

CARE AFTER LUNG TRANSPLANT

Follow-Up Appointments and Testing



Clinic Visits

After discharge from the hospital, lung transplant patients will see their surgeon once, about a month after the transplant surgery. Patients will follow up with their transplant pulmonologist every two to three weeks after their hospital stay. After the first several months an individual plan for follow up care will be developed for you. Once a lung transplant patient becomes stable, they will minimally need to follow up with the transplant pulmonologist every three months and as needed.

On the Day of Your Appointment

You will see your transplant pulmonologist and nurse coordinator. A social worker is available to you as needed.

On the morning of your appointment, you may eat and take all your medications except for your Tacrolimus or Cyclosporine until your blood draw is completed. Once your blood specimen is collected, you may take your Tacrolimus or Cyclosporine medication.

What to Bring to Your Clinic Visit

- Your Tacrolimus or Cyclosporine morning medication dose to take after your blood draw
- Pain medication if needed
- A snack
- Your list of medications
- A list of any refills you may need
- A list of questions that you may have
- Your caregiver

Blood Draw, Pulmonary Function Test and Chest X-Ray Check-In Procedure

When you arrive for your follow-up appointment, you will check in at your scheduled clinic area. Any laboratory or chest x-ray orders will be in the electronic MIChart system. The clinic staff can help direct you to the chest x-ray and laboratory areas to have the ordered testing.

Blood Medication Trough Levels

A trough level is the measurement of the drug level in the blood at the time when it is the lowest. It happens just before the next dose is due. Trough levels should be within one hour of when your medication is to be taken.

When to Go to the Emergency Department

- A major change in your breathing or need for oxygen
- Fever over 101°F
- Nausea and vomiting, unable to keep down your transplant medications
- Severe pain
- Any serious or life-threatening medical condition

Your local emergency department medical staff can contact our lung transplant team any time day or night to discuss your case as needed. Often transfer or admission to a lung transplant center is requested. The local emergency department or treating doctor will need to contact our lung transplant program to arrange for the transfer process.

University of Michigan Emergency Department: 734-936-6666

University of Michigan Pulmonary Fellow on Call (24 hrs. a day): 734-936-6267

Rejection and Infection

The two most common complications after lung transplant are rejection and infection. The signs and symptoms of rejection and infection are very similar. Rejection and infection can also be present without any symptoms. Lifelong follow up and testing, as recommended by our lung transplant center, is essential to carefully monitor for lung transplant complications. You also will have to take lifelong medications to prevent both rejection and infection after lung transplant.

Signs and Symptoms of Rejection or Infection

- Increased shortness of breath – especially with activity (stairs, carrying items)
- Low grade fever 99-100 F
- Fatigue, chills, aches
- Cough
- Chest congestion
- A decrease in lung function testing

Allograft Rejection

Your body will recognize the transplanted lung as a foreign object and the body's normal response will be to try to fight or reject it. After transplant surgery, you will be prescribed immunosuppressive medications to help your immune system prevent rejection. Rejection is very common within the first six months following lung transplant but can occur at any time. Acute rejection can often be treated successfully, especially if the signs of rejection are recognized early.

Rejection is diagnosed by a lung biopsy which is obtained during bronchoscopy. Since rejection is common for the first six months after lung transplant, you will need to have routine surveillance bronchoscopies for the first year after transplant. You will be scheduled for these bronchoscopies which will be performed at the University of Michigan Hospital.

Medications to prevent rejection will need to be taken for life following lung transplant. If you have a rejection episode, a treatment plan typically will be arranged at your home. A visiting nurse will place an IV catheter and administer IV steroids. Typically high dose IV steroids are administered for three days followed by high dose oral steroids (Prednisone) that are gradually reduced. Your immunosuppressant medications will be adjusted and follow up testing for rejection will be ordered. Acute rejection is often reversible.

