

TEN COMMANDMENTS OF LUNG TRANSPLANT

1 ALWAYS CALL YOUR TRANSPLANT COORDINATOR WHEN EXPERIENCING ANY SYMPTOMS OF INFECTION, INCLUDING FEVER, COUGH, EXTREME FATIGUE, OR SHORTNESS OF BREATH.

2 ALWAYS WASH YOUR HANDS AFTER USING THE BATHROOM AND BEFORE EATING; AVOID TOUCHING YOUR FACE WITH YOUR HANDS!

3 ALWAYS WEAR A MASK WHEN YOU COME TO THE HOSPITAL, TO THE LAB, TO A DOCTOR APPOINTMENT, OR IN ANY CROWDED ENVIRONMENT.

4 ALWAYS TAKE YOUR MEDICATIONS ON TIME AND HAVE YOUR LABWORK DONE AT THE TIMES INSTRUCTED. Always call your transplant coordinator if you go off of your schedule.

5 ALWAYS ADHERE TO YOUR SURVEILLANCE and lab SCHEDULE. Surveillance is how we monitor you for rejection. You will always be at risk for rejection.

6 ALWAYS AVOID EXPOSURE TO SMOKE, DUST, MOLDY ENVIRONMENTS, AND RESPIRATORY IRRITANTS.

7 ALWAYS AVOID EXPOSURE TO THE SUN; WEAR SUNSCREEN AND PROTECTIVE CLOTHING ANYTIME YOU ARE OUTDOORS.

8 ALWAYS CALL FOR MEDICATION REFILLS WELL BEFORE YOU RUN OUT OF MEDICINE!

9 ALWAYS AVOID ILL CONTACTS, EVEN IF THEY ARE RELATED!!

10 ALWAYS BRING YOUR BLUE MEDICATION CARD TO CLINIC. You should also bring your blue medication to any medical appointment including your Primary Care Provider.

Module 1: INFECTION

Background

Several of the medications you are taking are called “immunosuppressants.” By decreasing the strength of your immune system, these drugs limit your body’s ability to recognize the donor lungs as foreign. But with a suppressed immune system, you will be at increased risk for different types of infection.

Always remember that using prevention strategies is the single most important thing you can do.

Types of Infection

- Bacterial
- Viral
- Fungal
- Parasitic

Prevention

Hand Hygiene

This is the single most effective measure you can use to reduce your risk.

- Wash with soap and water for at least 30 seconds.
- Use alcohol based gels when soap and water not available.
- Avoid touching surfaces that may not be cleaned regularly.
- Avoid touching your face.
- Do not reuse tissues.
- Avoid cleaning moldy areas (bathrooms), litter boxes, animal cages and fish tanks.
- Wash your hands after petting animals, handling money and touching objects that may be dirty.
- Do not change diapers of children who have been recently vaccinated.

Sick Contacts

- Avoid anyone who has been sick recently (even those with the “common cold”).
- If someone in your household is sick, both parties should wear a mask and be diligent about the prevention measures listed above. Refer to the cold and Flu handout for more detailed information.
- Avoid crowded environments if possible. Wear a mask when you are within arms distance of others. Always wear a mask when using mass transportation (buses, planes and trains).

Exposures and Environment

- Avoid dust, smoke, construction and remodeling areas when possible. This includes fireplaces.
- If you have fresh flowers, have someone change the water daily. You can add 2 drops of bleach to the water.
- Always avoid standing pools of water and stagnant ponds.
- No hot tubs or saunas.
- Only swim in treated pools and fresh water (after approval from your doctor).
- No swimming or tub baths for at least the first 6 months.
- Avoid gardening. This is potentially very dangerous.
- Wear a mask when you will be around strong fumes and perfumes (e.g., hair salon).
- Be wise about when you will be in crowded areas. Try to pick off-peak hours for dining, shopping and traveling.
- All meats need to be cooked well-done, no pink. No Sushi.

Signs and Symptoms

Early recognition of infection leads to early treatment and can help preserve the integrity of your new lungs. It is up to you to alert the Lung Transplant Team if you think you are developing an illness.

ANY SYMPTOM, NO MATTER HOW SMALL, SHOULD NOT BE IGNORED.

Call the clinic if you have any of the following symptoms:

- Temp >99.0 F. Ok to take acetaminophen (Tylenol) after contacting the clinic
- Cold/Flu Symptoms: cough, shortness of breath, sputum production, fatigue
- Body aches, chills and/or night sweats
- New skin rash
- Change in your incisions (redness, pain, swelling, tenderness, drainage)
- Weight gain or loss (usually a change of greater than 5lbs in a week).
- If your blood pressure is greater than 170/100 or less than 100/60.
- If you start developing reflux or heartburn symptoms.
- Nausea, vomiting and/or diarrhea
- If you develop diarrhea, you MUST call. Do not treat with antidiarrheal meds.

