Lung Transplant Program
Patient Education

Congratulations on your lung transplant. To many people, having a lung transplant is an emotionally and physically draining process. Many have been waiting for a new lung for a long time. Your lung transplant team understands this and we want both you and your family to know that we are committed to helping you recover, both emotionally and physically and to gain control of your life again.

To help you understand the special needs of your body, and to help you anticipate what will happen as you recover in the hospital as well as at home, we have created this packet of information. We hope it will answer the majority of your questions and prompt you to ask ones you hadn’t thought of yet. Remember, we’re your partners, committed to your wellness. Since you are an equal partner in this wellness relationship, we know that both you and your family will do your best to follow the guidelines in this packet, and help yourself on the road to recovery.
What to Expect While You are Recovering in the Hospital

Protecting Yourself Against Infection

**Hand washing:** This is the *most important thing you can do* to protect yourself from an infection - for the rest of your life! It doesn't matter if you are here in the hospital, at home or out with friends.

Most of the time you "get sick" after you have touched a surface (computer keyboard, shopping cart door handle etc...) that someone has sneezed or coughed on, and then you touch your face (scratch your nose, eat, wipe your eye etc...) Frequent hand-washing greatly reduces the chances of these germs being transmitted from your hands to your face, where they can enter your body. While this is important for everyone to remember this, it is vital for a person with a lung transplant because your immune system is weakened by the medications you need to protect your lung from rejection.

**Handwashing Tips!**

- Use warm water to wet your hands. Apply any antibacterial soap, such as Ivory, Dial, Softsoap etc..., and rub your hands together vigorously for **15 seconds**. (Time yourself the first time... you'll be surprised how long 15 seconds really is!) Then rinse thoroughly.

- **When should you wash your hands?**
  1. Before you prepare food
  2. Before and after you eat
  3. After you use the restroom – every time!
  4. After handling pets
  5. After working in the yard
  6. After you have contact with someone who is sick
  7. After you take out the garbage
  8. When you are in places with large groups of people

- If there is no convenient place to wash your hand, consider purchasing the new pocket-sized hand sanitizers (they look like liquid soap), which don’t require water. You can keep it in your pocket, purse, car etc…
What to Expect While You are Recovering in the Hospital (continued)

**Wearing a Mask:** A person with a new lung transplant has a large amount of medication in their body that suppresses their immune system to fight any rejection. This makes them more prone to infections. Wearing a mask can help protect you from some infections.

**While you're in the hospital:** You should wear a mask whenever you are in a public area… basically, anytime you leave your room. You should also wear one when young children visit you and around anyone who may be sick.

**When you return home:** For the first few weeks, you should wear a mask whenever you are in a very public area, like the mall, church or a stadium etc., and do not let sick friends and family come over for a visit.

**What is Rejection?** Acute rejection, which generally occurs days to weeks after surgery, is a systemic inflammatory disorder that occurs when your body recognizes your new lung as foreign. Systemic signs and symptoms of rejection are similar to signs of an infection and include fatigue, fever, chills, muscle aches, and joint pain. You may also notice palpitations (a fluttering feeling in your chest), increased swelling and shortness of breath. Keep in mind that while you may have one or more of these symptoms, often people do not experience any symptoms what-so-ever. This does not mean that your rejection is any less severe. All rejection should be taken seriously.

Rejection of your new lung can only be detected through a bronchoscopy with a lung biopsy. The biopsied tissue is examined for rejection by a pathologist.

Although it can be scary to hear that you have rejection, it is important to remember that everyone will encounter this during some point - keep in mind that your immune system is just trying to protect you. Your doctors have special medications to quiet your immune system down and help the rejection disappear.
Adjusting to Your Medications

Cyclosporine (Neoral): This medication is one of the most important immunosuppressive pills you will take. Cyclosporine acts on your T-cells. T-cells are a type of white blood cell (WBC), which scan your body for foreign material. T-cells know that your new lung is foreign and can attack it. When you take cyclosporine, the ability of your T-cells to react to your lung becomes hampered, keeping your lung healthy.

Side Effects:
1. Increased susceptibility to infections
2. Kidney dysfunction
3. Tremor (unintentional shaking)
4. Hirsutism (excessive growth of hair, or hair in unusual places)
5. High blood pressure
6. Gum hyperplasia (when the tissue around your teeth grows more than it should and can swell and bleed)
7. High potassium levels

Dosing: Cyclosporine comes in two doses, a **25mg capsule** and a **100mg capsule**. You will have to count out how many you will need of each to make your daily dose. Cyclosporine should never be taken with grapefruit juice, as this affects its metabolism.

