



LUNG TRANSPLANT PROGRAM

# After your transplant





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## THE DUKE LUNG TRANSPLANT OPERATION AND HOSPITALIZATION

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When a donor organ becomes available we will call for you come to the hospital for your transplant. It is vital that you arrive at Duke University Hospital (DUH) within two hours, and you must have a reliable plan for doing so.

When you arrive at the hospital, some testing will be completed including a chest X-ray and blood work, and you will be given some medications to prepare your immune system for the new lungs. The surgeons will recover the organ from the donor and return to DUH to perform the surgery. Sometimes, the surgeon arrives at the hospital where the donor is located and finds the lungs are not as expected. In these cases, your surgery will be cancelled. However, your time on the wait list is not lost, and you will likely be called in the near future for another donor.

The transplant surgeon will perform the operation that will remove your lungs and replace them with the donor lungs. The perioperative nursing staff and anesthesiologist will provide care for you while you are in surgery and will communicate with your family throughout the procedure. The surgery may take from 5 – 9 hours. While the surgery is in progress, your family will be able to wait in our comfortable waiting rooms. Please go to [dukehealth.org/locations/duke\\_hospital](http://dukehealth.org/locations/duke_hospital) for more detailed information about the hospital.

How well our patients respond to surgery is reported publicly through the Scientific Registry for Transplant Recipients (SRTR). These outcomes' data, publicly reported every six months, appear at [ustransplant.org](http://ustransplant.org). Visit this Web site for the most current data about our program outcomes. Duke Lung Transplant Program outcomes meet the Centers for Medicare & Medicaid Services' requirements and conditions for participation by transplant centers.

### The Intensive Care Unit

Immediately following your transplant surgery, you will be brought from the operating room to the ICU in your bed. Once in the ICU, it will take approximately one hour for the nurses to do their initial assessments and help get you comfortable. The nurses will then call in your family members so that they may see you. You will still be asleep because the anesthesia will take several hours to wear off.

Once you wake up, it is normal to feel confused. Your nurses will tell you that your surgery is over, and they will tell you what day it is, what time it is, and where you are. You will have many IV lines and tubes, and you will be in a room with many monitors and machines. Your arms may be gently restrained until you are fully awake, to prevent you from pulling out any of your tubes. Most patients do not remember the first 12-24 hours after surgery.

You will have a breathing tube in your mouth and throat. This tube will be connected to your ventilator, which will breathe for you until you are able to breathe on your own. It will be impossible for you to talk as long as this tube is in place. The breathing tube will be removed when the team believes you will be able to breathe independently. This may be a few hours or several days after surgery, based on your response.

You will also have another small tube in your nose that goes to your stomach, called a nasogastric (NG) tube. This tube will drain your stomach contents and help prevent you from feeling nauseated. The NG tube will be removed after your anesthesia wears off and your stomach and intestines begin to work again.

You will also have a large IV catheter in a vein in the side of your neck. This will allow us to monitor your heart function closely. You may have an IV in your arm for fluid or medication and another in your wrist to monitor your blood pressure continuously.

Pumps by your bed will supply you with fluid from the IV bags hanging overhead. This fluid contains various medications to control your heart rate and blood pressure. You will also be receiving IV medications to prevent rejection of your new lung.

The drainage tubes you will have in your sides are called chest tubes. These tubes, designed to drain fluid and air from the space around the new lungs, will be connected to suction for a few days to help the lungs completely expand. Once the lungs are fully expanded and there is no longer any air or fluid draining from the chest tubes, the tubes will be removed.

You will also have a catheter in your bladder to drain your urine output. Your nurses will measure and record your urine output every hour to ensure that you stay in good fluid balance. In a few days, when you are able to go to the bathroom on your own, the bladder catheter will be removed.

Finally, you will have a small sensor on your finger connected to a machine at your bedside (called a pulse oximeter) to monitor your pulse rate and the oxygen level in your blood.

Every patient experiences pain after a major operation, but each person feels differently. The anesthesia physician may discuss pain management with you prior to your surgery. Many patients have an epidural catheter in their back immediately after surgery. Pain medicine is given through this catheter to help numb the nerves that are causing the pain. Another method of giving pain medicine is through your IV and a button that the patient uses to deliver pain medicine when needed. Please let the nurses and doctors know if your pain is not being controlled, so that different treatment measures can be ordered. Controlling pain is essential to your ability to breathe deeply and prevent complications.

## **Visiting Hours in the Intensive Care Unit**

Visiting hours in the ICU are flexible, depending on the condition of the patient. Generally, visitation can occur any time between 9 am and 9 pm, with the exception of 7 to 8 pm, when nurses are changing shifts. Please note that visits must be cleared with the patient's nurse. Please request your visit by using the intercom located in the ICU waiting room. At times, visitation may be limited due to emergent patient care activity.

We would like to have one family member who is identified as the family spokesperson. This allows us to communicate with one person for consistency and reduces the possibility of misunderstanding between family members if communication occurs to several people. The spokesperson is usually a spouse, parent, or sibling, but it may be anyone designated by the patient.

## **Complications**

Patients may experience complications that occur during the transplant procedure or immediately afterward that may require additional therapies and treatments. It is difficult to predict who may experience these complications ahead of time, however, the team is prepared should this occur. These complications may include:

- Stroke
- Heart attack
- Loss of fingers and toes
- Inability to wean off the ventilator which

- Bleeding
- Infection
- High blood sugar or post-transplant diabetes
- Immediate rejection of the transplanted lung
- Inability to maintain blood pressure
- Kidney failure which may require short or long term dialysis
- Depression or anxiety
- Inability to swallow which would require placement of feeding tube
- Bed sores (break down of the skin)
- Death

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## SPECIAL PROCEDURES THAT MAY BE NEEDED DURING AND AFTER THE TRANSPLANT

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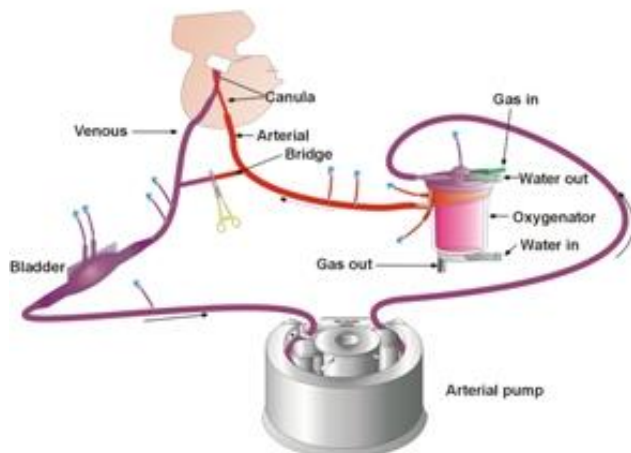
In some cases, some special procedures may be necessary after transplant to help you recover from your operation. They include:

### **Extracorporeal Membrane Oxygenation (ECMO)**

This refers to the delivery of oxygen by “extracorporeal” measures, and it literally means by mechanical bypass that takes place outside of the body. An ECMO machine is a medical device that performs this task. In fact, it is very similar to a heart-lung machine that is used to continue the supply of blood and oxygen while the heart is stopped, such as during open-heart surgery. ECMO therapy, however, is intended for patients whose heart and lungs cannot normally function on their own. To initiate ECMO, large catheters are placed in large blood vessels to provide access to the patient's blood. Anticoagulant drugs or blood thinners, usually heparin, are given to prevent blood clotting. The ECMO machine continuously pumps blood from the patient through a “membrane oxygenator” that imitates the gas exchange process of the lungs, i.e., it removes carbon dioxide and adds oxygen. Oxygenated blood is then returned to the patient.

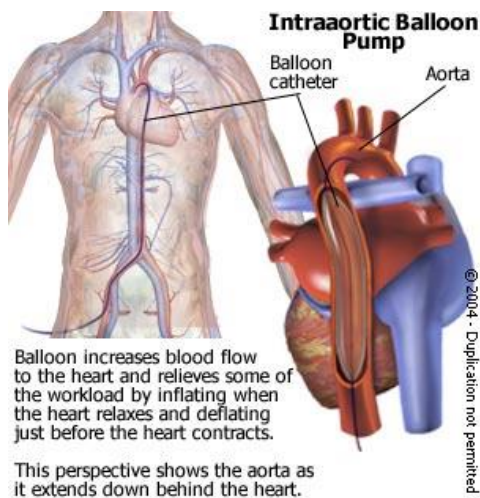
Management of the ECMO circuit is done by a team of ECMO specialists that includes ICU physicians, perfusionists, respiratory therapists, and registered nurses who have received training in this specialty.

