

What is Lung Transplantation?

Lung transplants are performed as a life saving treatment for people with end-stage lung disease. A lung transplant is a surgery to remove diseased lungs and replace them with lungs from a deceased donor with healthy lungs. There are only a few specialized centers around the world where lung transplants are performed. You will need to be referred to one of these centers to be considered for the surgery.



Do I need a lung transplant?

Lung transplantation is an option for people with 'end stage' lung diseases such as chronic obstructive pulmonary disease (COPD), pulmonary fibrosis, cystic fibrosis (CF), pulmonary arterial hypertension (PAH), sarcoidosis, and other more rare lung diseases (See "Recipient Selection for Lung Transplantation"). Lung transplantation should only be considered when you and your physician have exhausted all other forms of available treatment. However, lung transplant should be performed before you become too sick to tolerate the surgery. Hence, the timing of evaluation and the surgery itself is very important.

In order to qualify for surgery, you need to be evaluated at a lung transplant center. During your evaluation, you will meet with a transplant surgeon, transplant pulmonologist (lung doctor) and other staff. They will inquire about other medical problems that you may have such as heart or kidney disease. They will make sure that you have been screened for cancers that are relevant for your age, such as colon, prostate (in men), breast and cervical cancer (in women). You will have a thorough evaluation that may include a CT scan of your chest, pulmonary (lung) function tests, an echocardiogram (ultrasound of your heart) and possibly a heart catheterization. You may have testing to see if you have gastroesophageal (acid) reflux. Finally, they will also make sure that you have good social support from those who will take care of you after your transplant. At the end of the evaluation, the transplant team will determine if surgery is the right option for you and whether to put your name on the lung transplant waiting list.

What is the "list"?

The waiting list includes the names of all people who have been accepted by a transplant program and are currently waiting for a transplant. United Network for Organ Sharing (UNOS) maintains a list of accepted candidates from all centers across the United States. If your transplant team decides that you are a candidate for lung transplantation, you will be assigned a score called the Lung Allocation Score (LAS). The LAS is used to help direct donated organs to people who would most benefit from a transplant. Some (but not all) of the factors that are used in calculating the score are your age,

oxygen requirement, pulmonary function test results, distance walked in 6 minutes and the type of lung disease you have. Your transplant team may update your score over time if some of these factors change.

Other factors used when matching donor lungs to a transplant recipient include:

- where the donor is,
- donor and recipient blood types,
- antibodies you may have against certain donors' blood and tissues,
- donor lung size and your chest size (often related to your height).

The time spent on the waiting list by an adult is no longer a factor in deciding who receives the transplant.

What do I do while I am waiting?

After your name is added to the lung transplant waiting list, the waiting time varies depending on the availability of suitable donor organs and your position on the list determined by your LAS. The typical waiting time can be a matter of weeks to several months. However, during this time you should not be idle. You should use this time to exercise as tolerated to get your body in the best shape possible for the surgery. Your transplant team may recommend you work with a pulmonary rehabilitation program. In general, the better shape you are in before the surgery, the easier and quicker your recovery will be. Your team may also ask you to move closer to the lung transplant center to follow you closely as your disease progresses, and to shorten the travel time to the center when organs becomes available. It is very important during this period to let your team know when your health changes.

When a suitable organ becomes available, you will receive a phone call telling you to come into the hospital. Because this call can come at any time, you should have a bag packed and be ready to get to the hospital immediately. Sometimes the call may result in a "dry run", in which the donor organ is found to not be suitable for transplantation after further evaluation.

What is the surgery like?

The operation can vary between each person and center. Your team will decide if either a single lung or a double lung transplant is better for you and explain the surgery to you. A single lung transplant may be better tolerated in sicker and older people. The operation itself usually lasts about six to eight hours but people are typically in the operating room for much longer. Some people may temporarily require heart-lung bypass support and other invasive measures to get through the operation. You will be asleep for the entire surgery, with medicines given by an anesthesiologist. The incision is generally located below your breast. When you wake up, you will have chest tubes in your sides and a breathing tube in your mouth. You will be given medicine to control the discomfort from the surgery until you fully recover.

How long is recovery?

After the surgery, you may be in the ICU for 3-5 days if no complications occur during the surgery. In that case, you should be discharged from the hospital after about 2-3 weeks. However, the duration of the hospital stay can extend to several months if problems occur during the recovery. Much of your hospital stay will be focused on getting the right doses of immune suppressing medicines into your body to prevent your body from rejecting the lung transplant. The most common medications your doctors will prescribe to suppress your immune system are tacrolimus (or cyclosporine), mycophenolate mofetil (or azathioprine), and prednisone. The other major part of your hospital stay is rehabilitation. A physical therapist will start working with you to get you out of bed and walking as soon as is medically possible. This pulmonary rehabilitation may be continued after you are discharged from the hospital in an outpatient monitored setting.