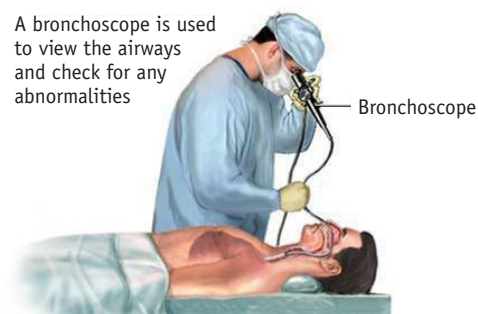
Infection

Immunosuppression medications limit your body's ability to fight infection so you will be at risk for other infections. Many types of infections such as bacterial, viral, and fungal infections can be a problem after lung transplant. Lung transplant patients will need to take anti-infective medications to prevent some common infections after transplant. Cultures to monitor for infections are obtained during bronchoscopy. If an infection is detected, it may be treated with oral, inhaled, or IV medications. If IV treatment is needed, often home IV therapy with a visiting nurse agency will be arranged.

Bronchoscopy

The insertion of a fiberoptic tube through your mouth or nose into your lungs under conscious sedation is termed “fiberoptic bronchoscopy.” This procedure allows the doctor to examine the airways and test for infection and/or rejection. Regular, routine bronchoscopies will be scheduled during the first year after lung transplant to check for rejection and infection. Bronchoscopies are done at three weeks, six weeks, three months, six months, one year and as needed when rejection or infection are suspected.

The lung transplant bronchoscopies will be performed at the University of Michigan. Bronchoscopy is an out-patient procedure. Sedation is given with the procedure so a driver must be with you before the procedure will begin. The bronchoscopy preparation, procedure, and care following the procedure generally take three to four hours.



For your bronchoscopy please:

- Do not eat or drink after midnight before your procedure
- Your nurse coordinator will advise you on how to take your medications the day of the procedure
- Do not take your Insulin before the procedure as you will not be eating
- Have a driver with you when you arrive for the procedure. You will not be able to drive following the procedure, and the driver must be with you before the procedure will be started.

Life After Lung Transplantation

- **Do not smoke** and avoid second hand smoke after lung transplant.
- **Call the transplant clinic if you are not feeling well.** Do not wait for symptoms to get worse. The sooner your transplant team becomes aware of an issue the better.
- Remain within a **four hour range** of Michigan Medicine for a minimum of three months after lung transplant.
- Continue cough and deep breathing exercises and increase your physical activity. These should become easier to do following transplant.
- **Lifting restrictions** – you will have a **10 lb** upper arm lifting limit for at least six weeks after lung transplant. The lifting weight limit will then be increased by your transplant doctor.

- Avoid activities that are hard on the chest such as baseball, bowling, golf, hunting, etc. for at least three months after surgery. Wait to be cleared for the activity by your doctor.
- **Avoid soaking the incision** area for at least six weeks after transplant and clear with your doctor. This includes avoiding activities such as swimming and taking a bath in a bathtub. You will be able to shower during this recovery time. You will need to avoid hot tubs and spas life long after transplant due to increased risk for infection.
- **Do not drive for at least one month** after lung transplant surgery and until you've been cleared to drive by your doctor. You must no longer be taking narcotic pain medications before you are safe to drive. You should always wear a seatbelt while driving or riding in the car.
- **Do not travel in an airplane** until cleared by the transplant team.
- Avoid contact with people who are sick, inhaled irritants and mold after transplant.
 - Wear **a mask** to the hospital and while in crowded areas for **three months** post-transplant.
 - **Always wear a mask** when entering **construction areas** because mold and dust are often in the air.
 - Wear **a mask and gardening gloves** when **gardening**. Avoid mulch and other potentially moldy substances.
- **Do not handle or have birds or reptiles** as pets and do not empty litter boxes.
- **Avoid grapefruit, grapefruit juice, papaya, pomegranate, pomelo, starfruit and seville oranges** after transplant since they have many medication interactions.
- **Avoid alcohol** while taking anti-fungal medications that impact your liver. Voriconazole and posaconazole are typical anti-fungal medications used after lung transplant. You should not drink alcohol while taking these medications.
- You may resume sexual relations when you feel comfortable to do so. **Avoiding pregnancy** lifelong after lung transplant is recommended by our program for both males and females. Exposure to immunosuppressive medications may cause harm to the fetus (immediate and long term). Birth control pills often may not work after transplant due to many medication interactions. Two forms of birth control are recommended. Surgical birth control such as an Essure procedure, tubal ligation, or vasectomy can be performed after you have recovered from transplant. Condoms should be used to protect from sexually transmitted diseases.
- **Wear sunscreen (SPF 30 or greater)**, avoid extended sun exposure, and avoid tanning booths or beds. Transplant medications increase your risk of developing skin cancer.



