

# A Guide to Lung Transplantation

Patient Education Guide



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The American College of Chest Physicians is the leading resource for the improvement of cardiopulmonary health and critical care worldwide. Its mission is to promote the prevention and treatment of diseases of the chest through leadership, education, research, and communication.

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# Why Are Lung Transplants Needed?

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## What Lungs Do When They Are Healthy

Every cell in your body requires oxygen to do its job. When a cell uses oxygen, it produces carbon dioxide, which then has to be quickly removed.

Your lungs have the all-important job of providing the oxygen your body needs and expelling the carbon dioxide. The lungs do their job when you breathe—oxygen IN, carbon dioxide OUT. Your blood carries oxygen FROM the lung to cells and carries carbon dioxide TO the lungs for disposal when you exhale. Your heart is the pump that propels blood to and from the lungs.

When lungs are healthy, you are rarely aware of the automatic process of breathing. The only times you feel “short of breath” is when your lungs have to work harder to supply oxygen and get rid of carbon dioxide—for example, when you exercise hard or when oxygen is in short supply at high altitude.

## What Happens When Your Lungs Are Not Healthy

When your lungs are not healthy, you may feel “short of breath” and fatigued almost all the time. Unhealthy or damaged lungs are not able to keep the flow and exchange of oxygen and carbon dioxide moving at the rate your cells need to function efficiently. The cells then send out a signal that tells you to work harder at breathing—much like your body cells send a thirsty-feeling signal that makes you want to drink more when there is a danger of dehydration.

This constant fatigue and struggle to breathe diminishes your quality of life. Your life may even be shortened if your body is unable to get enough oxygen and remove carbon dioxide. If your lungs become so damaged that even extra oxygen and other therapies are inadequate to improve your condition, you may be a candidate for lung transplantation.

# Diseases and Conditions That Affect the Lungs

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A number of diseases and conditions can cause the lungs to become so unhealthy that one or both lungs need to be replaced with a transplant. These diseases and conditions include:

- Chronic obstructive pulmonary disease (COPD) and/or emphysema: due to tobacco smoking, alpha<sub>1</sub>-antitrypsin deficiency (an inherited condition), or other causes
- Pulmonary fibrosis (scarring of the lung)
- Sarcoidosis
- Cystic fibrosis
- Bronchiectasis (chronic airway infection and damage)
- Primary pulmonary hypertension
- Lymphangioleiomyomatosis (LAM)
- Langerhans cell histiocytosis of the lung (also known as eosinophilic granuloma or histiocytosis X)
- Congenital heart disease with Eisenmenger syndrome

Other rare conditions may also be considered for transplantation.

# What Kind of Transplants Can Be Considered?

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## Single-Lung or Double-Lung

The transplant team's assessment of your medical needs and the availability of donor lungs are considered in determining whether one or both lungs should be transplanted.

## Heart-Lungs

Both lungs and the heart are replaced when both have irreversible damage, either due to one disease or a combination of diseases that affect both organs.

## Pediatric Lung Transplantation

Lung transplantation in children is usually considered for:

- Cystic fibrosis with end-stage lung disease
- Pulmonary hypertension
- Pulmonary fibrosis

# Can You Be Considered for Lung Transplantation?

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To be considered for lung transplantation, you must:

- Have a condition for which transplantation is considered an effective treatment
- Have severe and progressive lung disease that no longer responds to medical treatment
- Be willing to accept the risks of surgery and subsequent medical treatment
- Be physically capable of undergoing surgery and subsequent medical treatment
- Not be smoking or abusing alcohol or drugs

Even if you otherwise qualify, the transplant team may determine that you are not a good candidate—for example, because of severe, coexisting medical conditions that may be worsened by a surgical procedure and follow-up treatments with powerful immunosuppressive (antirejection) drugs.

# How Will Your Transplant Candidacy Be Evaluated?

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While you may be referred to a transplant center by your physician, this does not mean that you are automatically accepted as a transplant candidate. You will be evaluated, physically and psychologically. You and members of your family will be interviewed by the transplant center team. You will undergo a number of testing procedures that are used to assess your physical condition. These tests may include:

## Heart

- Catheterization of the heart to examine blood supply and pressure (this test requires a catheter to be threaded through a large vein into your heart and dye injected into the heart through the catheter while an x-ray picture is taken)
- Nuclear cardiology studies to determine heart function and blood supply (these require injection of a radioactive substance to “tag” red blood cells)
- Electrocardiogram to determine heart electrical activity
- Echocardiogram (ultrasound) to assess heart muscle and valve function and to estimate pulmonary pressures

## Lungs

- Ventilation-perfusion lung scan to determine blood and air supply to the lungs (this requires an injection of radioactive “tracer” into a vein)
- Pulmonary function tests to measure lung size and function (requires inhaling/exhaling into a machine)
- Chest CT scan to get a three-dimensional x-ray picture of your lungs

## Other

- Laboratory tests of blood to determine your blood type, help determine the risk of rejecting a transplanted lung or getting a serious infection, and look at the function of your other organs
- Bone density test
- Exercise capacity
- Any other tests that physicians may believe are needed to complete a thorough evaluation

All information from tests, interviews, and your medical history will be considered in determining whether you can be a candidate for lung transplantation. The team will also assess whether you have adequate financial resources and social support to meet the requirements of the program. Different transplant centers may have additional criteria for transplantation evaluation.

