

POST-OP LUNG TRANSPLANT PATIENT GUIDE



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INTRODUCTION

Thank you for choosing the UK Transplant Center as your medical provider and congratulations on your transplant! We understand the challenges of recovering after a lung transplant, so we will do our best to help you return to good health.

Read this guide carefully. We hope it will help you prepare for your life at home after your transplant, but your health care team will work with you to decide your specific plan of care.

If you still have questions, please ask. Our doctors, nurses and staff members are happy to help.



TRANSPLANT CLINIC VISITS

Location

The Transplant Center is on the third floor, Wing D, of the Kentucky Clinic.

Your schedule

You will have regular clinic visits for the next three years. Your appointment time will be the time you are scheduled to see your doctor, but you will need to arrive one to two hours earlier in order to complete your testing. Testing includes blood draws, chest X-rays and lung function tests.

Your appointment schedule will look like this:

- You will have one to two visits each week during the first four weeks after you return home from surgery.
- For one to two months after that, you will have one to two visits every other week.
- For the rest of your first year after transplant, you will have a visit once a month.
- Visits will then be every other month in the second year after your transplant.
- In the third year after your transplant, visits will be every three months.
- Your labs will be done halfway between each clinic visit after the first year.
- You will have bronchoscopies and biopsies after one, three, six, 12, 18, and 24 months, and as needed to check for rejection.

- Before each bronchoscopy and biopsy, you will need a lung function test. Depending on the scheduled time of the procedure, we may do this the day before.

Medicines

Always bring your medicine journal to the clinic. On the day of your visit, do not take any medicines until after we draw your labs.

What to expect during your appointment

Once we draw your labs, you can take your medicines. You will then have a chest X-ray and lung function test. After that, you will return to the clinic to see your doctor.

We recommend bringing something to read or another quiet activity to help pass the time while you wait.

After your visit

We will call you once your doctor reviews your lab results. **We will only call you if there are any changes to be made.**

- We must be able to contact you or leave a message. Make sure you know how to receive messages on your cellphone or answering machine.
- Tell your transplant team if your phone numbers change.

PROTECTING YOUR NEW LUNG(S)

Wear your mask

After your lung transplant, you will be at a higher risk of infection, so it's important to wear a mask.

- For three months after transplant, wear a mask if you are in crowds. However, crowds should be avoided, if possible.
- If you are treated for rejection, you may need to start wearing your mask again.
- Wear your mask to and from the transplant clinic. There is often construction in or near the hospital.
- Avoid construction sites, yard work or anything that stirs up dirt or debris. This will reduce your risk of pneumonia from breathing in fungus.

Incision care

Once you are strong enough, you can take showers.

- Use soap and water. Wash right over the wound and staples.
- The incision may itch, feel numb or sore, and be red or bruised.
- In most cases, we remove staples or sutures in the clinic two to three weeks after surgery.

Wash your hands often

This is the best way for you and your family to prevent infection. Use antibacterial soap or alcohol-based hand sanitizer.

Yard work and plants

You should not mow grass after transplant. This will reduce your risk of pneumonia from breathing in fungus.

Additionally, be sure to follow these guidelines:

- Avoid live plants.
- Do not touch soil after your transplant.
- You do not have to remove plants from your home, but do not have them in your living or sleeping areas.

Sexual activity

Once you feel strong enough, you may resume sexual activity.

- Take care to not become pregnant or cause someone else to become pregnant. The effects of most antirejection medicines on fetuses are still unknown. Cellcept and Myfortic are harmful and may cause birth defects.
- Always practice safe sex to avoid the risk of sexually transmitted diseases.



NUTRITION

Healthy eating

Eat a healthy, low-fat diet with lots of fruits and vegetables.

- Wash fresh fruits and vegetables well before eating.
- Do not eat raw fish. All meats should be cooked to a minimum of medium-well.
- Avoid all grapefruit and grapefruit juice as they may interfere with your antirejection medications.

Weight gain

It is common to gain weight after your transplant. Often, this is because the steroid medicines you're taking will cause you to eat more.

- To control your weight, eat fewer calories and avoid fried foods and carbohydrates.
- You may need to see a dietary specialist if you keep gaining weight.
- Once your team tells you it is OK, you may begin an exercise program.

Weight loss

Weight loss is also common after transplant, especially during the first six weeks. Some people have a loss of appetite caused by medicines and by feeling weak. To prevent weight loss:

- Eat five to six small meals a day, rather than three large meals.
- See a dietary specialist if you keep losing weight.