- **Do not have any routine dental cleanings or procedures until six months after transplant.**
- Check with the lung transplant office before receiving a vaccine. **You cannot have live vaccines after transplant.** It is often recommended that immediate family members of a transplant patient, also not receive live vaccines. Precautions may be necessary if a family member does receive a live vaccine. Discuss this with your transplant coordinator. The flu shot and pneumonia vaccine are safe after transplant and may be given to you at a lung transplant follow-up appointment.
- Attend a physical therapy or lung (pulmonary) rehabilitation program to assist with increasing your activity tolerance. Your transplant team arranges for you to start one of these programs about six weeks after transplant.
- Develop a schedule to make sure you take your transplant medications after lung transplant as instructed.
- **Call for medicine refills ahead of time.** Do not wait until you are out of a medicine to request a refill. Some transplant medicines will not be available and need to be ordered by your pharmacy. Insurance may require the transplant office to get authorization to cover a medicine. Authorizations may take a few days to receive. Generally, we suggest that when you have seven days left of a medicine that you call for a refill.
- **Notify your transplant team of any new medicines that you start taking** – prescribed, over the counter, or herbal.
- **Notify your transplant team of any changes in your health** such as a new medical condition or surgical procedure. Also please contact our office with financial changes, stressful issues, or other concerns. Please notify us if you are having a hard time getting your medications or with follow-up appointments after surgery.
- Have transplant lab work completed as instructed by the transplant team.
- **Avoid taking non-steroidal anti-inflammatory medications (NSAIDS) after transplant.** Motrin, Aleve, Advil, Ibuprofen are examples of these types of medications to be avoided after transplant. Taking these medicines with your transplant medicines can be harmful to your kidneys.
- Maintain a healthy weight by eating a healthy diet after transplant.
- Stay well hydrated and avoid excessive caffeine (greater than 2 cups per day), soda and sports drinks.
- Patients usually do not feel well enough to return to school or work until three to six months after lung transplant. Please discuss your plans to return to these activities with your transplant team to develop a plan that is best for you.

- Normal symptoms after lung transplant surgery include shakiness/tremors (side effect of Tacrolimus or Neoral), hard time sleeping (side effect of Prednisone), a tight feeling around the lower rib cage area, some nausea, ankle swelling, moodiness or feeling more emotional (side effect of Prednisone).

Incision and Wound Care

Clean your incision by showering daily. If there is any redness, swelling, or drainage, contact your nurse coordinator.

You may be discharged with a JP (Jackson-Pratt) drain in your chest. If so, you will be instructed on how to empty and care for the drain. Please record the JP drain output daily.



Step 1



Step 2



Step 3

You may have some drainage from your incision, previous chest tube, or JP drains sites. This is not unusual. If you have drainage, use clean, absorbent material (towels, gauze, feminine pads, baby diapers) to soak up the fluid. Note what the fluid looks like, any odor, and discuss the appearance and amount with your transplant coordinator.

Do not take a bath (in a bathtub) or swim in a swimming pool, lake, or pond until your incision is completely healed and cleared by the lung transplant team.

Staples and sutures will be removed about one month after surgery at a clinic visit with your transplant surgeon or pulmonologist.