You will have regular blood tests, chest x-rays and spirometry after your transplant. You may also need to have a bronchoscopy done from time to time (see "Flexible Bronchoscopy"). In general, your initial pulmonary function testing will continue to improve during the first year after transplant as long as your new lungs stay healthy. You will also be asked to monitor your pulmonary function on a regular basis with a portable micro-spirometer. This may help you detect problems early, even before you have symptoms. You will have blood tests to be sure your immune system is adequately suppressed and that other organs (such as your kidneys and liver) are not affected by your new medications.

What different problems might I encounter after a lung transplant?

While a lung transplant is often a life saving treatment, there are certain problems that recipients may face. The two major problems are infections and rejection of the transplanted lung (see "Rejection after Lung Transplantation"). Because you are taking medications to suppress your immune system, you are more prone to infections. Your team will prescribe preventative antibiotics for some common infections. Unfortunately, not all infections can be completely prevented. You should do what you can to avoid contact with ill people and wash your hands well and often. Your team will tell you what vaccines to take and how else to avoid infection.

In addition to infection, acute rejection can occur early on after lung transplantation. Acute rejection occurs when your immune system recognizes your new lungs as foreign and starts to attack them. Acute rejection requires prompt attention and may need adjustment of your immune suppressing medicines.

The main limiting factor in the long-term survival for patients who have had a lung transplant is chronic lung allograft dysfunction (CLAD). Bronchiolitis obliterans syndrome (BOS) and restrictive allograft syndrome (RAS) are forms of CLAD (see ATS Patient Information Series piece "Bronchiolitis Obliterans Syndrome" at www.thoracic.org/patients). It also can occur many years after your transplant and is usually identified by specific changes in your pulmonary function tests. If these changes occur, your transplant team may perform a bronchoscopy with biopsies of your transplanted lungs before considering specific treatments for Chronic Lung Allograft Dysfunction (CLAD).

Other problems can also occur in recipients, including scarring or stenosis in the windpipe at the attachment site of the transplanted lung or in other areas of your airways. You will also be more likely to develop skin cancer and other types of cancers because of the immune suppressing medicines you will be taking. However, with regular visits with your transplant team, you will be able to watch out for and manage these complications if they arise.

Considering lung transplantation for your lung disease can be a scary process. However, a lung transplant can offer people with end stage lung disease a longer life expectancy and improved daily quality of life.

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Rx Action Steps

- ✓ Talk with your lung specialist and primary healthcare provider about whether you should consider a lung transplant.
- ✓ If you have end-stage lung disease and want to consider a transplant, arrange to talk with or visit a lung transplant center.
- ✓ Take part in pulmonary rehabilitation to help stay as well as possible before and after transplant.
- ✓ Work with your transplant team to get necessary tests before and after transplant.
- ✓ Enlist friends and family who can help support you along the way.

Healthcare Provider's Contact Number:

For Additional Information:

Organ Procurement and Transplantation Network (OPTN)

<http://optn.transplant.hrsa.gov>

United Network for Organ Sharing (UNOS)

<http://www.unos.org>

Lung Transplant Foundation

<http://www.lungtransplantfoundation.org>

American Thoracic Society Patient Education Documents

<http://www.thoracic.org/patients>

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Recipient Selection for Lung Transplantation

Lung Transplantation Mini-Series #2

Lung transplantation is a treatment option for certain patients with advanced lung disease. It is mainly considered after other medical therapies have been exhausted. It is time to consider lung transplantation when your life expectancy is predicted to be only 1 to 2 years without the transplant, or when your lung symptoms have severely limited your quality of life.



Good candidates for lung transplantation are people who do not have many other medical conditions (besides lung disease), carefully and regularly follow treatment plans devised with their healthcare providers, and have support from family and friends. Not everyone with severe lung disease will be a good candidate for a lung transplant. You may not qualify because of concerns about surviving a major surgery, being able to take care of the new lungs, or because of the risks from the medicines required after transplantation to prevent lung rejection. See Box 1 for additional information. These will be reviewed in detail when you have an evaluation by a lung transplant team.

How do I find out if a lung transplant is right for me?

If your healthcare provider thinks you may be a good candidate for lung transplantation, you will be referred to a lung transplant center. The lung transplant team does a full evaluation that starts with looking at why you need a lung transplant. This includes the type of lung disease you have, its severity, and what other treatments you have tried. For more information, see 'What is Lung Transplantation?' at www.thoracic.org/patients. The team will work with you to see if you have any potential contraindications (reasons not to proceed with the surgery) or barriers to transplantation. Some contraindications may be treated (for example, body weight that is too high or too low, or untreated medical conditions like diabetes or obesity) to improve your chances for a successful lung transplant.