## ECMO PUMP CIRCUIT



## Intra-Aortic Balloon Pump (IABP)

This is a device that increases blood flow to the heart muscle and decreases the heart's workload through a process called counterpulsation. It can produce up to 20 percent of the heart's workload. The IABP is placed in the aorta, which is the main artery that carries oxygen-rich blood to the rest of the body.



## Hemodialysis or CVVHD (Continuous Venovenous Hemodialysis)

This therapy is started when a patient develops kidney dysfunction and the kidneys are not removing fluid or chemicals as they normally would. Special catheters are placed in the body to do the dialysis. How long this is needed is based on the patient's individual response.

## Physical Therapy

While you are in the ICU, you will be asked to lie in certain positions to increase drainage from the transplanted lungs and help them expand more completely. You will begin physical therapy/occupational therapy about 12 hours after the end of your surgery.

First, you will have chest physical therapy, postural drainage, percussion, and vibration. You will progress quickly to sitting on the side of your bed and dangling your feet, then to getting up in a chair a few days after your surgery. You will likely be able to walk by the third or fourth day. Your participation in frequent physical therapy is an essential part of your recovery and will help you maintain or build strength after your surgery. Pain is a major barrier to participating in physical therapy. For this reason, please request pain medicine to prevent the pain so you can breathe deeply and cough easily while recovering.

## **Keeping Your New Lungs Clear**

Transplanted lungs do not have the usual nerve attachments. Therefore, your new lungs will not feel irritation below the airway connection in the donor lungs. This means that you will not feel like coughing when you have secretions below the airway suture line. However, since it is common for the lungs to have many secretions after surgery, it is extremely important to cough. You must make yourself cough as deeply as possible and take deep breaths at least every couple of hours. You need to help your nurses and physical therapists keep your lungs clear and open.

Each therapy session will focus on the areas of your lungs that appear to be congested. You will also have frequent chest X-rays. Throughout your recovery, you will be taught various ways to maintain clear airways.

## **Transferring to the Stepdown Unit**

When you are ready to leave the ICU, you will be transferred to the thoracic surgery step-down unit. On this unit, you will continue to recover and regain your strength. Again, each person recovers at his or her own rate.

As you recover, the IVs, chest tubes, and oxygen will be removed. Oxygen is usually not needed by a few days after surgery. Your physical therapy and occupational therapy will continue to be a priority. You will walk 3-4 x/day, increasing your distance each time. Your deep breathing, coughing, and chest physical therapy will also continue. Most patients are able to walk one mile per day by the third or fourth week after surgery and can go back to supervised treadmill and/or bicycle therapy in even less time.

During this time, the post-transplant coordinator and your bedside nurses will teach you how to care for yourself after discharge. Your primary caregiver will be needed to participate in your education after transplantation. We will teach you about many aspects of health maintenance including medications, preventing infection, health maintenance, monitoring for signs and symptoms of infection and rejection, foods, drug interactions, and other topics.

Members of the care team including the pulmonologist, transplant surgeon, social worker, transplant coordinator, transplant pharmacist, dietitian as well as other specialty areas will see you throughout your hospitalization to help monitor your recovery progress. The medical and surgical team will address your medical needs, and the social worker will provide support for you and your family. The transplant pharmacist will also provide information about your specific medications including those to prevent rejection.

When you will be able to eat after surgery depends on several factors. First and foremost, we will need to make sure you are able to swallow safely. Your ability to swallow can be affected by the ventilator tube, and swallowing food or liquids into your lungs instead of your stomach can cause damage to your new lung(s).

You will have swallow tests to help determine when it will be safe for you to eat and drink. Secondly, the stomach juices used for digestion can “reflux” or back up into the lung through the esophagus. This can



damage the lung and lead to rejection or other longer term damage. Therefore, you may have several different diets while in the hospital to help reduce the chance of getting food and/or liquids into your new lung(s).

- Mechanical soft diet
- Thickened liquids
- Soft diet
- Nothing to eat or drink by mouth
- Regular or diabetic diet

## **Preparing for Discharge**

Duke patients who receive lung transplants are hospitalized for an average of two weeks. However, in some cases, patients are hospitalized for several weeks or even longer. How long you are hospitalized is based on your response to the surgery. At discharge, patients should be able to perform activities of daily living with minimal assistance, eat or have adequate nutritional intake, and participate in pulmonary rehabilitation.

Here are several things that will happen before you can be discharged:

- A local residence and care provider must be established.
- The transplant coordinator will complete the teaching for you and your support person.
- The transplant pharmacist will provide medication education to you and your caregiver.
- Home care for IV infusions or tube feeding will be set up by the patient resource manager if needed.
- Appointments for your return visit and the Pulmonary Physical therapy program will be made.

Prescriptions will be faxed to a local pharmacy, and your support person will pick them up on the day of discharge. Please note that many medications require prior authorization which may take a few days for the insurer to approve. You must be able to demonstrate ability to monitor blood glucose and use insulin if needed for high blood sugar.

## **After Your Discharge**

Making plans to manage your needs after transplant can reduce the amount of stress you have to cope with during the recovery process. The transplant coordinator and the hospital Patient Resource Manager will make sure you have everything you need to care for yourself after discharge.

Some common considerations:

The transplant coordinator will work with you to assure your medications are available. It is not uncommon for patients to require the assistance of a home-care nurse for antibiotic and/or anti-rejection IV infusions. Patients may also need to have liquid nutrition provided (tube feedings).

Plan your pulmonary physical therapy time into your daily routine. Patients must participate in 23 or more physical therapy sessions at the Duke Cardiac and Pulmonary Rehabilitation Program. This program helps you recover more quickly and gives the transplant team time to monitor your progress closely before you go home.

Plan to have help at discharge. A primary care provider is essential to help you prepare meals, administer medications, and bring you to clinic appointments and pulmonary physical therapy. You should also have a secondary care provider available in case there is a problem with the primary care provider.

Participate in your care with routine health monitoring that may identify a problem even if there are no symptoms of illness. These are the routine things for you to start right away:

- Micro spirometer readings at the same time every day.
- Blood glucose monitoring should be before meals and at bedtime (four times a day). This is necessary because many antirejection drugs are known to cause diabetes after transplant.
- Weigh yourself as one of the first things you do in the morning.
- Blood pressure at least once a day.
- Temperature once a day and whenever you feel as if you might be developing a fever.
- Use the worksheets in the back of this book to record this home care information.

Lung transplant patients are commonly readmitted to the hospital to treat new problems. If this happens to you, we will work to have you discharged as soon as possible so you may resume your rehabilitation activities.

### **Nissen Fundoplication (Stomach Wrap)**

This is a surgical procedure used to treat gastroesophageal reflux disease (GERD). This surgery will NOT be performed at the same time as your lung transplant. It is typically done within the first few months after you have recovered from your transplant, if you tested positive for reflux in the pre-transplant evaluation. There is a small population of patients who receive a Nissen before transplant. The surgery is normally performed laparoscopically through a series of small incisions. The average length of stay in the hospital is only a few days. After surgery you will initially start a clear liquid diet and will slowly be advanced to a soft diet, and eventually a regular diet after about one week. It is possible for the stomach wrap to “come loose” and should that be the case, a “re-do” Nissen may be necessary. If you have a feeding tube in place, it will temporarily remain in place after the Nissen, and will be removed once your weight and nutritional status are deemed to be stable.

GERD can lead to food particles and stomach acid entering the lungs. This causes injury to the lungs and can lead to infections and rejection after transplant. Should your reflux testing be normal pretransplant we will repeat this testing post-transplant. The transplant surgery as well as the medications can increase the risk for GERD. *Reflux, just like rejection and infection, is a “moving target” and can occur at any time post-transplant.* Some of our physicians have published papers on GERD related to transplant patients should you be interested in reading more about the research that has been done.

