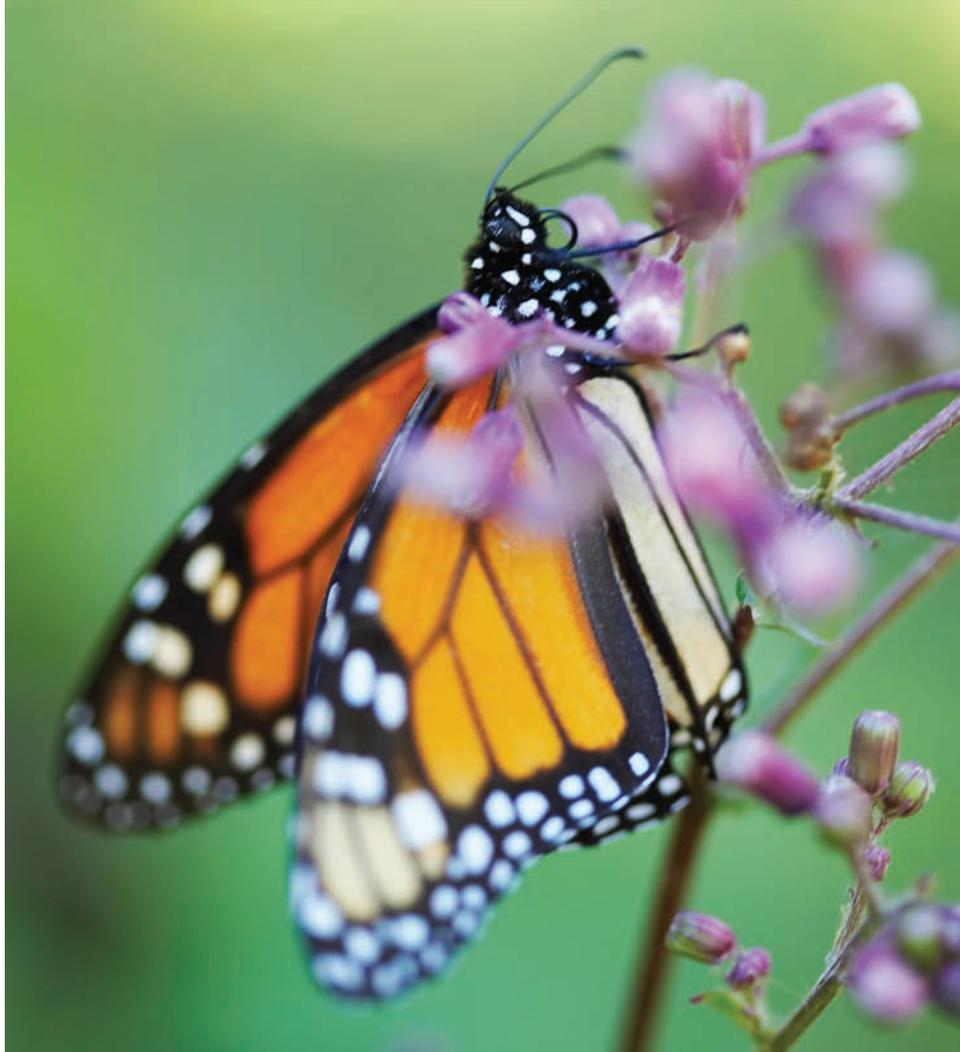


*Provided as a Service to Our Patients by
The Transplant Center, Massachusetts General Hospital*



Transplantation: What Do I Need to Know?