Special diets

Most patients don't need a special diet after transplant, but some patients have difficulty controlling their blood sugar when taking steroids. Your transplant team will let you know if you need to make any changes to your diet.

CAREGIVER RESPONSIBILITIES

You must have at least one caregiver who is prepared to help you after transplant. Here's what your caregiver must do:

Patient care

- Come to the hospital before you go home. Your nurse coordinator and bedside nurse will teach you both about your care.
- Stay with you 24 hours a day, seven days a week for four to six weeks after transplant. If you live more than an hour from the Transplant Center, you and your caregiver must stay in Lexington during this time.
- Call your transplant coordinator if there is an emergency or if your temperature is more than 100 degrees. If this occurs after hours or on weekends, call the transplant coordinator on-call at 859-257-2211.
- Make sure you take all medicines as ordered. If you need insulin, your caregiver will help with your shots.
- Check and record your health information each day. This includes your blood pressure, blood sugar levels as needed, temperature and weight.
- Drive you to your clinic visits.

Everyday tasks

- Run necessary errands. This includes grocery shopping, going to the pharmacy and doing laundry.
- If needed, help with bathing, dressing and wound care.
- Help cook meals.
- Encourage you to drink fluids and eat healthy.
- Encourage and help you exercise daily.

DOS AND DON'TS OF LUNG TRANSPLANT

Protect your health

- Wear your mask when appropriate.
- Wash your hands often.
- Take your medicines as ordered.
- Spirocheck three times a day. Record the best of the three.

Know your numbers

- Take and record your blood pressure at least once a day.
- Take and record your temperature every morning and every night. Call your transplant nurse coordinator if it's 100 degrees or greater.
- Weigh yourself every morning and record the results.
- Check your blood sugar as ordered.

Be active in your care

- Keep all of your doctor's appointments.
- Ask questions and keep notes.
- Always ask your coordinator before you start taking a new medicine.

Think of your finances

Consider fundraising to help pay for your expenses, as a transplant is expensive. You have to pay for travel, medicines, hospital stays and more. Depending on your financial situation, fundraising

might be an option for you. Talk to your transplant coordinator for more information.

Avoid these activities

- Do not use cigarettes or illegal drugs.
- Do not drive until your doctor says it is OK. This is usually 60 days after transplant.
- Do not lift anything heavier than a gallon of milk until your doctor says it is OK.

Avoid these situations

- Avoid direct sunlight. Wear long sleeves, a hat and sunblock with at least SPF 25.
- Avoid large crowds of people without your mask for the first three months after transplant.
- Avoid anyone with an illness you could catch. This includes colds, fevers and sore throats.
- Avoid anyone who has had an oral polio vaccine for at least two weeks after that person got the vaccine.

Avoid these medicine mistakes

- Do not take any over-the-counter medicine without your doctor's approval.
- Do not adjust or change your medicines unless your doctor tells you to.
- Follow your lung transplant team's instructions rather than the labels on your pill bottle.



GUIDELINES FOR LIVING WITH YOUR NEW ORGAN

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 after your transplant, do not lift anything heavier than a gallon of milk.
- Begin increasing your activity level by walking.
- Avoid contact sports, such as contact boxing, martial arts, football and hockey.

Health maintenance

Regular health maintenance is important to staying healthy.

- You must get a routine colonoscopy as recommended by your primary care physician.
- For women, get Pap smears and mammograms as recommended by your primary care physician.

Dental care

Good oral hygiene is also vital, especially following your transplant.

- Visit your dentist about every six months.
- Get any infection treated right away.
- If you require any dental work, you may need to have a short course of oral antibiotics. Routine cleanings and exams do not require any special medications.
- Your dentist will arrange for antibiotic therapy before dental work and follow American Heart Association guidelines.

Immunizations

You may only get killed-virus immunizations (shots). You must not get any live or weakened virus vaccine, such as mumps, measles, rubella, chicken pox, shingles and oral polio.

- You may get the flu shot six months after your transplant.
- Family members should also get a flu shot.
- You and your family must avoid the nasal flu vaccine.

POSSIBLE COMPLICATIONS

Most patients do well after their lung transplant, but some may experience complications. These can lead to long hospital stays and additional follow-up care.