Module 2: REJECTION

Background

Your donor lungs are recognized as foreign tissue by your body's immune system. Rejection is a natural response of your body's defense mechanism. If left untreated, rejection may cause severe and/or irreversible damage to the donor lungs.

Types

Acute Rejection: Usually occurs in the first 6 months but can occur anytime. Certain immune cells (known as T-lymphocytes) attack the donor lungs.

Chronic Rejection: Clinical syndrome that generally occurs over time. Risk factors include, but are not limited to, prior episodes of acute rejection, gastroesophageal reflux (GERD) and previous viral infections.

Diagnosis

- Radiographic imaging: CT scans, Chest X-rays
- Signs and symptoms: Similar as described in the Infection Module (fever, shortness of breath, cough, sputum production, change in your blood pressure or weight).
- Bronchoscopy and tissue biopsy (done during the bronchoscopy).

Treatment

- Usually requires an adjustment in your immunosuppressant regimen.

Prevention

- Be aware of the signs and symptoms
- Maintain a strict compliance with your medication regimen
- It is very common to develop GERD (reflux) after Lung Transplant even if you didn't have symptoms before surgery. This can occur while you are sleeping and may not know it is happening. We *strongly* encourage you to prop the head of the bed up so that the head is higher than the feet. This cannot be done with pillows but can be done with phone books, cement or wood blocks or a device called Mediwedge.

Module 3: Self-Monitoring and Personal Responsibility

Background

As a lung transplant recipient, it is important for you to be mindful about notifying the Lung Transplant Team for any life changes, travel, new symptoms, or new medications you are taking. The key to having a successful post-transplant life is taking personal responsibility.

Laboratory Monitoring

- Initially you will need to have blood drawn twice weekly (Mondays and Thursdays)
- You must get your blood drawn at 8 am in the morning on lab days. The lab is open at 7:30am.
- DO NOT take any medications before your blood draws. But DO bring your medications with you and taken them immediately following completion of your blood work.

Equipment

Blood Pressure Cuff

- Please check and record your blood pressure at the same time twice daily.
- Call the clinic if your blood pressure is greater than 170/100 or less than 100/60.

Glucose Monitoring Kit

- Refer to the pharmacy section for how often you should be checking your blood sugar.
- Record all of your blood sugar checks and how much insulin you are taking.

Thermometer

- Please check and record your temperature twice daily (usually along with your blood pressure).
- Call the clinic if you temperature is greater than 99.0 F.

ID Bracelet

- Always wear your medical alert bracelet that identifies you as a transplant recipient.

Scale

- Weigh yourself at the same time everyday with the same amount of clothing.
- Call the clinic if you gain more than 2 lbs in 24hours or 5 lbs in one week.

Surveillance

During the first several months following transplant, there will be an intensive follow-up and testing period. During this time, the Lung Transplant Team will closely monitor your symptoms, lung function and taking regular X-rays. Your nurse coordinator will help you organize all the various appointments. As time progresses, there will be fewer appointments and testing.

Bronchoscopy

- By now, you should be familiar with this procedure.
- Do not eat or drink ANYTHING after midnight the day before your procedure.
- Please bring your medication with you to the bronchoscopy procedure. You will be able to take them afterwards.
- You **MUST** be accompanied by an adult for each procedure. You will likely receive sedation and cannot drive for 24 hours.
- After the procedure, a slight fever is common.
- A very small amount of blood with coughing may be normal. Call your coordinator immediately or go the nearest emergency room if you experience bright red blood or produce more than one teaspoon.

CT Scans

- These are done on the 3d floor of the hospital in the radiology department.
- No special preparation is required.

Spirometry

- Generally done either in the 13th floor of the hospital or the 5th floor of the clinic.

Clinic Visits

- During your routine visits, you will have access to your physician, nurse coordinator, pharmacist and dietician.
- **ALWAYS** write down your questions beforehand and bring them to the visit.

Personal Responsibility

- **NEVER** hesitate to call your coordinator or the physician on call.
- **ALWAYS** wear a mask when in crowded places.
- Report any symptoms, no matter how small, to your coordinator. Your Lung Transplant Team will help you decide what steps to take next.
- Keep track of your medication stock and refill your supply in a timely manner.
- Never take another medication until it's been cleared by the Lung Transplant Team.

Module 4: Life after Transplant

Background

We want you to enjoy your new lungs as much as possible! There will be precautions that you will need to take with certain activities, but our goal is to help you achieve a life of maximum quality.

