The Gift of Life
A PATIENT’S GUIDE TO LUNG TRANSPLANT POSTOPERATIVE CARE

UKHealthCare®
Joe Grigsby

Received a bilateral lung transplant January 30, 2013 due to Cystic Fibrosis.
Congratulations on your new lung(s)! This manual is for you and your caregiver. Please become familiar with the contents, as it will serve as a guide and resource to you in the coming months. It is important to understand that, although this is a guide, your specific plan of care will be determined by your surgeon and pulmonologist.
The Transplant Clinic is located on the fourth floor of Pavilion H in the UK Albert B. Chandler Hospital.

Visits will be three times a week for two to four weeks after discharge. Then you will have weekly visits for the next two months.

After this your visits will be moved to biweekly, monthly and then every three months for the first year.

Arrive at the clinic at your scheduled time. You will have blood drawn for tests that will measure your liver function, kidney function, blood count, and cyclosporine or Prograf® levels.

Always bring your medications and journal to the clinic.

Do not take any medications until your labs have been drawn. Once the labs have been drawn, you may take your medications and go to the cafeteria for breakfast.

You will then go to have your chest xray and pulmonary function test, and then report back to clinic for your doctor visit.

Please be prepared to spend all morning in the Transplant Center. You may want to bring reading material or another quiet activity to help pass the time.

We will call you between 4 and 6 p.m. on the day of your clinic appointment if any changes need to be made in your medications. We must be able to contact you or leave a message so please know how to retrieve messages on your answering machine or cell phone.

You must notify the transplant team if your phone numbers change so that we may
Protecting your new lung(s)

Wear your mask
It is important to wear a mask. This is critical immediately after lung transplantation.
• You should wear a mask everywhere outside of your home for the first three months after your surgery.
• If you are treated for rejection, you may be asked to start wearing your mask again.

Incision care
Once you are feeling strong enough, you will be allowed to shower.
• Use soap and water and wash right over the wound and staples.
• After you shower, replace the dressings that cover any open wounds.
• The incision may itch, feel numb, and be bruised and/or sore.
• Staples are generally removed in clinic two to three weeks after your surgery.

Handwashing
Frequent handwashing by you and your family is the most effective way to prevent infection. Use antibacterial soap or alcohol-based hand sanitizer.

Plants and yardwork
Avoid live plants and do not touch the soil for three months after your transplant. Houseplants do not have to be removed from your home, but they should not be in your immediate living or sleeping areas.
• After three months, you must wear gloves and a mask when disturbing the soil.
• Mowing grass, including riding lawnmowers and using a weed eater, is not recommended until six months after transplant.

Sexual activity
Once you feel strong enough, you may resume sexual activity.
• Be careful not to become pregnant or cause someone else to become pregnant following your transplant. The effects of anti-rejection medications on fetuses are still unknown.
• It is important to always practice safe sex to avoid the risk of sexually transmitted diseases.
Eat a healthy, low-fat diet with lots of fruits and vegetables. You may eat fresh fruits and vegetables, but be sure to wash all produce thoroughly. Do not eat raw fish. All meats should be cooked to a minimum of medium well. Avoid grapefruit and grapefruit juice completely.

**Weight gain** is a very common problem after transplantation.
- This is usually the result of increased appetite from steroid medications.
- Eliminating nearly all fat or fatty and fried foods from your regular meals will help control this problem as well as your cholesterol.
- You may need to see a dietary specialist if weight gain becomes severe.

**Weight loss** is also common after transplant. Some people experience a loss of appetite.
- Medications and general weakness may cause loss of appetite.
- Eating five or six small meals daily rather than three large meals is often helpful.
- You may need to see a dietary specialist if weight loss becomes severe.