Here are some possible complications:

- **Primary lung nonfunction:** This occurs when your new lung does not start working right after transplant. This is a serious condition, but it is rare.
- **Bleeding:** In any surgery, there is a risk of bleeding. If this occurs, you may have to return to the operating room.
- **Rejection:** Rejection refers to how your body responds to anything it thinks is foreign, including your new organ. Your body will not think the new organ is a part of you and will try to reject it. Antirejection medicine will help your body accept the new organ, but rejection can happen any time after your transplant. If rejection occurs, it is often an easy problem to treat.

Rejection may have no symptoms, but some signs of rejection include:

- o Shortness of breath
- o Cough
- o Same symptoms as a cold

The medicines you take to prevent rejection are called immunosuppressants. Breathing tests will become abnormal if you are experiencing rejection. If this happens, you may need a biopsy to test for rejection. You may be admitted to the hospital for treatment if rejection is suspected.

When you go home, you may have medicine changes. You may also need to have labs and clinic visits more often.

- **Infections:** Antirejection medicine makes it harder for your body to fight infections. It's very important to avoid people who have an illness you could catch. This includes colds and the flu. Common infection types include:
 - o **Viral:** Most people have been exposed to viral infections during daily life, and antirejection medicines may activate them. This can be a serious problem that needs treatment. Medicine can usually treat these infections. If the infection is severe, you may need to go to the hospital for IV medicines.
 - o **Bacterial:** This is the most common cause of pneumonia after transplant.
 - o **Fungal:** Fungal and yeast infections may occur, but taking your medicine and practicing good hygiene will help prevent them. Fungal infections can be very serious if they occur in the lungs. This may happen if you breathe in dust or mold.
- **Kidney problems:** Antirejection medicines may cause your kidney function to decrease. About 5 percent of patients need dialysis several years after transplant.
- **Mood changes:** You may experience mood changes after your transplant. Examples are depression, crying spells, irritability, difficulty sleeping, night sweats or memory loss. This is often caused by your antirejection medications (Prograf and prednisone). Let us know if you have any of these issues for more than a week.



CONTACTING YOUR TRANSPLANT TEAM

For emergencies, weekends, holidays and after hours

Call the 24-hour UK Answering Service at 859-257-2211. Follow these steps:

- You or your family will call the number above. You do not need to dial the area code if you are calling from Lexington.
- A UK HealthCare operator will answer. Tell the operator that you need to speak with the on-call lung transplant nurse coordinator. Do not use the emergency contact for non-emergency questions.

For non-emergencies

Call your nurse coordinator. The team's office hours are Monday-Friday, 8 a.m. to 4 p.m.

- Please note that the nurses see patients in the clinic, so your nurse may not be in the office when you call.
- If your nurse coordinator does not answer, leave a message and your call will be returned as soon as possible. This is usually within 24 hours or the next business day.

My main nurse coordinator is:

For prescriptions

Please tell your coordinator seven to 10 days before you run out of medicines.

- Many insurance companies need to have preauthorization.
- Make these requests during regular business hours.
- Try to avoid running out of medications.

Call the emergency contact right away if you have any of the following:

- Temperature greater than 100 degrees.
- Systolic (top number) blood pressure greater than 180 or less than 100.
- Vomiting, diarrhea or constipation lasting more than two days.
- Pain that is not helped by your pain medicine.
- Lower FEV-1 for two days.
- Shortness of breath.
- Cough or sore throat.

(Affix coordinator business card/contact information here.)

MEDICINE REMINDERS

You must take your medicines as directed by your care team. This is the most important thing you can do to protect your new lung. Never skip a dose or change your dose unless your doctor orders it.

Here are some general rules for taking your transplant medicines:

- Always call your transplant team before you start taking a new medicine. This includes medicines ordered by another doctor.
- Store all medicines at room temperature, unless the instructions on the medicine container say otherwise.
- Keep medicines in their prescription bottles or your pillbox.
- Make sure children cannot get to your medicine.
- When flying, keep your medicines in your carry-on. Laws say you must keep all medicine in the original pill bottles. If not, they will be thrown away.

- Make taking your medicines part of your daily routine.
- While you are in the hospital, the transplant pharmacist will teach you about your medicines.
- Always bring your pill bottles or medicine list and journal to every clinic visit.

