

*Provided as a Service to Our Patients by
The Transplant Center, Massachusetts General Hospital*



Transplantation: What Do I Need to Know?



MASSACHUSETTS
GENERAL HOSPITAL

TRANSPLANT CENTER

TRANSPLANTATION: What Do I Need to Know?

Provided as a Service to Our Patients by
The MGH Transplant Center,
Massachusetts General Hospital

First Edition Created and Edited by:

- Shirley P. Biddle
- Lucia Coale
- Eleanor Coughlin
- Kitty Craig-Comin
- Tony Digiovine
- Jay A. Fishman
- Patricia A. Flaherty
- Jayne Galley-Reilley
- Kelly Gramstorff
- Coral Haggan
- Nina H. DalPozzal
- Cindy Hayes
- Sally Keck
- Eilleen Keegan
- Anne Marie King
- Marissa Legare
- Ellen MacLaughlin
- Jackie Mulgrew
- Susan Noska
- Karen Tanklow
- Debra Whitaker

Second Edition Revised by:

- Jay A. Fishman
- Sarah H. Shao
- Linda Irwin
- The Staff of the MGH Transplant Center

Third and Fourth Edition Revised: Jay A. Fishman, MD

Copyright 2017, The General Hospital Corporation

Contents

Page

- 3. Welcome to the MGH Transplant Center and the Goals of Transplantation
- 4. Preparation for Transplantation
- 5. How the Transplant System Works: Matching Donors and Recipients
- 6. Questions to Ask Your Transplant Team
- 8. Financial Information and Insurance
- 13. Going to Surgery
- 14. After Your Surgery
- 16. Your New Organ and Your Health
- 18. Medications after Transplant Surgery
- 20. Caring for your New Organ: Rejection
- 22. Routine Care and Clinic Visits
- 24. Infection
- 28. Cancer
- 29. Emotions, Stress, Counseling and Support Services
- 30. Going Home
- 32. Post-Transplant Activities: What Should I Expect?
- 35. Exercise and Physical Therapy
- 40. Healthy and Safe Eating After Transplantation
- 44. Sex and Sexuality
- 48. Writing to Families of Deceased Organ Donors
- 50: My Transplant Team!

Appendix 1: **Glossary**

Appendix 2: **Medications**

Appendix 3: **Health Care Proxy/Advanced Directives**

Welcome to the Massachusetts General Hospital Transplant Center!

You want to know more about organ transplantation! We will try to answer your questions.

Feel free to ask any member of your transplant team if you have questions or concerns.

The goals of transplantation

Patients with organ failure may have been sick for a long time – or hardly at all. Regardless of how you came to seek medical care at MGH, our goal is to restore patients organ injury – heart, lungs, liver, kidney, intestine or pancreas – to good health and *to allow them to return to their normal lives*. It is important for our patients and their families to be informed about what transplantation means for them and the risks and benefits of transplantation. **Transplantation is a life-long commitment to good health.** It is a team effort between the patient, their family and friends, and the medical team. Taking care of yourself and your transplanted organ requires hard work and may be confusing. Keep a positive attitude. Ask questions if there is something that you don't understand. ***The MGH Transplant Center is committed to your good health!***

What to expect before transplantation

When your doctor or other healthcare provider sends you to the Massachusetts General Hospital, they have selected a world-renowned hospital to help care for you. You will meet a team of expert staff. This will include one or more of our physicians who is expert in your type of problem. This is generally a **specialist** in heart (cardiology), lung (pulmonary), kidney (renal or nephrology), liver (hepatology or gastroenterology) or pancreas (diabetes or endocrinology) diseases. Feel free to ask questions from each staff member you meet. A **transplant coordinator** or secretary will set up a series of appointments to help decide whether transplantation is the best option for your care. You will be asked to sign a “consent” form to allow the team to complete your evaluation for transplantation. You may have to undergo some testing (blood tests, radiology or X-rays, or others) and meetings with other specialists. Depending on the tests, the evaluation process may take several days to weeks. Once you have met all of the team members and tests are completed, the team will offer you a plan for your care with your local physician.

You may be placed on the “**list**” to wait for a deceased donor organ. You may have a family member or other individual willing to offer their organs to help you (“**live donation**”). You may have special needs including physical therapy, antibiotics, psychological or psychiatric care, or addiction treatments. **Your medical and surgical team will consider all of the available options.**

You will continue to need care by your local physician and specialists. The MGH transplant team will work with you and your care providers to provide excellent care.

WELCOME!

Preparation for transplantation

- **Contact Information:** Once you are on the transplant waiting list, we will ask you for an emergency contact number in addition to your home phone number. This can be either a cell phone or a pager. If we need to reach you, we will try you at home first and then your emergency contact number.
- **New Problems:** Let your doctors know if your **medications have changed**, if you have trouble finding them at your pharmacy or paying for them. We also need to know **if you have been sick or hospitalized recently or have needed blood transfusions. Let us know if** you have other concerns while waiting for your transplant.
- **Finances:** The hospital needs to know about your insurance coverage and finances for transplantation. Please let your social worker or the financial coordinator know if there are any changes in your insurance policies or pharmacy (drug) coverage plans or if you have any questions about coverage. The MGH Admitting Office has a **Transplant Financial Coordinator** to help you with these concerns.
- **Travel Plans:** Transplantation from a deceased organ donor may occur at any time, day or night. If you are called for transplantation you need a way to get to the hospital. **Make a plan in advance for transportation to MGH** when you are called for your transplant. You should try to have at least two plans in place – update your plans as needed. Make contact with an ambulance service even if you have plans for your family or a friend to take you to the hospital. This will serve as a back up plan. If your travel time to MGH is greater than 4-6 hours, you will need to let the hospital staff know and, possibly, to make special arrangements for air transportation or other services. Lung and heart recipients need to get to the MGH within 3-4 hours.
- **Diet and Exercise:** Try to be in the best physical shape possible. Maintain the exercise regimen prescribed by your team. Watch your diet. If you have any questions, talk with your doctor, dietician, and/or physical therapist.
- **Personal affairs:** Do you have a plan for your family and home in case you are called to the hospital for transplantation? Who is going to take care of your children, pets, parents, and home? Your social worker can talk with you about difficulties that may occur and help you make plans. You may also think about who might help you when you come home from the hospital.
- **Emotional health:** Transplantation, illness and recovery are very stressful. You may ask for advice from your physician, social worker, transplant coordinator, or psychiatrist. Let us know if you have had problems with stress in the past. If you are interested in talking to another transplant recipient, we can arrange this. You may want to consider talking to a social worker and/or a psychiatrist about how you are handling the transplant process.
- **Family and friends:** Involve your family and friends in the transplant process. They will be a great help to you if you keep them informed about your progress and concerns during your evaluation and while waiting for transplantation.
- **Legal issues:** Are there any legal issues you need to take care of? Have you filled out a health care proxy?

HOW THE TRANSPLANT SYSTEM WORKS: MATCHING DONORS AND RECIPIENTS

Once your physicians have determined that organ transplantation is the best treatment for you, there are a number of options. For some, you will have a living donor, a relative or close friend, who is willing to donate a kidney or part of a liver or lung to replace your damaged organ. For many, the best option will be to be placed on a national “waiting list” until an organ becomes available from a deceased donor – a person who has died and whose organs have been made available for transplantation. **An organ is an incredible gift!** The amount of time you will have to wait depends on the organ and the region in which you live. Up to date information is available on a number of web sites (see below). If you have further questions please ask your transplant coordinator.

If you have someone who is interested in learning more about donation he/she can contact the Live Donor Transplant Coordinator at 617-643-7126.

United Network for Organ Sharing (UNOS): www.unos.org/resources/patientResources.asp

Transplant Resources

Massachusetts General Hospital Transplant Center www.massgeneral.org/transplant

New England Organ Bank (NEOB) – www.NEOB.org

Scientific Registry Transplant Recipients (SRTR) – www.srtr.org

American Heart Association – www.heart.org

Liver Foundation – www.liverfoundation.org

National Kidney Foundation – www.kidney.org/transplantation/living

American Society for Transplantation -- <https://www.myast.org/patient-information/patient-information>

QUESTIONS TO ASK YOUR TRANSPLANT TEAM

Patients usually have many questions as they go through the transplant process. It is important to ask members of your transplant team about your transplant and your health. Below are samples of questions you may want to consider. Some additional information is also available on our website: www.massgeneral.org/transplant.

What are my choices other than transplantation?

What are the benefits and risks of transplantation?

What tests and other procedures will I need as part of the evaluation process?

How does the evaluation affect whether or not I am put on the waiting list? (Yes – transplantation is major surgery and may not be the best option for your illness.)

How will I know I am definitely on the waiting list? (You will receive a letter after completing your evaluation and your condition has been discussed by the Transplant team.)

How long can I expect to wait? (This depends on the type of organ you need and the availability of a good organ matched for your body.)

How many transplants does M.G.H. and my surgical team perform each year?

How long will my organ survive if I have it done at the M.G.H. or at other centers?

How does this medical team decide whether or not to accept a particular organ for a patient?

Who are the members of the M.G.H. transplant team and what are their roles? How do I reach them if I have questions? (Website: <http://www.massgeneral.org/transplant/>)

How many surgeons at this hospital are available to do my type of transplant?

Who will teach me about the transplant process?

Are there special wards of the hospital for transplant patients? (Yes – the Transplant Unit, Blake 6, and a number of intensive care units and other specialty units)

Does MGH have clinical research programs in transplantation? Will I be asked to take part in research studies? (Yes, MGH has a well-known research program that has made many advances in transplantation. You may be offered the chance to participate in research studies – if so, you will be told all about the study in advance and have a chance to offer to participate or to refuse without affecting your transplant care.)

Is a living donor transplant a possibility for me? If so, how do you know who is the right donor? What risk there is for the donor? What type of evaluation do they need? What is the process for living donation?

For a living organ donor, are there options for the type of surgery such as laparoscopic surgery? Who can explain laparoscopic surgery to me? What are the advantages and disadvantages?

Can I be listed for a transplant at a second hospital (yes)? And how does this affect my waiting time (depends on the nature of the waiting list at each center and in each region – but will not affect your wait at the first center)?