MASSACHUSETTS
GENERAL HOSPITAL

TRANSPLANT CENTER



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MEMBERS OF MY TRANSPLANT TEAM

PHONE NUMBER

Primary Care Physician: _____

Address: _____

Fax: _____

Transplant Clinic: _____

Transplant Surgeon: _____

Organ Specialist (Nephrologist/Gastroenterologist/Cardiologist/Endocrinologist/or Pulmonologist):

Medical Specialist: _____

Pre-Transplant Nurse Coordinator: _____

Psychiatrist: _____

Social Worker: _____

Primary Care Nurse: _____

Pharmacist: _____

Nutritionist: _____

Physical Therapist: _____

Post-Transplant Nurse Coordinator: _____

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Phone Number _____

Fax Number _____

Welcome to Massachusetts General Hospital

The Massachusetts General Hospital Transplant Center is providing this information because you want to know more about organ transplantation. We will try to answer many of your questions. Feel free to ask any of us if you have additional questions or concerns.

THE GOAL 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 Mass General, our goal is to restore patients with diseases damaging various organs — heart, lungs, liver, kidney, intestine or pancreas — to good health and to allow them to return to their normal activities. It is important for our patients and their families to be informed about what transplantation means to 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 Mass General Transplant Center is committed to your good health!

WHAT TO EXPECT BEFORE TRANSPLANTATION

When your doctor or medical insurance company sends you to Massachusetts General Hospital, they have selected a world-renowned hospital to help take care of you. First, one of our expert physicians will meet with you. 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. The specialist will decide whether you are a candidate for organ transplantation. 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 may have to undergo tests (blood tests, radiology or X-rays, or others) and meetings with other specialists. Depending on the tests, evaluation may take several days. Once all of the team members have met you and the laboratory 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 while you undergo further medical care. You may have special needs including physical therapy, antibiotics, psychological or psychiatric care, or addiction treatments. You may have a family member or other individual willing to offer their organs to help you (“**live donation**”). Your medical and surgical teams will consider all of the available options.

The disease that caused your organ failure will not stop while you wait for transplantation. So, you will continue to need care by your local physician and specialists. If you have health problems in the mean time, you, your doctor and the Mass General transplant team will work together to address your healthcare issues.

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.

Problems?

Let your doctors know if your **medications have changed**, if you have trouble affording them, or if you have been **hospitalized** or have other concerns while waiting.

Finances

The hospital needs to know about your insurance coverage and finances for transplantation. Please let your social worker or financial coordinator know if there are any changes in your insurance policies or if you have any questions about coverage. The Mass General 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 Mass General** when you are called for your transplant. You should 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

Mass General 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 Mass General in 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, parent and home? Your social worker can talk with you about difficulties that may occur and help you make plans. You should 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.

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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 healthcare proxy?

How the Transplant System Works: Matching Donors and Recipients

Once your physicians have determined that an organ transplant is the best treatment for you, you will have 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 another organ to replace your damaged organ. For many, the best option will be to be placed on a “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. Either way, 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.

United Network for Organ Sharing (UNOS):

www.unos.org/resources/patientResources.asp

Partnering With Your Transplant Team

www.unos.org/SharedContentDocuments/Transplantation_Guide_Final-3-04-04.pdf

healthytransplant.com

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. A space is provided for the answers. There is also a section for notes and other questions you may have.

What are my choices other than transplantation?

What are the benefits and risks of transplantation?

What tests and other procedures are 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 be told after completing your evaluation.)*

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

How long has Mass General been doing my type of transplant?

How many of these transplants does Mass General and my surgical team perform each year?

How long will my organ survive if I have it done at Mass General 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 Mass General transplant team and what are their roles?
How do I reach them if I have questions?

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

Who will tell me about the transplant process?

Is there a special ward of the hospital for transplant patients? (*Yes — the Transplant Unit, Blake 6*)

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Does Mass General have clinical research programs in transplantation? Will I be asked to take part in research studies? *(Yes, Mass General 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 a 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 it 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 organ donor (for kidney, liver or lung transplantation)?

Can my own doctor take care of me after I have received my new organ?