### **Pyloroplasty**

This surgical procedure can be performed in combination with a Nissen. A pyloroplasty is often necessary for patients with delayed gastric emptying, and involves stretching the opening between the stomach and intestines. This allows the stomach contents to empty more easily into the intestines.

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## MEDICATIONS

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After your transplant, you will be required to take medications for the rest of your life to prevent your body from rejecting your transplanted lung(s). The types and doses of medications will be determined and adjusted by your physicians and pharmacists based on your condition and health. Following transplantation you will receive individual instruction from our transplant pharmacist, but it your responsibility to familiarize yourself with these medications. Listed below are some of the antirejection medications and other common medications you might have to take when you are discharged.

### Immunosuppressives

These medications modify your own immune system to prevent damage or rejection of your new lungs. Some medications have a generic formula available and others do not. We prefer brand formulations when possible. *If your insurance will not cover brand name medications, please contact your transplant coordinator.*

### Prograf (Tacrolimus)

Available in three strengths: 0.5 mg, 1 mg, and 5 mg capsules.

- Medication dose may change often, depending on blood work results. Doses may be different from what is on your prescription bottle. Please follow the instructions given to you by your transplant coordinator, transplant pharmacist, or physician. If in doubt, please contact your coordinator for clarification.
- Take Prograf twice daily, 12 hours apart (10 am and 10 pm).
- Take this medication at the same time each day or at least within 30 minutes of the regular time
- Always take your medication **after** lab work is drawn.
- Avoid grapefruit or grapefruit juice.

### Common Side Effects

- High blood pressure
- Hand tremors
- Nausea
- Headaches
- Kidney toxicity
- Hair loss
- High blood sugars
- High cholesterol levels
- Increased swelling in legs
- Tingling/numbness in extremities
- Abnormal vision

## Neoral, Gengraf (Cyclosporine)

Available in two strengths: 100 mg capsules and 25mg capsules.

- Medication dose may change often (depending on blood work results). Doses may be different from what is on your prescription bottle. Please follow the instructions given to you by your transplant coordinator, transplant pharmacist, or physician. If in doubt, please contact your coordinator for clarification.

The liquid preparation comes in a 50 mL bottle. Each mL contains 100 mg.

- It has an olive-oil base and must be measured with a graduated dropper that comes with each bottle.
- Liquid cyclosporine can be mixed with orange juice, apple juice, or chocolate milk in a glass container. Do not mix in a plastic container.
- Do not mix with grapefruit juice.
- Once dose is mixed, drink immediately.
- Take twice daily, 12 hours apart (10 am and 10 pm).
- Always take your medication **after** lab work is drawn.
- It is important to always stay on the same formulation, if this is changed please inform the coordinator or pharmacist.

### Common Side Effects

The most common side effects are similar to those of Prograf. Additionally, it can cause hair growth on the face. It also causes gum swelling, so good dental hygiene is important.

## Imuran (azathioprine)

Available in 50 mg tablets.

- Dosage of Imuran depends on your weight and your white blood count (WBC) which will be monitored closely. If your WBC falls too low, we will decrease dosage.
- Medication dose may change often (depending on blood work results). Doses may be different from what is on your prescription bottle. Please follow the instructions given to you by your transplant coordinator, transplant pharmacist, or physician. If in doubt, please contact your coordinator for clarification.
- Take once daily at same time each day.

### Common Side Effects

- Decrease in WBC count.
- Hair loss (generally mild and temporary).

## CellCept (mycophenolate mofetil)

- Available in two strengths: 250 mg and 500 mg tablets.



- Medication dose may change often (depending on blood work results). Doses may be different from what is on your prescription bottle. Please follow the instructions given to you by your transplant coordinator, transplant pharmacist, or physician. If in doubt, please contact your coordinator for clarification.
- Take two times a day, 12 hours apart.
- May take at the same time as the other antirejection medications.

### **Common Side Effects**

- Nausea
- Vomiting
- Diarrhea
- Abdominal pain
- Low WBC count
- Low platelet count

### **Prednisone**

You will be started on an initial dose of 20 mg daily, and this will be reduced by the transplant pulmonologist over the coming months.

- Prednisone is available in multiple strengths. Typically, our patients are discharged with 5 mg tablets (and take four tablets at once, for a total dose of 20 mg daily).
- Medication dose may change often. Doses may be different from what is on your prescription bottle. Please follow the instructions given to you by your transplant coordinator, transplant pharmacist, or physician. If in doubt, please contact your coordinator for clarification.
- You may cut tablets in half. It may require multiple tablets to equal current prescribed dose.
- Take once a day, preferably in the morning with food.
- You may take at the same time as other antirejection medications.

### **Common Side Effects**

- Full face and cheeks
- Increased appetite and weight gain
- Weak bones (osteoporosis)
- Cataracts
- Blurred vision (which may improve after the dose is less than 15 mg/day)
- Increased sun sensitivity (wear sunblock SPF 30)
- Slows wound healing
- Increased risk for diabetes (elevation of blood sugar)
- Fluid retention (puffy hands, ankles, and/or
- Stomach or mouth ulcers may occur (notify coordinator)
- Acne
- Insomnia (sleep abnormalities)
- Heat intolerance
- Hypertension (high blood pressure)
- Avascular necrosis (painful arthritis of shoulders or hips)
- Night sweats
- Mood swings

feet)

### **Rapamune (sirolimus)**

Available in two strengths: 1 mg and 2 mg tablets

- Medication dose may change often (depending on blood work results). Doses may be different from what is on your prescription bottle. Please follow the instructions given to you by your transplant coordinator, transplant pharmacist or physician. If in doubt, please contact your coordinator for clarification.
- Take once daily.
- Do not take at same time as Prograf (tacrolimus) or cyclosporine.

### **Common Side Effects**

- Increased cholesterol levels
- Increased lipid levels
- Nausea
- Low platelet counts
- Delayed wound healing

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## ANTI-INFECTIVES

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These medications are used to prevent infections that a patient may be at higher risk of developing because of a suppressed immune system.

### Acyclovir (Zovirax)

Available in 200 mg to 800 mg capsules

- Acyclovir works to prevent infection with the herpes virus. It also inhibits the chicken pox virus and the Epstein-Barr virus.

#### Common Side Effects

- Headache
- Nausea
- Vomiting
- Diarrhea
- Dizziness

### Ganciclovir/Valganciclovir

Available as an IV infusion administered once or twice daily.

- This drug inhibits herpes virus as well as cytomegalovirus (CMV).
- Dosage depends on body weight and kidney function.
- Take Valganciclovir (Valcyte), oral form of Ganciclovir, once or twice daily.
- Take with food.

### Nystatin

Available as an oral suspension

- Nystatin oral suspension is used to prevent fungal infections in the mouth.
- Swish in the mouth and swallow.
- Drug should be taken four times daily after meals and at bedtime.
- Do not rinse mouth for 20 minutes after swallowing.
- If you wear dentures, remove before you take this medication.

### Septra SS (Bactrim SS, TMP/SMX)

- Septra SS is an antibiotic used to help prevent bacterial infections.
- Prevents a certain type of pneumonia called pneumocystis jiroveci pneumonia that may develop when in an immunosuppressed state.
- You will usually take one SS tablet daily.

- If patient is allergic to sulfa, he or she cannot take this medication.

Other options include (for sulfa allergy):

- Inhaled pentamidine (administered once monthly).
- Nebulizer provided by a home health company.
- Drug is to be picked up from pharmacy.
- Dapsone, 100 mg daily oral.

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## OTHER MEDICATIONS

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The medications below are prescribed to patients based on their own condition. You may be given medications not listed here.

### Pain Medications

Pain medication will be prescribed when you are discharged from the hospital. You should take pain medications so you will be able to breathe deeply and cough. A few points about pain medications

You need a paper prescription for most pain medication. **Do not leave the hospital without it.** These *cannot be called into the pharmacy* by the transplant nurse coordinator.

- Drink plenty of water, and take your prescribed stool softener as directed to prevent constipation while taking pain medications.
- Take before planned activity like your Center for Living sessions or sleeping.

### Lasix (furosemide)

- Diuretic or fluid pill used to treat swelling and high blood pressure.
- Weigh yourself daily.
- Report weight loss or gain of two or more pounds daily. Try to take in the morning.