Is my age an issue?

How long does an evaluation take if I have a possible living donor (for kidney, liver, or lung transplantation)?

Will my own doctor help to take care of me after I have received my new organ? (yes!)

FINANCIAL INFORMATION AND INSURANCE

MGH Transplant Center patients have access to a person who can answer questions about medical insurance coverage and transplant-related charges. This is the Transplant Financial Coordinator. Good financial preparation will allow you to focus on what is most important -- your health.

The Transplant Financial Coordinator will review your insurance coverage and work with your insurance company to authorize treatment. Patients and families must understand financial costs and medical insurance coverage in each phase of the transplant process. You should also be aware of the benefits and limitations of your insurance policy. Below are some common questions and answers that may help you.

Q: What types of coverage do I need as a transplant patient?

A: You will need medical insurance that covers inpatient care, outpatient visits, physician fees, and prescriptions. Please call the telephone number on the back of your insurance card to speak with an insurance customer service representative. They can explain your insurance benefits.

Q: How much will the out of pocket costs for my transplant health care be?

A: Generally called premiums, co-pays, or deductibles, the amount of money you may have to contribute to your care depends on the terms of your insurance policy. For example, some plans may have higher monthly premiums, but lower co-pay amounts for doctor visits. When you call your insurance company to ask about coverage, make sure you ask for your deductible and co-pay amounts. Here are some common insurance terms:

<i>Premiums</i>	The monthly cost the patient pays to stay enrolled in the health insurance plan. If you have health insurance through your employer, usually your employer will pay a part of your premium cost.
<i>Deductibles/ Maximum Out of Pocket Costs</i>	A specific dollar amount set by an insurance company that a patient must pay before the insurance company pays any medical claims.
<i>Co-Pays</i>	The out-of-pocket amount a patient pays when coming to the hospital or a doctor's office. Sometimes a patient pays this amount up front, other times the doctor or hospital will send a bill.
<i>Lifetime Maximums / Caps</i>	Some insurance policies have a lifetime benefit maximum. After you have received care costing the maximum amount of your policy, the insurance company is no longer obligated to pay for your care. The amount will vary depending on your policy. Some

policies have an unlimited lifetime maximum.
--

Q: What if I do not have enough health insurance coverage or cannot afford my out of pocket costs?

A: You will need a secondary insurance. We recommend that patients obtain a secondary insurance, especially if their primary insurance has a lifetime maximum. State Medicaid Programs are often a source of secondary coverage.

If you are a resident of Massachusetts AND you are:	Under 300% of the Federal Poverty Level (\$36,180 for an individual in 2017)	You may be eligible for MassHealth, MassHealth Careplus, or ConnectorCare – subsidized health insurance options.		CONTACT: Call Ellen Babine, Transplant Financial Coordinator 617-724-0009 ebabine@partners.org MassHealth Customer Service: 800-841-2900 MA Health Connector: 800-623-6765 www.mahealthconnector.org
	Over 300% of the Federal Poverty Level (\$36,180 for an individual in 2012)	And need insurance, or supplemental insurance	You may be eligible for Commonwealth Choice through the MA Health Connector	

Medicaid is available in all states, but program eligibility requirements vary. Below are some resources in neighboring states. If we did not list your state, or if you have any other questions, please contact us for more information.

Connecticut	800-842-1508	http://www.ctmedicalprogram.com/
New Hampshire	800-852-3345 x 4344	http://www.dhhs.state.nh.us
Rhode Island	877-267-2323	http://www.dhs.state.ri.us/
Vermont	800-250-8427	http://ovha.vermont.gov/

Q: I have Medicare. Am I covered for everything?

A: Not completely. However, there are many options to complete your coverage.

Medicare is split into different parts: A, B, C and D.

- **PART A** covers hospital inpatient admissions. There is a deductible, but after the patient meets it, Medicare A covers bills for your first 60 days at 100%. For more information: www.medicare.gov, Medicare, Basics, Part A.
- **PART B** covers outpatient and physician services. There is a monthly premium for Part B and it covers bills at only 80%.
- **PART C** is a Medicare replacement plan. Not everyone is eligible for Part C, and enrollment is optional. If you are enrolled in Part C, a private plan (for example, Tufts Health Plan or Harvard Pilgrim) manages your health care, but your benefits are similar to regular Medicare A and B. Extra premiums may apply.
- **PART D** covers prescription drugs. You must choose and enroll in this plan separately. Plan premiums and co-pays vary. For more information: www.medicare.gov, Medicare Basics, Part D.

There are usually remaining costs that the patient is responsible for paying. Medigap Plans help pay for these remaining costs. These plans vary depending on your area and there are different levels of ‘Medigap’ coverage. Patients enroll in these plans separately. If you have a secondary insurance such as a Medigap Plan, hospitals, doctors and pharmacies will bill this plan before billing you, leaving you with fewer out of pocket costs. Please check with your contacts at MGH if you have any questions.

Q: Are there any other resources that can help?

A: Some transplant patients find fundraising helpful. There are many fundraising organizations in the United States and around the world. Here are some other resources patients have found helpful:

Name	Transplant Type	Phone Number	Website	Summary
National Foundation for Transplant	Solid Organ and BMT / Stem Cell	800-489-3863	www.transplants.org	Helps cover transplant related costs that aren't covered by insurance. Assists families in raising funds to assist with transplant costs.
Leukemia & Lymphoma Society	BMT / Stem Cell	914-949-5213	www.leukemia-lymphoma.org	Can reimburse up to \$500 per year for transplant related costs
Children's Organ	Pediatric Solid	800-366-2682	www.cota.org	Assists families in the raising of

Transplant Association	Organ, Tissue and Bone Marrow			funds to assist with transplant costs.
Help Hope Live	Solid Organ and BMT / Stem Cell Transplants	800-642-8399	www.helphopelive.org	Helps cover transplant related costs that aren't covered by insurance Assists families in raising funds to assist with transplant costs

Q: Whom should I contact if anything in my insurance changes?

A: If anything about your insurance changes, including: loss of coverage, change in insurance company or change of policy, please contact:

Massachusetts General Hospital Patient Service Center
Toll Free: 1-866-211-6588

ELLEN BABINE

Transplant Financial Coordinator, MGH

617-724-0009 Fax: 617-643-0433

Email: ebabine@partners.org

Mailing Address: Massachusetts General Hospital,
55 Fruit Street, Wang 016A, Boston, MA 02114

Q: What about my prescriptions?

A: There are many important points about your transplant medications.

- You must take them every day for the rest of the life of your organ.
- Be sure to refill your medications 5 days before you run out of your old supply. Some pharmacies do not always have specialty drugs like immunosuppressives in stock all the time – so calling ahead to be sure will help.
- Call your transplant team if you receive a new medication from what you are used to receive from your pharmacy. *Some medications, such as tacrolimus and cyclosporine, come in multiple different forms – so keep track of the size and color, labeling)*
- Mail order companies could save you money. Be sure your transplant doctor has settled on medications and doses before you order a 90-day supply.
- If you have no insurance, your medications can cost between \$20,000 and \$25,000 per year. This is a great deal of money, so be sure that you can get prescription drug coverage.

Know your drug benefit.

Get a list of potential medications you may take after transplant. Call your prescription insurance benefits phone number and ask a representative what your co-pays or coinsurance amounts might be. Since you must pay this every month, it is important to know ahead of time.

If you feel you cannot afford the co-pays, contact Patient Financial Services or your Transplant Financial Coordinator for help.

GOING TO SURGERY

When you come to the hospital for your transplant, you will experience several things:

- Bloods for testing will be drawn
- Intravenous lines (IV) may be placed
- You may be given a laxative
- Your skin will be prepped (cleaned)
- You will not be allowed to eat or drink any food or fluids
- You will see several doctors and/or nurses who will take medical information and perform a physical examination
- Your records will be reviewed
- You will receive further information about the transplant process and be asked to sign a consent form for surgery
- A priest or minister can be called if you would like to see one
- Your questions will be answered

PLEASE NOTE: If your transplant is planned, i.e. is a “living donor”, some of this may be done prior to your surgery date.

YOUR FAMILY DURING SURGERY

A waiting room for your family is available on the first floor of the Gray Building in the Gray Lobby. The doctors will notify the waiting area personnel when you are out of surgery and when they are able to see you.

AFTER YOUR SURGERY

After surgery you will generally go to one of a number of locations within the hospital generally either to the **Transplant Unit** or to an Intensive Care Unit (ICU). Visiting times are limited in the ICUs and for a period of time after surgery. Family members are asked to keep their visits brief, usually between 5-10 minutes each hour. Family members will be required to follow strict hand washing guidelines. Visitors may be asked to wear gowns, gloves, or masks while in your room. The immediate family is welcome to visit.

During surgery you will have a breathing tube (**endotracheal tube**) inserted in your throat. This tube will be inserted while you are asleep in the operating room. The tube will be attached to a machine that will help you breathe until you can breathe on your own. This may be for the first several hours after surgery or, in many cases, a longer period depending on the nature of your surgery and your progress. Since this tube will also pass between your vocal cords, you will not be able to talk. Although the endotracheal tube is not painful, it can be frustrating because of your inability to talk. Try to relax and let the breathing machine do the work. You may receive medication to help you to relax. Fighting the machine uses a lot of energy and makes it more uncomfortable.

The **intravenous tubes or lines** (IV's) inserted prior to surgery will provide you with fluids and medications. There may be a **nasogastric** (NG) tube inserted into your nose. The tip of the "NG tube" rests in your stomach and allows the staff to give you medications or to keep your stomach empty. You will be unable to eat or drink fluids if you are ordered to be "nothing by mouth" (NPO). You may have plastic drainage tubes ("drains") or suction drains in your abdomen or your chest. These will be monitored and drained on a regular basis. When you are ready, they will be removed. Many patients will also have a urinary or bladder catheter or "Foley" which drains urine until you are able to get out of bed and no longer need this assistance. Some patients will have some tubes that may stay in place a bit longer to help with the healing of your kidney (called a urinary "stent") or liver (called a "T-tube").