**Special diets** are usually not needed after transplant.
- Occasionally, patients have problems controlling their blood sugar due to steroid medications. The transplant team will review any special dietary changes that you may need to make.
Caregiver responsibilities

You must have at least one caregiver to assist you post-transplantation. The caregiver(s) must:

• Be present at the hospital prior to the patient’s discharge. The transplant nurse coordinators will provide education to the patient and the caregiver.
• Stay with the transplant patient 24 hours a day, seven days a week for four to six weeks after surgery. If the patient lives more than an hour away from the Transplant Center, the patient and caregiver must stay in Lexington during this time.
• Provide transportation to the Transplant Clinic three times a week and as needed.
• Perform general errands such as grocery shopping, picking up medicine from the pharmacy, doing laundry, transportation to the clinic for unscheduled appointments, emergency department visits and anything else that is needed.
• Ensure that the transplant patient takes all medications as prescribed, including insulin injections if needed.
• Check and record patient’s blood pressure, blood glucose levels as needed, temperature and weight daily.
• Assist with meal preparation, bathing, dressing and wound care, if needed.
• Encourage the patient to drink fluids and eat healthfully to avoid dehydration.
• Encourage and assist the patient with minimal daily exercise.
• Make sure the patient wears his/her mask.
• Notify the transplant team in case of emergency.

Erma Tirey

Received a bilateral lung transplant January 7, 2013 due to Idiopathic Pulmonary Fibrosis and she subsequently received a right lung transplant February 6, 2013.
Do’s and Don’ts

**Things you must do**
- Wear your mask!
- Take your medications as directed.
- Take and record your blood pressure four times a day.
- Take and record your temperature every morning and every night.
- Weigh yourself every morning and record the results.
- Check your blood sugar as directed.
- Drink 2-3 liters of fluid every day.
- Use an incentive spirometer or flow meter every four hours.
- Walk at least every four hours.
- Continue to abstain from alcohol, cigarettes and all illegal drugs.
- Keep all of your appointments.
- Wash your hands often!
- Stay involved with your care – ask questions and keep notes.

**Things to avoid**
- Do not drive until your physician says it is okay.
- Avoid direct sunlight. Wear long sleeves, a hat and sunblock with at least SPF 25.
- Avoid swimming in public pools, lakes, rivers or oceans for at least six months.
- Avoid anyone who has had a live vaccination for a minimum of two weeks after that person received the vaccine.
- Avoid climbing multiple steps (more than two) until directed otherwise.
- Avoid large crowds of people for three months.
- Avoid being around others with colds, fevers, sore throats, etc.
- Do not lift anything heavier than a gallon of milk until otherwise instructed.
- Do not take any over-the-counter medication without approval.
- Do not adjust or change your medications unless instructed to do so.
- Avoid using hair color or permanents for three months.
- Avoid strong chemicals and toxic fumes for three months.
Physical activity
Be patient with yourself. Regain your strength through a gentle, gradual increase in the amount of physical activity you do each day.
• For the first month, do not lift anything heavier than a gallon of milk.
• Begin increasing your activity level by walking.
• Contact sports such as boxing, martial arts, football and hockey are not recommended.

Dental care
It is important to practice good oral hygiene.
• You should see your dentist approximately every six months.
• For patients on immunosuppressive medications, some routine dental infections can become quite serious if the treatment is delayed.
• When you receive dental work of any kind you will require a short course of oral antibiotics.
• Your dentist will arrange for antibiotic therapy prior to dental work according to the American Heart Association guidelines.

Immunizations
The standing rule is that all patients must be given ONLY killed-virus immunizations (shots). Under NO circumstances should live or weakened virus vaccines such as mumps, measles, rubella, chicken pox, shingles or oral polio be given.
• It is okay to get a flu shot once you are six months post-transplant.
• Family members do not have to wait six months and should get a flu shot immediately.
• You and your family must avoid the nasal flu vaccine.

Alcoholic beverages
Alcohol is a toxin. Alcohol can harm your transplant and should be avoided.
• People who choose to return to drinking alcohol after surgery will NOT be considered for a second transplant if needed.

Smoking
• The blood vessels in transplanted organs have a faster rate of hardening. Smoking and other tobacco use further increases this process.
• Nicotine found in all tobacco products causes spasms of arteries in the body.
• Chewing tobacco is also a known source of oral cancer.
• All forms of tobacco should be avoided. If you test positive for nicotine, you will be considered non-compliant.
• The transplant team is in the office Monday through Friday 8 a.m. – 5 p.m.
• Call your coordinator with any questions that are not emergencies.
• You will be directed to leave a voicemail when your nurse is unavailable. Expect this to happen frequently. Leave a message and your call will be returned as soon as possible.

