PRE-TRANSPLANT GUIDE FOR THE LUNG TRANSPLANT SURGERY CANDIDATE

The University of Utah Health
This guide is a brief overview of the process of lung transplantation, from your initial appointment through the surgery. It includes answers to the questions patients and families most often ask when considering this treatment option. The transplant team is available to answer any questions you may have and to assist you in the transplant process.

Patients are seen in Clinic 3 on the first floor of the main hospital.

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50 North Medical Drive, room AC144
Salt Lake City, UT 84132

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ABOUT THE LUNGS

The lungs are the two large organs which lie in your chest on either side of your heart. The lungs provide oxygen to the rest of your body and remove excess carbon dioxide from the blood through a process called gas exchange. Without this gas exchange, the body would not get enough oxygen and carbon dioxide would build up to toxic levels in the blood.

The lungs are protected and supported by 12 pairs of ribs, the intercostal muscles which lie between the ribs, the neck muscles, and the diaphragm. The right lung is divided into 3 lobes; the upper, the middle, and the lower lobe. The left lung is divided into 2 lobes; the upper and the lower lobe. 2 layers of tissue that are called pleura surround each lung, they protect the lungs and allow the lung to expand and move smoothly against the chest wall.

In certain diseases such as chronic obstructive pulmonary disease (COPD), emphysema, pulmonary fibrosis or cystic fibrosis, the tissues of the lung are damaged by infection, exposure to toxins or even the body’s own immune system. As more tissue is destroyed, the lungs are less able to get oxygen to the blood or remove carbon dioxide. In other types of lung disease, such as pulmonary hypertension, the pressure within the lung’s blood vessels becomes too high. This can result in damage to blood vessels in the lung and can also affect the heart muscle.

Lung transplant is considered only after all other treatments have been tried and are no longer effective. At this point gas exchange is so poor that patients are extremely disabled and have a life expectancy of 12-18 months. The types of lung diseases which will be considered for transplant include:

1. Chronic obstructive pulmonary disease (COPD).
   - Chronic Bronchitis
   - Emphysema
   - Alpha 1 Antitrypsin Deficiency
2. Idiopathic Pulmonary Fibrosis
3. Airway Diseases
   - Bronchiectasis
   - Cystic Fibrosis
4. Pulmonary Hypertension

Some patients may receive a single lung transplant. Patients can lead a normal life with a single lung and this approach allows the maximum number of patients to benefit from donor lungs. We feel that this is an important consideration given the fact that there are many more people in need of lung transplantation than there are lungs available. The existing lung disease in the remaining original lung does not spread to the transplanted lung. In certain lung diseases such as Cystic Fibrosis or pulmonary hypertension, a double lung transplant is performed.

WHO IS ELIGIBLE FOR A LUNG TRANSPLANT?

Lung transplant is considered only after all other treatments have been tried and are no longer effective. At this point, gas exchange is so poor that it is disabling. A lung transplant requires that candidates be free of tobacco products for a minimum of six months and may be asked to complete a smoking cessation program prior to being evaluated. If alcohol or drug consumption is identified, patients may be required to complete a chemical dependency treatment program.
HOW DO I BECOME A TRANSPLANT CANDIDATE?

In order to determine if transplant surgery is appropriate for you, a complete evaluation is necessary. We need to be aware of any diseases or problems that may exclude transplantation.

Several tests and scans will be performed to evaluate your health status. If you have recently completed some tests, you should not have to repeat them. If any abnormal results arise, further tests may be ordered. The transplant team will then look at all the data collected and discuss your best option.

ASPECTS OF EVALUATION

In addition to the following tests needed for the transplant evaluation, health maintenance check-ups are important. This includes a recent dental visit, and ophthalmology exam, as well as a colonoscopy for those over 50. Women need a pap and pelvic exam, and, over the age of 40, a mammogram. A prostate exam is required for men over the age of 50.

Several specialists will interview and examine you during the evaluation. The specialists include the transplant pulmonologist, surgeon, nurse coordinator, social worker, financial facilitator, pharmacist, anesthesiologist, and a dietician. Our program’s social worker will meet with you and discuss the psychosocial aspects of the transplant process. This psychosocial assessment covers many areas including the emotional and financial factors involved in having a transplant, and you and your family’s ability to cope with the transplant process.