If the lung transplant center decides you are a good candidate, you will be put on the waiting list and given a Lung Allocation Score (LAS). The LAS system gives priority to the sickest people who are in need of a lung transplant to reduce the number of people who die while waiting for new lungs. The LAS also considers patient factors (age, type of disease, and presence of certain other medical conditions) to minimize the number of people who die in the first year following transplantation. Thus, it aims to optimize the risk-benefit ratio.

Box 1: Contraindications to Lung Transplantation

Absolute contraindications (patients will very likely not be considered for a lung transplant):

- Recent history of cancer (in last 2-5 years, depending on the cancer)
- Untreatable advanced disease in other organs (for example, heart, liver, or kidney)
- Acute unstable medical problems (e.g., sepsis or major heart attack)
- Active tuberculosis
- Poorly controlled chronic infection (such as HIV or hepatitis B virus)
- Certain abnormalities of the chest wall or spine
- Inability to follow-up or follow through with medical therapies (based on your past history of care of your medical problems)
- An untreatable psychiatric or psychological condition that interferes with one's ability to follow medical therapy
- Absence of a reliable social support system
- Severely limited exercise capacity that does not allow the patient to do pulmonary rehabilitation
- Morbid obesity (BMI more than 35 kg/m²)
- Substance abuse (for example, alcohol, tobacco, or drugs)

Relative contraindications (patients may still be considered for a lung transplant in special circumstances):

- Age older than 75 years
- Age older than 65 years AND a low capacity to exercise
- Obesity (BMI more than 30 kg/m²)
- Malnutrition that is severe (BMI less than or equal to 18 kg/m²) or is getting worse
- Patients requiring mechanical ventilation or extracorporeal life support (ECLS)
- Significant prior surgery involving chest wall or lungs
- Colonization with highly resistant infectious organisms (e.g., Burkholderia or certain mycobacterial infections)
- Severe or symptomatic osteoporosis (bone mineral problems)
- Other medical conditions that are not yet optimally treated (for example, GERD, epilepsy, high blood pressure, or diabetes) that may pose a risk to surviving surgery, wound healing, and/or the new lungs after surgery

Abbreviations: HIV, human immunodeficiency virus; BMI, body mass index; GERD, gastro-esophageal reflux disease

Timing of Referral and Transplantation

Lung transplantation is done for many lung diseases that have advanced to the point where no other therapy will be helpful. Common reasons for lung transplantation include chronic obstructive pulmonary disease (COPD), cystic fibrosis (CF), pulmonary fibrosis (PF) and pulmonary hypertension (PH). Other rare or uncommon lung diseases may be considered for lung transplantation as well. If you have an advanced lung disease not listed above, discuss with your healthcare provider whether referral for a lung transplant would be right for you.

The right timing of referral for a lung transplant and timing of placement on the waiting list depends on a number of factors that may be different for various lung diseases.

The Online Supplement of this factsheet at www.thoracic.org/patients has some considerations based on the type of lung disease you may have.

You can discuss these factors with your healthcare provider to see if it may be appropriate for you to consider lung transplantation.

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*Mr. Goldstein passed away in July, 2021. We are indebted to his tireless efforts to help people with lung disease. May his memory be a blessing.

Rx Action Steps

- ✓ Work with your healthcare provider to manage your lung disease and do your best to follow your treatment plan
- ✓ Talk with your lung specialist about which, if any, criteria you meet to be considered for lung transplant evaluation
- ✓ Enlist the support of family and friends to help you
- ✓ Make a list of questions you want answered and consider the pros and cons of lung transplantation for you. Share these with the lung transplant team.

Healthcare Provider's Contact Number:

Resources

American Thoracic Society

www.thoracic.org/patients
– Transplant Mini-series

National Heart, Lung and Blood Institute

<https://www.nhlbi.nih.gov/health/health-topics/topics/lungtxp/whoneeds>

Who Needs A Lung Transplant.

Lung Transplant Foundation

<http://lungtransplantfoundation.org/patient-resources/before-you-transplant/>
Before Your Transplant.

UNOS

https://www.unos.org/wp-content/uploads/unos/Lung_Patient.pdf
Questions and Answers for Transplant Candidates about Lung Allocation.