(continued)

Going to Surgery

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

- blood for testing will be drawn
- an intravenous line (IV) will be placed
- you may be given a laxative or an enema
- your skin will be prepped (shaved and cleaned)
- you will not be allowed to eat or drink any food or fluids
- you will see several doctors and/or nurses to do a medical history and physical examination
- your records will be reviewed
- a priest or minister can be called if you would like to see one

PLEASE NOTE: If your transplant is planned, i.e. is a "living donor," some of this will be done a day or two prior to your surgery date.

Your Family During Your 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.

A monarch butterfly is shown in profile, perched on a flower. The entire image is overlaid with a semi-transparent light blue filter. The butterfly's wings are spread, showing the characteristic orange and black pattern with white spots. The background is a soft-focus view of the flower and its stem.

After Transplant Surgery

After Your Surgery

After surgery you will generally go to one of a number of locations within the hospital: either to the **Transplant Floor** 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 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.

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

During surgery you will have a breathing tube (**endotracheal tube**) inserted in your throat. This tube will have been inserted while you were 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 relax. Fighting the machine uses a lot of energy and makes it more uncomfortable.

The **intravenous lines** (IVs) inserted prior to surgery will continue to provide you with fluids. These intravenous lines also allow the staff to give any medications you may need. 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.

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

You will have **pain** in you incision(s). Your doctor will order medication for your pain. Over time your pain will decrease. You will receive injections or pills to help with the pain. 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

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sit up and walk very soon, often within the first 24 hours 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 help prevent infections. A physical therapist is available to you if needed.

It is common to have congestion in your lungs after surgery because of the anesthesia and breathing tube. Coughing, deep breathing and use of your spirometer are important to help you to heal more quickly.

Your New Organ

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:

REJECTION

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

Immunosuppressant 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 the amount of these drugs you take.

HIGH BLOOD PRESSURE

High blood pressure is a common problem after transplant. It can damage your new organ and cause strokes and heart attacks. If you have high blood pressure, your doctor will put you on medication.

DIABETES MELLITUS

Anti-rejection medications can cause diabetes, or high blood sugars. If you had diabetes before your transplant, you may find it harder to control your blood sugar level after your transplant.

HIGH CHOLESTEROL

Your anti-rejection medication can also cause high cholesterol.

KIDNEY DISEASE

Some medications may damage the kidneys. Your doctor and transplant staff will monitor your blood and urine for signs of this problem.

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, or other changes in your skin.

BONE DISEASE

Transplant patients taking steroids are at risk for osteoporosis (os-tee-o-por-osis), which is a condition that causes your bones to thin. Your doctor may order a bone density test and put you on medication to help prevent this condition.

PREGNANCY

A woman should not plan to get pregnant for at least one year after her transplant. If you want to get pregnant, you and your transplant doctor should talk about it before your transplant.

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.** You should never change or skip a dose of your medication without consulting the doctor. During your recovery the nurse will bring a box of medicines to your bedside, filled with small envelopes with individual medicines in varying doses. Over a period of days, the nurses will teach you all the critical information about these new medicines. Please ask if you have any questions!

Dos 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, call us immediately.
- **Never stop taking any of your medications.** Your body will always need your immunosuppressants (such as Prednisone, Cellcept, Prograf, Cyclosporine, Rapamune or Imuran). Even after years of taking these drugs, your body will reject the transplant if the drugs are discontinued. Do not take any medications other than those prescribed by your transplant physician, especially over-the-counter remedies such as cough or cold medications, aspirin, laxatives, herbal supplements and nonsteroidal anti-inflammatories
- Let the transplant clinic know if you have new or changed medications prescribed by other physicians. Remember, many drugs interact with your immunosuppressants.
- Avoid repeated use of pain medications unless you discuss it with the transplant team.
- Avoid sleeping medications and sedatives.
- Do not keep outdated medications. Check the expiration dates on all your medicines periodically.
- Report any symptoms that might be related to your medications, such as:
 - Vomiting or diarrhea for more than two days or if you cannot 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 degrees for more than four hours
- 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 question your pharmacist if the pills look different or are a different size or color from what you are used to taking. It is NOT safe to switch or substitute new drugs for your prescribed medications without informing the transplant team.
 - Make sure that you refill your medication prescriptions so that you never run out — plan ahead! It may take up to two days for some pharmacies to get your medications.
 - 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.
 - There are other prescription drugs that should not be taken with anti-rejection medications. Ask your transplant team which ones you should avoid.