How do my doctors know that I’m getting enough cyclosporine?
Your Transplant Coordinator will ask you to get your blood checked periodically (at least weekly in the beginning). The blood must be drawn in the morning, approximately 11 to 12 hours after your last dose. This level is called a trough and represents the lowest amount of cyclosporine circulating in your body before you take your next pill. It is vital that you do not take your morning cyclosporine before your blood is drawn! If you do, it will falsely elevate your drug level making it look too high.

What if I miss a dose of my cyclosporine?

1. If you miss a dose of cyclosporine and it is within 4 hours of your normally scheduled time, go ahead and take your dose.
2. If it is beyond 4 hours, then contact your transplant coordinator or the physician on call (if it is after regular business hours) right away. Don't decide what to do on your own. Do **not double the next dose**!
Adjusting to Your Medications

**Medication Interactions:** You must *always* be cautious when taking new medications because they can make your cyclosporine level go higher (potentially hurting your kidneys or making you more at risk to get an infection), or making your level too low (putting you at risk for developing rejection). *It is best to contact your outpatient transplant coordinator before starting any new medication!*

**Other types of cyclosporine:** Cyclosporine is the generic name for this medication, The brand name most people take is called Neoral. Other formulations of cyclosporine such as Sandimune or Sang Cya are **NOT interchangeable with Neoral** because they are absorbed differently in your body. Make sure you are getting the correct one from your pharmacist.

**Imuran:** This medication may be used together with your other immunosuppressive medications to prevent rejection. The effect of Imuran is broader than cyclosporine. It impairs the function of T-Cells and other types of white blood cells that make up your immune system.

**Side Effects:**
1. Increased susceptibility to infections
2. Stomach upset and vomiting
3. Diarrhea
4. Blood abnormalities

**Dosing:** Imuran comes in **50mg tablets**, and you should take the dose that is directed by your physician. Checking your blood for Imuran levels isn’t necessary.

**What if I miss a dose?**

1. If you miss a dose of Imuran and it is within 4 hours of your normally scheduled time, go ahead and take your dose.
2. If it is beyond 4 hours, then skip that dose and take your next regularly scheduled dose at the appropriate time.
3. If you have any concerns, then contact your Transplant Coordinator.
Adjusting to Your Medications

**Prednisone:** Also a very powerful immunosuppressive agent, prednisone is a steroid that is used in combination with cyclosporine and CellCept to reduce your chances of developing rejection. It reduces inflammation in your lung and also inhibits some of the actions of your T-cells.

**Side Effects:**

1. Increased susceptibility to infections
2. Sodium and fluid retention
3. Muscle weakness and loss of muscle mass
4. Loss of calcium, leading to loss of bone density and a higher chance of bone fractures and osteoporosis
5. Stomach ulcers
6. Difficulty healing wounds, cuts, and sores.
7. Development of Cushingoid features: full cheeks, redistribution of body fat away from arms and legs and toward your stomach
8. Increased appetite
9. Menstrual irregularities
10. Cataracts
11. Elevation of blood glucose (you may require insulin now)
12. Dramatic fluctuation of your emotions
13. Insomnia
14. Acne
15. Elevated cholesterol

**Dosing:** Prednisone comes in 1 mg, 2.5mg, 5mg, 10mg and 20mg tablets. Initially, you will be taking fairly high doses of steroids to allow your immune system to adjust to your new lung. However, before you leave the hospital, you will notice that you will begin a "prednisone taper." This taper will reduce your steroid dose gradually until it reaches a certain level that is predetermined by your doctor. Once your taper is complete, you should maintain this dose until you are directed by your doctor or transplant coordinator to change it. Over time (months to years) your prednisone will gradually be reduced to the lowest possible level to reduce your side effects, but still keep you safe from rejection. As with Imuran, no blood levels are necessary to monitor its effectiveness.
Your Transplant Coordinator
A Life-line to Health

When you go home, you may have contact with any of our two out-patient transplant coordinators.

The transplant coordinators play a vital role in helping you stay healthy at home. They may frequently call you to see how you are feeling. They keep track of your lab work and what tests you need as well as what the results of those tests results are. The coordinators also monitor what medications you are taking, and they will call you at home to let you know when to change your doses. The coordinators are in constant contact with your transplant pulmonologist and will let your doctor know how you are doing.