### Zantac, Prilosec, Prevacid, Nexium, Protonix

- These medications are used to decrease the amount of acid in your stomach.
- You are at risk for developing an ulcer and heartburn because you are taking prednisone. These medicines reduce the risk of an ulcer developing.
- Should heartburn occur despite being on one of these medications, please notify your coordinator.

### Metoclopramide (Reglan)

Available in 5 mg and 10 mg tablets.

- Reglan helps with the normal movement of the stomach and intestines. It can cause diarrhea and confusion.

### Magnesium Oxide (Mag-Ox)



Available in 400 mg tablets. Dosage will be dependent on patients' needs.

- Cyclosporine, Prograf, and Lasix can cause an excess loss of magnesium through your kidneys, so you may need to supplement your magnesium intake.

### **Metered Dose Inhalers (MDI)**

- Albuterol and Atrovent metered dose inhalers are often used after lung transplant to help keep airways open and to help ease breathing.
- Take two puffs of each inhaler four times daily.

### **Anti-Hypertensives**

These drugs are used to control high blood pressure and are prescribed based on your blood pressure measurements.

### **Anti-Diabetic Agents and Insulin**

You may develop high blood sugar or diabetes after your transplant. Patients may be prescribed insulin injections to control blood glucose. Medications may differ between patients and will be explained to you if you need them.

### **Antifungals**

Posaconazole (Noxafil)

- Available as an oral solution (40 mg/1ml) and tablets (100mg)
- Solution
  - The typical dose is 400mg twice daily (10ml twice daily)
  - Take with a fatty meal snack and acidic beverage (peanut butter, ginger ale, orange juice). Shake well prior to each dose and use a calibrated spoon for measuring
  - If you take this medication, your tacrolimus (Prograf) or cyclosporine (Neoral, Gengraf) dose will need to be reduced. Please contact your coordinator for proper dosing instructions prior to starting posaconazole.
  - We will also be monitoring blood levels of posaconazole, like we do for tacrolimus (Prograf), and cyclosporine (Neoral, Gengraf). It is important to get these labs drawn in a timely manner when they have been ordered for you.
- Tablets
  - The typical dose is 300mg daily(three 100mg tabs daily)
  - If you take this medication, your tacrolimus (Prograf) or cyclosporine (Neoral, Gengraf) dose will need to be reduced. Please contact your coordinator for proper dosing instructions prior to starting posaconazole.
  - We will also be monitoring blood levels of posaconazole, like we do for tacrolimus (Prograf), and cyclosporine (Neoral, Gengraf). It is important to get these labs drawn in a timely manner when they have been ordered for you.

### **Common Side Effects**

- Blurred vision
- Dizziness
- Fatigue
- Altered taste
- Abdominal pain
- Increased liver function tests
- Nausea/Vomiting
- Diarrhea/Constipation

### **Voriconazole (Vfend)**

Available in an oral solution (40 mg = 1 mL) and tablet form.

- Voriconazole is used to treat fungal infections.
- Dose usually is 200 mg every 12 hours.
- Give at least one hour before or one hour after a meal.
- Do not mix oral suspension with other drugs or beverages.
- If you take this medication, your Prograf or cyclosporine dosage must be reduced. Please call your transplant coordinator for proper dosing instructions.

### **Common Side Effects**

- Headaches
- Fever
- Sensitivity to light and increased susceptibility to sunburn
- Abnormal vision, usually see yellow or green colors
- Hallucinations
- Dizziness
- Abdominal pain
- Nausea
- Vomiting
- Hypertension

### **Inhaled Abelcet (Amphotericin B Lipid Complex)**

Available in a solution for inhalation using a nebulizer (with a high-volume compressor provided by a home health company)

- Abelcet is used to treat fungal infections
- 5 mg = 1 mL no dilution dose = 50 mg (10 mL)
- Dilution directions: Each vial of Abelcet has 100 mg in it. You will draw out ½ (10 mL) for your dose and put this directly into your nebulizer. You won't need to dilute it. Put the remaining Abelcet vial in the refrigerator, and use it for your next dose that week.

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## MEDICATION SAFETY AND PLANNING

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1. Keep at least one week of medications on hand at all times. If you are required to use a mail order pharmacy, plan for shipping and handling.
2. Request refills one week in advance to allow for prior authorizations, if needed.
3. Contact your pharmacy for refills; they will request them from our office. This method will help our office complete the refill request more quickly.
4. Do not share your medicines with other patients or family members.
5. Notify the transplant nurse coordinator if your pharmacy changes you to a generic formula of your medicine. We prefer you take brand medication, but if you must take generic, please request the same generic product with each refill.
6. When traveling, keep at least three days of medication with you. If your luggage is lost or delayed, you will still have your medications.
7. When traveling, bring more medicine than you need in case you are delayed in your return.
8. When you are at home, the pharmacist in your retail store is a good resource for questions about your medication.

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## MONITORING YOUR HEALTH AFTER DISCHARGE

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### Clinic Visits

You will be seen quite frequently in the Lung Transplant Clinic during the first two or three months after your discharge from the hospital. As time passes and your condition improves, we will see you less frequently.

Your visits to the Lung Transplant Clinic will always start in the morning. At each clinic visit, you will have blood drawn, a chest X-ray, arterial blood gas measurement, and pulmonary function tests before seeing your doctor and transplant coordinator.

A cyclosporine or Prograf blood level will be drawn each time you come to clinic. Remember, do not take your cyclosporine, Prograf, and Rapamune until after the blood has been drawn. How much medication you need is determined by your lab results. You may take all your other medications, but put your Prograf, cyclosporine and Rapamune in your pocket. Take these medications right after your blood work is done.

In addition, please remember to bring:

- A day's supply of all your medications with you, in case you are delayed
- Home records of your micro spirometer readings, glucose monitoring, daily weight, blood pressure and personal notes
- Any questions for your doctor and transplant coordinator

You will normally be finished with your clinic visit by the end of the day; however, certain extra studies may be ordered from time to time. You will receive a schedule in the mail for each clinic visit or be notified in advance when possible.

Medical Psychology is available as needed for assessment and psychotherapy anytime throughout the transplant process.

### Self-Monitoring

Measurements of your body's functions such as blood pressure, heart rate (pulse), temperature, and fluid status (weight) are vital signs. To help us monitor your progress and adjust your medications, we ask that you record your vital signs and weight each day. Recording vital signs is an important way you can help the transplant team help you do well after your transplant.

#### Blood pressure (B/P)

You will need to get a blood pressure cuff that you can easily use to monitor your own blood pressure. BP cuffs that require a stethoscope for listening to blood pressures are very difficult to use when checking your own blood pressures. Instead, please obtain a semi-automatic blood pressure cuff that runs on batteries or electricity. With a semi-automatic cuff, you can easily put the cuff on your arm and pump it up. The machine then causes the cuff to deflate on its own and displays the BP reading. There are many good brands of semi-automatic BP cuffs available for around \$35 to \$95.

Cuffs can usually be purchased in many pharmacies or drug stores, hospital supply stores, or at discount stores with pharmacy services. Store personnel can help you make an appropriate selection.





Mytech® Technology Co., Ltd.



OMRON® HealthCare

Become familiar with your usual blood pressure and pulse rate. Blood pressure readings have two parts. The top number is called the systolic blood pressure, and the bottom number is called the diastolic blood pressure. Record your blood pressure and pulse rate this way in your home record:

Systolic BP/ Diastolic BP: 118/ 78

Pulse: 70

Always check your vital signs at rest. In most instances, we do not need to know how your vitals change with exercise. Sit and rest for at least five minutes before checking your vital signs.

### **Bronchoscopy Monitoring**

After your transplant, you will have a biopsy of your transplanted lung(s) at regular intervals to check for the presence of rejection. Biopsies will be done at one month, three months, six months, nine months, twelve months, and then just once a year unless there is a problem with your lungs.

Biopsies are done through a lighted tube, called a bronchoscope, that is inserted through your nose or mouth and into your transplanted lung(s). You will receive instructions prior to each bronchoscopy that will detail eating and medication restrictions.

The bronchoscopy will be done in a special procedure room, and you will be given medication to help you relax before your procedure if necessary. Your throat will then be sprayed with a numbing medication, and the bronchoscope will be inserted through your nose or mouth. Insertion of the bronchoscope is normally uncomfortable and will make you cough.