Caring for Your New Organ

Rejection

Most transplant recipients are at risk of 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 tries to destroy 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.

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 a 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 appointments. The table on the following page lists some of the warning signs of rejection. A piece of tissue (“biopsy”) may be taken to determine if a rejection episode has occurred. This is done by collecting a small piece of tissue from the organ and examining it under a microscope. Based on how the tissue looks, your transplant team can determine if something is wrong and how to treat it.

TYPE OF ORGAN TRANSPLANT	WARNING SIGNS OF REJECTION
Kidney, Kidney/Pancreas	<ul style="list-style-type: none"> • Pain or tenderness over the transplant site • Fever • Flu-like symptoms such as chills, nausea, vomiting, tiredness, headache, dizziness, body aches and pains • Little or no urine output • Sudden weight gain or swollen feet or ankles
Heart	<ul style="list-style-type: none"> • Fever • Shortness of breath • Flu-like symptoms such as chills, nausea, vomiting, diarrhea, tiredness, headache, dizziness, body aches and pains • Difficulty sleeping on your back • Abnormal or irregular heartbeat • Weight gain or swelling • Decrease in blood pressure
Liver	<ul style="list-style-type: none"> • Yellow skin or eyes • Itching • Tea-colored urine or light-colored stool • Weight gain or swelling of the legs or stomach • Sudden tiredness
Lung	<ul style="list-style-type: none"> • Unexplained shortness of breath • Chest pain • Dry cough • General ill feeling • Decreased amount of air inhaled and decreased speed of air flow during a breath
Pancreas	<ul style="list-style-type: none"> • Increased blood sugar (glucose) measurements or sugar in the urine • Increased urination • Abdominal pain or fever or pain over the surgery site

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Emotions, Stress, Counseling and Support Services

Most transplant recipients look forward to their transplant as a chance to return to normal, everyday activities. Indeed, most transplant recipients experience great happiness as their new organ begins to work and they 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. However, some find that these concerns, or others, may interfere with quality of life in the post-transplant period. This may affect your ability to deal with problems at home, at work or in working with your transplant team.

If you experience these or other worries, it is important for you to know that resources are 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.

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 the bedside. The 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.

Clinical Social Worker

There are social workers available to transplant patients both before and after transplantation, for support or guidance with resources available after transplantation.

Financial Information and Insurance

Mass General 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:

Premiums	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.
Deductibles/Maximum Out-of-Pocket Costs	A specific dollar amount set by an insurance company that a patient must pay before the insurance company pays any medical claims.
Co-Pays	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.
Lifetime Maximums/Caps	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.

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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 (\$30,636 in 2007)	Over 19 and deemed disabled:	You may be eligible for MassHealth	<p>CONTACT:</p> <p>Call Ellen MacLaughlin, Transplant Financial Coordinator 617-724-000 emaclaughlin@partners.org</p> <p>MassHealth Customer Service: 800-841-2900</p> <p>MA Health Connector: 800-623-676 www.mahealthconnector.org</p>
		Over 18, not deemed disabled and do not have access to other insurance:	You may be eligible for Commonwealth Care through the MA Health Connector	
	Over 300% of the Federal Poverty Level (\$30,636 in 2007)	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 at 100%.

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.