Exercise

- It's common to feel weak and tired in the weeks following surgery.
- Increase your activity level daily. Start with 10 minute walks three times daily.
- Do not do any heavy lifting (greater than 10 lbs, about a gallon of milk in each hand) for at least 6 weeks following the surgery. Check with the clinic staff as to when you can lift more.
- Generally, it's ok to walk, bike, play golf or tennis and do yoga. But do not start within the first 6 weeks after transplant. Check with the clinic staff before participating in any strenuous activity.

Diet

- Refer to the nutrition section for details about your specific nutrition needs.

Sexual Activity

- Wait 6 weeks before resuming sexual activity.
- Modify your position to avoid weight-bearing in the upper body.
- Condoms are an acceptable form of contraception.
- Females: check with your gynecologist for alternative birth control options.

Sun Exposure

- Some of your medications increase your risk for skin cancer. Your pharmacist will explain this in further detail.
- Always wear a broad –spectrum (covers UVA and UVB) sunscreen (even on a cloudy day). Wear at least 50 SPF. Pay special attention when applying to your ears, nose, forehead, scalp and arms. Apply every 2 hours in general and every 1 hour if swimming or sweating. This is very important since sunscreen does not last all day.
- Use a wide-brim hat, sunglasses and long sleeved shirts. You may even purchase UV protective clothing online or at sporting goods stores
- Exam your body on a regular basis for changes in moles, new spots and changes of skin color.
- You will need to see a Dermatologist (skin doctor) twice yearly. Your first appointment will be within 3 months of your transplant.

Travel

- Always check with the clinic prior to any travel (even for short trips).
- No international Travel for 1 year post transplant.
- Plan to use bottled water.
- Stay in reputable places.
- Always carry a full supply of medications. Always carry on your medications. Never check them in your luggage.
- Wear a mask when in crowded or public places.

Driving

- No driving for 6 weeks post-transplant
- Always sit in the backseat of the car. A car accident that activates the airbags can damage your sternum (breastbone) in the first 6 weeks.

Alcohol

- No alcohol for 6 months post-transplant. After such time, you may have limited amounts of alcohol unless you have been asked to completely refrain from alcohol indefinitely.

Routine Medical Screening

- **Establish a relationship with your Primary Care Practitioner.** S/he will help you organize routine medical testing and screening (such as cancer screening, bone density testing and immunizations).
- See your dentist 6 months after your transplant.
- See your ophthalmologist (eye doctor) yearly.
- As noted above, see your dermatologist (skin doctor) twice yearly.
- You will need a colonoscopy every 5 years.
- Females: see your gynecologist yearly. They will perform your PAP smears and mammograms.
- Males: see your primary care practitioner for prostate evaluation.

Vaccines

- After you are out from transplant six months, you need to get your flu vaccine every year.
- You cannot get live vaccines at any time after transplant. Always ask before getting a vaccine if it is live.
- If your family members get a live vaccine (like the shingles vaccine and fluMist) they cannot have contact with you for 2 weeks.
- Pneumonia vaccine every 5 years.

QUIZ

Module 1: INFECTION

1. What is the single most important thing you can do to reduce infection:
 - a. Wearing a mask in public
 - b. Washing hands with soap and water for at least 30 seconds
 - c. Avoiding sick family and friends
 - d. Avoiding pets
2. When should you call the Lung Transplant Team if you think you are developing an illness?
 - a. Temp >99.0 F
 - b. Cold/Flu Symptoms: cough, shortness of breath, sputum production, fatigue
 - c. Nausea, vomiting and/or diarrhea
 - d. All of the above. You should call the Lung Transplant Team if you have any of these symptoms
3. One of your grandchildren is coming over for a visit today however they currently have a runny nose, sneezing and a cough. Your best option to avoid getting an infection is to:
 - a. Wear a mask when the grandchild comes over
 - b. Have your grandchild wear a mask when they come over
 - c. Reschedule your visit for when they are not sick
 - d. Nothing is wrong with them coming over in this condition

Module 2: REJECTION

4. You are on immunosuppression medications. These medications decrease the risk of rejection. Please circle the medications which are your immunosuppression regimen:
 - a. Voriconazole, Valganciclovir, Septra
 - b. Tacrolimus (Prograf), Mycophenolate (Cellcept), Prednisone
 - c. Albuterol, Amphotericin, Tobramycin
 - d. Aspirin, Metoprolol, Lipitor
5. The symptoms of rejection and the symptoms of infection can be very similar: Shortness of breath, desaturation, fatigue and cough.
 - a. True
 - b. False
6. Your tacrolimus (Prograf) needs to be at a certain level to work best. In order to measure the trough level properly you should have the lab drawn after you take your morning dose.
 - a. True
 - b. False