You will be monitored closely throughout the procedure, so try to relax as much as you can and listen to the instructions from the nurse and the physician. After your doctor has carefully examined your lungs through the bronchoscope, several tiny pieces of lung tissue will be removed. When the biopsy is finished, you will be required to remain in bed with nothing to eat or drink for the next two hours.

You will always need to bring someone with you who can be responsible for driving you home after the bronchoscopy, since you will be unable to drive after receiving the medication to help you relax.

The tissue from your biopsy will be taken to a special laboratory, where it is examined carefully under a microscope for the presence of rejection and infection. The transplant physician will plan treatments based on your biopsy results and you will usually be notified of these results in 48–72 hours. If your biopsy is done on Thursday or Friday, results will usually be provided Monday afternoon. If you require admission to the hospital for urgent treatments, the transplant coordinator will contact you.

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## CONTACTING THE TRANSPLANT NURSE COORDINATOR

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The transplant nurse coordinator will work with the physician who saw you in clinic to make a plan for your care. He/she will contact you after clinic visits and provide you with information about lab results, medication changes and the plan for your next appointment. The transplant nurse coordinator is an excellent resource for questions about your continued care and recovery. One of transplant nurse coordinators will see you each clinic visit, however the same coordinator will work with you on a regular basis when you contact the office or when you are hospitalized.

All questions about your health are important. The transplant nurse coordinators are available in the Lung Transplant Office, Monday-Friday from 8 am-4:30 pm. The number is 919-613-7777. Your call may be directed to the voice mailbox. Transplant nurse coordinators check voice mail messages throughout the day and will call you back as soon as possible. Please leave a message on the “pharmacy refill” voice mailbox if you need prescription refills or prior authorizations for medication, and our nurse clinicians will take care of your request.

Examples of common calls to the transplant coordinators:

- Questions about food or drug interactions.
- Travel or pet advice.
- Reporting symptoms that have been present for a long period of time or are chronic problems.
- Questions about studies or testing that has been planned.
- To obtain recent lab or test results.
- Medication questions including approval to take new medications.

### Urgent Symptoms to Report

- Temperature greater than 100°F or 38°C.
- Either blood pressure number above 150/100.
- Productive cough, change in sputum or shortness of breath.
- New sores, blisters, or lumps.
- Chills or shaking episodes of fever.
- Flu-like symptoms or severe cold symptoms.
- Drainage from a wound or cut.
- Nausea, vomiting, or diarrhea that is severe or prolonged (for longer than 24 hours).
- Increase in fatigue and decrease in exercise tolerance.
- Burning during or frequent urination.
- Decrease of FEV1 or FVC by 10% in a 24-hour period or a downward trend over three days.
- Blood glucose below 60 or higher than 400.

### Paging the Transplant Coordinator During Business Hours (8:00 am – 4:30 pm)

There are times when contacting the transplant nurse coordinator is urgent during business hours. If you need to speak urgently with the transplant nurse coordinator and he/she is not in the office, you may page him/her.

You may reach your transplant nurse coordinator by calling the DUH operator at 919.684.8111. Please always ask for your transplant nurse coordinator by name; if he/she is not available, your call will be forwarded to another transplant nurse coordinator. Please always contact the DUH operator for paging services.

### **Contacting the On Call Transplant Coordinator Outside of Business Hours**

When the office is closed, holidays and weekends, the on call coordinator will be available to assist you for urgent issues that cannot wait until the next business day. To reach the on call coordinator, simply call the DUH operator at 919.684.8111 and ask him/her to page the on call lung transplant coordinator, then hold the line until you are connected. Please recognize that the nurses are not at the hospital during non business hours.

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## **EXERCISE, NUTRITION AND PULMONARY PHYSICAL THERAPY AFTER LUNG TRANSPLANT**

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While you are in the hospital, a major part of your recovery will include vigorous physical therapy.

The average lung transplant patient no longer needs oxygen within a few days after the operation, and is able to walk one mile per day by two to four weeks after the operation.

Most patients are discharged from the hospital one to four weeks after the transplant operation. Some patients will stay longer or shorter, based on what is best for them. It is normal to compare your situation with that of other lung transplant recipients, but everyone is different, so do not worry if your situation differs from others.

### **Outpatient Pulmonary Physical Therapy**

Every lung transplant patient is required to participate in the outpatient pulmonary physical therapy program offered by the Duke Cardiac and Pulmonary Rehab Center. You must complete at least 23 sessions (which takes approximately six weeks). Most patients participate in the program prior to their transplant to get ready for their transplant.

The group meets from 12:30 pm to 4:30 pm, Monday through Friday. The pulmonary physical therapy staff consists of physical therapists and respiratory therapists who will work with you both individually and within a group to ensure you are exercising properly.

Prior to beginning the course, you will undergo an exercise test to determine the level of activity at which you should begin. In addition to exercise sessions, classes are offered on various topics of interest related to your lungs. You and your care provider should attend the education sessions anytime you are available.

All patients are given a home exercise program upon completion of the course. You are expected to continue a program of regular exercise for the rest of your life. Staying in shape is not easy, but exercise can prevent some of the side effects of your medications, and is one of the best things you can do to help yourself live a longer and healthier life.

### **Nutrition After Transplant**

Immediately after transplant your nutritional needs will be increased due to the stress of surgery and need for wound healing. You will also be burning extra calories at pulmonary rehab. To promote healing after surgery, you should get adequate calories, protein, vitamins and minerals in your diet. High protein foods include meats, seafood, milk, dairy products, eggs, soy products, beans and legumes.

To minimize aspiration risk and to get adequate nutrition, it may be necessary to provide nutrition via feeding tube for a period of time after your transplant. If this is the case, you may get a tube placed called a GJ tube, or gastrojejunal tube. It is placed into your stomach through the abdominal wall, and has 2 ports—one into your stomach and the other ends in your small intestine. If you go home on tube feeding, you will likely be fed via a feeding pump into your small intestine over 12-14 hours at night. Your physicians will decide if you will also be able to eat during the day and what consistencies of food are appropriate. You may be restricted to pureed or soft foods or thickened liquids for a period of time after your transplant.

**Controlled Carbohydrate:**

Some of the medicines that you take to keep from rejecting your new lungs may cause high blood sugars. You may be started on medications to help, but you will also need to control your timing and quantity of foods concentrated in sugar and carbohydrates. Carbohydrates are found in sugar, fruit, breads, crackers, cereals, pasta, rice, grains, milk and yogurt, starchy vegetables such as potatoes, corn, beans, and peas. You don't need to avoid these foods, but you should control the amount you eat at each meal/snack. Aim for about 30-75 grams of total carbohydrate per meal. Use nutrition labels to learn about the carbohydrate content of foods. Make sure you compare the serving size you are eating to the serving size on the label.

**Food Safety:**

Since your immune system is weakened by the immunosuppressive drugs used to prevent rejection of the transplanted lung(s), you will be more susceptible to food borne illness. To avoid contracting a food borne illness, you must be especially cautious when handling, preparing, and consuming foods. Your Registered Dietitian can provide further information during your hospital stay and in clinic after transplant.

The following website is a guide for food safety for transplant recipients that reviews good food safety practices. [http://www.fsis.usda.gov/pdf/food\\_safety\\_for\\_transplant\\_recipients.pdf](http://www.fsis.usda.gov/pdf/food_safety_for_transplant_recipients.pdf). This booklet is also available in transplant clinic.

**Food and Drug Interactions:**

For patients who take Cyclosporine or Tacrolimus, you need to avoid all forms of grapefruit and any drinks that contain a significant amount of grapefruit juice. Seville oranges should also be avoided and you should limit your intake of pomegranate. You will discuss this in more detail with your pharmacist and dietitian after transplant.

**Calcium:**

Steroids may cause bones to lose calcium. Osteoporosis is a common consequence of long-term steroid use. Dairy products are the main sources of calcium and should be included in your diet to help keep bones strong. You should also take a calcium + vitamin D supplement daily.

## Potassium:

Your immunosuppressant medications may also cause your serum potassium to be elevated. If your potassium is elevated on your blood work, you may be asked to limit the high potassium foods below. If your potassium is NOT elevated then you may consume these foods.