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 Mass General 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:

NATIONAL FOUNDATION FOR TRANSPLANT Solid Organ and BMT / Stem Cell Transplants <i>Helps cover transplant related costs that aren't covered by insurance</i>	800-489-3863	www.transplants.org
LEUKEMIA & LYMPHOMA SOCIETY BMT / Stem Cell Transplants <i>Can reimburse up to \$500 per year for transplant related costs</i>	914-949-5213	www.leukemia-lymphoma.org
CHILDREN'S ORGAN TRANSPLANT ASSOCIATION Pediatric Solid Organ, Tissue and Bone Marrow Transplants <i>Assists families in the raising of funds to assist with transplant costs.</i>	800-366-2682	www.cota.org

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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 BOTH:

**MASSACHUSETTS GENERAL HOSPITAL
REGISTRATION AND REFERRAL CENTER**

Toll Free: 1-866-211-6588

**ELLEN MACLAUGHLIN
TRANSPLANT FINANCIAL COORDINATOR, MGH**

617-724-0009

Fax: 617-726-7464

Email: emaclaughlin@partners.org

Mailing Address: Massachusetts General Hospital,
55 Fruit Street, Gray Building 140, 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 a few 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.
- 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 an extreme out-of-pocket burden, so be sure you can always secure prescription 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.

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 Rapamycin levels

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

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

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

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 (pancreatic)	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 suppress your immune system. This means that your ability to fight infection is decreased. You have a greater chance of catching something than someone with a normal immune system.

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 this with your transplant team.

Is there anything I should avoid to prevent infection?

Because of your immunosuppressant medications, you will always have a higher risk of getting a lung infection. **Do NOT smoke.** Try to stay away from others who are smoking and avoid second hand smoke. See “Vaccines” on page 26.

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 the transplant office.
- Wash your hands well and often. Wash before meals, and always after using the bathroom. Alcohol-based hand cleansers may also be used.
- Clean any cuts or scrapes. Watch them closely for redness, drainage and swelling. Call the transplant office if this occurs.

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
- 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

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VIRAL INFECTION	SIGNS AND SYMPTOMS	PREVENTION OR TREATMENT
Herpes simplex virus (HSV)	Cold sores or genital sores	Antiviral medications (acyclovir, famciclovir, valacyclovir, ganciclovir or valganciclovir)
Varicella zoster virus (VZV) chicken pox 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 (acyclovir, ganciclovir, or valganciclovir) 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 such as interferon and ribavirin
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

VIRAL INFECTION	SIGNS AND SYMPTOMS	PREVENTION OR 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 infection (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

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 Flumist (but should get a flu shot to prevent influenza).

PNEUMONIA VACCINE

Pneumovax 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 three 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” above, 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 Travel Clinic by Dr. Camille Kotton, a specialist in both Travel Medicine and Transplant Infectious Diseases. The clinic number is 617-724-1934. You should be seen even if you are traveling home to your native country.

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MARIJUANA

Marijuana is illegal in the United States. Nonetheless, people use it. There are mold spores on marijuana that could give you a bad infection of the lung or sinuses after transplant. If you decide to 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 10 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 and 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).

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.

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.

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 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 will you 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 (a nurse) 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.

Follow up care after transplant

Initially you may expect to come to the hospital frequently; gradually the frequency of your clinic appointments will be reduced.

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 >10%) Increased need for oxygen

A monarch butterfly is perched on a flower, its wings spread. The image is overlaid with a light blue filter. The butterfly's wings are dark with white spots and stripes. The background is a soft, out-of-focus light blue.

After You Go Home

Post-Transplant Activities: What Should I Expect?

After your transplant, you may experience a number of health issues such as fatigue, graft rejection or the development of some side effects of medications. Knowing what you can do to prevent certain health issues two to six months after your transplant as well as more than six 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

TWO TO SIX MONTHS AFTER TRANSPLANTATION

- **Keep all doctor appointments and 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 as soon as 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.
- You should not visit the dentist for the first six 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, let the transplant team know **in advance**.
- Do daily self-exams by weighing yourself, taking your temperature and checking your

blood pressure. Call your transplant coordinator if anything changes.