Prescriptions
It is your responsibility to notify the transplant team 7-10 days prior to running out of medications.
• Many insurance companies need to have preauthorization. Requests must be made to your coordinator during regular business hours.
• Prescription refills are never an emergency, and the pager should not be used.

For Emergencies
Contact the 24-hour UK Answering Service. Follow these steps:
UK Answering Service: 859-257-2211
1. From your home phone, dial 859-257-2211. You do not need to dial the area code if you are calling from Lexington.
2. Your call will be answered by a UK operator. Inform the operator that you need to speak with the on call lung transplant nurse coordinator.

Contact us immediately for the following:
• Temperature greater than 100.5˚ F.
• Systolic (top number) of blood pressure greater than 160 or less than 100.
• Diastolic (bottom number) of blood pressure greater than 100.
• Significantly increased or new drainage from your wound.
• Vomiting, diarrhea or constipation lasting more than two days.
• Pain that is not relieved by your pain medicine.
• Bright red blood in your urine or stool.
• New onset of weakness.
• Decrease in peak flow over two days.
• Change in sputum color to yellow or green, or if blood in sputum
• Shortness of breath

DO NOT use the emergency contact for nonemergency questions. Please direct nonemergency-related questions to your transplant nurse coordinator during normal business hours. The transplant nurse coordinators will return your routine calls within 24 hours or during the next business day.
Most patients do well after transplantation, however, some can develop complications resulting in long hospital stays and even death. Possible complications include:

**Primary nonfunction** A serious, rare condition in which the transplanted organ did not start working immediately after surgery. It can be caused by multiple factors.

**Bleeding** As with any surgery, there is a risk of bleeding. It is possible that after surgery bleeding may still occur and you may have to return to the operating room.

**Rejection** This term is used to describe how your body responds to anything it recognizes as “foreign.” Your body will not recognize the new organ as being part of you. Anti-rejection medication will help your body accept the new organ. Rejection is the easiest problem to treat and can happen any time after your transplant.
- Rejection has no symptoms, although some patients experience shortness of breath and fatigue.
- Lab tests and pulmonary function tests will become abnormal. If this occurs, you may need a biopsy.
- You may need to be admitted to the hospital for treatment.
- When you are discharged, you may have medication changes and require more frequent follow-up — labs and clinic visits, etc.

**Infections** Anti-rejection medication reduces your body’s ability to fight infections, so you should stay away from people who have colds, flu or any other contagious illnesses.
- **Viral** – Two common viral infections are cytomegalovirus (CMV) and the epstein barr virus (HBV). Most people have been exposed to these viruses during normal daily activities. With anti-rejection medication the viruses can become reactivated and cause significant illnesses that may require treatment. Medicine is available to treat these infections. If the infection is severe, you may require a period of hospitalization to receive this medicine intravenously.
- **Bacterial** – Wound infections can occur after transplantation. These will most often require antibiotics. Occasionally, they may require additional operations.
- **Fungal** – Fungal and yeast infections may occur. Medicine and good hygiene will help prevent infections. Fungal infections of the lungs can be very serious and may be contracted by inhaling dust or mold.

**Poor nutrition** from the inability to eat.

**Kidney dysfunction** and failure requiring dialysis.

**Neurological side effects** that can vary from mild confusion to seizures and stroke.

**Blood supply** to your new organ may become compromised after surgery, requiring an additional operation.

**Mood changes** (depression, crying spells, irritability, difficulty sleeping, night sweats or memory loss). Your caregiver and transplant team will help you through this difficult period. Please let your transplant team know if you have been experiencing any of these issues for more than a week.
Taking your medications correctly is the most important thing you can do to prevent rejection of your lung(s) transplant. Never skip a dose or change your dose unless you are instructed to do so. Here are some general medication rules for lung transplant patients:

- Always contact the transplant team before starting any new medications, whether over-the-counter or prescription.
- Store all medications at room temperature unless otherwise indicated on the medication container.
- Do not store medication in the bathroom medicine cabinet. Always keep medications in their prescription bottles or your weekly pill box.
- Please protect these medications from children.
- When flying, keep your medications in your carry-on. Airline regulations require you to keep all medication in the original pill bottles or they will be thrown away.
- Make taking your medications a part of your daily routine, just like eating and sleeping.
- While you are in the hospital, the transplant pharmacist and nurse coordinator will teach you about your medications.
- Always bring your pill bottles, medication list and/or journal to every clinic visit.