Module 3: Self-Monitoring and Personal Responsibility

7. You should get a flu vaccine yearly even though you are immunosuppressed.
 - a. True
 - b. False

8. Some of the medications can make your blood pressure high or low. This is one of the reasons we want you to check your blood pressure twice a day, every day at the same time. At what point will you call the Lung Transplant team:
 - a. Your blood pressure is 160/85
 - b. Your blood pressure is 105/65
 - c. Your blood pressure is >170/100
 - d. Your blood pressure is great than 20 points above your norm and you have symptoms such as headache, dizziness, swelling or pallor.
 - e. C and D

9. It's ok to have a small cup of decaf coffee before your bronch.
 - a. True
 - b. False

10. You should take your meds before having your blood drawn
 - a. True
 - b. False

Module 4: Life after Transplant

11. Which of the following significantly increases your risk for skin cancer?
 - a. Being immunosuppressed
 - b. Taking voriconazole
 - c. Living at altitude
 - d. All of the above

12. You are planning a big trip for a week, traveling by car to Oregon to go hiking at Crater Lake National Park. The first thing you need to do prior to leaving is:
 - a. Check with the Lung Transplant clinic prior to any travel
 - b. Change the air filters in the cabin of the car to reduce mold, bacteria and viruses
 - c. Start a new antibiotic for infection prevention
 - d. Take double your immunosuppression since you'll be in the wilderness away from medical personnel

13. Your regular doctor wants to prescribe a new medication for you. Before you start any new medication you should always:
 - a. Do nothing since your non-transplant doctor will know all the drug interactions
 - b. Google whether the new medication is appropriate for you
 - c. Call the Lung Transplant team and your nurse coordinator before starting any new medication
 - d. Assume that your non-transplant doctor will call and discuss your new medication with the lung transplant team

COLD AND FLU HANDOUT

Take everyday preventive actions to stop the spread of germs and be proactive in receiving immediate care for viral symptoms.

1. CALL YOUR TRANSPLANT COORDINATOR IMMEDIATELY IF YOU HAVE ANY SIGNS OR SYMPTOMS OF THE FLU OR ANY OTHER RESPIRATORY VIRUS!!!!!!!
2. Cover your nose and mouth with a tissue when you cough or sneeze.
3. Throw the tissue in the trash after you use it; do not re-use tissues
4. Wash your hands often with soap and water frequently especially before eating and using the bathroom. If soap and water are not available, use an alcohol-based hand rub.
5. Avoid touching your face. Germs spread this way.
6. Try to avoid contact with sick people (including children or grandchildren); if you observe anyone near to you experiencing flu-like symptoms you should distance yourself from them.
7. If you feel as though you are becoming ill, call the lung transplant office right away to speak with a care provider. (415) 353-4145, Option#1.
8. While sick, limit contact with others as much as possible to keep from infecting them.
9. If you get the flu virus, antiviral drugs may be prescribed to treat your illness.
10. Antiviral drugs are different from antibiotics. They are prescription medicines (pills, liquid or an inhaled powder) and are not available over-the-counter.
11. Antiviral drugs can make illness milder and shorten the time you are sick. They may also prevent serious flu complications. It's very important that antiviral drugs be used early (within the first 2 days of symptoms).
12. Flu-like symptoms include fever, cough, sore throat, runny or stuffy nose, body aches, headache, chills and fatigue. Some people also may have vomiting and diarrhea. People may be infected with the flu, and have respiratory symptoms without a fever.
13. Drink plenty of liquids at the first sign of flu. Sick people with the flu need to drink extra fluids to keep from getting dehydrated. Mild fluid loss can most often be treated at home. Yet, severe dehydration is VERY serious and must be treated in the hospital.

If someone else in your household is sick, here are some tips to help you avoid the same illness:

1. Make a Sick Room

- Try to give the sick person their own room. If there is more than one sick person, they can share the sick room if needed.
- If you have more than one bathroom, have sick people use one bathroom and well people use the other one.
- Give each sick person their own drinking glass, washcloth, and towel.

2. Stock these items in the sick room

- Tissues
- Trash can with lid and lined with a plastic trash bag
- Alcohol-based hand rub
- Facemasks (Sick people should wear a facemask if available when they leave the sick room or are around other people.)

3. Obey Sick Room Rules

- Avoid having other people enter the sick room.
The sick person should not have visitors other than the caregiver. If visitors must enter, they should stay at least 6 feet away from the sick person.
- Cover coughs and sneezes.
Ask the sick person to cover their nose and mouth with a tissue when they cough and sneeze. Ask them to throw used tissues in the trash.
- Choose one caregiver.
If you can, choose only one caregiver to take care of sick family members. If possible, ask someone else to be the caregiver. If you get the flu, it could be much more serious for you.

Keep the air clean.

Open a window in the sick room, if possible, or use a fan to keep fresh air flowing.