Patients are carefully watched (**monitored**) in the immediate post-operative period. You will receive medicines for pain and stress if needed. Try to relax and let the staff help you.

Infection is a major concern for transplant recipients. The risk for infection is due to the anti-rejection medications that are you will receive to protect your new organ. **We ask that anyone who has a cold, cough, or other infection, and most children, not visit you.** If you have any questions please ask one of the staff. In the meantime, we will ask that all visitors (and staff) wash their hands before and after visiting you. If you do become ill, we may take various “cultures” of body fluids to detect infection and to guide treatment with antibiotics.

You may have **pain** in your surgical wounds (“incision”). Your doctor will order medication to relieve your pain. Over time your pain will decrease. You may not need any pain medicine by the time you go home. Your incision is held together by strong sutures. As your incision heals, the new skin will be strong.

ON THE MOVE

Moving around and daily activities start as soon after transplant as possible to help you to heal more quickly. Your nurses will be helping you to sit up and walk very soon, often within the first day after transplant. They will teach you how to sit up and move so that it is less painful. They may give you pain medication to help with movement. Walking will increase your endurance and helps to prevent infections. A physical therapist is available to help you.

It is common to have congestion in your lungs after surgery because of the anesthesia and breathing tube. Coughing, deep breathing, and blowing into your spirometer (small machine with a mouthpiece and a ball in it) are important to help open up your lungs and to prevent infection.

YOUR NEW ORGAN and YOUR HEALTH

As you recover from transplantation surgery, it is time to start to learn about your new organ and how to take care of it.

While you are recovering, you will learn about your medicines – why you are taking them and what they do; how much to take and any possible side effects. We will review signs of rejection and infection.

Common issues the team will discuss with you include:

Graft or Organ Rejection: Your new organ is “foreign” to your body and would be attacked by your body (“rejection”) unless you take immunosuppression or anti-rejection medications. The risk of rejection is greatest during the first few months after transplantation but never goes away. *You will always need anti-rejection drugs.* Your doctor may lower the dosage, but you should never skip or stop taking the drugs.

Infections: Immunosuppressive (“anti-rejection”) drugs increase the chance of getting infections. These infections can be treated. You need to tell your doctor if you have a fever, unusual pain, or any other new problems. The risk of infection will go down as your doctor lowers your dose of these drugs.

High blood pressure: High blood pressure is a common problem after organ transplantation. It can damage your new organ and cause strokes and heart attacks. If you have high blood pressure, your doctor can help treat this with medication. Some patients may experience an improvement in blood pressure control after kidney transplantation.

Diabetes Mellitus: Anti-rejection medications can cause diabetes, or high blood sugars. If you had diabetes before your transplant, or were close to developing diabetes, you may find it harder to control your blood sugar level after your transplant. It may be possible you will need insulin to keep your blood sugar under control. Nurses and pharmacists will help you learn how to regulate your blood sugars.

High cholesterol: **Some** anti-rejection medications can increase your risk for high cholesterol. Your blood lipids will be measured and medications provided if required.

Kidney disease: Some medications may damage the kidneys. Your doctor and transplant staff will monitor your blood and urine for signs of this problem and make adjustments if required.

Cancer: Transplant recipients are at higher risk for certain types of cancer, particularly skin cancers. You will be examined carefully, but you should tell your doctors immediately if you have any new skin lesions, sores that do not heal, swollen lymph glands, or other changes in your skin.

Bone disease: Transplant patients are at risk for osteoporosis (os-tee-o-por-osis), which is a condition that causes your bones to thin. There are many causes of bone loss after transplant, with corticosteroids such as prednisone being one contributor. Your primary care doctor may order a bone density test and put you on medication to help prevent this condition.

Pregnancy: (discussed below) A woman who has received a transplant should not plan to get pregnant until her physicians have approved pregnancy. Generally, women are asked to wait 6-12 months after her transplant before becoming pregnant. If you want to get pregnant, you and your transplant doctor should talk about it. Your doctors will discuss which anti-rejection medications can cause fetal harm and should be avoided before trying to get pregnant. Many transplant recipients have had successful pregnancies.

MEDICATIONS AFTER TRANSPLANT SURGERY

You will be required to take new medications after receiving your transplant to prevent “rejection” or failure of your new organ and to prevent infection and other post-transplant problems. Most of these are discussed below. **It is important to take your prescribed medication as ordered.** A medication card will be provided after transplant to help you track your medications. You should never change or skip a dose of your medication without consulting the doctor. During your recovery the nurse will teach you, and possibly your family members, critical information about these new medicines. **Please ask if you have any questions!**

DO’ S AND DON’TS ABOUT YOUR MEDICATION

- **Never skip or change your medication dose unless instructed by someone on the Transplantation Team.** If you miss a dose, or cannot take your medicines because of vomiting or other problems, please call your transplant team immediately. You will be given instructions on what to do with late doses.
- **Never stop taking any of your medications.** Your body will always need your immunosuppressive medications to prevent your body from “rejecting” your new organ. Even after years of taking these drugs, your body will reject the transplanted organ if drugs are discontinued.
- **Do not change the specific type of immunosuppressant medication without checking with your transplant team – they are not all the same!**
- **Some over-the-counter remedies are safe for your transplanted organ and some are not.** You will be provided a list of acceptable medications that can be used for problems such as common colds. If you have questions, please contact the transplant clinic.
- **Some drugs interact with transplant medications.** If a physician outside of transplant prescribes a new medication, the physician and your pharmacist should confirm that the new medication does not interact with any of your transplant medications. You will also be provided a list of commonly used medications that

interact with transplant medications so that you can be aware. If you have any questions about new medications, you can contact the transplant clinic.

- Avoid repeated use of pain medications unless you discuss it with the Transplant team
- Do not keep outdated medications. Check the expirations dates on your transplant medicines periodically.
- **Report any new symptoms, such as:**
 - ✓ Vomiting or diarrhea for more than two days or if you cannot eat or keep your medicines down.
 - ✓ Cough, shortness of breath, difficulty urinating, abdominal pain or headache, especially for more than three hours.
 - ✓ Skin rash especially if it is itchy or painful.
 - ✓ Painful swallowing or sores and patchy white areas in your mouth.
 - ✓ Fever over 100.5 degrees Fahrenheit (38 degrees Celsius) for more than 4 hours.
 - ✓ High blood pressure or high blood sugars
 - ✓ Blurred vision
- Learn the names of your drugs and know how much to take, when to take them, how to take them and important side effects. **Take your medications at approximately the same time every day.**
- Keep medications in a cool, dry place away from heat or light. Refrigerate only if the directions say to do so.
- **Keep all medications out of reach of children.**
- Always ask your pharmacist if the pills look different or are a different size or color from what you are used to taking.
- Make sure that you refill your medication prescriptions so that you never run out – plan ahead! It may take up to 2 days for some pharmacies to get your medications or to get the insurance approval.
- Remember to take your medications with you if you go on vacation or travel. Let us know when you travel outside the United States.
- Know the name of a nearby pharmacy or hospital if you plan to be away from home.
- When traveling, carry medications separately and do not check them with your luggage.

CARING FOR YOUR NEW ORGAN: REJECTION

Rejection

Many transplant recipients may experience a [rejection](#) episode at some point. A rejection episode can be scary, but it usually does not mean that the organ has stopped, or will stop working. 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. *Today's [anti-rejection medications](#) are stronger and better able to prevent rejection episodes than ever before.* Most rejection episodes can be successfully treated.

Preventing Organ Rejection

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. Your nurse or one of your doctors 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, call your Transplant Coordinator, one of the nurses on the Transplant Unit, or other members of your transplant team right away.

What to Do if Rejection Occurs

Rejection can usually be treated if it is recognized and treated early. Many patients do not have any symptoms of rejection; this makes it important to keep your clinic and blood test appointments. Some patients feel ill with aches or fevers or other symptoms. The table below lists some of the warning signs of rejection. 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 can determine if something is wrong and how to treat it.

Organ Transplanted	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 • NOTE: Most kidney transplant patients with rejection will not experience these symptoms. Most rejection is detected based on blood test results. Symptoms above would indicate severe rejection.
Heart	<ul style="list-style-type: none"> • Fever • Flu-like illness such as chills, nausea, aches and pains, vomiting, tiredness • Shortness of breath • Difficulty sleeping on your back • Irregular or abnormal heartbeat • Weight gain or swelling of body or legs • Fall 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
Lung	<ul style="list-style-type: none"> • Shortness of breath (dyspnea) • Chest pain • Dry cough • Decreased movement of air during breathing • Fever • Flu-like illness such as chills, nausea, aches and pains, vomiting, tiredness
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

ROUTINE CARE AND CLINIC VISITS

To be sure that your transplanted organ is working properly and that your medications are at the correct dosages, you will have a number of blood tests and other tests after transplantation. Some of these are listed below:

Cyclosporine, Tacrolimus or Sirolimus/everolimus levels

This test measures the amount of the drugs in your blood. We use the results to adjust how much of this medicine you take.

- This blood test is performed just before your next dose and 10 – 13 hours after your last dose.
- **Do not take your Cyclosporine, Tacrolimus, or Rapamycin on the morning you are having this test. Bring your medicine with you and take it right after the blood test.**
- If you need to have this test done at your local lab, we will give you more information about how this can be arranged.

Chemistry: These tests allow us to look at the many electrolytes in your system.

Complete Blood Count (CBC): The CBC is composed of three sections: white blood count (WBC), platelets and hematocrit. These are used to check for infection and to adjust your immunosuppressant medications.