Pain

The incision area will be painful for weeks to months after surgery. The level of pain decreases with time, and the pain sensation will also change over time. There will be days when the incisional pain may feel sharper and other times when the pain is more of a dull ache. Numbness around the area of your incision is normal. You will be prescribed pain medications at discharge. Your team expects that your need to continue taking pain medications will

decrease in the weeks following transplant. Remember to avoid taking non-steroidal anti-inflammatory medications (NSAIDS) after transplant, such as ibuprofen, as taking these medicines with your transplant medicines can be harmful to your kidneys. A heating pad and stretching exercises can also help with incisional discomfort after lung transplant.

Diabetes Mellitus

Post-transplant diabetes mellitus (PTDM) is a common medical condition after lung transplant. Early detection of high blood sugars after transplant and treatment is very important. You may have a specialist (endocrinologist) or your local primary care doctor manage your blood sugar. Your transplant pulmonologist will work together with your doctor for blood sugar control but will not manage your diabetes. Diabetes care will be with your endocrinologist or primary care doctor.

Constipation

Constipation is often a problem due to decreased activity and the use of pain medications. Stool softeners can be used to help keep stools soft. If you do not have a bowel movement within two days of your transplant, advise your transplant team. After you are at home, if you have constipation even with the stool softener, please notify your transplant coordinator.

Dental Care

Since many organisms are present in the mouth and you are immunosuppressed following transplant, you should do the following:

- Brush and floss your teeth at least twice a day
- Do not have any elective dental cleanings or procedures during the first six months after lung transplant
- See your dentist every six months and as directed
- Inform your dentist about your transplant and medications
- Take an antibiotic one hour before any routine dental care such as cleaning or any procedures. For more invasive dental work, antibiotics may be prescribed in coordination with your dentist and transplant doctor.

Your Local Physician/Doctor

It is necessary to have a primary care doctor see you for general health maintenance and non-transplant related care. We recommend you see your primary care doctor within the first few weeks after transplant and at least once a year. The transplant team cannot provide routine health care for you, such as monitoring your blood pressure or diabetes. It is important to continue your routine health maintenance activities (mammograms, prostate screening) through your primary care doctor.

Always make sure to inform us if you change your primary care doctor as the lung transplant team will be sending the doctor updates after your follow up appointments. It is important that your transplant team is informed of any new medications since many interact with transplant medications.

Your Local Lab

Initially, you will need to have labs drawn weekly after transplant. A visiting nurse will draw the labs for you for the first few weeks after discharge from the hospital. Once you are well enough and no longer require a visiting nurse, you will need to locate a blood drawing lab near your home. You may select a University of Michigan Lab or another lab near your home. A list of University of Michigan blood drawing stations can be found in the Resources section of this book.

The transplant team will provide you with a standing lab order for the needed blood tests. If you are using a local lab that does not have the capability to run a drug level blood test then you will need to mail your blood specimen to the University of Michigan Transplant Lab for testing. You will be provided mailers and labels to mail your blood specimen to our lab. Be sure that your name and date of birth are on the blood specimen. Only the drug level tube of blood will be mailed to our lab. All other blood tests ordered can be performed at your local lab and results faxed to our office.

Active Participation in Your Health Care

In order to have a successful lung transplant outcome, it is crucial that you and your caregiver develop a positive relationship with the transplant team. The transplant experience can include both ups and downs, and the team wants to develop regular, consistent, and accurate communication about all parts of your care. This communication may be related to medications, symptoms, testing, outside hospital stays, and discussions about managing the health of your transplant. Some of this communication may be with doctors, nurses, transplant

coordinators, social workers, or other support staff. Another very important key to success after lung transplant is your willingness and ability to follow the health care advice of your transplant team. Caring for your new transplanted organ includes taking your medications as directed, having blood tests done when instructed, regular follow up, and contacting us when you are not feeling well. The entire lung transplant team is committed to providing quality service and patient care to you and helping you achieve the best possible transplant outcome.