

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 no 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 Mediawedge.

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 take 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 your 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 24 hours 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 to 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 within 6 months of 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. After the first six months, 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.

Patient:

Date of Transplant:

Medication Overview

This is a general overview of your immunosuppressant regimen. The following medications are your most important medications to prevent rejection of your newly transplanted organ. Please pay special attention to these medications and any changes in the dosages to reduce your chance of rejection and complications.

1. Prednisone – This is a steroid to prevent and/or treat rejection. Your prednisone dose will be changing during your course. The dose may increase or decrease depending upon your general clinical picture, however it will generally follow the schedule written out below. Important: Before lowering your prednisone dose, please contact your lung transplant nurse coordinator a couple of days prior to make sure this drop in your steroid dose is still appropriate. This will be critical for us to keep our charts accurate.

Prednisone Taper Schedule: Please take prednisone as follows unless otherwise directed by a member of the Lung Transplant team.

Post-Transplant Day	Date	Dose

2. Mycophenolate (Cellcept®) – This is another important immunosuppressant. Occasionally we may stop or decrease the dose of this medication temporarily based upon your labs. If we change or decrease your dose, it is important for you to ask the lung transplant nurse coordinator if the medication has not been restarted within 4 weeks after stopping or decreasing the dose.

3. Tacrolimus (Prograf®) – We will be monitoring your tacrolimus level (or trough) periodically during your course to ensure that your level is appropriate. On the days that you are getting your labs drawn, please make sure that you do not take your morning dose so that the level we take is accurate. Remember, there are many drug interactions associated with tacrolimus so it is important to notify us of any changes to your medications (including any over the counter medications that you have started taking). Your general tacrolimus level should be:

0-3 months: 10-14 ng/mL

3-6 months: 10-12 ng/mL

> 6 months: 8-10 ng/mL

4. Azithromycin – We will start azithromycin 30 days after transplant to prevent long-term rejection. It is only taken on Mondays, Wednesdays and Fridays.

Prevention of Infection

This is a general overview of the medications that you will be taking to prevent infection from occurring. Please pay special attention to these medications and any changes in the dosages to reduce your chance of infection and complications.

- 1. Voriconazole (Vfend®)** — This medication will be used for approximately the first three months post-transplant to prevent fungal infections, particularly aspergillus. This medication has a significant interaction with tacrolimus (Prograf®) so whenever we start or stop voriconazole, your tacrolimus dose will have to be adjusted. If this medication is stopped or restarted, please contact the lung transplant nurse coordinator with instructions to change your tacrolimus dose.
- 2. Amphotericin B** — This is an inhaled medication that you will take twice daily for the first 2 months after your transplant. You might also restart this medication if you have an infection. If you have just been transplanted, a home nurse will come to your residence to help you learn how to use this medication once you leave the hospital. It is okay if you miss a few doses while waiting for the home nurse to come. Instructions on how to make this medication suitable for inhalation is provided to you but wait for the home care nurse to demo. It is important to remember that this medication needs to remain refrigerated.
- 3. Tobi® or Tobramycin** — This is an inhaled medication that you will most likely take for the first 3 months (for 28 days on, 28 days off, then 28 days on). It is possible that you might continue taking this medication longer, but in this case we would let you know. If you have just been transplanted, a home nurse will come to your residence to help you learn how to use this medication once you leave the hospital. It is okay if you miss a few doses while waiting for the home nurse to come. If you are taking Tobi®, it is important to remember that this medication is refrigerated, but may be left out of the refrigerator for 28 days.
- 4. Valganciclovir (Valcyte®)** — This medication is to prevent a viral disease known as cytomegalovirus (CMV). Your previous exposure and your donor's previous exposure to CMV may affect how long you take this medication. There are reasons that we may temporarily stop this medication, but it is important to contact the lung transplant nurse coordinator if this medication has been temporarily stopped for more than 4 weeks.
- 5. Sulfamethoxazole-Trimethoprim (Septra® or Bactrim®)** - You will be on this medication or a similar medication to prevent PCP pneumonia for the rest of your life. There are reasons that this medication may be held or switched to an alternative, however you should always contact the lung transplant nurse coordinator if you are not sure if you have a medication that prevent this type of pneumonia. Other medications that may be used to prevent PCP may include Dapsone, Pentamidine and Atovaquone.