LUNG TRANSPLANT EVALUATION TESTS AND PROCEDURES

VACCINATIONS

It is necessary to have the following vaccinations:

1. Pneumovax (pneumonia)
2. TDAP (Tetanus, Diphtheria, Pertussis)

You may have had some of these done through your local clinic. If so, please arrange to obtain a vaccination report from that clinic. We can make arrangements to have these done while you are here for your evaluation.

LUNG TESTS

Chest X-Ray:
This test is to look for lung and heart size, lung expansion, pneumonia, or abnormal growths.

Pulmonary Function Tests:
During this test you will breathe into a machine that measures how well your lungs expand, and how efficiently oxygen is carried to the blood.

VQ Lung Scan
This test involves an intravenous injection of a dye. An x-ray machine records the blood flow/oxygen flow supplied to your lungs. It can also measure if one lung is functioning better than the other.
Computerized Tomography
Also known as a CAT or CT scan. This non-invasive x-ray produces cross-sectional pictures of the chest and gives additional information about your lung disease.

6-Minute Walk Test
This test is used to determine your baseline functionality.

(V.0₂) Maximum Oxygen Consumption:
This is also called an exercise stress test. You will ride a stationary bicycle and your heart will be evaluated on its response to exercise. Arterial blood gas and EKG testing occurs during this procedure to record your heart’s electrical activity and performance under stress.

HEART TESTS

Electrocardiogram:
Also known as EKG, this is a recording of the electrical impulses traveling through the heart. Small electrodes are placed on the chest, arms and legs.

Echocardiogram:
This ultrasound measures the size of your heart, the motion of the heart walls, and the internal structures of the heart, such as the valves.

Carotid and Lower Extremity Ultrasounds:
This is another ultrasound. It evaluates the arteries that provide blood flow to your brain and legs.

Cardiac Catheterization/Coronary Angiogram
A Cardiologist will need to meet with you prior to scheduling this test to measure the pressures in the heart chambers, lungs, and the cardiac blood flow. It may also reveal abnormal motion of the heart walls. It also looks at the coronary arteries to help locate blockages that could prevent blood flow to the heart muscle.

GASTROENTEROLOGY TESTS

Abdominal ultrasound:
Examines the liver, pancreas, and gallbladder.

Esophagram:
An inspection of the esophagus to measure swallowing functions.

PH Manometry:
Esophageal manometry, also known as esophageal function or motility testing is a procedure that measures how well the muscles of the esophagus are working and the amount and seriousness of acid juices that may be backing up into your throat. The purpose of the test is to see if you have acid reflux.

Gastric Emptying:
This test is used to determine how quickly food leaves the stomach.
OTHER TESTS

Blood Tests:
Multiple blood samples will be taken to evaluate your overall health.

Urine and Stool Tests:
Random Urine Test:
We test a small sample of urine for infection, blood, and nicotine levels.
24-Hour Urine Test:
This test evaluates how well the kidneys are excreting waste. You can do this at home with supplies we give you.

Sputum:
You will be asked to submit a sputum specimen to look for infection.

Bone Density Scan (DEXA scan):
This determines the level of osteoporosis in your bones or the strength of your bones.

WHAT HAPPENS AFTER I HAVE BEEN ACCEPTED AS A TRANSPLANT CANDIDATE?

If transplant is felt to be the appropriate choice for you and we have received final approval from your insurance company, your name will be placed on a national waiting list through the United Network of Organ Sharing, or UNOS. UNOS is a nonprofit organization that maintains a list of all patients waiting for any type of organ transplant.

WHAT IS THE LUNG ALLOCATION SCORE?

Since the spring of 2005, lung transplant candidates have been assigned a lung allocation score. This score is based on each patient’s individual medical information. It reflects both the seriousness of each patient’s medical condition before transplant and his or her likelihood of success after a transplant. This information includes lab values, test results, and disease diagnosis. This medical information is used to calculate a lung allocation score from 0 to 100 for each transplant candidate. Candidates are prioritized according to their score: A candidate with a higher score will receive higher priority to be offered lungs when they become available. The lung allocation system was designed as a way to more effectively use the limited number of available donor lungs among patients in need of a transplant and to reduce the number of deaths among transplant candidates.

HOW ARE DONORS MATCHED?

