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), idiopathic pulmonary fibrosis (IPF), 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 provider 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 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 Lung Transplantation?

Lung Transplantation Mini-Series #1

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 healthy donor. 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.
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 will likely 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 most common type of rejection is chronic rejection (see ATS Patient Information Series piece “Bronchiolitis Obliterans Syndrome” at www.thoracic.org/patients), which is the main limiting factor in the overall survival for recipients. This type of rejection is sometimes called chronic lung allograft dysfunction (CLAD) or bronchiolitis obliterans syndrome (BOS) in certain situations. It 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 rejection.

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.

Authors: Bradford Bemiss MD, Erika D. Lease MD
Reviewers: Hrishikesh Kulkarni MD, Matthew Morrell MD, Marianna Sockrider MD, DrPH.

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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