- Limit sun exposure and wear sunscreen of at least SPF 30 unless you are very fair skinned (then SPF 45).

SIX 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.

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- Continue doing daily self-exams by weighing yourself, taking your temperature and checking your blood pressure. Call your transplant clinic if anything 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 two to eight weeks or until cleared by your physician; you will need to arrange transportation to and from your appointments
- You may not lift more than 10 pounds for the first two months or until cleared by your physician.

Pacing Yourself Throughout 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 everyday 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. Work from home to eliminate increased fatigue from commuting.

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 important 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 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

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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, two 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 exercises until your incision has healed.

4. AEROBIC EXERCISE: EXERCISE TO IMPROVE OVERALL CARDIORESPIRATORY 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 far away 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.

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Healthy and Safe Eating After Transplantation

Your diet and your drugs (medications) work together to protect your new organ(s).

To stay healthy after transplant surgery you need:

- Healthy foods to stay healthy
- More calcium for strong bones
- Usually not a lot of added sodium
- Less sugar for blood sugar control
- Less cholesterol and saturated fats to reduce your risk of heart disease
- No grapefruit / grapefruit juice with some drugs
- Food that is prepared and stored in a safe way

HEALTHY EATING

Eat healthy foods that give you vitamins, minerals, protein and calories. These will help your body to heal.

The food guide pyramid can show you how to get a balanced diet. Eat more food from the bottom of the pyramid. Eat less from the top of the pyramid.

- Eat more high-fiber foods: fruits and vegetables (see note below about uncooked fruits and vegetables), whole grain breads and cereals, and bran.
- Eat high-protein low-fat foods: chicken, turkey, seafood, lean red meats and low-fat dairy products.
- Stop eating when you are full. Do not overeat.

AVOID GRAPEFRUIT. AVOID GRAPEFRUIT JUICE.

Grapefruit can change the way your body absorbs medications and cause dangerously high levels in your blood.

Do not eat grapefruit or drink grapefruit juice if you are taking any of these drugs:

- Cyclosporine (Neoral®)
- Tacrolimus (Prograf®)
- Sirolimus (Rapamune®)

Food safety

Prepare and store foods in a safe way to prevent infection from germs. The drugs you are taking can make it hard for your body to fight germs. The following tips will help keep you safe and healthy when eating and drinking.

Transplant patients are restricted in intake of fresh fruits and vegetables for three months from the date of transplant and for three months after treatment for rejection.

Washed and peeled or cooked fruits and vegetables are acceptable.

Avoid garnishes.

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When Purchasing Food — at the Grocery Store

- Purchase frozen and refrigerated foods last. Refrigerate foods promptly. Unpack store-bought foods right away — do not leave foods in a hot car, direct sunlight or on a counter for a long time.
- Check use by dates, do not buy any foods that you will not use by the date indicated on the package.
- Don't buy food in poor condition. Refrigerated food should be cold to the touch and frozen foods should be rock solid. Cans should be free of dents and bulging lids.
- Select unblemished fruits and vegetables.
- Avoid unpasteurized foods such as soft cheeses (especially those marked as "raw"; American soft cheeses made with pasteurized milk are generally fine) and unpasteurized apple cider.

When Purchasing Food — Eating Out

- Do not eat out in places that you do not trust or do not seem clean
- Avoid unrefrigerated cream and custard desserts and pastries
- Avoid ice cream and yogurt from soft serve machines
- Avoid salad bars, raw vegetables or fresh fruits when eating out
- Use caution with delicatessen foods

When Storing Food

- Keep your refrigerator as cold as possible without freezing milk or lettuce. The refrigerator should be kept at 40°F and the freezer at 0°F.
- Place raw beef, fish, chicken and turkey on a plate on the bottom shelf of the refrigerator to avoid dripping bacteria-containing juices on other foods.
- Freeze meat, fish, chicken, or turkey if it can't be used within three days of purchasing.
- Thaw food in the refrigerator or in the microwave, never on the counter.
- Refrigerate foods promptly. Divide larger portions and use small, shallow containers to allow food to cool quickly.