Several criteria are used to match a donor to you. First, you must have a compatible blood type. The chart below describes which blood types are compatible with one another.
<table>
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<tr>
<th>Recipient (You)</th>
<th>Donor</th>
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<tr>
<td>A</td>
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If you have blood type O, you can only receive an organ from someone else with blood type O. This means that the waiting period for people with blood type O is usually longer. We try to match patients to an identical blood type donor as often as possible.

**WHAT IS INVOLVED IN THE WAIT FOR A DONOR?**

If you reside outside the Salt Lake City area, you will be required to relocate to within a one hour drive of the University of Utah Hospital. The transplant staff will follow you closely while you are waiting for your transplant. During this waiting time you will be seen in clinic by the transplant physician on a scheduled basis. In addition, it is recommended that you attend the transplant support group, which is open to those waiting and their families, as well as those already transplanted. The support group is lead by the transplant social worker. This group provides an emotionally supportive atmosphere where patients and families can share common experiences and assist each other in coping with the various issues that arise before and after transplant.

The Transplant Program also offers a pre-transplant education series for patients and their families while waiting for transplant. These classes are offered on subjects that patients must know to facilitate a good outcome after transplant. The classes are coordinated by the lung transplant social worker and are taught by health professionals. These classes are offered monthly with the transplant support group.

**WHY DO I NEED A SUPPORT PERSON?**

Support is needed both pre and post transplant to assist you with everyday physical and emotional needs. Progression of the lung disease may further debilitate patients while they are waiting for a transplant. The support person/persons need to understand the level of commitment required of them in the pre and post transplant period. Many times this job is shared among family and friends.

**HOW LONG DO I HAVE TO WAIT?**

There is no way to tell how long you will be on the waiting list. It may be a few days, several months, or even over a year in some cases. Many variables are taken consideration: the lung allocation score, the person’s blood group, and lung size. The donor must be of a compatible blood type, and body size should be similar. Once this is established, the donor is closely examined for signs of infection, damage to the organs, or a previous health history that may prohibit them from being a suitable donor. Our goal is to transplant healthy organs.

In some situations, the organs will deteriorate and cannot be used. You may have already been called into the hospital and actually in the process of being prepped for surgery when this happens. This is called a dry run. Dry runs are very disappointing, but are unfortunately, unavoidable as the status of the donor can change without warning.
WHAT IF I GET SICK WHILE I AM WAITING?

It is important for the transplant team to be kept informed of your health after you have been accepted as a transplant candidate. Please notify the transplant team of all illnesses and infections such as pneumonia, bronchitis, or major skin infections, and any time you are admitted to the hospital. Any infection must be treated before your transplant. Any dental work will require an antibiotic to prevent infection. If your overall health worsens, you will need to notify the transplant team. A change in your status with UNOS could be necessary until you can be stabilized.

WHAT HAPPENS ONCE I GET NOTIFIED THERE IS A DONOR?

Once you get the call that there is a potential donor, do not eat or drink anything from that point on. Once at the hospital, you will need to report to Admissions, which is on the first floor. You will then be directed up to the in-patient unit where your preparation for surgery will occur. Once on the unit, you will be prepped for the transplant, which entails blood draws, x-rays, placement of IV’s, interviews by different medical staff such as the anesthesiologist, the surgeon, nurses, and the operating room staff.

Lung transplant surgery generally takes around 4-8 hours. It may take longer depending on whether you have had previous chest surgery and if you are receiving two lungs instead of one. Remember that your lungs will not be removed until the new organs arrive in the operating room.

Your family and friends can wait in the third floor surgical waiting room. Staff from the operating room will keep members of your family updated throughout the procedure. Once surgery is finished, you will be admitted to the Cardiovascular Intensive Care Unit to be recovered. You will be on a respirator and have several tubes in place, such as a foley catheter in your bladder to drain your urine, and several drains in your chest cavity to draw chest fluids, as well as several intravenous lines for fluid management. These tubes will be removed as you recover from surgery.

Once you are breathing on your own, and your new lung/lungs are functioning well, you will be transferred to the Cardiovascular Medical Unit. Here you will begin to take an active role in your care, learning about your medications, follow-up care, and general health care.

WILL I KNOW WHO THE DONOR IS?