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*Recipient Selection for Lung Transplantation: Disease Specific Factors Online Supplement***Chronic Obstructive Pulmonary Disease (COPD)**

Your disease severity in COPD can be described by a scoring system called the BODE index. This score helps to predict which patients are most likely to die in the next 4 years as a result of their lung disease. A higher score is linked to a greater risk of death. It factors in your weight in relation to your height, the FEV₁ result (air that is forcefully breathed out of the lungs in the first second) measured on spirometry (a breathing test), the level of shortness of breath you have, and your ability to exercise. The ability to exercise is defined using the 6-minute walk test (6MWT), which provides the distance a person can walk in six minutes under specific conditions. Higher BODE index scores are seen when you have more severe shortness of breath, low body weight, low FEV₁, and/or low exercise ability. Patients with COPD should be referred for a lung transplant evaluation if they have the following:

■ A BODE index score that predicts a risk of dying in the next 4 years of at least 40% (BODE score 5-6)

■ Worsening disease despite using oxygen, doing pulmonary rehabilitation, and using prescribed medicines correctly

■ Very severe COPD based on breathing tests (FEV₁ < 25% of reference value)

Patients are often placed on the lung transplant waiting list when they meet at least 1 or more of the following criteria:

- A BODE index score that predicts a risk of dying in the next 4 years of at least 80% (BODE score 7-10)
- Three or more severe COPD exacerbations in the last year
- A history of being hospitalized for a COPD exacerbation that was associated with a high carbon dioxide (CO₂) level in the blood,
- Moderate to severe pulmonary hypertension (high blood pressure in the lungs)
- Very severe COPD based on breathing tests (FEV₁ less than 20%)

For more information, see 'Chronic Obstructive Pulmonary Disease' and 'Pulmonary Function Testing' at www.thoracic.org/patients.

Cystic Fibrosis (CF)

A number of factors may be considered when referring a person with cystic fibrosis for lung transplant evaluation.

A few factors that would prompt referral include:

- FEV₁ measured on spirometry less than 30% or a rapid fall in FEV₁, particularly in a female patient
- Increasing number of CF pulmonary exacerbations (flare-ups) and need for antibiotics, increasing number of infections resistant to available antibiotics, or poor recovery despite being adequately treated with antibiotics
- A severe CF pulmonary exacerbation that requires help from a ventilator
- Persistent or recurrent pneumothorax (air leak from the lung)
- Frequent or life-threatening hemoptysis (coughing up blood), especially that is not controlled by treatment
- Pulmonary hypertension (high blood pressure in the lungs)

■ Continual drop in exercise capacity (6-minute walk distance less than 400 feet)

■ Worsening nutritional status despite adequate intake of food and/or supplements

Being hospitalized often, having worsening oxygen requirements or increasing in carbon dioxide levels in blood, or requiring long-term assisted ventilation are often reasons to be listed for a transplant.

Many people with advanced lung disease in CF may be infected with bacteria that are resistant to commonly used antibiotics. This can be a concern in transplant as the resistant bacteria can get into the new transplanted lungs during and/or after surgery. Some of these infections may be a contraindication to transplant. Special testing is needed to identify these infections prior to the transplant and a plan for their treatment needs to be made.

Pulmonary Fibrosis (IPF)

Certain types of pulmonary fibrosis may have a more rapid decline and worse outcome than other types. For some people, the diagnosis of Idiopathic Pulmonary Fibrosis (IPF) may warrant immediate referral for lung transplant evaluation as they are at high risk for a rapid progression of the disease.

Other factors that may be considered for referring a patient for lung transplant evaluation are:

- A forced vital capacity (the total amount of air breathed out on a breathing test) less than 80% or a DLCO (diffusing capacity) of less than 40%
- Any shortness of breath believed to be due to lung disease
- A decrease in oxygen saturation level to less than 88% while doing a 6-minute walk test (6MWT)
- Findings on a chest CT or lung biopsy that may suggest certain types of pulmonary fibrosis

Significant worsening of values on spirometry (either FVC or DLCO) during 6 months of followup, pulmonary hypertension (high blood pressure in the lungs), increasing oxygen requirements or decreasing distance walked on a 6-minute walk test (6MWT), or being hospitalized due to the lung disease are often reasons to be listed for a transplant.

Pulmonary Hypertension

If patients with pulmonary hypertension have been treated with a maximal medical regimen and continue to have severe symptoms, they may be referred and considered for lung transplantation. Some factors that may be considered for listing a patient for lung transplantation are:

- Severe shortness of breath with minimal activity or inability to carry out any physical activity at all, despite being on medication
- Low or declining distance walked on the 6-minute walk test (6MWT)
- Declining heart function as measured on cardiac catheterization
- Life-threatening symptoms such as syncope (passing out unexpectedly) or hemoptysis (coughing up blood)