HEART AND LUNG TRANSPLANT

MEDICATIONS

Your pharmacists: Rebecca Boettger, PharmD, Christine Hui, PharmD and Katie Watkins, PharmD

Immunosuppressive medications are given to help prevent and/or treat rejection of your transplanted organ. You will need to take these medications for the rest of your life. Immediately after your transplant, the immunosuppressive doses will be higher because the chance of rejection is greatest at this time. The doses will be gradually lowered if there are no signs of rejection. You will also be taking anti-infective medications to prevent bacterial, fungal and viral infections because the immunosuppressive medications can weaken your immune system and make you more susceptible to infections.

As soon as you are able, an individualized self-medication program will be set up for you. As much as possible, the medication schedule will be tailored to fit your lifestyle and routines.

Information you should learn about your medications:

- Brand and generic name
- What the medication is used for
- What the tablets or capsules look like
- The strength per capsule or tablet
- The dose and schedule
- Any requirements for taking the medication
 - Special dosing time
 - With or without food
- What to do in case you forget to take a dose
- How to store the medication
- Side effects you may experience

Important General Information

- NEVER** stop or change any medication prescribed by the transplant team without contacting them first.
- Once your medication schedule (your med card) is set up, do not change the times of the day that you take your medications without talking to someone from the transplant team. **The times are important.**
- Always bring your med card along with your vitals to the clinic or to the hospital.
- Be sure to keep your medication card up to date.
- Always look at the strength of the medication before determining your dose. Certain medications come in a variety of strengths therefore, it is very important to verify the strength of the tablets to keep from mistakenly over or under dosing yourself.
- Because the doses of your medications may be constantly changing, follow your medication card (**which you are responsible for keeping UP-TO-DATE**) for dosing. **DO NOT** follow the directions on your prescription bottles because they may not be 100 percent accurate.

- At the time of discharge, your inhaled medications (amphotericin and tobramycin) will be HELD until the homecare nurse can assist in administering them in your hotel or house. They will usually not be visiting for 24-48 hours after discharge. It is okay to miss those inhaled doses until they visit. All of your pills must be taken as instructed and cannot be missed.
- On Lab days, you must get your blood drawn around 8 am before taking any of your morning medications.

Medication changes

Most medications changes will be done over the phone. It is very important that you understand which medication is being discussed and the dose being changed. Because there is more potential for miscommunication working over the phone, please follow these instructions:

- Get your medication card and pencil out to make the changes immediately. If you wait, there is a strong likelihood you will forget or mistake the dose.
- Repeat back to the person the change being made. An example: "So my tacrolimus level is a little low. I will change my dose from 0.5mg twice daily to 0.5mg in the am and 1mg in the pm. Correct?"
- We will only call to make medication changes. Therefore, on lab days if you do not get a call to make a dosage change then continue to take all medications as instructed by the medication card.

Missed Doses

It cannot be stressed enough that missing a medication alters the drug levels in the body which can have detrimental effects. It is very important that medications are not missed. If you accidentally miss one dose, follow the half way rule (below). If you miss two or more doses, call the transplant coordinator (during work hours) or the on-call physician (415-353-4145 after 5pm) for instructions.

The half way rule: you can take a medication up to half way to the next scheduled time for the dose. An example: if a medication is taken every 12 hours, the half way rule would be to take the dose up to 6 hours from the missed time and skip the dose if longer than 6 hours.

Side Effects

All medications have side effects. You may experience side effects, especially in the beginning when immunosuppressive doses are high. However, you may experience some symptoms that are very general and may not be caused by medications. Inform the transplant team if you think a medication is causing any side effects.

Medications prior to transplant

Your pre-transplant medication list will be analyzed at the time of transplant. The transplant team will continue only the medications which are still appropriate. Only those approved medications will be written on your medication card. If you are concerned about any of your old medications being stopped after transplantation please talk to your physician or pharmacist.