Online medicine resources

- Abbott, the makers of Gengraf®: abbott.com
- Astellas, the makers of Prograf®: us.astellas.com; prograf.com
- Novartis, the makers of Neoral® and Myfortic®: novartis.com; myfortic.com
- Genetech, the makers of Cellcept and Valcyte: cellcept.com; valcyte.com
- RxAssist, patient assistance program: rxassist.org
- Rx Outreach, patient assistance program: rxoutreach.com
- Pfizer, the makers of Rapamune: rapamune.com



- Partnership for Prescription Assistance: pparx.org
- Transplant Experience: transplantexperience.com
- MyMedSchedule: mymedschedule.com

Types of medicines

Tacrolimus (Prograf)

Type of drug: Antirejection

How often to take: Every 12 hours

Possible side effects:

- Decreased kidney function: We will closely check your kidney function through lab tests. Take the correct dose to 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.

- High 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 it within six hours, go ahead and take it. If you remember after six hours, do not make up for the missed dose. Take your next dose at the regular time and get back on schedule. Never take a double dose. If you miss two or more doses, call your transplant nurse coordinator.

If your body cannot take tacrolimus, we may replace it with cyclosporine (Neoral® or Gengraf®).

Do not eat grapefruit or drink grapefruit juice while taking this medicine.

Mycophenolate Mofetil (Cellcept)

Type of drug: Antirejection



How often to take: Every 12 hours

Possible side effects:

- Decreased blood counts: We will follow your labs closely and adjust this medicine as needed.
- Dizziness or drowsiness.
- Nausea, vomiting or diarrhea.
- Insomnia.
- Mood changes.

What to do if you miss a dose: If you remember it within six hours, go ahead and take it. If you remember after six hours, do not 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: Antirejection, steroid

How often to take: Once a day in the morning

Possible side effects:

- Salt and water retention: This may make your ankles puffy.
- Stomach ulcers: Always take this medicine with food. You will take medicine to prevent ulcers until we reduce your dose.
- Weight gain: This may be from storing extra fluid or extra fat. A common problem is “moon face.” Weight gain in the face is common problem with steroids. This improves as your steroid dose is lower.
- Increased appetite: You may have to “push yourself away from the table” to avoid weight gain.
- Muscle weakness: Be careful when you get out of chairs or climb stairs until you get your strength back. Continue to walk and exercise to keep your strength.
- Blurred vision: This improves as your steroid dose is lowered. Do not get new glasses right after your transplant. Your vision will change over the next six months.

- You may also develop cataracts. Have an ophthalmologist check your eyes regularly.
- Sleep problems.
- 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 lower.
- Increased risk for infection.
- High blood sugar: Tell your doctor if you have any sign of high blood sugar, such as increased thirst or tiredness. You may need to start on insulin if your blood sugar stays high.
- Osteoporosis or low bone density: This medicine can make your bones brittle. You should have your family doctor check this every year. You may need to take a medicine to treat osteoporosis.

What to do you if you miss a dose: If you remember it within 12 hours, take it right away. If you remember after 12 hours, do not make up for the missed dose. Take your next dose at the regular time and get back on schedule. Never take a double dose.

Do not stop this medicine unless your transplant team says it is OK.

Most of the time, the dose will be decreased at three months, at six months and at one year, but you will be on this medication for the rest of your life.

Sulfamethoxazole/Trimethoprim

(Bactrim, Septra, Cotrim)

Type of drug: Antibiotic (to prevent infection)

How often to take: Once a day in the morning, usually three times a week on Monday, Wednesday and Friday. You’ll take this for the rest of your life.

Possible side effects:

- Nausea, vomiting, belly cramps or diarrhea: If you have these symptoms, take the medicine with food.

- Skin rash or itching: If you have these symptoms, call your doctor right away.
- Sensitive to light: Always wear sunscreen when outdoors.

What to do you if you miss a dose: If you remember it within 12 hours, take it right away. If you remember after 12 hours, do not make up for the missed dose. Take your next dose at the regular time and get back on schedule. Never take a double dose. If you are allergic to sulfa drugs, we will prescribe either dapsone or an inhaled medication.

Valganciclovir (Valcyte)

Type of drug: Antiviral drug (to prevent viral infections)

How often to take: Once or twice a day

Possible side effects:

- Lower blood counts: We will follow your labs closely and adjust this medicine as needed.
- Nausea: If you feel nauseous, take your dose with a meal or snack.
- Tremors and neurological side effects: Let us know if you have tremors or confusion. You may need to reduce the dose or stop taking it.

What to do you if you miss a dose: Wait for your next scheduled dose and keep taking it as ordered. Do not take a double dose.

Voriconazole (Vfend)

Type of drug: Antifungal drug (to prevent fungal infections)

How often to take: Once a day

Possible side effects:

- Upset stomach.
- Change in sense of taste.
- Headache.
- Dizziness.