**Medication resources**

Abbott, the makers of Gengraf®
www.abbott.com

Astellas, the makers of Prograf®
www.us.astellas.com
www.prograf.com

Novartis, the makers of Neoral® and Myfortic®
www.novartis.com
www.myfortic.com

Genetech, the makers of Cellcept and Valcyte
www.cellcept.com
www.valcyte.com

RxAssist, patient assistance program
www.rxassist.org

Rx Outreach, patient assistance program
www.rxoutreach.com

Pfizer, the makers of Rapamune
www.rapamune.com

Partnership for Prescription Assistance
www.pparx.org

Transplant Experience
www.transplantexperience.com

MyMedSchedule
www.mymedschedule.com

See page 12 for more information.
Received a left single lung transplant January 9, 2013 due to Pulmonary Hypertension.

Teresa King
Medications

**Tacrolimus (Prograf®)**
Type of drug: Anti-rejection
How often to take: Every 12 hours

**Possible side effects**
- Decrease in kidney function: We will closely check your kidney function by lab tests. Keeping to the correct dose will minimize the risk.
- Tremor of hands: This usually stops as the dosage is reduced. A new onset of tremor may indicate the level is too high.
- Increased blood pressure: We will use medications to keep your blood pressure under control.
- Headache.
- Increased blood sugar: We will closely check your blood sugar with lab tests.
- Flushing of the skin.

**What to do if you miss a dose**
If you remember the missed dose within six hours, go ahead and take it. If you remember the dose after six hours, do NOT try to make up for the missed dose. Take your next dose at the regular time and get back on schedule. Never take a double dose.

**Prednisone**
Type of drug: Anti-rejection, steroid
How often to take: Once a day in the morning

**Possible side effects**
- Sodium (salt) and water retention: Because of this, your ankles may become puffy.
- Stomach ulcers: Always take the medicine with food. You will be started on a medication to prevent ulcers until your dose is decreased.
- Weight gain: This may be from extra fluid or from your body storing extra fat. “Moon face,” gaining weight in your face, is a common side effect of steroid treatment. This is usually reduced as your steroid dose is lowered.
- Increased appetite: You may have to “push yourself away from the table” to avoid weight gain.
- Muscle weakness: Be careful getting out of chairs and climbing stairs until you regain your strength. Continue to walk and exercise to maintain your strength.
- Blurred vision: This improves as your steroid dose is reduced. Do not get new glasses immediately after your transplant, as your vision will change over the next six months. You may also develop cataracts. Have your eyes examined regularly by an ophthalmologist.
- Difficulty sleeping.
- Slow wound healing.
- Mood swings: You may feel happy one minute and depressed the next. You should feel like your normal self again when your steroid dose is reduced.
- Increased risk for infection.
- High blood sugar: Any signs of high blood sugar such as
increased thirst or tiredness should be reported to your doctor. You may need to start on insulin if your blood sugar remains high.

- Osteoporosis or low bone density: This medication can make your bones brittle. We will be monitoring this every year after your transplant. You may need to start taking a medication to help treat osteoporosis.

**What to do if you miss a dose**

Take the missed dose as soon as you remember if it is within 12 hours from the time you should have taken it. If it is more than 12 hours past your regular time to take it, then skip the missed dose. Never take a double dose. Do not stop this medication suddenly without approval from the transplant team.

**Sulfamethoxazole/Trimethoprim (Bactrim, Septra, Cotrim)**

Type of drug: Antibiotic (to prevent infection)

How often to take: Once a day in the morning

**Possible side effects**

- Nausea, vomiting, abdominal cramping or diarrhea: If these side effects occur, take the medication with food.
- Skin rash or itching: If these side effects occur, contact your physician immediately.
- Light sensitivity: Always wear sunscreen when outdoors.