If we decide you will need one of your old medications after transplant, it may be difficult to get that medication filled at the transplant pharmacy especially if you just filled it. Therefore, please bring all medications from home. Please keep them local so they are available at the time of discharge. Unfortunately, they cannot be stored in your hospital room.

Other Medications

Do not take any other medications without first checking with the transplant team. This includes ANY medications prescribed by other doctors, ANY over-the-counter (non-prescription) medications, and vitamins or herbal products. Check with the transplant team BEFORE you buy the medication. A simple med like TUMS® can cause issues with your immunosuppressants (Prograf®).

- If a medication is not on your card, it has not been approved and should not be taken.
- On rare occasions, it is important for your health to immediately start a medication being prescribed by a non-transplant physician. Please take the medication and then call the transplant coordinators to see if any medication adjustments need to be made.
- Taking medications which are not emergent without checking with the transplant team first may result in serious and dangerous side effects.
- The only over-the-counter pain medication that is allowed is Tylenol® (acetaminophen). **NO** ibuprofen (Advil®, Motrin®) or naproxen (Aleve ®).
- Make sure your doctors know all of the medications you are taking, including those prescribed by other doctors.

Labs

Your blood will be drawn twice to three times weekly when you leave the hospital. Mondays and Thursdays for the lung transplants and Monday, Wednesday and Friday for the heart transplant patients. You must get your blood drawn around 8 am **BEFORE** you take ANY of your morning medications. This level is ideally drawn 11-12 hours after your evening dose the night before so it is important to take your night time dose at 9 pm as instructed and get labs drawn the next morning at the instructed times. If you accidentally forget that it is a lab day and already took your morning medications, then wait another day to have your labs drawn.

On lab days, please continue to take your tacrolimus (Prograf®) as directed. We will not call unless we need to make a dosage change with you. If you do not hear from us, then continue to take Prograf® as instructed on blue card.

Organizing your Meds

Medisets or pill boxes are a great way to keep your medications organized BUT we do not recommend them right after transplant because the medications are changing too often. After several months, when your medications have become stabilized, we recommend using a weekly medisets to help with adherence.

Pharmacies

A transplant pharmacy close to UCSF Medical Center will be used to fill your medications for the first several months after transplant. This is preferred to your usual home pharmacy because access to your pharmacy is limited since you are asked to stay in San Francisco for the six weeks following discharge. If you wish to transfer all prescriptions to another pharmacy once you are released back to your home, have your home pharmacy call the transplant pharmacy and transfer the medications. Prior to transferring your prescriptions, please make sure that your home pharmacy can handle transplant medications. If you wish to continue with the transplant pharmacy, they will mail medications to your home.

Although, mail order pharmacies are great and can save a significant amount of money, we do not recommend them in the first several months after transplant. During this time, we are usually making a significant amount of medications changes and mail order pharmacies are difficult to coordinate with.

Filling/Refilling Medications

The first 30 days of medications have been coordinated by the transplant pharmacists with a transplant pharmacy and will be delivered to the hospital. Once they have been delivered, the transplant pharmacist will inventory the medications to quickly make sure everything we have ordered has been filled. We will then ask you and your caregiver to inventory the medications against your finalized medication card. You may think this is redundant but it is a very important process. You and your caregiver must know you have the all medications listed on the card. If there is a different brand name on the bottle compared to the medication card, you may not recognize that they are the same medication. If this happens, it can be identified and corrected before you leave the hospital.

Refills and delivery of your medications need to be coordinated by you. Always have enough medication on hand; call your pharmacy for refills 7-10 days **BEFORE** you run out. This is really important. If you keep on top of when you will need refills, it will save you from a lot of worrying

Medication questions

If you have medication questions, leave a message with the nurse coordinators and the coordinator will contact one of the pharmacists to call you back. You will also be seeing a transplant pharmacist during your clinic visits and questions can be answered then.