Organ-Specific Tests (below)

TYPE OF ORGAN TRANSPLANT	TESTS	RESULTS
Kidney	Blood urea nitrogen (BUN) and creatinine are measures of the kidney's ability to clear normal waste products	Elevated BUN or creatinine could mean that the kidney is not functioning properly
	Protein in urine (proteinuria) — too much protein in urine is not normal	Protein in the urine is a sign of a kidney disorder
	Urinalysis measures the amount of white blood cells, red blood cells, bacteria, and protein in the urine	An abnormal urinalysis could indicate kidney disease
Liver	Albumin is a protein that is produced by the liver and released into the bloodstream	Low albumin could indicate kidney disease, hepatitis, cirrhosis, or malnutrition

	Alanine transaminase (ALT) and aspartate transaminase (AST) tests measure the amount of enzymes produced by the liver	High ALT/AST could indicate that the liver is not working properly
	Bilirubin is a waste product of hemoglobin that is found in bile	High bilirubin could indicate liver damage or use of anti-clotting medication
Heart	Biopsy of the right ventricle (endomyocardial biopsy) is used to check for rejection or infection	Biopsy may indicate rejection
	Echocardiogram takes a video image of the walls of the heart and the valves	Echocardiogram indicates whether the heart is pumping efficiently or whether the valves are leaking
	Cardiac catheterization measures the pressure in the heart and may be performed with or without a coronary angiogram	Cardiac catheterization shows any blockage of coronary vessels and overall functioning of the heart
Lung	Spirometry - Pulmonary Function Testing (PFT) - measures lung function	Worsening PFT may be a sign of lung rejection or infection
	Bronchoscopy (with or without a biopsy) is used to obtain fluid or lung tissue	Bronchoscopy can detect infection or rejection
Pancreas	Blood amylase, lipase Blood glucose/sugar Hemoglobin A1c C-peptide	High blood sugar may mean that the pancreas is not working well. High amylase or lipase may occur with rejection or other injury to the organ
Islets (from pancreas)	Blood glucose/sugar Hemoglobin A1c C-peptide	High blood sugar may mean that the islets are not working well

INFECTION

Why am I more likely to get an infection?

The medications that you take called immunosuppressants prevent your immune system from attacking your new organ. They also reduce your ability to fight infections. You are more likely to catch an infection and to have more serious infections than in people with normal immune systems.

When do I have to wear a mask?

While you are a patient in the hospital, you need to wear a mask anytime you leave the floor for a test. Once you are an outpatient your doctor will tell you if you need to wear a mask in the hospital. You should not need to wear a mask at any other time (For example, going to the store), but you can discuss with your transplant team.

Is there anything I should avoid to prevent infection?

Keep your hands clean. Stay away from others who are coughing or appear ill. **Do NOT smoke.** Try to stay away from others who are smoking and avoid second hand smoke. See “Vaccines” below.

Try to stay away from common sources of infection like:

- People with colds or flu
- Dirty or dusty buildings (For example, buildings under construction)
- ◆ If you are exposed to Chicken Pox, you should report it immediately (within 24 hours) so appropriate measures can be taken to prevent the development of the disease.

What can I do at home to monitor for infection?

- Check and record your temperature every day. If your temperature is greater than 100.5-101 degrees Fahrenheit, call your local physician or the transplant clinic.
- Wash your hands well and often. Wash before meals, and always after using the bathroom. Alcohol-based hand cleansers may be used.
- Clean any cuts or scrapes. Watch them closely for redness, drainage and swelling. Call your physician or the transplant clinic if this occurs.

INFECTION	SIGNS & SYMPTOMS	TREATMENT
Pneumonia	Cough (usually producing sputum), fever, chills, nausea, chest pain, shortness of breath, wheezing, or weakness	Antibiotics
Meningitis	Severe headache, confusion, stiff neck, or fever	Antibiotics
Rash	Skin rash	Ask your transplant team about treatment

Urinary tract infections (UTIs)	Pain or burning during urination, discomfort in the lower stomach, cramping in the pelvic area or lower back, or cloudy urine that may have a strong odor	Antibiotics
Wound infections	Redness, swelling, tenderness, or fluid draining from the incision	Antibiotics
Fungal infections	Fever, headache, cough, bloody sputum, or chest pain	Antibiotics

Call your Transplant team right away if you have any of these signs of infection:

- ◆ Fever over 100.5 degrees Fahrenheit
- ◆ Cough with green or yellow phlegm (mucous discharge)
- ◆ Cold or flu symptoms or Sore throat
- ◆ Diarrhea, vomiting, particularly if you are unable to hold down your medications
- ◆ Pain on urination, frequency or loss of control of your bladder.
- ◆ Persistent redness, swelling, drainage from incisions or cuts
- ◆ Mouth sores
- ◆ Rashes

VIRAL INFECTION	SIGNS & SYMPTOMS	PREVENTION OR TREATMENT
Herpes simplex virus (HSV)	Cold sores or genital sores	Antiviral medications (acyclovir, famciclovir, valacyclovir, ganciclovir, or valganciclovir)
Varicella Zoster virus (VSV), chickenpox virus, shingles	Cluster of blisters on one side of the chest, back, stomach, legs, or arms that may be painful	Antiviral medications (acyclovir, famciclovir, valacyclovir, ganciclovir, or valganciclovir)
Cytomegalovirus (CMV)	Fever, ache, swollen lymph nodes, headache, chills, diarrhea, nausea, vomiting, or difficulty swallowing. May cause infection of certain organs such as the liver, lungs, heart, kidney, bowel, esophagus, or eyes	Antiviral medications (valacyclovir, ganciclovir, or orvalganciclovir) can be used to prevent or treat CMV infection
Epstein-Barr virus (EBV)	Fever, chills, swollen lymph glands, sore throat, diarrhea, sore muscles, or stiff neck	Antiviral medications or reduced dose of immune suppression medications (never reduce the dose without your doctor's supervision)
BK polyomavirus (BKV)	No signs or symptoms	Ask your transplant team about treatment options
Hepatitis B virus (HBV)	No symptoms or stomach pain, fever, fatigue, yellow skin or eyes (jaundice), or light-colored stools	Antiviral medications

Hepatitis C virus (HCV)	No symptoms or nausea, vomiting, loss of appetite, yellow skin or eyes (jaundice), dark urine, light-colored stools, or reaction to fatty foods	Antiviral medications
Human Immunodeficiency virus (HIV)	AIDS	Antiretroviral medications
Influenza (flu)	Dry cough, fever, headache, body ache, chills, tiredness, weakness	Antiviral medications
Respiratory syncytial virus (RSV)	High fever, severe cough, wheezing, rapid or difficulty breathing, a bluish color of the lips or fingernails, or pneumonia	Antiviral medications
Papillomavirus	Skin warts, skin cancers, or cancer of cervix	Consult your transplant team

VACCINES:

“Flu shots”

In most instances you should get a flu shot each year if you are medically stable. Check with your transplant team if you are unsure. **Do not get “Flu Mist”** – the live, nasal vaccine. Your family should also not get Flu Mist (but should get a flu shot to prevent influenza).

Pneumonia vaccine

Pneumococcal vaccination can help protect you against one of the most common forms of bacterial pneumonia. We recommend that you be given this vaccine every five years, as long as your health is stable and it is more than 3 months after your transplant or treatment of rejection.

Shingles vaccine

The shingles vaccine, Zostavax, is a **live virus vaccine** and **has not been shown to be safe in transplant patients**. As with other live virus vaccines (“Flumist”, varicella or chickenpox, yellow fever) we recommend that you not be given this vaccine. Family members can get the shingles and varicella (chickenpox) vaccines; if they develop a rash, do not touch it directly.

TRAVEL

If you would like to travel outside of the United States, Canada, and Europe, we would suggest that you be seen in the outpatient Transplant ID or Travel Clinic. The clinic number is 617-724-1934. You should be seen even if you are traveling abroad to your native country.

MARIJUANA

Marijuana use is legal for medical use in some parts of the United States. For transplant patients, it is best to avoid it. There are mold spores (fungi) in marijuana that could give you a bad infection of the lung or sinuses after transplant. If you use marijuana, we would recommend that you heat it to destroy the mold spores, such as by baking the marijuana at 300 degrees for 15 minutes. Some recommend putting marijuana in the microwave for ten or more seconds; the exact time needed to kill the fungus will vary depending on the wattage of the microwave as well as the quantity and moisture content of the marijuana. Smaller microwave ovens put out less power and would therefore require longer “cooking” times to kill a fungus. Baking before eating marijuana (as in pot brownies and cakes) may also be helpful in reducing your risk of fungal infection. Heat should not alter the active ingredient in marijuana (THC).

PETS

Many transplant recipients or their families own pets. Pets can be an important part of your family life but some are also capable of transmitting disease. To reduce the chances of getting an infection follow these safety points:

- Make sure your pet has regular check-ups, has received all vaccinations and is well groomed
- Wash your hands after petting your pet
- Avoid cleaning: cat litter box, fish tanks, bird cages (have someone else do it for you, wear gloves/mask if you have to)
- Avoid stray or sick animals and exotic animals including: reptiles (lizards, snakes, turtles), baby chicks, ducklings

You should be evaluated by a physician if you have been bitten or scratched by any animal. Ask if you have questions about your pets.

CANCER

Why should you be concerned about cancer?

Transplant recipients have a higher risk of developing certain types of cancers than people who have not had a transplant. The immunosuppressive medications that allow your new organ to function and survive also decrease the ability of your immune system to detect and fight cancer cells. There are many things you can do to help prevent cancer, including wearing sunscreen and not smoking.

Some transplant recipients will develop skin cancers. Others may develop certain types of lymphoma (cancer of the lymph glands) and cancer of the cervix, which are caused by viruses. Transplant recipients also have an increased risk of developing other types of cancer such as breast cancer, lung cancer, and colon cancer. Regular medical exams to detect cancer are very important to your ongoing health and well-being.

Skin Cancers

Some skin cancers can be avoided, so efforts should be made to prevent them. Some things you can do to prevent skin cancer include:

- ✓ Limiting the time you spend in the sun (especially when the sun is most intense between 10:00 am and 2:00 pm)
- ✓ Wearing sunscreen (SPF 45 or higher)
- ✓ Wearing a wide-brimmed hat and gloves

Most skin cancers can be cured if detected early, so it is very important that you recognize the early signs of skin cancer and seek treatment if you notice anything unusual. *A yearly visit to the dermatologist is important.* The MGH High Risk Skin Cancer Clinic can be reached at 617-726-6097.