When Preparing Food

- Wash your hands with soap and hot water before handling foods and before eating.
- Avoid using sponges.
- Always use a clean dish cloth or disposable cloth to wash and dry dishes. Never use the same cloth/paper towel to wipe your counters. Wash dishcloths daily.
- Keep raw beef, fish, chicken, turkey and their juices away from other food.
- Use separate cutting boards for raw beef, fish, chicken and turkey. Use plastic cutting boards instead of wooden boards which can hide bacteria. Replace cutting boards with grooves.
- Wash all fresh fruits and vegetables with cool running water even if you plan to peel and discard the skin.
- Wash the tops of canned goods before opening.

When Cooking Food

- Cook beef, chicken, turkey, fish and seafood until well done.
- Avoid sushi, raw oysters and raw eggs in any form. Cook eggs until the yolk and white are firm. Do not eat runny egg or egg yolk or foods that contain raw eggs (cookie dough, Caesar dressing, unpasteurized egg nog or hollandaise sauce).
- Cook turkey, chicken, stuffing, stuffed meats, stuffed pasta and casseroles to 165° F for 15 seconds.
- Cook ground meats, flaked fish, sausage and gyros to 155° F for 15 seconds.
- Cook pork, ham, beef, veal, lamb, game, fish and eggs to 145° F for 15 seconds.
- Bring sauces, soups and gravies to a boil. Heat frozen left overs to 165° F.
- Use a meat thermometer to check the internal temperature of meats. A thermometer is the safest way to determine doneness.
- Observe the standing time called for in a recipe or on the package to allow food to finish cooking.

When Serving Food

- Never leave foods out for longer than two hours.
- Use clean dishes and utensils to serve food.
- Serve grilled food on a clean plate, not one with raw juices.
- Pack lunches in insulated carriers with a cold pack and refrigerate if able. Never leave any food in direct sunlight.

Safe Drinking Water

Drink safe water that is free from germs.

TAP WATER

- You can drink tap water if it is safe.
- Tap water can be used for cooking.
- To make unsafe water pure (sterilized), bring water to a full boil for one minute before use.
- Please ask a registered dietitian if you are interested in finding a way to test your tap water to be sure it is safe.
- If you have well water, yearly testing should be done

BOTTLED WATER

If you prefer to drink bottled water choose a major brand of bottled water when possible.

FILTERS

- Filters can reduce many water impurities but will NOT help if your town or city says your water is unsafe.
- Look for a filter that uses reverse osmosis, is “absolute” 1-µm filters and is labeled as certified by National Sanitation Foundation International under standard 53 for “Cyst Removal.”
- Have someone else change the filter on a regular basis.

NOTE: DO NOT drink from public water fountains.

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 four 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 unit nurses, transplant coordinator or the doctors. Remember, you are not alone, and options are available to you. If you and your mate are thinking of having children, consult the transplant team first.

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 healthcare 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. 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); 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 teenage girls and women 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 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

The 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 our 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
One Gateway Center
Newton, MA 02458

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 at 800-446-6362.





Appendix A: Glossary

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 PTLD (post-transplant lymphoproliferative disorder).

EXHALATION

The act of breathing out.

F**FATIGUE**

Lack of energy.

FERTILITY

The ability to become pregnant.

FRACTURE

Broken bone.

FUNGUS:

Organisms such as mold and yeast that can cause infection.

G**GAMMA GLUTAMYL TRANSPEPTIDASE (GGT)**

A test to detect liver disease.

GASTROINTESTINAL SYSTEM

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

GINGIVAL HYPERTROPHY

Enlarged or swollen gums that increase the risk for infection. It may be caused by some 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.