Notes:

AMPHOTERICIN B FOR INHALATION

UCSF Lung Transplant Program

Equipment needed:

- Sterile water in vials (10 ml or 30 ml)
- Amphoterin B 50 mg vials
- 10 ml syringes
- Needles for 10 ml syringes
- Nebulizer cup and tubing
- Air compressor

How to prepare Amphoterin B for self-administration:

1. WASH HANDS BEFORE AND AFTER THIS PROCEDURE.
2. Remove plastic caps from top of sterile water and Amphoterin B (AmphoB) bottles. Clean top of each bottle with an alcohol pad.
3. Attach needle to 10 ml syringe, remove cap from needle, and draw up 10 ml of sterile water.
4. Inject 10 ml sterile water into powdered Amphoterin bottle. Withdraw and recap the syringe. Gently roll the vial until the powder is dissolved. The solution will be bright yellow.
5. Clean top of AmphoB bottle with an alcohol swab. Using the same needled syringe, withdraw **4 ml** of the Amphoterin solution. This 4ml is equal to Amphoterin 20 mg.
6. Now, using either another 10 ml vial of sterile water OR the same 30 ml vial, draw up **6 ml** of sterile water (in the same syringe as the 4ml of AmphoB) for a **total of 10 ml**. (Clean the top of the 30 ml sterile water bottle with an alcohol pad if you are reusing.) Put that amount (4 ml Amphi B and 6ml sterile water for a total of 10 ml) into the nebulizer cup. Discard the needled syringe.
7. Attach the top of nebulizer cup and mouthpiece, connect the nebulizer tubing to the compressor and turn it on to start the treatment. Take slow deep breaths during the treatment.
8. After the treatment, clean the nebulizer cup with soap and water after each use and allow to air dry.
9. The remaining solution in the Amphoterin B vial can be used for a second treatment. Withdraw that second treatment using the steps above starting with step #4 using a new needle and syringe. Multiple doses may be made up in advance and stored in refrigerator for up to 1 week.
10. After this second treatment, there is still a partial dose of Amphoterin B left in the vial which can be discarded.
11. Use a separate nebulizer cup for Amphoterin and Tobramycin. Wash each cup with soap and water after each use and allow to air dry.
12. While using Amphoterin B nebulizer treatment, sit in a well-ventilated area and have family members wear face masks, to avoid inhaling the medication, as much as possible.

Stability after reconstitution

Refrigerated: 1 week

Room temperature: 24 hours

(Unmixed vials of Amphoterin B are refrigerated until use.)

Side Effects: cough, bad taste, nausea, vomiting, wheezing, dysphagia (difficulty swallowing), epistaxis (nose bleed)

ACTIVITY GUIDELINES UPON DISCHARGE

You have been participating in a daily activity program during your hospitalization with the help of your Nurses and your Physical Therapist. Upon discharge it is important that you continue with a regular activity program to help you maintain and improve your activity tolerance. Regular exercise will also help you maintain weight and promote healing.

- Strive to be active everyday
- Find an activity you enjoy doing (i.e. walking, hiking, riding an exercise cycle))
- Start with a reasonable goal of 10 minutes, try to increase a little every week until you can maintain up to 30 minutes at a time,
- Intensity does not matter as much as endurance does. Find a pace you can sustain without needing to rest
- The Physical Therapist assigned to you will give you further guidelines before discharge for any specific needs you might have

STERNAL GUIDELINES UPON DISCHARGE

For surgery, your sternum (breastbone) was cut. Your breastbone was then closed back together with wire sutures to aid in the healing process. For eight weeks after the surgery, you need to protect your sternum so that it will heal properly.

Please follow these guidelines, known as sternal precautions. If your doctor or surgeon has given you more instructions, please follow their instructions.

For the first 8 weeks after surgery:

- No lifting, pushing or pulling more than 10 pounds.
- Use your arms minimally when standing or sitting.
- When coughing or sneezing hold a pillow against your incision for support.
- Do not allow others to pull on your hands, wrists, or arms when assisting you.
- Do not lie on your stomach. Sleep on your side or your back.
- You may move your arms in a pain free range but limit any overhead movements
- Stop any activity that increases pain.
- Do not hold your breath.
- Breathe out when you feel the need to bear down.

Notify your doctor if:

- Your surgical incision is pulling apart or opening.
- Your sternum feels like it is popping, clicking or moving.
- There is any drainage from your incision.

Specific Exercise Program for you