Post-Transplant Lymphoma (PTLD)

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

EMOTIONS, STRESS, COUNSELING and SUPPORT SERVICES

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. In spite of these good feelings, some people find the adjustment to their new organ more difficult than they had expected. Some experience physical or emotional changes from the new medications including the immunosuppressive drugs. They may have concerns about the donor of the organ or fears about rejection. The recovery process may seem too slow or too confusing. You may find yourself concerned about other transplant patients who are experiencing difficulty with their grafts. You may have concerns about life at home or family changes and their adjustment to your new needs after transplantation.

These concerns are quite normal. Many individuals who have been quite ill experience anxiety or depression that tends to improve as their health improves. Some find that these concerns may interfere with the quality of their life after transplantation. This may affect your ability to deal with problems at home, at work, or in working with your transplant team.

There are resources available to help! Feel free to discuss your concerns with your nurse or a physician. They can put you in touch with any of the following people.

Psychiatrist

Consultation is available to review special concerns before transplantation or adjustments to your new organ. A visit with the psychiatrist may include instruction in relaxation techniques, use of appropriate medications or just the opportunity to talk.

Clinical Social Worker

Social Workers are part of the multi-disciplinary team available to you throughout the transplant process. During the evaluation phase they will get to know you and your family in order to identify any areas of concern that may present during the course of transplantation. Social workers are available to help find resources and to help you cope with stresses related to your illness. The social workers also provide supportive counseling to both patients and families. In order to help you through this process, we need to know how you are doing. Please call or page your social worker at any time so we can be there to help you.

Chaplain Services

Chaplain Services for most denominations are available on the unit. You may request to see a chaplain either before or after your surgery, or anytime during your stay. Catholic patients may arrange for communion at your bedside. The nondenominational hospital chapel is located on the first floor of the Ellison building and is open day and night for patients, family and visitors. Times of services are posted on the door.

GOING HOME

You will need to think and plan for things, such as,

- Who will provide you with **transportation** at the time of discharge, and to and from your clinic appointments and blood check appointments until you are cleared by your physician to drive yourself?
- Who will be able to **help** you **after discharge** with things such as food shopping, housework, errands, and meal preparation if you need assistance?
- Where you will have your prescriptions filled and who will be able to pick them up and bring them to the hospital before you are discharged?
- What is your **prescription coverage** (insurance) for the medications that you will need to continue to take after you are discharged? What are your **co-pays**? How will you pay for them?

After your surgery, the Transplant Unit's Case Manager will be available to meet with you and your family. She/he will:

- Work with you, your physicians and nurses to **plan** for your discharge. You will be given an appointment for **clinic follow-up** prior to your discharge.
- Assess your need for home nursing services (VNA), physical therapy, occupational therapy, acute rehabilitation hospital or skilled nursing facility transfer;
- Arrange for home services or screening for transfer to a rehabilitation facility **if indicated** and work with your insurance company to ensure the agency or facility is contracted with your insurance company;
- Discuss options for obtaining your prescription medications **before discharge** based on your insurance coverage.

A Transplant Pharmacist, Social Worker, and other specialists will also meet with you before you leave.

Follow up care after transplant

Early after transplantation, you may expect to come to the hospital frequently. This may be twice a week for a few weeks; you may be in clinic for several hours. The frequency of your clinic appointments will be reduced over time.

On the Day of Your Clinic Visit

- You should **not** take your morning dose of cyclosporine, tacrolimus or rapamycin on the day of your clinic appointment until **AFTER** your blood is drawn. Bring the medication with you so that you can take it **after** your blood is drawn.
- Your doctor and/or nurse will see you in the clinic or offices
- **Bring your medication card to your appointments so that changes may be recorded on your card.**

When to call the transplant clinic:

Kidney	Fever greater than 100.5 Abdominal pain Decreased urine output Swelling of the legs or ankles
Liver	Fever greater than 100.5 Increased in abdominal size Abdominal pain Swelling of the legs or ankles
Pancreas	Fever greater than 100.5 Blood sugars higher than 200 for more than 24 hours Blood sugars lower than 80 for more than 24 hours.
Heart	Fever greater than 100.5 Chest pain or palpitation Swelling in the legs or ankles
Lung	Fever greater than 100.5 Shortness of breath Decreased FEV1 (by $\geq 10\%$) Increased need for oxygen

POST-TRANSPLANT ACTIVITIES: WHAT SHOULD I EXPECT?

After your transplant, you may feel better or you may experience a number of health issues such as fatigue, graft rejection, or some side effects of medications. Knowing what you can do to prevent certain health issues 2 to 6 months after your transplant as well as more than 6 months after your transplant will help improve your quality of life for the long term. This information is a summary of ways you can **take charge of your health**.

Timeline of Health: 2 to 6 Months after Transplantation:

- **Keep all medical appointments and blood check/lab visits. Continue to take all your medications. Make sure that you have a routine so that you do not forget!**
- Learn signs of rejection and infection. Call your doctor if symptoms appear.
- Develop an **exercise routine** that has been discussed with your physician or physical therapist and that includes stretching, weight lifting, and aerobic activity. Exercise will help you get stronger and prevent illnesses such as heart disease, diabetes, and bone loss
- 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
- Maintaining good dental health is important for overall physical health. You should not visit the dentist for the first 3-6 months (even just for cleaning) following your transplant because there is a chance of getting an infection. If you do need to see a dentist or oral surgeon for a problem, let the transplant team know in advance. Transplant patients should see a dental health professional regularly. Most transplant patient **do not** require antibiotics when they visit the dentist for routine care but you should check with your transplant team in advance.
- You may need antibiotics during the procedure.
- Do daily self-exams by weighing yourself, taking your temperature, and checking your blood pressure. Call your transplant team if you notice major changes. You might be

able to stop daily monitoring soon depending on how you are doing – discuss with your doctor or nurse coordinator.

- Limit sun exposure and wear sunscreen of at least SPF 45

6 Months to a Year after Your Transplant:

Continue taking all of your medications as prescribed

- Review the signs and symptoms of rejection; call your doctor if any of them appear
- Exercise regularly to strengthen your bones and prevent fractures. 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 often seems to be one of your most difficult jobs.
- Stick with your **diet plan** to stay healthy years after a transplant. Talk to your dietician if you're having trouble following the diet
- 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 clinic or coordinator for help.
- Continue doing daily self-exams by weighing yourself, taking your temperature, and checking your blood pressure unless discontinued by your care team. 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
- When you do go to the dentist, your doctor may want you to take antibiotics before you have any dental work
- Limit sun exposure and wear sunscreen of at least SPF 30 unless you are very fair skinned (then SPF 45)

Restrictions after transplant surgery:

- You may not drive for 2-8 weeks or until cleared by your physician; you will need to arrange transportation to and from your appointments
- You may not lift more than ten (10) pounds from the first 2 months or until cleared by your physician.

Pacing Yourself Through the Day

Because of the effects of the surgery, medications, and inactivity, you may feel more tired when you go home and try to do your every day activities. It may be helpful to give yourself more time and to spread your activities throughout the day during your recovery. Here are some more tips:

- 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.
- Schedule rest periods or naps to help recharge yourself.
- Stop activity before you are overtired.
- Ask family and friends to help with tasks or activities that may be too tiring for you.
- Chose one person to organize help offered from others. It also takes energy to think, plan and respond to offers of help.
- Standing takes more energy than sitting. Use a shower chair and hand-held showerhead to bathe or sit at the counter to prepare meals.
- 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. 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, work from home to reduce fatigue.

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.
- ❖ **Speak with your physician before you start an exercise program.**
- ❖ After your transplant you will be taking a number of 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:
 - Improves your ability to sleep
 - Contributes to better bone health
 - Improves your fitness level
 - Improves your cholesterol
 - Helps lower blood pressure
 - Controls blood sugar
 - Helps control weight
 - Increases muscle mass
 - Delays or reduces effects of arthritis
 - Improves strength and flexibility
 - May help increase concentration
 - Reduces feeling of stress, anxiety and depression
 - Leads to living a longer and healthier life

There are different parts of an exercise program. These include:

1. Warm Up: 3-5 minutes of light activity to prepare your body for exercise. This is important for all transplant recipients, but especially for heart and lung transplant recipients.

For heart recipients, during the surgery, the nerves to the new heart are cut. Your heart rate does not respond to exercise as quickly as it did before your transplant. Your new heart needs to rely on hormones released in your body when you exercise to allow your heart rate to increase. This takes more time, so it is important to incorporate a warm-up of 5-10 minutes so that your new heart can accommodate to exercise. For lung recipients, the ability of the lungs to adjust to exercise will increase over time. However, all transplant recipients need to get into a regular exercise regimen!

The warm up:

- **Gradually increases your heart rate and body temperature**
- **Helps to protect your body from injury**
- **Prepares the muscles and joints for exercise**

2. Stretching: Slow movements that elongate muscles

- Best to stretch your arms and legs after warming up
- May decrease the chance of injury
- Improves posture
- After surgery, stretch until you feel a pull, but it should not be painful at your incision

3. Strength Training: Exercises that increase muscle strength

- Examples are: lifting weights, using resistance bands
- Combats long-term side effects of transplant medications
- Increases bone mass, which can delay onset of osteoporosis
- Decreases body fat, which can lead to weight loss
- Increases muscle strength, which can decrease risk of injury and decrease pain from arthritis
- Recommend doing a combination of upper body, lower body and trunk exercises
- Do each exercise 8-12 repetitions, 2 sets, every other day
- Start with low weights and gradually increase the weight while maintaining correct lifting techniques

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

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

- Examples are walking, cycling, running, dancing
- Decreases the risk of cardiac disease and other chronic health conditions
- Increases your endurance so you can return to your everyday activities
- Build up to 30 minutes a day, 5 times per week

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

- Decreases risk of muscle soreness and tightness
- Reduces likelihood of irregular heart beat
- Decreases chance of low blood pressure and dizziness after exercise

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.

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
- Get a pedometer and try to walk 10,000 steps each day

Tips to Avoid Injury

- 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
- 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

Ask a physical therapist for help if you have questions about starting a new exercise program or using new equipment.

Activity Log

This can be a helpful way to track your daily exercise.