GUAIAIC

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 chicken pox 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 B: Medications

Appendix 2: The Medicines

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

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 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 three to five days. After these large doses, you will start to take smaller doses.

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 six 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. 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 , 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. There are many 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.

Azathioprine (Imuran®)

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 or Zyloprim®. You can still take colchicine 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.

Cyclosporine

Neoral®, Sandimmune® and SangCya® are brand names for cyclosporine (SYE-kloe-spor-een). Cyclosporine is sometimes called “cyclo” for short. These medicines are the same, but they are made in different capsules and 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 two strengths: 25 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 have to take the capsule within seven 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 for three years 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.

Sirolimus and Rapamycin

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

How does sirolimus work?

Sirolimus 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?

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

Sirolimus should be taken once a day, four 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. This is very important.

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

How should I store sirolimus?

The bottle or pouches 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 one

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 on hand.

What are the side effects?

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. This could cause anemia.

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.

PNEUMONIA/BREATHING/EDEMA

Rarely, people may develop problems with breathing or with fluid accumulating in their legs that may cause your physicians to stop the medication.

WOUND HEALING

Sirolimus may slow the healing of wounds including surgical wounds.

STOMACH PROBLEMS

You may have diarrhea.

LOW BLOOD POTASSIUM LEVELS

Sirolimus can make the potassium level in your blood go down. You may need to take medicine that will bring your potassium level back up. You may also have to eat foods high in potassium. Talk to a dietician if this is a problem.

BLOOD CLOTS IN ORGAN VESSELS

- Sirolimus may raise the chances of blood clots in your legs or other sites.
- Most patients who have received sirolimus, especially children, have taken it to replace medicines such as cyclosporine or Prograf.

NOTE: If you are planning to get pregnant, please talk to your transplant doctor first. Your doctor may take you off sirolimus before you try to get pregnant, or stop it while you are pregnant.

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. This drug and your food work together. So if you take your pill one hour before you eat, then you must always take it one hour before you eat. If you take it one hour after you eat, then you must always take it one hour after you eat. The idea is to decide when you will eat and when you will

take your tacrolimus, then stick to that. 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. To help with this, your doctor may change the amount of tacrolimus you take.

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.

OTHER SIDE EFFECTS

- You might get headaches. You might have problems with your blood pressure, stomach or organ. Or you may have high blood sugar or high potassium in your blood. You may need to take other medicine for these side effects.
- Tacrolimus does not cause extra hair growth on your face, arms or legs. It does not usually cause problems with your gums. Rarely, tacrolimus causes tremors, headaches or seizures. Blood sugar problems due to diabetes may also occur.

Mycophenolate mofetil, mycophenolic acid

CellCept®, MMF and RS are brand names for mycophenolate mofetil. Myfortic® is the brand name for a longer acting 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 take MMF drug two to three 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.

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.

VERY LOW NUMBER OF WHITE BLOOD CELLS

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.

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 flouroquinolone (levofloxacin or Levoquin[®]) to provide protection against infections.

Acyclovir, Famciclovir, Valaciclovir

Zovirax® is the brand name for acyclovir (acyclovir), 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) acyclovir 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). It comes 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). Valcyte® is the brand name for valganciclovir.

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 effect of these drugs is on 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 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 five minutes, then swallow it. You should not eat or drink anything for 30 minutes after doing this.

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.

MEDICINE FOR ULCERS

Pepcid[®], Zantac[®], Prilosec[®],
Prevacid[®], Nexium[®], 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 Carafate[®] because it prevents these drugs from working.

What are the side effects?

Most people have very few side effects from these medicines.



Appendix C:
Healthcare Proxy / Advanced Directives

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 healthcare 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.

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 healthcare decisions. Your agent cannot act for you until your doctor determines, in writing, that you lack the ability to make health care decisions.

Which is Better:

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 healthcare instruction”) due to incapacity.

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.

Additional 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.







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