Contact Numbers:

2. During office hours, they will check the voice mail very frequently and will return your phone call as soon as possible. If it is after office hours and you need to speak to someone you may call (734) 936-6267, and ask for the Pulmonary Fellow on call.

You should call this number:
- Whenever you aren’t feeling well, even if you aren’t sure why, or you think it is just a cold... you must contact them! They may tell you just to monitor your symptoms, but it is always better to error on the side of safety.
- If you have a question about how to obtain or send your lab work, Your Coordinator will contact you if you have an abnormal lab value.
- If you have a question about a test result.
- If you have a medication question.
- If you need a prescription refill, Remember, do not wait until a Friday at 4pm to get your refills especially on a holiday weekend. Plan ahead!
- Contact the Transplant office if you get admitted to any hospital.
- Any other questions you may have.

Office Hours: Monday thru Friday from 8:00 am to 4:30 pm

3. If it is an EMERGENCY, go to your local emergency room or call 911. "Tell them you have had a lung transplant. Remember to bring your list of medications with you."
Your Transplant Coordinator
A Life-line to Health (continued)

Your Primary Care Physician:

- Please keep us informed whenever you see another physician (your primary doctor, urologist, dermatologist, nephrologist etc...).
- Ask him/her to send us a letter after your office visit, so we can understand your special needs.
- Also, if any doctor prescribes a new medication for you, please contact your Coordinator prior to taking that medication.
- Sometimes, that medication could have a severe interaction with your immunosuppressive pills and inadvertently hurt you instead of helping you. When this happens, another medication can often be substituted.
Going Home - What You Need to Know!

Caring for your body:
1. Measure and record your weight each morning. Bring this with you to all appointments as well. Watch for signs of "fluid overload" such as swelling of your ankles, feet, hands etc. or shortness of breath.
2. DO NOT SMOKE!
3. Do not use illicit or "recreational" drugs
4. Eat a low sodium, low cholesterol diet
5. Exercise - perform at least 20 minutes of aerobic exercise 3 times a week.

Signs and Symptoms of Infection: It is vital that you pay close attention to your body when you go home after surgery. You should contact your Transplant Coordinator if you note any of the following:

1. Increased redness, drainage, or tenderness of your incisions
2. A temperature exceeding 100 degrees F. orally or a persistent low-grade temperature (99 to 100 degrees F.) for more than 3 days.
3. A new cough lasting more than two days.
4. Increasing shortness of breath

Medications:
1. Become very familiar with all of your medications, what they do, their side effects, and how to take them properly.
2. You should carry a current list of your medications with you at all times.
3. Do not take over-the-counter medications containing aspirin or ibuprofen (read the label carefully). Check with your Coordinator for recommended "cold remedies"

Lab Draw Guidelines:
1. **Timing:** On a blood draw day, do not take your cyclosporine in the morning until after the blood is drawn. Your blood should be drawn the hour before you normally take your pill. If you take your cyclo at 9am and 9pm, then your blood should be drawn between 8am and 9am If you take your cyclo at 11am and 11pm then get your blood drawn between 10 am and 11am.
2. **Labeling your blood properly:** In order to properly process your blood, each blood tube must have a label identifying you with your U of M ID number. Please take the sheet of labels we give you to each blood draw, and label the **purple tube** with a sticker. This tube will measure your cyclosporine level.
Going Home - What You Need to Know! (continued)

3. **Sending your blood:** If you get your blood drawn somewhere other than U of M, you must send your cyclosporine tube here to be processed. Please use the Federal Express slips we have provided you. They are already correctly addressed for delivery. The mailing service is provided to you free of charge. Additionally, the boxes for mailing the tubes are free of charge and you can pick them up in the Transplant Office when you come for your appointments- we cannot mail them to you.

**Biopsy Days:** Do not eat or drink anything for at least 6 hours before your bronchoscopy. Do not take your cyclosporine before the biopsy. Bring your medications with you so that you can take it after the biopsy. Please always bring your current medication list with you along with the strength of each medication and the times it is taken.

**Immunizations/Vaccines:**

1. Check with the Transplant Office before being around anyone who recently received MMR (measles, mumps, rubella) or polio immunizations.
2. Check with the Transplant Office before getting immunizations or flu vaccines for yourself.