Date	Activity	Duration	Intensity: Easy, Moderate, Hard	Weight	Comments

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 low-fat 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, which are a natural source of fiber and protein
- Keep meat and poultry servings lean and trimmed of fat
- Include low fat dairy 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 salt shaker, 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
- 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
- Choose nonfat or low fat dairy products
- 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 products

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 low fat 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 and grapefruit juice

If you take tacrolimus, cyclosporine, or sirolimus/everolimus , you should avoid grapefruit and grapefruit juice (also Fresca or grapefruit flavored seltzers/sodas) 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, 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.
- All foods from restaurants should be made fresh to order. Hot foods should be served steaming hot and cold foods should be served cold.
- Avoid public water fountains. Municipal water is routinely tested and usually safe for cooking and drinking. Well water should be tested routinely for safety. It is generally advised to avoid well water for drinking unless it is treated or filtered. Let your transplant team know if you have well water. Boiling water will help to make your water safe to drink. Bring water to a full boil for 3-5 minutes before use to make unsafe water safe to use.

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.**

My nutrition goals:

SEX and SEXUALITY

Any illness can be expected to limit sexual desire and function. Patients with any chronic disease are frequently aware of a decrease in sexual desire and function. Together with the effect that some medications have on the body, there may be a decrease in a person's feelings of sexuality and participation in sexual relationships. With a general feeling of wellness after a successful organ transplant, this may change. Sexual activity is usually permitted when you feel better, typically about 4 weeks after your transplant. Whenever your sexual function resumes, always remember to protect yourself against sexually transmitted diseases (STD).

In order to help prevent the transmission of certain viruses, such as Cytomegalovirus (CMV), Human Immunodeficiency Virus (HIV), and especially Herpes Simplex Virus (HSV), transplant recipients are strongly encouraged to use condoms during sexual activity. Oral sex may be discouraged if there is a chance of acquiring herpes, especially if the non-transplant partner has had herpes or "cold sores" previously. If you note any sores or ulcerations of the mouth, genital area, or anus, you need to let your doctor know. This could be herpes. Transplant recipients are at greater risk for this virus. It can be treated easily with proper medication.

After having a transplant, men and women often regain previous sexual function, but not always. If you do have a problem, it may be related to medications you are on, or some other treatable cause. Always feel free to discuss this with the transplant team. Remember, you are not alone, and options are available to you. If you are thinking of having children, consult the transplant team.

For Women:

Talk to your nurse or physician about **birth control**. If you are thinking about having children, talk with your doctor FIRST. The decision to have children is influenced by many factors, and together with the doctor you can decide what is best for you, and how long you should wait after your transplant before becoming pregnant. Pregnancy may be harmful to your transplant and also to you if it occurs too soon after your surgery. The baby may also be affected by the immunosuppressive medications you

take. The type of birth control you use will be adjusted based on individual factors for each woman.

- Routine breast self-examination [BSE], mammograms and pap smears are a woman's three most valuable tools for early detection of cancer of the breast and uterus. BSE checks should be performed every month about one week after your period. If you do not know how to do this self-exam, speak with your transplant team.
- A pap smear should be done every year after transplantation with a pelvic examination by a health care professional (especially if person is sexually active). Annual gynecologic examinations help to avoid cervical cancers which are more common after transplantation due to the HPV viruses that cause cervical cancer and skin warts.
- A mammogram is advised at age 40 and then every year. This is a detection method for breast cancer.

Because you are a transplant recipient, any pregnancy will be considered "high risk" and requires special attention from the gynecologist and obstetrician who cares for you. You will need close monitoring throughout pregnancy.

For Men:

It is equally important for men to discuss the use of birth control measures with the transplant team. Some of the medications that are taken for immunosuppression for a transplant may cause birth defects when used by the mother; it is unclear if these medications are dangerous when they are used by the father. Make sure to discuss this important issue with your physician. It will be important to discuss this with your transplant team so that changes can be made if necessary.

Other important issues for men who have received a transplant are:

- monthly testicular self examinations (TSE) for men under age 40; if you are not sure of how to do this self-exam, speak with your transplant team doctor or nurse for instructions

- men over 50 years of age should have annual prostate examinations as a detection for prostate cancer

SEXUALLY TRANSMITTED INFECTIONS

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). For young girls and boys there is now a vaccine against certain forms of HPV; discuss with your physician whether you should receive this immunization.

If you note sores in your mouth, genital area, or anus, you need to let your transplant team know. This could potentially be the first signs of an HSV or HPV infection. Transplant recipients are more susceptible to these viruses because of immunosuppression. There is treatment; the sooner the treatment is started the faster you will get better.

WRITING TO FAMILIES OF DECEASED ORGAN DONORS

A decision to write to your donor family is a very personal one. You do not need to do this. However, sometimes, transplant recipients choose to write to their donor family to express their gratitude. In response, many donor families have said that a card or personal note from the recipient(s) of their loved one's organs and/or tissues offers them comfort and consolation. Whether you decide to write to your donor family is your choice. The New England Organ Bank supports written correspondence between transplant recipients and donor families. All correspondence is anonymous, and identities are kept confidential.

If you would like to write to your donor family, you may send a greeting card or a letter.

You may decide to talk about yourself. You may include your first name if you choose. You may discuss your job, occupation, hobbies or interests. You may choose to talk about your family. Since the religion of the donor's family is unknown, please consider this if you are including religious comments. You may want to talk about your transplant experience. You may wish to recognize the donor family and thank them for their gift. You may choose to describe how long you waited for a transplant and what the wait was like for you and your family. Explain how the transplant has improved your health and changed your life. Can you participate in activities now that you couldn't before your transplant? You may wish to explain what has happened in your life since the transplant. Did you celebrate another birthday? Did your son or daughter marry? Did you become a parent or grandparent? Did you return to school or accept a new job?

When closing your card or letter you may sign your first name if you choose.

Do not reveal your address, city, or telephone number. Do not reveal the name or location of your transplant center or the name of your physician. Place your card or letter in an unsealed envelope. Include in the envelope on a separate piece of paper your full name and the date of the transplant. Place these items in another envelope and mail them to your transplant coordinator or directly to the New England Organ Bank at the following address:

New England Organ Bank, 60 First Avenue, Waltham, MA 02451

The New England Organ Bank Donor Family Services Representative will review your card or letter.

This will ensure confidentiality. The NEOB will then notify your donor family that correspondence has arrived for them from you. If they are ready to read your correspondence, the Donor Family Services Representative will forward your letter. It may take a few weeks after you have mailed your correspondence for your donor family to receive it.

You may or may not receive a response from your donor family.

Some donor families have said that writing about their loved one and their decision to donate helps them in their grieving process. Other donor families, even though they are comfortable with their decision to donate, prefer privacy and choose not to write to the recipients of the loved one's organs and tissues. Remember the donor family may still be coping with the loss of their loved one and individuals manage grief in different ways. While you may be celebrating the anniversary of receiving your transplant, it is also the anniversary of someone else's loss. Please communicate in a sensitive manner. If you need further information about writing to donor families, please call Donor Family Services at New England Organ Bank - 800-446-6362.

Should a donor family like to contact you regarding how you are doing after transplantation, the transplant coordinator will reach out to you. Your confidentiality is guaranteed.

MY TRANSPLANT TEAM!!

Primary Care Physician: _____ Phone: _____

Address: _____
_____ Fax: _____

Transplant Clinic: _____

Transplant Surgeon: _____

Organ Specialist (Nephrologist, Gastroenterologist, Cardiologist, Endocrinologist, or
Pulmonologist): _____

Other Medical Specialist: _____

Pre-Transplant Nurse Coordinator: _____

Psychiatrist: _____

Social Worker: _____

Primary Care Nurse: _____

Pharmacist: _____

Nutritionist: _____

Physical Therapist: _____

Post-Transplant Nurse Coordinator: _____

Pharmacy _____

Phone Number _____ Fax: _____

Appendix 1:

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 phosphates:

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).

Bronchiolitis obliterans (BO) or obliterative bronchiolitis (OB):

Inflammation of the small airways (bronchial tubes) of the lung, which often occurs after lung transplantation. It may progress to permanent lung injury (obliterans) with scarring. This can be a form of chronic lung rejection.

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 PTLN (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 anti-rejection 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.

Appendix 2: Common Medications

This is a list of some medicines you might take and what they are used for:

Induction immunosuppression

Some medications are given during or immediately after transplantation to prevent rejection. These may include Atgam, Thymoglobulin, Belatacept, Daclizumab, or Basiliximab. Some of these may be continued long-term to prevent rejection including Belatacept.

Steroids

There are many different types of steroids. Not all transplant patients take steroids. These are to prevent graft rejection and are not the same type as used by some athletes. Here are the names of some steroids used by transplant patients:

Prednisone, Methylprednisolone, Prednisolone, Deltasone®, Medrol®, Pediapred®, Prelone®, Solu-Medrol®

How do steroids work?

Steroids help your body to not reject your new organ. They can also affect your blood sugar, blood pressure, and mood. Doctors will give you high doses of steroids by mouth or through your vein (IV). If your body tries to reject the organ, you may be given a large dose through an IV for 3 to 5 days. After these large doses, you will start to take smaller doses by mouth.

When you are back home, you might take steroids once a day, twice a day, or once every other day (or not at all). Some people are able to stop taking steroids. Most people are taken off steroids or kept on a very low dose 6 to 12 months after the transplant. Never stop taking steroids before talking to your doctor.

What are the side effects?

Steroids can have many side effects. Low doses are generally well tolerated. There are more side effects if you have to take a high dose for a long time, but your doctor can help you with these side effects.

Changes in the way you look

Most of these changes do not last. They will begin to go away when your steroid dose goes down.

- Your face might get more round. You may get more fat deposits around your waist and the back of your neck.
- Some people get stretch marks; others get bruises.
- Teenagers and young adults may get acne on the face, back, and chest.
- You might become very sensitive to the sun.

Stomach problems

- Steroids can cause mild heartburn and ulcers.
- Take your steroid medicine with food. This will lessen the side effects. Your transplant team can also give you other medicine for your stomach.

Fluid retention and high blood pressure

- Steroids can cause your body to retain salt and water. This can raise your blood pressure. You may need to take high blood pressure medicine.
- Do not eat salty foods. This can help keep your blood pressure down.