FRUITS	VEGETABLES	OTHER FOODS
Apricots	Artichokes	Bran Products
Avocado	Dried Beans	Coffee (limit 2 cups/day)
Banana	Broccoli	Chocolate
Cantaloupe	Brussel Sprouts	Coconut
Casaba Melon	Escarole	Granola
Dates	Endive	Milk (ice cream, yogurt)
Dried Fruits	Greens	Molasses
Figs	Kale	Nuts/Seeds
Honeydew Melon	Kohlrabi	Salt Substitutes
Mango	Lentils/Legumes	Tea (limit 2 cups/day)
Nectarine	Tomatoes/Tomato Products	
Orange	Lima Beans	
Papaya	Mushrooms	
Prunes	Parsnips	
Raisins	Potatoes	
Rhubarb	Rutabagas	
Fruit Juices (grapefruit, orange, prune)	Vegetable Juices (tomato, V8)	
	Spinach	

## Ways to optimize nutrition for life:

The immunosuppressive drugs you will need to take may cause or worsen diabetes, osteoporosis, elevated lipids, high blood pressure, and weight gain. A few months after your transplant, once you have healed and your condition has improved, it is important to follow The American Heart Association's Diet and Lifestyle Recommendations. These guidelines can help minimize the side effects of these medications and are an important aspect of everyday care after transplant.

Eat a variety of [fresh, frozen and canned vegetables and fruits](#) without high-calorie sauces or added salt and sugars. Replace high-calorie foods with fruits and vegetables.

Choose fiber-rich [whole grains](#) for most grain servings.

Choose [poultry and fish](#) without skin and prepare them [in healthy ways](#) without added saturated and *trans* fat. If you choose to eat meat, look for the leanest cuts available and prepare them in healthy and delicious

ways. Eat a variety of fish at least twice a week, especially [fish containing omega-3 fatty acids](#) (for example, salmon, trout and herring).

Select fat-free (skim) and low-fat (1%) dairy products.

Avoid foods containing partially hydrogenated vegetable oils to reduce [trans fat](#) in your diet.

Limit saturated fat and trans fat and replace them with the better fats, monounsaturated and polyunsaturated. If you need to lower your blood cholesterol, reduce saturated fat to no more than 5 to 6 percent of total calories. For someone eating 2,000 calories a day, that's about 13 grams of saturated fat.

Cut back on beverages and foods with [added sugars](#).

Choose foods with less sodium and prepare foods with little or no salt. To lower [blood pressure](#), aim to eat no more than 2,400 milligrams of [sodium](#) per day. Reducing daily intake to 1,500 mg is desirable because it can lower blood pressure even further. If you can't meet these goals right now, even reducing sodium intake by 1,000 mg per day can benefit blood pressure.

**A registered dietitian is available in the hospital and pulmonary clinic to provide education on managing blood sugar, weight control, diet consistency modifications, tube feeding, food safety, and other nutritional concerns.**

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## COMMON SENSE PRECAUTIONS TO PREVENT INFECTION AFTER LUNG TRANSPLANT

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Your immune system is the part of your body that is responsible for fighting infection. When this system is weakened by the immunosuppressive drugs used to prevent rejection of the transplanted lung(s), you become more susceptible to infections. Your susceptibility to infection is directly related to the amount of immunosuppression that you are receiving at any given time. Your level of immunosuppression is also very high after you receive therapy for rejection.

The highest level of immunosuppression is immediately after the transplant operation and isolation precautions are most strict at that time. Everyone who comes into your room will be required to wash their hands thoroughly to prevent transfer of bacteria, viruses, and other infection-causing microorganisms to you. Infections in a transplant patient can be quite serious, even life-threatening. Good hand washing along with the following practices will help prevent infection.

### **Avoid Large Crowds**

After lung transplant, avoid large crowds where people could carry contagious illnesses. While you don't have to be confined to your home, use common sense and intuition to avoid crowds that carry illness and germs.

Here are a few precautions to take:

- Plan to eat out when restaurants are not crowded, for an early lunch or dinner.
- Go see a matinee movie since they are often less crowded than later movies.



- Limit the number of people in your home. If you are staying in a small apartment after transplant, do not invite guests and family members to come see you right away. It is best not to have a large number of house guests at any one time for at least two months after your transplant.
- Wear a mask if you fly on an airplane.
- Carry a mask and a bottle of hand sanitizer with you whenever you go out in public.

## Practice Safety at Home

Light housekeeping will not harm you and is a very good way to get back into shape. It is important to observe the following safety precautions:

- Do not empty vacuum cleaner bags, change furnace filters, or clean very dusty areas, such as a garage or attic.
- Do not lift more than five pounds for the first six weeks after your surgery.
- Avoid inhaling strong fumes from some cleaning products, such as ammonia or bleach.
- Wear N95 masks and gardening gloves if you work with plants and flowers, since many infectious organisms live in the soil.

## Pets

- If you have always enjoyed having a pet or pets in the house, there is no reason for that to change. However, you should follow some guidelines to prevent infection:
- Keep your overall number of pets to a minimum. Just as having too many people in one house can be unhealthy, so can having too many pets.
- You should never change cat litter boxes, clean up after birds or any other animals, or clean pets' ears. Get someone else to do these tasks.
- Be sure to take the pets to your veterinarian for their shots and check-ups. Avoid exposure to live vaccines, such as the Bordetella vaccine.
- Pets should not be allowed to sleep on your bed. Your mattress should be vacuumed at least once a month. This is a good idea even if you don't have pets.
- Should you get bitten by a dog or cat or scratched by a cat, please contact your transplant coordinator.

## First Aid and Hygiene

The natural ability of your body to heal wounds will be slowed down because of the immunosuppressive medication you take to prevent transplant rejection. If you do need first aid care, follow these guidelines:

- Clean any cut or injury, and keep a clean, dry dressing on the wound.
- If healing is prolonged or if you experience pain, swelling, redness, or other signs of infection, notify your transplant coordinator right away.
- Notify the transplant coordinator if you notice any unusual rashes, blisters, or other lesions on your skin.

- Visit your dentist every six months to avoid tooth and gum disease. We do not prescribe antibiotics for routine dental work. If your dentist wants to put you on one, please call your coordinator to confirm that it is all right to take with your immunosuppressant medications.
- Notify your transplant coordinator if you notice sores, ulcers, or white patches in your mouth and throat.

## Water Prevention Guidance after Transplant

Water safety, not just food safety, is also of vital importance in the post-transplant time period. We have three phases of water-based precautions at Duke:

- Phase 1: In-hospital, post-transplant surgery; highly immunosuppressed, freshly healing wounds
- Phase 2: Immediate post-discharge from hospital; incisional staples still in place
- Phase 3: Staples removed and wound well-healed

Phase 1: While in the hospital, expect tight water restrictions. Ice chips, drinking water and showering, for example, will all be strictly limited.

Phase 2: After discharge, but before staples and stitches are removed from your incisions, the wounds remain at risk for water-born infection.

- Use boiled water or sterile water for (a) drinking, (b) oral care (e.g. toothbrushing), (c) tube flushes, and (d) washing wounds.
- Showers and baths are not recommended in this phase; chest tube sites and incisions should be cleaned specifically with boiled or sterile water.
- Of note, bottled water is not recommended during this phase; boiled water or sterile water are the most reliable way of ensuring safety.

Phase 3: Once incisions are healed, showering is allowed.

- Hot tubs, because of the aerosols generated, should be avoided.
- Well water, even if filtered, is not considered safe unless it has been tested, as it is rarely appropriately chlorinated and may contain infectious organisms.
- Most water filtration devices will not make water safe. Portable water filters (such as Brita® or Pur® system) as well as refrigerated-dispensed water and ice machines do not meet filtration standards. Portable water systems filter for impurities, but not for bacteria. Boiled or sterile water is safest for drinking.
- Questions about water use and supply can be directed towards your Transplant team, or the Infectious Diseases service.