**Antibiotic prophylaxis:** Lung transplant patients who undergo certain procedures such as dental work, some kind of scope or camera to look in your throat, lungs, esophagus, or genitourinary tract are at risk for developing an infection from this. To prevent this infection, you must take an antibiotic before having the procedure. Here are some guidelines recommended by the American Lung Association.

1. If you will have a procedure involving your mouth, teeth, throat, lungs, or esophagus, then you will need:
   - **Standard prophylaxis:** Amoxicillin: 2 grams by mouth, one hour before the procedure.
   - **Unable to take medication by mouth:** Amoxicillin: 2 grams as a shot in your muscle (IM) or in an IV 30 minutes before the procedure.
   - **Penicillin/Amoxicillin/Ampicillin allergic:** Clindamycin: 600mg by mouth one hour before the procedure or Cephalexin or Cefadroxil: 2 grams by mouth one hour before the procedure.
Going Home - What You Need to Know! (continued)

- **Penicillin/Amoxicillin/Ampicillin allergic and unable to take oral medications:**
  Clindamycin: 600mg IV 30 minutes before the procedure, or Cefazolin: 1 gram as a shot in your muscle (IM) or IV 30 minutes before the procedure.

2. If you are having a genitourinary procedure or a procedure done on your gastrointestinal tract, the doctor doing the procedure will determine your risk for developing an infection, and give you the proper antibiotic. He/she may use the guidelines below or call the transplant office if there are any questions:

- **High-risk patients:** Ampicillin: 2 grams IM or IV plus Gentamycin: 1.5 mg/kg IM or IV 30 minutes before the procedure, and **6 hours after** you will need ampicillin: 1 gram IM or IV or amoxicillin: 1 gram orally.

- **High-risk patients allergic to penicillin agents:**
  Vancomycin: 1 gram IV over 1-2 hours **plus** gentamycin: 1.5mg/kg IM or IV. Complete the injection/infusion 30 minutes before starting the procedure.

- **Moderate-risk Patients:** Amoxicillin: 2 grams by mouth one hour before the procedure
  -OR-
  Ampicillin: 2 grams IM or IV 30 minutes before starting the procedure.

- **Moderate-risk patients allergic to ampicillin/amoxicillin:**
  Vancomycin: 1 gram IV over 1-2 hours. Complete infusion within 30 minutes of starting the procedure.
Going Home - What You Need to Know! (continued)

General Guidelines:

1. Visit your dentist every 6 months!

2. Remember to wash your hands frequently, especially after contact with animals. Do not clean bird cages or handle cat litter.

3. Do not drink water from unsafe sources such as streams, rivers, or lakes.

4. Swim only in waters specified as safe for swimming. Do not swim if you have open sores, cuts, or other lesions on your skin.

5. Do not handle soil or plants if you have open sores, cuts, or other lesions on your hands. It is imperative that you wear gardening gloves to reduce your chances of infection from bacteria in the soil.

6. Avoid extended exposure to direct sunlight. Many medications can make you especially sensitive.

7. Check with the Transplant Office before traveling.
Writing to Your Donor Family

Writing to your donor family can be an emotional experience. Many transplant recipients are unsure of how to express gratitude to a family that has lost so much. Here are some suggestions from *The Gift of Life* organization that may help.

- Send a hand written or typed letter or card.
- Include your first name only
- Share information about yourself: your family, your hobbies, occupation etc...
- Write about your transplant experience and how your life has changed.
- Please do not feel obligated to feel too much personal information.
- Please consider the appropriateness of religious comments
- You may include a photograph of you and your family.

Closing Your Card or Letter
1. Sign your first name only.
2. Do not reveal your last name, address, phone number or e-mail address.

Mailing Your Correspondence
1. Place your card or letter in an unsealed envelope.
2. Include a separate piece of paper in the envelope with your full name, address, and date of transplant

Please send your correspondence to:

   Penny Colthurst, RN, BSN  
   Donor Family Follow-up Coordinator  
   Gift of Life Agency  
   2203 Platt Rd.  
   Ann Arbor, MI 48103

Although it can be difficult to find the words to express your gratitude, your donor family will very much appreciate your thoughtful gesture.

Gretchen & Todd, Erica's parents, "We believe letters from the recipient family are comforting." They give added life & memories to the donor family."

Kim, wife of Arnie, "If I hadn't heard from the recipient I would always wonder. It made me realize that I made the right decision."

Pam, mother of Michael, "Thank you for sending us the letter. It really helps with the healing process."