**What to do if you miss a dose**

Take the missed dose as soon as you remember, if it is within 12 hours from the time you should have taken it. If it is more than 12 hours past your regular time to take it, then skip the missed dose. Never take a double dose. If you are allergic to sulfa drugs, we will use another drug called dapsone.

**Valganciclovir (Valcyte)**

Type of drug: Anti-viral drug (to prevent viral infections)

How often to take: Two times a day

**Possible side effects**

- Decreased blood counts: We will follow your labs closely and adjust this medication as needed.
- Nausea: If nausea occurs, take your dose with a meal or snack.
- Tremors and neurological side effects: Let us know if you develop tremors or confusion. The dose may need to be reduced or the drug stopped.

**What to do if you miss a dose**

Resume taking the medication with the next scheduled dose. Do not take a double dose.

**Voriconazole (Vfend)**

Type of drug: Anti-fungal (to prevent fungal infection)

How often to take: Twice a day in the morning

**Possible side effects**

- Upset stomach.
- Altered sense of taste.
- Headache.
- Dizziness.

**What to do if you miss a dose**

Take the missed dose as soon as you remember, if it is within 12 hours from the time you should have taken it. If it is more than 12 hours past your regular time to take it, then skip the missed dose. Never take a double dose.

**Docusate (Doss)**

Type of drug: Stool softener

How to take: Two times a day as needed

**Possible side effects**

- Upset stomach.
- Cramping.
- Diarrhea: If you have diarrhea, do not take.

**Pain medication**

Pain medications will be prescribed for a short while after transplant. If you were taking pain medications for chronic pain before transplant, contact your local physician for new prescriptions to continue these medications. The transplant team will prescribe pain medications related to the transplant surgery only.

**Other medications**

Other medications may be prescribed for you after your transplant. Common drugs include antibiotics, blood pressure medication and insulin. However, not all patients will need these medications.

**Disclaimer**

This is not an all-inclusive list of medications and side effects. This information is to be used only as a guide and is not considered a formal drug reference. Please contact the Transplant Center for more information.
ATM
There is an ATM located on the first floor of Pavilion H, near the Registration Desk. Another ATM is located near the elevators on the ground floor and in the emergency room of Pavilion A.

Buses
Lextran bus schedules are available at the Information Desks. Taxi cab service is available by calling 859-231-8294.

Calling cards
Calling cards are available for purchase in the gift shops.

Dining Options
Hospital cafeteria  The cafeteria is located on the first floor of Pavilion H. It is open daily from 6:30 a.m. to 11 p.m.

Coffee Shop  The Coffee Shop is located on the first floor of Pavilion H, just inside the main entrance. Call 859-323-5000 for hours of operation.

Courtyard Café  The Courtyard Café is located on the ground floor of Pavilion A, near the auditorium. It is open Monday – Friday, 7 a.m. – 3 p.m.

Terrace Café  This kiosk is located on the first floor of Pavilion A. Call 859-323-5000 for hours of operation.

Vending area  The vending area is located on the first floor in Pavilion H, near the cafeteria. It is open daily, 24 hours.

Don and Cathy Jacobs Health Education Center
This resource center is open to visitors and family members. It offers health information as well as Internet and fax machine access for patient families. Located on the first floor of Pavilion A, the center is open Monday – Friday, 9 a.m. – 4:30 p.m. For information, please call 859-323-7808.

Gift shops
Our gift shops sell various personal care items, reading materials, candy and gifts. One gift shop is located in the Pavilion H lobby, across from the Information Desk. A second gift shop is located on the first floor of Pavilion A. Both are open Monday – Saturday, 10 a.m. – 6 p.m. and Sunday, 1-5 p.m.

Mail
A post office is located on the ground floor of Pavilion H in Room M63. It is open Monday – Friday, 8 a.m. – 4:30 p.m. Mail slots are located at the main elevator on each floor.

Newspapers
Newspapers can be purchased from a vending machine located beside the ATM near the Registration Desk in Pavilion H.

Parking
You can park in the Hospital Parking Garage located on South Limestone between Conn Terrace and Transcript Avenue. Enter the garage from Transcript Avenue.