Donor information is confidential. A recipient and family may express their gratitude by writing an anonymous letter to the Intermountain Organ Donor Service; we will assist you with this.
Lung Transplant Program Patient Caregiver Agreement

You have been identified as the caregiver for __________________, a patient at University of Utah Health Care (UUHC) who is being considered for lung transplantation.

Before we place patients on the United Network for Organ Sharing (UNOS) lung transplant waitlist, we require our patients to secure the commitment of a caregiver who will be expected to provide patient support before, during, and after their transplant. This person must be a responsible adult. In our experience, excellent caregiver support significantly increases the odds of positive patient outcomes. A caregiver is a key component to a full and safe recovery. A caregiver may be a family member or friend who can assist the person receiving a lung transplant for their hospitalization and for, on average, 6 months after hospital discharge. Caregivers can rotate, but at least one caregiver is needed to support the patient throughout the process.

We encourage you, in your role as caregiver, to be present during as much of the transplant evaluation process as possible. Your participation will give you the opportunity to become informed about the upcoming transplant as well as help the patient with the great amount of information provided. Being a transplant caregiver requires a significant time commitment. A lung transplant patient needs a caregiver available 24 hours per day, 7 days a week for, on average, 6 months after their discharge from the hospital. The caregiver must also be available during the transplant hospitalization. There are several classes to attend, as well as educational opportunities for you at the patient’s bedside.

Please read this Patient Caregiver Agreement carefully. If you have any questions or concerns please contact the Transplant Social Worker, Jeness Woodard, LCSW, at 801-581-3298.

The caregiver (you) will be responsible to commit to the following:

- Have a current driver’s license and provide transportation to and from clinic and hospital appointments.
- Go with the patient to medical appointments.
- Provide emotional support and encouragement before, during and after the transplant.
- Participate in transplant education opportunities before, during and after the transplant.
- Spend time at the patient’s bedside during the hospitalization, learning about post-transplant care and medications.
- Remain present within the hospital setting on a daily basis.
- Understand that a post-transplant hospital admission can vary depending on the patient’s operative course.
- Understand that readmissions to the hospital may occur depending on the patient’s post-transplant course.
- Assist with the scheduled oral and intravenous medications after hospital discharge.
- Keep an eye on the patient’s condition and identify any changes or new symptoms.
- Know what to do in an emergency and call for medical help when needed.
- Maintain a clean and comfortable home environment.
- Assist patient with daily activities (e.g., food, laundry, house-keeping).
- Aide in the patient’s communication with transplant team members.
- Communicate with transplant staff, family members and friends.
- Help the patient with paperwork, including medical bills, hospital bills, and insurance paperwork.
- Reside locally with the patient during hospitalization and after discharge for, on average, 6 months.

It is also important that you take care of your own health and emotional well-being. Education and support is provided to you so that you can be confident in your responsibilities. The transplant team is here for support throughout this challenging experience. Please let us know if you have any questions or concerns.

DISCLAIMER: Each transplant patient is unique. While we have seen some patients heal rapidly and attain their independence quickly, other patients heal slowly and require help from their caregivers for an extended period of time. In addition, there is the possibility that patients will not require a caregiver for the entire 6 month period. This decision will be made by the patient’s provider.
As the caregiver, I understand and agree to the above responsibilities in order to assist the patient in their care before, during and after transplant.

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RECIPIENT CAREGIVER AGREEMENT
For Patients undergoing Lung Transplantation

The Lung Transplant Program requires all patients who are having a lung transplant to have a caregiver. This caregiver will be required to provide support before, during and after the transplant. The average amount of time required for a caregiver is 6 months after discharge from the hospital. In some cases the caregiver may be required for more or less time. Your physician will give medical clearance and inform you that your caregiver is no longer needed when the time comes. In our experience, excellent caregiver support significantly increases the odds of positive patient outcomes. Individuals who agree to be primary caregivers will receive training and ongoing support from the transplant team. The role of the caregiver is vital in the patient transplant journey.

The caregiver has many responsibilities. These include: helping with transportation to and from clinic appointments and rehabilitation; assisting with daily activities (e.g., food, laundry, housekeeping); helping the patient to communicate with the medical team; monitoring and assessing symptoms; assisting with medications, and providing emotional support. The expectation of our program is that a responsible adult will provide the caregiver duties. The individual you identify as your caregiver will be asked to sign a separate agreement.