What to do you if you miss a dose: If you remember it within 12 hours, take it right away. If you remember after 12 hours, do not make up for the missed dose. Take your next dose at the regular time and get back on schedule. Never take a double dose.

Pain medication

Your doctor will have you take a pain medicine for a short time after transplant. If you were taking pain medicines for chronic pain before transplant, contact your primary care physician for new prescriptions to continue these medicines. Your transplant team will only order pain medicines related to the transplant.

Other medicines

We may order other medicines for you after transplant. Some common drugs include antibiotics, blood pressure medicine and insulin. However, not all patients will need these.

Here are over-the-counter treatments you may take after transplant:

Constipation

- Metamucil.
- Fiber con.
- Docusate sodium.
- Increase fiber and fluid in your diet.

Diarrhea

- Imodium.
- Increase your fluids (Gatorade or Pedialyte) to prevent dehydration.

Headache, muscle ache and pain

- Tylenol.
- Aspirin.
- Do not take ibuprofen, Motrin, Advil, Midol or Aleve. These could damage your kidney when taking immunosuppressants.

Allergy and cold symptoms

- Claritin.
- Zyrtec.
- Flonase.
- Nasonex.
- Corcidin HBP.
- Robitussin.
- Tylenol Cold.
- Do not take medicines with ibuprofen, pseudoephedrine or dextromethorphan (DM).

Indigestion and heartburn

- Pepcid.
- Zantac.
- Tums.
- Roloids.

Sleep aids

- Unisom.
- Benadryl.
- Melatonin.

Vitamin supplements

- Vitamin E 400 IU twice daily.
- Vitamin C 500mg twice daily.
- Multi-vitamin.

Herbal supplements

- Do not take St. John's Wort or any herbal supplement unless your transplant team says it is OK.



HOSPITAL 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 and taxis

Lextran bus schedules are available at the Information Desks. Taxi 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.
- **Courtyard Café:** The Courtyard Café is located on the ground floor of Pavilion A, near the auditorium.

- **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.

Located on the first floor of Pavilion A, the center is open Monday-Friday, 9 a.m. to 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. Visit an information desk for gift shop hours.

Mail

A post office is located on the ground floor of Pavilion H in Room M63. It is open Monday Friday, 8 a.m. to 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

Location: The Hospital Garage on South Limestone between Conn Terrace and Transcript Avenue. Enter the garage from Transcript Avenue.

Parking fee: There is a fee for parking. Please note the rates posted as you enter the garage. Parking is free on weekends and at certain hours of the day. You may buy extended stay parking passes in the parking office. It is on Level A of the Hospital Garage. Once you buy seven-day passes two weeks in a row, parking in the garage is free for the rest of your visit. You may call the parking office at 859-257-1000 or 1-800-333-8874.

Shuttle from garage to hospital: Free shuttle service provides door-to-door service from garage to hospital. Shuttles leave from Level A of the garage every three to five minutes. There is an ambassador in the parking garage. There is an ambassador in the garage during day and evening hours to answer questions and help patients and visitors onto the shuttles, which are wheelchair accessible. Passengers who have a hard time walking may be dropped off in the passenger drop-off and pickup areas. These are on each floor of the garage near the



elevators. The transplant clinic is in the Kentucky Clinic, which is the third shuttle stop.

Walk bridge: Instead of the shuttle, you may take the bridge from Level C of the garage. You may walk or ride a golf cart to the hospital.

Pastoral services

A chaplain is available 24 hours a day, seven days a week. You can call the chaplain at 859-323-5301.

There is a sanctuary 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

These are 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. You may buy nicotine replacement products in the gift shops.





An Equal Opportunity University

Section 1557 of the Affordable Care Act
STATEMENT OF NONDISCRIMINATION
For UK Health Programs and Activities

The University of Kentucky complies with applicable Federal civil rights laws and does not discriminate on the basis of race, color, national origin, age, disability, or sex. The University of Kentucky does not exclude people or treat them differently because of race, color, national origin, age, disability, or sex.

Language assistance services, free of charge, are available to our patients in more than 200 languages. Please let us know if you need an interpreter.

Si usted habla español, tiene a su disposición servicios de asistencia con el idioma sin costo alguno.

如果您使用繁體中文，您可以免費獲得語言援助服務

UK HEALTHCARE TRANSPLANT CENTER
859-323-1691