Hunger and weight gain

- Steroids can make you feel hungry. Try to eat low-fat foods and limit the amount of sweets you eat. Ask the dietitian on your transplant team to help you with an eating plan.

High blood sugar levels

- Your blood sugar may go up if you are on a high dose of steroids. You may need to take drugs to lower your blood sugar such as insulin or other medications.

Problems with bones and muscles

- Steroids can cause your muscles to get weak, especially the muscles in your thighs and shoulders.
- Some people get muscle cramps and pains in their joints, mostly in their hips and knees. These problems should go away when your steroid dose goes down.
- Steroids can take calcium out of your bones, which can lead to weak bones (osteoporosis). Sometimes these drugs can damage hip or knee bones, and surgery may be needed. You can prevent this by taking calcium, vitamin D, and other supplements. Talk to your doctor about how to prevent bone loss.

Changes in behavior

- Steroids can cause mood changes. You may have trouble sleeping or have nightmares. You might feel depressed. Steroids can make you feel nervous or hyperactive, especially in children. This mainly happens with high doses. It should go away when the dose is lower. Taking this steroid medication in the morning can help to decrease these side effects and improve your sleep. There are some medicines that can relieve these symptoms, so be sure to tell your doctor if you are having any of these side effects.

Eye problems

- Some people get eye diseases like cataracts or glaucoma. Regular eye exams are an important part of your treatment. Talk to your doctor about eye checkups.

Cyclosporine

Gengraf®, Neoral® and Sandimmune® are brand names for cyclosporine (SYE-kloe-spor-een). Cyclosporine is sometimes called “cyclo” for short. These medicines are made in different capsules. Different brand names of the drug may be absorbed differently in your body. **Do not switch back and forth between different forms of these drugs.** Take only the one your transplant doctor gives you and do not allow your pharmacist to switch brands without discussing with your Transplant physician.

How does cyclosporine work?

Cyclosporine can help keep your body from rejecting your new organ. It weakens your body's white blood cells, so they do not damage the new organ.

How do I take it?

In the hospital, you will usually get cyclosporine by mouth. When you go home, you will take it by mouth as a liquid or a capsule. When you take cyclosporine as a liquid, you must mix it in a glass container and use a metal spoon. Cyclosporine capsules come in three strengths: 25 mg, 50 mg and 100 mg. You will take this drug one, two, or three times a day. It depends on how quickly your body uses the drug and what you are eating when you take it. (Children often need to take the drug three times a day.)

Take your medicine the following way. This is very important!

- Take cyclosporine at the same time each day. You must take it with the same kind of food every time. So, if you take it in the morning when you eat a bowl of cereal, then

you should take it every morning with a bowl of cereal. Do not change how you take it from day to day.

How should I store cyclosporine?

Each capsule comes in a foil package. Leave each capsule in this package until you are ready to take it. Once you open the foil package, you should use it within a few days.

You may notice a slight odor when you open the foil package. This is normal and does not mean the capsule has gone bad. Capsules are good until the expiration date on the package if you keep each one in its foil package and store them in a cool place. Always make sure you have enough of this medicine on hand so you never run out.

Note: Blood samples will be taken to measure the amount of drug in your blood. Do not take your cyclosporine on the morning of your blood test. Wait until after your blood has been taken.

What are the side effects?

Decrease in kidney function

- Cyclosporine may slow down your kidney function. Your doctor may need to lower your dose of cyclosporine. Do not lower the dose yourself.

High blood pressure

- This drug can make your body retain salt and water. It may also cause your blood vessels to narrow. These things can cause high blood pressure, even though your organ is working well. You might need to take high blood pressure medicines.

Changes in your body

- You might grow more hair on your face, arms, and legs. Talk to your doctor if you have any questions about this.

Swollen and bleeding gums

- You will have to take good care of your mouth and teeth. Brush and floss your teeth at least two times a day. See a dentist at least once a year.

Shaking and headaches

- You might get headaches. Your hands might shake, and your hands and feet might tingle. These are signs that the cyclosporine levels in your blood are high. These side effects can go away, but tell your doctor if you have them.

High blood potassium levels

- Cyclosporine will make the potassium level in your blood go up. You may need to take medicine to bring your potassium levels down. You may also have to stay away from foods that have a lot of potassium. Talk to your doctor and a dietitian if this is a problem.

High blood lipids (hyperlipidemia, hypercholesterolemia)

- Cyclosporine may cause a rise in blood triglycerides, lipids (cholesterol) and blood sugars. These effects can be treated by diet or medication.

Tacrolimus

Prograf® and FK506 are brand names for tacrolimus (ta-KROE-li-mus).

How does tacrolimus work?

Tacrolimus can help keep your body from rejecting your new organ. Tacrolimus makes your body's white blood cells weaker so they cannot damage the new organ. Tacrolimus works the same way as another medicine called cyclosporine. Many of their side effects are the same.

How do I take tacrolimus?

Most people take tacrolimus two times a day either before or after they eat. You must take it at the same time each day before or after you eat. The amount of drug you absorb is affected by food. So take your pill at the same times each day. For example, if you take your pill 1 hour before you eat, then you must always take it 1 hour before you eat. If you take it 1 hour after you eat, then you must always take it 1 hour after you eat. Once you start to take tacrolimus, take it the same way every day. Make sure you always have enough tacrolimus on hand.

Note: Blood samples will be taken to measure the amount of drug in your blood. Do not take your tacrolimus on the morning of your blood test. Wait until after your blood has been taken.

What are the side effects?

Decrease in kidney function

- Tacrolimus may slow down your kidney function or cause high potassium levels in your blood. To help with this, your doctor may change the amount of tacrolimus you take. You may need to reduce the potassium in your diet.

Tremors and shakiness

- You could feel shaky and have tremors. This could be a sign of high tacrolimus in your blood. These side effects might go away, but tell your doctor if you experience this.
- You might get headaches.

Diabetes

- Blood sugar problems due to tacrolimus may occur and may require additional care.

High Blood Pressure

- You might have problems with a rise in your blood pressure. This needs to be discussed with your physician.

Other Problems

- Tacrolimus may cause hair loss. It does not usually cause problems with your gums.

Sirolimus and Everolimus

Sirolimus (sir-OH-li-mus) and rapamycin are the same medicine. Rapamune® is the brand name. A similar drug is called Everolimus (Zortress®)

How does sirolimus/everolimus /everolimus work?

Sirolimus/everolimus helps keep your body from rejecting your new organ. It weakens the white blood cells that could attack and damage your organ.

How do I take sirolimus/everolimus?

Sirolimus/everolimus is a tablet or liquid that comes in a bottle or individual pouches. The liquid dose should be mixed in a plastic or glass container with at least 2 ounces of water or orange juice. Never mix it with grapefruit juice. After drinking this mixture, you need to pour another 4 ounces or more of water or orange juice into the same glass, stir it, and drink it again.

Sirolimus/everolimus should be taken once a day, 4 hours after you take your cyclosporine or tacrolimus if you are on both medications. It must be taken at the same time each day and with the same kind of food.

Everolimus is a tablet that is available in the following strengths: 0.25mg, 0.5mg and 0.75mg. It must be taken two times a day at the same time every day and with the same kind of food.

Note: Blood samples will be taken to measure the amount of drug in your blood. Do not take your on the morning of your blood test. Wait until after your blood has been taken.

How should I store sirolimus/everolimus?

Tablets may be stored at room temperature. The bottle or pouches of liquid should be kept in a dark container in the refrigerator at 36 to 46 degrees F. Do not store in the freezer. Once you open the bottle, you need to use the medicine within 1 month. If you need to, you can store the bottle or pouches at room temperature, but only for a couple of days. Always keep enough sirolimus/everolimus on hand.

What are the side effects?

Edema

- Swelling of your legs or body may occur. The extra fluid may also cause your blood pressure to rise. This will be discussed by your physician.
- Rarely, people may develop problems with breathing that may cause your physicians to stop the medication

Low blood cell counts

• Your white cells count can go down. You can get an infection. It can cause a drop in the number of platelets in your blood. You need platelets to help clot your blood. The number of red cells can also drop (anemia). Low white blood cell counts may cause you to get more infections with fever. Any fevers should be discussed with your care providers.

High lipid counts

• Lipids are cholesterol and triglycerides. They can go up. This can lead to hardening of the arteries. You may need to take other medicine to lower your lipid levels.

Skin rash or acne

• You may get a rash or acne on your face or body.

Wound Healing

• Sirolimus/everolimus may slow the healing of wounds including surgical wounds

Stomach problems

• You may have diarrhea or abdominal pain.

Blood clots in organ vessels

- Sirolimus/everolimus may increase the chance of blood clots in your legs or other sites

Note: If you are planning to get pregnant, please talk to your transplant doctor first.

Your doctor may decide to take you off certain medications before you try to get pregnant, or stop it while you are pregnant.

Mycophenolate mofetil, mycophenolic acid

CellCept® is the brand name for mycophenolate mofetil (also referred to as MMF).

Myfortic® is the brand name for an enteric-coated form of this drug, mycophenolic acid.

How does mycophenolate mofetil work?

Mycophenolate mofetil can help keep your body from rejecting your organ.

Mycophenolate (my-ko-FEN-oh-late) keeps down the number of white blood cells.

These white cells are the cells that could attack your new organ. It is usually used with cyclosporine or tacrolimus and prednisone.

How do I take mycophenolate mofetil?

You will usually take MMF two times a day by mouth. It comes in a capsule or a tablet. It comes in two strengths: 250 mg capsules and 500 mg tablets. Myfortic is taken twice a day – as a 180 mg or 360 mg tablet. You will be instructed on the correct amount and timing of your medications. These two forms of the drug are not the same. Do not switch the type of MMF without approval of your physician.

Do not take antacids at the same time you take mycophenolate. Do not take azathioprine (Imuran®) and mycophenolate mofetil at the same time. If you are planning to get pregnant, talk to your transplant doctor. You may need to stop taking mycophenolate mofetil while pregnant, but first talk to your doctor before you stop this or any other medicines.

What are the side effects?

Stomach problems

• This medicine can give you diarrhea, nausea, vomiting, or heartburn. These are very common side effects. You might also get an ulcer, but this is rare. These side effects can get better if you can take a lower dose, but do not lower your dose without talking to your doctor.