## Common Infections after Transplant

After transplant, you are susceptible to the same types of infections that people around you have. These infections include upper respiratory infections (colds and flu) and stomach bugs. Common infections can quickly become severe and perhaps even life-threatening because of your weakened immune system. **Because of this, notify your transplant coordinator if common cold symptoms linger or if a stomach virus is causing you to be unable to take your medications. Remember to always notify your transplant coordinator if you develop a fever higher than 100°F.**

## **Avoiding Colds and the Flu**

After your transplant, you will probably get the same number of colds and flu-like illnesses that you always did, but, understandably, these will cause you more concern than they did before. For both your physical and emotional health, therefore, you should do all you can to prevent colds and flu. This is largely a matter of careful hygiene and common sense.

- It is important to wash your hands frequently, since most infections travel hand-to-hand rather than through the air.
- Do not eat after people (out of bowls of popcorn, for example), drink after people, or reuse a bathroom glass.

## **Responding to a Cold or the Flu**

Despite your best efforts, you will catch a cold or flu from time to time. You may want to take medications to control symptoms like nasal drainage, sore throat and coughing. Please check with the transplant coordinator for recommendations for medications for symptoms.

Should symptoms of a cold linger, or if you develop a fever, symptoms of chest congestion, or a productive cough, be sure to call the transplant coordinator right away. The lung is the most susceptible site of infection after your transplant, and you may need a chest x-ray to determine infection or to decide if antibiotics are needed.

## **Cytomegalovirus (CMV) Infection**

Cytomegalovirus (CMV) is a virus that is very common in the general population. It does not usually cause problems in healthy people, but can cause very serious illness in transplant patients whose immune systems are weakened by immunosuppressive drugs.

The risk of CMV infection is especially high during the first few weeks after transplantation and after treatment for rejection, when larger doses of immunosuppressants are given. Most patients will be given ganciclovir during this time to try and prevent CMV infection.

CMV infection can occur at any time after transplantation and is easily treated if detected early. For this reason, it is important for you to be able to recognize possible signs and symptoms of a CMV infection.

Symptoms of CMV include:

- Fever (may be low-grade and cyclical; e.g. fever in the morning that is gone by afternoon)
- Shortness of breath
- Extreme fatigue
- Muscle and joint aches
- Decreased white blood cell count
- Decreased FEV1 and FVC

Often, CMV infection will occur without any symptoms that you can detect. For this reason, we will routinely check for CMV infection with a blood test when you come to clinic.

Treatment of CMV infection usually consists of a 14- to 21-day course of the antiviral medicine ganciclovir, given intravenously once or twice a day, depending upon your kidney function. We will usually arrange for you to receive this treatment at home with the assistance of a home care company. Ganciclovir capsules (known as Valcyte) may be used in some circumstances or may be needed after the IV therapy for an extended period.

### **Shingles (Reactivation of Varicella)**

Some transplant patients will develop a skin infection known as shingles, which is also caused by a virus. This virus is the same one that causes chicken pox in children. In adulthood, the virus can be reactivated and is exhibited as a skin infection called shingles. Shingles generally looks like small red blisters on your skin that are often grouped together in a line. The blisters may be itchy, tingly, and quite painful. Notify your local doctor or transplant coordinator if you think you may have shingles.

If a diagnosis of shingles is confirmed, it is often treated with a medication called Valtrex. If left untreated, shingles can spread to all parts of your body and become very serious. Shingles is also contagious to others until all the blisters have dried up.

Please note that you and your caregivers should NOT get the shingles vaccine after transplantation, as this is a live-virus vaccine!

### **Fungal Infections**

Transplant patients are also more likely to develop fungus infections than the general population. Fungus infections can occur in almost any part of the body, including skin, nails, and your new lung(s) and can be difficult to treat.

Fungus is located in damp areas as well as dusty areas, so avoid being in areas where there is mold, mildew, dust, and dirt whenever possible. While most fungus infections are usually treatable, the drugs used to treat fungus are generally very expensive, and treatment lasts a long time. Most drugs used to treat fungus infections also interact with anti-rejection drugs.

Your transplant nurse coordinator will instruct you to adjust your anti-rejection drug doses and monitor you closely while you are being treated for a fungus infection.

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## REJECTION OF TRANSPLANTED LUNGS

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Rejection of your transplanted lung(s) can occur at any time following your surgery. Episodes of rejection most commonly occur during the first 12 months after transplant. Try not to become too alarmed if you are told that you are experiencing rejection. Episodes of rejection are common, and other than taking your immunosuppressive medications, there is nothing you can do to prevent them from happening.

Rejection is easily treated if it is detected early. For this reason, it is important for you to be able to recognize signs and symptoms of rejection. These include:

- Fever
- Shortness of breath
- Decreased exercise tolerance
- Decrease in FEV1 and FVC

Very often, rejection will occur without any symptoms that you can detect. For this reason, we will biopsy your transplanted lung at regular intervals.

### Treatment of Rejection

We have a number of ways to fight rejection of your new lungs, including steroids, RATG, and Campath.

#### Steroids

Treatment of rejection usually consists of three daily doses of an intravenous steroid drug called methylprednisolone. This drug is also known as Solu-Medrol and is an intravenous form of prednisone. If you are not feeling well, you may be admitted to the hospital to receive the Solu-Medrol. However, if you are having no symptoms, we will arrange for a home care company to give you your Solu-Medrol at home.

When you have received the third dose of Solu-Medrol, we will increase your dose of Prednisone and taper it by five milligrams daily until you are back to baseline.

Higher doses of steroids may lead to high blood sugar or the development of post-transplant diabetes mellitus. Therefore, you should check your glucose before meals and at bedtime when you are being treated for rejection. Contact the transplant nurse coordinator for questions or concerns with your glucose levels and if your glucose increases above 400 at any time.

#### Rabbit Anti-Thymocyte Globulin (RATG)

If rejection is extremely severe, or if it persists after you receive Solu-Medrol and the prednisone taper, a preparation called Rabbit anti-thymocyte globulin (RATG or Thymoglobulin) may be used.

As its name implies, RATG is prepared from the serum (part of the blood) of rabbits. It contains powerful antibodies against human rejection cells, and must be given in a hospital setting.

You will receive three or five daily doses of RATG intravenously while you are in the hospital. The first dose often causes uncomfortable side effects such as fever, aches, nausea/vomiting, and low blood pressure. Your nurse will monitor your vital signs very frequently while you are receiving the RATG. Side effects are usually much less severe after the first dose.

Because the RATG works by weakening your immune system even further than your maintenance anti-rejection drugs, you will be even more likely to develop infections for a while after receiving this therapy.

Be extra careful to avoid exposing yourself to infection, and as a precaution against CMV infection, you will receive ganciclovir or Valcyte for three weeks after receiving your RATG therapy. A long-term IV line (PICC line) will be inserted in your arm while you are in the hospital, so that you can finish the three-week course of ganciclovir at home.

## **Campath**

If rejection persists after treatment with both steroids and RATG, you may receive a drug called Campath to treat the rejection. Campath is an extremely powerful anti-rejection drug that may be given in the hospital, or in an outpatient infusion facility.

You will receive just one dose of Campath, but its effect on your immune system will last a very long time. After receiving your dose of Campath, you will need to take medication to prevent both CMV infection and fungus infection for a very long time.

Because these drugs are very expensive, and you will need to stay on them for a long time (often years, until your immune system's function returns), we will check your insurance coverage of the drugs to prevent fungus and CMV infection prior to scheduling your Campath infusion.

## **Antibody-Mediated Rejection**

Your body's immune system has more than one way of recognizing and trying to destroy things that are inside you that it perceives are not supposed to be there. While this is a wonderful thing about the human body, and allows us to fight off bacteria, viruses, and other such things that cause infection, it is not so good when it comes to having an organ transplant. The body's immune system will recognize the new lung(s) as something that is not part of "you" and therefore should be destroyed. This is why transplant patients have to take drugs to suppress their immune systems and thereby hopefully prevent rejection.