# Benefits and Risks of Lung Transplantation

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## Benefits

Lung transplantation has the potential both to lengthen life expectancy and substantially improve quality of life. It is impossible to predict how long you may survive after transplantation. The most critical period for survival is the first year after transplantation; this is the period when surgical complications, rejection, and infection (see Risks below) are the greatest threat to survival. Patients who survive the first year are more likely to survive 3 years or longer after transplantation. There are patients alive today who had lung transplantation 10 or even 15 years ago.

Each lung transplant center has survival statistics for its transplantation programs. For American transplant programs, these statistics are available from the United Network for Organ Sharing (UNOS). The UNOS telephone number and World Wide Web address are given at the end of this brochure. You should discuss this information with your physician and the transplant team.

## Risks

Rejection and infection are the two major complications of lung transplantation. You must cooperate completely with your physicians to try to keep these complications from developing or to keep them under control if they do occur.

## Rejection

Because your transplanted lung(s) is “foreign” to your body, your body’s immune system will try to destroy it—just as it tries to destroy “foreign” bacteria and viruses when they invade. Your immune system helps protect you from illness, but the process has to be “turned off” to keep your transplanted lung(s) from being destroyed.

Immunosuppressive (antirejection) medications prescribed by your doctors will help slow down and control the rejection process. Other medications may be necessary to control and treat rejection if your immune system breaks through the immunosuppressive blockade. Following your doctors’ orders and taking all medications as prescribed help to prevent or control rejection. However, sometimes rejection can occur even despite your best efforts.

The most likely time for rejection to begin is during the first 3 months after transplantation surgery. Symptoms of rejection include fever, chills, flu-like aches, and shortness of breath. Your transplant team will instruct you regarding who to call to immediately report any such symptoms. Regular check-ups, x-rays, and breathing tests are also necessary to detect rejection that can occasionally occur without noticeable symptoms. Some programs take tiny biopsies of the lung through a device called a bronchoscope to screen for this “silent” rejection.

Immunosuppressive medications you will be taking in combination may include prednisone, cyclosporine or tacrolimus, azathioprine or mycophenolate, or other medications. The dosages of these drugs may be adjusted frequently by your physicians in response to drug levels, rejection, or side effects.

## Infection

Because you will be taking immunosuppressive medications, your immune system will be less able to fight off invading bacteria and viruses. You will be much more susceptible to infections, which can become severe.

You have an important role in the prevention of infection—by following instructions to avoid exposure to infection, and immediately reporting any symptoms of infection.

## Other Complications

Many other complications are possible, including medication side effects, long-term problems with function of the transplanted lungs, and certain types of cancer. Your physicians and the transplant team will discuss these potential complications with you before transplantation and help you manage them after transplantation.

# What Will Happen When You Are Accepted Into a Lung Transplant Program?

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Once you are accepted into a medical center's transplant program, you will be placed on the waiting list for a lung transplant. Each medical center has its own rules to follow, but, in general, you will:

- Be given regular tests while you are waiting
- Be put on a regimen of "healthy living" that will get you into the best possible physical condition for surgery, with exercise, good nutrition, no smoking, and limited or no use of alcohol
- Be put in touch with the medical center's social services to help you with problems, such as lodging and transportation, legal issues, and finances
- Be counseled, along with members of your family, as to what to expect before, during, and after lung transplantation
- Be told what to do when it is your time to receive a donor lung—for example, how to get to the medical center as quickly as possible if you live in a city or town other than the one where the medical center is located

# How Will You Get Your Donor Lung?

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In the United States, all organs available for transplantation are listed on a national transplant waiting list maintained by the United Network for Organ Sharing (UNOS). The UNOS list matches donor organs to potential recipients, based on a number of criteria:

- Compatibility of donor and recipient (blood type, lung size)
- The severity of the recipient's lung disease, and the likelihood of a lung transplant improving his or her survival

Every medical center matches donors and recipients through UNOS, but each center has its own rules for accepting or declining transplant candidates.

Other countries may have other criteria for allocation of donor lungs, such as the amount of time the recipient has been on the waiting list.