Free shuttle service from the garage provides door-to-door service to the hospital. Shuttles depart from Level A of the garage every three to five minutes. An ambassador is stationed in the parking garage from 6 a.m. to 11 p.m. daily to answer questions and help patients and visitors onto the shuttles, which are wheelchair accessible. Passengers who have difficulty walking may be dropped off in the passenger dropoff and pickup areas located on each floor of the garage near the elevators. The Transplant Clinic is located in Pavilion H, which is the second shuttle stop.

In lieu of the shuttle, you may walk across the concourse bridge, located on Level C of the Hospital Parking Garage. On the concourse bridge, golf carts are available for those who find the walk difficult.
Received a bilateral lung transplant January 15, 2012 due to Coal Workers Pneumoconiosis (Black Lung).

Pastoral services
A chaplain is available 24 hours a day, seven days a week. The chaplain can be contacted at 859-323-5301.

A sanctuary is located on the first floor of Pavilion H in room H-122. In Pavilion A, the nondenominational Myra Leigh Tobin Chapel is conveniently located on the ground floor.

Showers and laundry
Located on the fifth floor of Pavilion H in the South Wing. As a courtesy to patients and staff, please do not use the showers after 9 p.m.

Tobacco free
The UK HealthCare campus is tobacco free. Nicotine replacement products may be purchased in the gift shops.
Contact Information

University of Kentucky Transplant Center
UK Chandler Hospital, Pavilion H
800 Rose Street
Lexington KY 40536-0293
Toll-free: 888-808-3212
Local: 859-323-8500
Fax: 859-257-3644
Website: ukhealthcare.uky.edu/transplant

Patient/Lab Appointment Line
859-323-1691

Transplant Surgeons
Charles Hoopes, MD, Director, Transplant Center;
Jason Alexander Gill Professor of Cardiothoracic Surgery
Roh Yanagida, MD, Assistant Professor of Surgery

Transplant Pulmonologists
Harish Seethamraju, MD, Medical Director, Transplant Center
Micahel Anstead, MD, Associate Professor of Pediatrics
John McConnell, MD

Transplant Advanced Practice Providers
Kristyn Gordon, ARNP

Transplant Nurse Coordinators
Julie Leigh, RN, CCTC
859-323-1704
jaleig2@email.uky.edu
Belinda Conner, RN, CCTC
859-323-5058
bconn2@email.uky.edu
Dawn Wilson, RN
awilson12@uky.edu
Alicia Alvarado, RN, BSN
859-323-3821
alicia.alvarado@uky.edu
Transplant Scheduling Coordinators
Jennifer Whittaker

Jill Marion
jill.marion@uky.edu

Transplant Social Workers
Summer Davies, MSW
859-323-2557
sdbert2@email.uky.edu

Transplant Clinical Pharmacists
Ann Fugit, PharmD, BCPS
859-218-1249
ann.fugit@uky.edu

Transplant Dietitian
Leslie Eble, RD
859-323-6987
leble2@email.uky.edu

Transplant Financial Counselor
Kim Million
859-323-5002
kayo223@email.uky.edu

Frequently Called Numbers
All numbers below are local to Lexington. If the number begins with the prefix 323- or 257-, you only need to dial the last five digits if you are calling from within the UK HealthCare system. Otherwise, if you are using a UK HealthCare phone to call out, dial 9 + the seven digit number.

Kentucky Clinic Pharmacy 323-5855
UK Chandler Hospital Information 323-5000
Gift Shop 257-1559
Chaplain Services 323-5301
Customer Services/Patient Representative 257-2178
Health Education Center 323-7808
Hospital Security 323-6152
Housekeeping 323-5133
Medical Records 323-5117
Parking 257-5757
Patient Accounts 257-8111
Post Office 257-6360
Wildcat Taxi Service 231-8294
Extended Stay America (local hotel) 278-9600
Lextran Bus Service 255-7756
UK Chandler Emergency Department 323-5901

Local Housing
Extended Stay America 271-6160
MicroTel 299-9600
Red Roof Inn 277-9400
Super 8 299-6241
University Inn 278-6625
CONTACT US
859-323-4620  |  24 hours a day/7 days a week
859-330-2484  |  24 hours a day/7 days a week
800-456-5287  |  Monday – Friday, 8 a.m. – 4 p.m.