Low white blood cell counts

- If you do not have enough white blood cells, you can get a serious infection. To help, your doctor may lower your dose of mycophenolate mofetil for a period of time.

Azathioprine

Azathioprine and Imuran® are the same medicine. Imuran® is the brand name for azathioprine (ay-za-THYE-oh-preen).

How does azathioprine work?

Azathioprine helps keep your body from rejecting your new organ. It cuts down on the number of white blood cells that your body uses to fight diseases.

How do I take it?

Azathioprine is a pill you can take by mouth once a day at any time. If your blood count goes too low, your doctor may change the amount you are taking.

- If you have gout, you need to discuss taking azathioprine with your doctor before taking medicine for gout, such as allopurinol (Zyloprim®) or febuxostat (Uloric®). You can still take colchicine (Colcrys®) if needed.

What are the side effects?

For most people, there are few side effects from taking azathioprine.

Changes in cell counts

- You might get an infection because of a low number of white blood cells. If your white blood cell count goes too low, your doctor may change your dose. It can also cause a drop in the number of platelets in your blood. You need platelets to help clot your blood.
- The number of red cells in your blood may also fall. This could cause anemia.

Stomach problems

- Some people have nausea and vomiting.
- On occasion, this medicine can cause organ damage, but this is rare. You will have organ tests to check for this side effect.

Other side effects that are uncommon

- Fever, rash, thinning hair, loss of appetite, diarrhea, joint or muscle pain, or pancreas problems, predisposition to skin cancers.

Belatacept

Belatacept is sometimes called “bela” for short. Belatacept can be used with or in place of other medications after transplant. Nulojix® is the brand name of belatacept (belaTA-sept).

How do I take belatacept? You will receive belatacept as an intravenous (IV) infusion in your arm vein, usually in clinic. Each IV infusion takes about 30 minutes. After the first dose, you will be placed on a regular schedule as directed by your transplant doctor. Typically, it is dosed more often in the first month and then every 4 weeks after the first month. You should receive this medication regularly to get the most benefit from it.

What are the side effects? There is some increased risk of Post-Transplant Lymphoproliferative Disorder (PTLD) in which white blood cells grow out of control after transplant. It is more common with a viral infection (Epstein-Barr virus) and can become a type of cancer. Your transplant doctor will test if you have had an exposure to EBV. You should contact your transplant team if you develop fevers, night sweats, swollen glands, unexplained weight loss, or unusual tiredness. Belatacept may also increase the risk of a rare and brain infection called progressive multifocal leukoencephalopathy (PML). Contact your transplant team if you notice new clumsiness, difficulty speaking, problems with balance, confusion, memory loss, vision changes, or weakness of the arms and legs. This may be also due to other important medical conditions.

Medicines for infections

Trimethoprim-sulfamethoxazole

Bactrim®, Cotrim®, and Septra® are brand names for trimethoprim-sulfamethoxazole (try-METH-oh-prim) (sul-fameth-ox-a-zole). They are all the same medicine. They are antibiotics that are a type of sulfa drug.

How does trimethoprim-sulfamethoxazole work?

This medicine is used to prevent infections in the lungs and urinary tract.

How do I take trimethoprim-sulfamethoxazole?

It comes in a pill, liquid, or IV (intravenous) form. The pills come in two strengths: single-strength (SS) tablets and double-strength (DS) tablets. This medicine has sulfa in it. If

you have an allergy to sulfa, tell your doctors. They will give you a different medicine. Do not take this medicine if you are pregnant.

What are the side effects?

Most people do not have side effects from this drug, but it is possible you may have the following:

- Nausea, vomiting, diarrhea, or stomach cramps
- Skin rash
- Low numbers of white blood cells and other blood changes
- Your skin may become sensitive to sunlight. Use sunscreen when you are outdoors, and take your medicine with a glass of water.

People who cannot take trimethoprim-sulfamethoxazole will receive another drug (Dapsone, atovaquone or Mepron®) usually with a flouoroquinolone (levofloxacin or Levoquin®) to provide protection against infections.

Acyclovir, Famciclovir, Valaciclovir

Zovirax® is the brand name for acyclovir (acy-clo-vir), Famvir® is the brand name for famciclovir. Valtrex® is the brand name for Valaciclovir. .

How do these drugs work?

These agents fight viral infections. You will probably take one of these drugs or ganciclovir or valganciclovir (below) for the first few months after your transplant. It helps to prevent certain kinds of viral infections such as herpes, chicken pox, shingles, and cold sores.

How do I take these drugs?

They come as a pill, liquid, or are given intravenously (IV) in several strengths. It is very important that you stay away from people who have any type of viral infection, such as the flu, chicken pox, herpes, or cold sores. Be sure to tell your doctor if you have been around anyone with chicken pox.

What are the side effects?

These drugs have few side effects, but some people feel tired, get headaches, or feel nausea.

Ganciclovir and Valganciclovir

Cytovene® and DHPG are the brand names for ganciclovir (gan-ci-clo-vir).

How do these drugs work?

Ganciclovir and valganciclovir fight viral infections like cytomegalovirus (CMV), herpes simplex (cold sores), chicken pox and shingles. You will probably take one of these drugs or acyclovir or famciclovir or valaciclovir (above) for the first few months after your transplant.

How do I take ganciclovir or valganciclovir?

It comes in a pill, liquid, or IV (intravenous) form.

What are the side effects?

You will not have many side effects from this medicine, but you may have some nausea, vomiting, or diarrhea. The main side effect of these drugs is decreases in the number of white blood cells and platelets in your blood. You may need to have a growth factor to stimulate production of white blood cells (G-CSF) or a reduced dose of ganciclovir or valganciclovir depending on your kidney function. You may have blood tests to check whether you have infection due to one of these viruses.

Nystatin and Clotrimazole

Mycostatin® is the brand name for nystatin. Mycelex® is brand name for clotrimazole.

How do nystatin and clotrimazole work?

Nystatin (nye-STA-tin) and clotrimazole (kloe-TRIM-a-zole) are used to prevent or treat yeast infections in your mouth. This type of yeast infection is called thrush. Thrush looks like a white coating all over your tongue. Thrush is common in immunosuppressed patients especially if you are taking other antibiotics.

How do I take nystatin and clotrimazole?

When you take nystatin, you swish and hold the medicine in your mouth for 5 minutes, then swallow it. You should not eat or drink anything for 30 minutes after using this medication.

Clotrimazole comes as a lozenge. When you take clotrimazole you suck on the lozenge until it dissolves. Both nystatin and clotrimazole are used up to four times a day.

What are the side effects?

You will not have many side effects from these medicines, but, you may have some nausea, vomiting, diarrhea, or stomach cramps.

Medicines to prevent or treat Ulcers

Famotidine Pepcid® Ranitidine Zantac® Omeprazole Prilosec® Lansoprazole
Prevacid® Esomeprazole Nexium® Rabeprazole Aciphex®

How do these medicines work?

Because some transplant medicines such as prednisone may be hard on your stomach, you may need to take medicine to prevent stomach ulcers. The medicines listed above, as well as the generic brands, are the ulcer medicines used by most people.

How do I take these medicines?

Follow the directions on the label, and ask your doctor if you have any questions.

Note: If you are taking mycophenolate, cyclosporine or tacrolimus, you should not take sucralfate (Carafate®) because it prevents these drugs from working.

What are the side effects?

Most people have very few side effects from these medicines.

Appendix 3: HEALTH CARE PROXY/ADVANCED DIRECTIVES

You can decide in advance what medical treatment you want to receive in the event you become physically or mentally unable to communicate your wishes.

Your Rights as a Patient

All adults in hospitals, skilled nursing facilities, and health care settings have certain rights. For example, you have a right to confidentiality of your personal and medical records and to know what treatment you will receive.

You also have the right to prepare a document called an "advanced directive." In one type of advance directive, you state in advance what kind of treatment you want or do not want if you ever become mentally or physically unable to choose or communicate your wishes. In a second type, you authorize another person to make those decisions for you if you become incapacitated. Federal law requires hospitals, skilled nursing facilities, hospices, home health agencies and health maintenance organizations (HMOs) serving persons covered by either Medicare or Medicaid to give you information about advance directives and explain your legal choices in making decisions about medical care.

H Health Care Proxy/Durable Power of Attorney for Health Care

A durable power of attorney for health care is a signed, dated, and witnessed paper naming another person, such as a husband, wife, daughter, son, or close friend, as your authorized spokesperson to make medical decisions for you if you should become unable to make them for yourself. You can also include instructions about any treatment you want to avoid. Your agent will make decisions about your health care only when you are, for some reason, unable to do that yourself. This means that your agent can act for you only if you are temporarily unconscious, in a coma, or have some other condition in which you cannot make or communicate health care decisions. Your agent cannot act for you until your doctor determines, in writing, that you lack the ability to make health care decisions.

Living will: A living will usually covers specific directives as to the course of treatment that is to be taken by caregivers, or, in particular, in some cases forbidding treatment and sometimes also food and water, should the principal be unable to give informed consent ("individual health care instruction") due to incapacity.

Which is Better: Living Will or Durable Power of Attorney for Health Care?

In some states, laws may make it better to have one or the other. It may also be possible to have both, or to combine them in a single document that describes treatment choices in a variety of situations (ask your doctor about these) and name

someone (called your "agent" or "proxy") to make decisions for you, should you be unable to make decisions for yourself.

The law on honoring an advanced directive from one state to another is unclear. However, because an advance directive specifies your wishes regarding medical care, it may be honored wherever you are, if you make it known that you have an advance directive. But if you spend a great deal of time in a state other than your home state, you may wish to consider having your advance directive meet the laws of both states, as much as possible.

A dditional Information

If you need help in preparing an advance directive, or if you would like more information, you may want to contact a lawyer, a nearby hospital, hospice or long-term care facility, or your state attorney general's office.

Massachusetts General Hospital Transplant Center
55 Fruit Street
Boston, MA 02114

massgeneral.org/transplant



MASSACHUSETTS
GENERAL HOSPITAL

TRANSPLANT CENTER