By signing below I understand that the Lung Transplant Program requires me to have a caregiver for, on average, 6 months after my transplant. I also understand that my caregiver and I must remain in the Salt Lake City area for, on average, 6 months after discharge from the hospital. Before listing for transplant, my medical team will talk with the proposed caregiver to confirm willingness and availability. I give my permission for this contact to occur. I agree to contact my coordinator as soon as possible, if my caregiver plan should change. The caregiver requirement remains in effect until I receive medical clearance from the transplant team.

My caregiver(s) will be:

Primary Caregiver: ___________________________ Phone: ___________________________

Secondary Caregiver: ___________________________ Phone: ___________________________

Additional Caregiver(s) or comments:

________________________________________________________________________________

________________________________________________________________________________

Signatures:

Patient Signature ______________________________________________ Patient Printed Name ______________________ Date ______________________

Transplant Social Worker Signature ____________________________ Transplant Social Worker Printed Name ______________________ Date ______________________

PLEASE RETURN TO YOUR TRANSPLANT COORDINATOR
From I-15 northbound

1. Take the 600 South exit and go east approximately 2 miles to 700 East.
2. Turn left and drive for five blocks until you reach 100 South.
3. Turn right and proceed east on 100 South for one mile.
4. When you reach the University of Utah campus 100 South changes to North Campus Drive.
5. Continue on North Campus Drive one mile. University Hospital is located at 50 North Medical Drive on the right side of the street.

From I-15 southbound

1. Take the 400 South exit. At the first stoplight, turn left onto eastbound 400 South.
2. Proceed eastbound about two miles to 700 East.
3. Turn left and proceed northbound three blocks to 100 South.
4. Turn right and proceed east on 100 South for one mile.
5. When you reach the University of Utah campus 100 South changes to North Campus Drive.
6. Continue on North Campus Drive one mile. University Hospital is located at 50 North Medical Drive on the right side of the street.

From I-80 westbound / Foothill Drive

1. Take exit 129 for Foothill Drive.
2. Continue along Foothill drive approximately three miles and turn right at the University of Utah sign onto Mario Capecchi Drive.
3. Continue along Mario Capecchi Drive to North Campus Drive.
4. Turn right at North Campus Drive.
5. University Hospital is located at 50 North Medical Drive on the right side of the street.

From Salt Lake International Airport / I-80 eastbound

1. Take I-80 East towards Salt Lake City to exit 121 for 600 South.
2. Follow 600 South approximately 2 miles to 700 East.
3. Turn left and drive for five blocks until you reach 100 South.
4. Turn right and proceed east on 100 South for one mile.
5. When you reach the University of Utah campus 100 South changes to North Campus Drive.
6. Continue on North Campus Drive one mile. University Hospital is located at 50 North Medical Drive on the right side of the street.

Parking
As you enter the driveway follow the signs directing you to free valet parking. Self-parking is also available in the patient/visitor parking terrace. Parking is free for patients and visitors. If you choose to self-park, please allow an additional 15-20 minutes to locate a parking spot and walk to your appointment.
PUBLIC TRANSPORTATION

Utah Transit Authority (UTA) Buses and Trax
UTA schedules, bus routes, and maps can be found at rideutah.com, or you may call (888) RIDE-UTA. There is a UTA bus stop located directly in front of University Hospital. TRAX trains arrive and depart from the University of Utah campus approximately every 15 minutes. The Medical Center TRAX stop is located directly across the street from Primary Children’s Medical Center. You may access University Hospital by entering Primary Children’s Medical Center and taking the skybridge on the 4th floor. For locations other than University Hospital, there is a bus stop across Mario Capecchi Drive from the TRAX station where you can catch a campus shuttle directly to your appointment. The shuttle will also return you to the TRAX station after your appointment.

University of Utah Campus Shuttle
Campus shuttles are in service from 6 a.m. to 6 p.m. Campus shuttle bus information can be online by visiting parking.utah.edu or you may call (801) 581-4189. There is no campus shuttle service on weekends or University holidays.

Taxi Cabs / Rental Cars
City Cab Co. (801) 363-5550
Ute Cab & Rent-A-Car (801) 359-7788
Yellow Cab (801) 521-2100

Dollar Rent-A-Car (801) 575-2580
National Car Rental 1-800-CAR-RENT