One of the ways that the body's immune system works is by making "antibodies" against certain parts of human tissue that it perceives should be destroyed, such as the human tissue of your donor lung(s). We will draw blood to test you for the presence of such antibodies both before and after your transplant. Our transplant immunology lab can also tell the specific human tissue types against which the antibodies are made. The presence of these human tissue antibodies before transplantation can make it difficult to find a donor that does not have the kind of human tissue that there are already antibodies against. If human tissue antibodies develop after transplantation, and particularly if the antibodies that develop are specifically targeted against the human tissue of your donor lung(s), they can cause a kind of rejection that requires specific treatment. We may want to give you special medications and/or treatments to try and stop or at least reduce the production of these antibodies. These special medications are all given through your veins, and include intravenous immune globulin (IVIG), rituximab (Rituxan), and bortezomib (Velcade). We may also want you to undergo a series of treatments called "plasmapheresis," which removes the antibodies from your bloodstream using a special machine. Your transplant physician and coordinator will work closely with you to determine what medications, or combination of medications and plasmapheresis treatments, will be best for you if you have rejection that is caused by antibodies.

## **Bronchiolitis Obliterans Syndrome (BOS)/Chronic Rejection**

Bronchiolitis Obliterans Syndrome (BOS) is a term that refers to progressive deterioration in the function of a transplanted lung(s) in the absence of reversible causes. Unlike acute rejection, it doesn't respond to currently available medical treatment. It may be related to repeated infections or rejection episodes. Unfortunately, BOS is common in lung transplant recipients and is the most common cause of death.

We have an active research program focused on better understanding, prevention, and treatment of BOS. If you develop BOS, we will do our best to stabilize and maintain the function of your transplanted lung(s) for as long as possible. This usually involves changing some of your immunosuppressive drugs or adding other drugs such as azithromycin.

You may be considered for another lung transplant in certain circumstances. It is of utmost importance that you take the best possible care of yourself, report any signs or symptoms of rejection and infection as early as possible, and carefully follow the instructions of the lung transplant team, which are designed to help you avoid the development of BOS.

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## MAINTAINING YOUR HEALTH AFTER YOU RETURN HOME

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Your long-term success depends on many things, including your adherence to recommended treatments and monitoring. Sometimes, a patient will do exactly as we ask and still experience problems. When you have completed the pulmonary rehabilitation program and are ready to return home, your local doctor may resume some of your care. We recommend that you continue to see your other physicians, including your primary care provider and specialists. The lung transplant team members are available to both you and your doctor 24 hours a day if our help is needed.

### Starting New Medications

Please inform our office if another doctor wants to start you on any new medications, so that we can update your records and monitor any potentially dangerous drug interactions. We will also continue to follow you at regular intervals in the Duke Lung Transplant Clinic.

### Record Your Lung Function

Continue to maintain a log of your pulmonary function using the micro spirometer. This is one of the best ways to see your lung health.

### Complete Your Labs at Home

While you are at home between lung transplant clinic visits, it is very important that you have blood work done at least once a month to monitor the levels of anti-rejection medication in your blood, as well as any toxic side effects these drugs may be having on your kidneys, liver, and bone marrow.

Contact our office if you need a new a standing lab order that can be taken to a hospital or blood lab that is close and convenient for you. Always remember that for the blood levels to be accurate, blood must be drawn in the morning just prior to your first dose of Prograf or cyclosporine.

Your coordinator will let you know the results of your blood work as soon as those results are received and reviewed. If you have not heard from your coordinator within five days of your lab draw, please contact the coordinator to let him/her know you had labs drawn so we can request the results.

Please remember that it is up to you to remember to have these labs checked at regular monthly intervals, and to make sure results are received in the lung transplant office. This is an important part of taking care of yourself after transplantation, and making sure your new lungs serve you well for as long as possible!

### Maintain a Healthy Weight

Reaching and maintaining your ideal body weight is very important in your overall health. Your dietitian will help you determine your ideal body weight, and will counsel you to help you gain weight if you are underweight, or lose weight if you are overweight.

If you are already at your ideal body weight, a good diet including moderate serving sizes and limited added fats and sugars will help you to maintain it. Exercise is also very important in controlling your weight.

### Medical Condition Alert Bracelet

- We recommend that each lung transplant patient wear an identifying tag on either a bracelet or necklace after transplant. The following information should be included:



- Your name
- Lung transplant recipient
- Call Duke University Hospital at 919.684.8111

## **Routine Health Maintenance**

After your lung transplant, please maintain a relationship with your primary care physician for general health maintenance and routine cancer screening tests. You should arrange to complete your routine physical examinations and vaccines, as well as Pap smears, breast exams, mammograms, prostate exams, and colonoscopies. This is a very important part of your overall health care that must not be neglected. In addition to increasing your risk of infection, the immunosuppressive medications may increase your risk for developing cancer. For this reason, all patients should follow the guidelines recommended for the general population for cancer prevention and screening.

## **Skin Care**

Always remember to wear sunscreen when outside for any prolonged period. Hats and sunscreen should be a routine part of your outdoor supplies. Skin cancers occur more often in transplant patients due to their weakened immune systems. Always contact your doctor to examine any unusual skin or mouth lesions. As always, earlier detection and treatment can prevent a condition from becoming serious or even life-threatening.

## **Vaccines**

Transplant patients should have seasonal vaccines and routine vaccines to maintain health. You should NOT get live vaccines such as oral polio, flu/H1N1 nasal spray, and shingles vaccines. We suggest you avoid close contact with anyone who has received these types of vaccinations within the last three weeks. This includes caring for infants who have had immunizations as virus is shed in the feces and sputum.

You and each of your family members should get a flu shot as soon as they are available each year. If you have small children, discuss the flu shot with their pediatrician. You should also keep up with other routine vaccinations, such as tetanus and pneumonia vaccines.

## **Sexual Activity after Lung Transplant**

Sexual activity may be resumed after your incision heals, which is usually about six weeks after surgery. You should be careful at first to minimize the weight or strain that is put on your incision, especially over the breast bone in patients with a bilateral lung transplant. Pain is the best indicator that too much weight is being put on the incision.

Everyone who is sexually active should take precautions to make sex as safe as possible. This is especially true for you, as the immunosuppressive medications that you are taking make you more susceptible to sexually transmitted diseases, as well as other infections.

The use of a latex condom is essential to safe sex. Using a condom does not guarantee that you will not get a sexually transmitted disease, but it is your best preventive measure after abstinence.

If you are certain that your partner is faithful, use of a condom may not be necessary. But since something as simple as a woman's common vaginal infection could cause serious infection in a male transplant patient,

complete, candid communication with your partner is essential. In such a situation, even faithful partners should use a condom or abstain from sexual intercourse.

Single people must insist on using a condom when a relationship becomes sexual. This is not always an easy or comfortable thing to do, but you have come too far to make what could be a very dangerous mistake.

Finally, do not forget about birth control. Pregnancy could be hazardous for a female lung transplant patient. Your transplant coordinator and doctor are available to discuss these matters with you if you so desire, so please don't be afraid to ask about your concerns.

## **Summary**

Caring for yourself or a loved one after a lung transplant can feel overwhelming at times. Please ask questions to help you understand the plan of care. Seek members of the transplant team when you have questions. You and the transplant team are partners in your continued health. We look forward to working with you and your family as you recover and return to an improved state of health.

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## **HEALTH MAINTENANCE RECORDS**

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Please use the following sheets included in this material to track your health data as directed by your coordinator.

NAME		MONTH				YEAR		
DAY	TIME	1	2	3	4	5	6	7
WEIGHT	AM							
BLOOD PRESSURE	AM							
TEMPERATURE	AM							
BLOOD PRESSURE	PM							
PULSE	PM							
DAY	TIME	8	9	10	11	12	13	14
WEIGHT	AM							
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TEMPERATURE	AM							
BLOOD PRESSURE	PM							
PULSE	PM							
DAY	TIME	15	16	17	18	19	20	21
WEIGHT	AM							
BLOOD PRESSURE	AM							
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PULSE	PM							
DAY	TIME	22	23	24	25	26	27	28
WEIGHT	AM							
BLOOD PRESSURE	AM							
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PULSE	PM							
DAY	TIME	29	30	31				
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NAME		MONTH				YEAR		
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NAME			MONTH				YEAR			
DATE	BREAKFAST		LUNCH		DINNER		BEDTIME			
	GLUCOSE	INSULIN	GLUCOSE	INSULIN	GLUCOSE	INSULIN	GLUCOSE	INSULIN		
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NAME			MONTH				YEAR	
DATE	BREAKFAST		LUNCH		DINNER		BEDTIME	
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**Exercise Log - Time Spent Walking, Swimming, or Biking, etc.**

NAME		MONTH		YEAR		
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