | | |
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| | Insulin Type | | | | | |

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| | BS | | | | | |
| | Insulin Dose | | | | | |
| | Insulin Type | | | | | |
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Urine Output Recording Sheet

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Urine Output Recording Sheet

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Drain Output Sheet

| | Drain #1 | Drain #2 | Drain #3 | Drain #4 | Drain #5 |
|---------|----------|----------|----------|----------|----------|
| Date | | | | | |
| 8:00 AM | | | | | |
| Midday | | | | | |
| Bedtime | | | | | |
| Other | | | | | |
| Total | | | | | |
| Date | | | | | |
| 8:00 AM | | | | | |
| Midday | | | | | |
| Bedtime | | | | | |
| Other | | | | | |
| Total | | | | | |
| Date | | | | | |
| 8:00 AM | | | | | |
| Midday | | | | | |
| Bedtime | | | | | |
| Other | | | | | |
| Total | | | | | |
| Date | | | | | |
| 8:00 AM | | | | | |
| Midday | | | | | |
| Bedtime | | | | | |
| Other | | | | | |
| Total | | | | | |
| Date | | | | | |
| 8:00 AM | | | | | |
| Midday | | | | | |
| Bedtime | | | | | |
| Other | | | | | |
| Total | | | | | |
| Date | | | | | |
| 8:00 AM | | | | | |
| Midday | | | | | |
| Bedtime | | | | | |
| Other | | | | | |
| Total | | | | | |

Drain Output Sheet

| | Drain #1 | Drain #2 | Drain #3 | Drain #4 | Drain #5 |
|---------|----------|----------|----------|----------|----------|
| Date | | | | | |
| 8:00 AM | | | | | |
| Midday | | | | | |
| Bedtime | | | | | |
| Other | | | | | |
| Total | | | | | |
| Date | | | | | |
| 8:00 AM | | | | | |
| Midday | | | | | |
| Bedtime | | | | | |
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| Other | | | | | |
| Total | | | | | |