Your donor lung(s) come from a person who has died and whose organs have been made available for transplantation. You will never know the name of your organ donor, because transplant centers respect donor confidentiality. Working through your transplant center, you can send an anonymous letter of appreciation to the donor's family.

Criteria for matching donors and recipients change from time to time. To get current information, you may contact UNOS at the toll-free telephone number given at the end of this brochure.

# What Is the Surgical Procedure?

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A transplant operation will require many hours—about 1 hour to prepare you for anesthesia and to attach necessary monitoring lines, 4 to 8 hours of surgery for a single-lung transplant, and 6 to 12 hours for a double-lung transplant. Additional time may be required if you have had prior chest surgery.

Single-lung transplants are usually done through an incision made on the right or left side, depending on which lung is being replaced. Double-lung transplants are generally done using an incision across the entire chest, just below the breast.

The operation begins when the donor lung arrives in the operating room. Your lung(s) is removed and the donor lung is placed in the chest cavity. The surgeon connects the blood vessels to and from the lung (pulmonary artery and pulmonary vein) and the main airway (bronchus) of the donor lung to your airway. The same connections are made for the other lung if you are having a double-lung transplant.

For a heart-lung transplant, you are connected to a heart-lung machine that circulates your blood while the operation is in progress. After both lungs and the heart are removed, the donor lungs are attached as described in the paragraph above. The donor heart is attached to a "cuff" of the old heart's atrium that was left in place for just that purpose, and the main artery (aorta) is attached to the aorta of the donor heart.

After surgery is completed, you will be taken to an intensive care unit (ICU) for postsurgical recovery and monitoring. You will be in the ICU for at least several days. While you are in the ICU, you will have a breathing tube and mechanical ventilation for 1 or 2 days, a nasogastric tube to remove stomach contents that might be aspirated or make you nauseous, chest tubes to drain blood and postsurgical fluids from the chest cavity, a Foley catheter to drain urine, and intravenous (IV) catheters in your neck and arm for monitoring and for providing necessary fluids and medications. After leaving the ICU, you will go to a hospital room. The average stay in a hospital varies between transplant programs but is generally 1 to 3 weeks. However, since many complications can occur, some people are in the ICU and in the hospital for much longer—sometimes many weeks or even months.

## What Happens After Discharge?

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During the first 90 days after discharge from the hospital, you will make frequent trips to the medical center for blood tests, breathing tests, x-rays, and other monitoring of your condition. If you are doing well after 90 days, trips to the medical center may be less frequent.

You are also instructed to self-monitor your weight, blood pressure, pulse, temperature, lung function, and (if you are diabetic) blood sugar.

Of primary importance is the following: no smoking, limited use of alcohol, and good nutrition.

As soon as you are able, you will start a program of exercise rehabilitation. This may be conducted at the medical center or at a rehabilitation facility under professional supervision.

## Commitment of You and Your Family

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Lung transplantation requires full commitment from you and your family to:

- Maintain optimism during the months or years you may be on the waiting list for a donor lung
- Cooperate with your physicians, especially in taking transplant medications
- Maintain a healthy lifestyle to make the most of your second chance at life

# Questions You Should Ask Your Physician and Medical Center

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Is transplantation my best option for treatment of my condition?

What are organ and patient survival rates at this institution for the type of transplant I will need?

How many transplants of this type are done every year at this institution? How many by my physicians and surgeons?

How long have they been doing this type of transplant surgery?

What costs of transplantation and rehabilitation are covered by my insurance? What out-of-pocket costs will I have to pay?

## Where Can I Get More Information About Transplants?

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Contact the United Network for Organ Sharing (UNOS) at (888) 894-6361, or visit their Web site at [www.unos.org](http://www.unos.org).

ACCP Lung Transplant Resources: [www.chestnet.org/about/links/lungTransplant.php](http://www.chestnet.org/about/links/lungTransplant.php)

Other patient education guides available from the ACCP  
in print and on the ACCP Web site ([www.chestnet.org](http://www.chestnet.org)) are:

Controlling Your Asthma (English and Spanish versions available)

Flexible Bronchoscopy

Cough: Understanding and Treating a Problem With Many Causes

Mechanical Ventilation: Beyond the ICU

Pulmonary Rehabilitation: A Team Approach To Improving Quality of Life

Living Well With COPD

Additional Resources:

[www.thoracic.org](http://www.thoracic.org)

[www.yourlunghealth.org](http://www.yourlunghealth.org)

[www.goldcopd.com](http://www.goldcopd.com)

[www.copdresourcenetwork.org](http://www.copdresourcenetwork.org)

[www.nationaljewish.org](http://www.nationaljewish.org)

[www.lungusa.org](http://www.lungusa.org)

[www.smokefree.gov/talk.html](http://www.smokefree.gov/talk.html)

[www.centerwatch.com](http://www.centerwatch.com)

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