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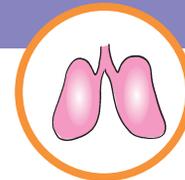
Authors

Teresa DeMarco
Adaani Frost
Edward Garrity
Marshall Hertz
Joren Madsen
Janet Maurer

Branislav Radovancevic
Bruce Rosengard
Frank Smart
George Tellides
Jonathan Zaroff

GETTING A
NEW LUNG

Facts About Lung Transplants



*The American Society of Transplantation
Patient Care and Education Committee*

*17000 Commerce Parkway
Suite C
Mount Laurel, NJ 08054
Phone: 856-439-9986
Fax: 856-439-9982
E-mail: ast@abint.com*

GETTING A NEW LUNG: FACTS ABOUT LUNG TRANSPLANTS

THE TRUTH ABOUT LUNG TRANSPLANTS



1 The first truth is that a lung transplant involves more than just having an operation. There are things to do before the transplant. There are things to do after the transplant.

2 The second truth is that a lot depends on you. You will need to work closely with the transplant center team to keep your new lung healthy. How long a new lung lasts depends on many factors—some you can control and others you cannot.

Before the transplant, you will need to work with the transplant team to speed your transplant evaluation. After the transplant, you will need to keep in contact with your transplant team to help maintain lung function and ensure your good health.

Every transplant, no matter what organ—heart, lung, liver, or kidney—is a partnership between the transplant center and you to keep you and your new transplant healthy.

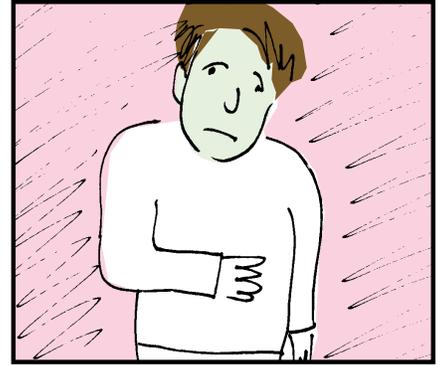
WHAT HAPPENS WHEN YOUR OWN LUNGS FAIL

- Many different diseases can harm your lungs and make them work poorly. Some of these diseases can damage the lungs very quickly—sometimes in just weeks or months. Other diseases take years to irreversibly damage the lung.
- Unless you are a *very* physically active person, sometimes you don't notice the progressive lung disease until it is very severe. The more fit and active you are, the earlier you notice that the lungs aren't working well.

Some lung diseases start off with cough, sometimes with sputum; some start with infections; some start with just symptoms of fatigue, dizziness, and lightheadedness; and some start with shortness of breath. The pattern of lung failure depends on why the lungs are failing. The following are some of the common diseases that result in lung failure leading to lung transplantation:

- Emphysema
- Cystic fibrosis
- Pulmonary fibrosis
- Pulmonary hypertension (a disease of the blood vessels in the lungs)
- Bronchiectasis
- Sarcoid

These are just a few diseases. There are many—some very rare fortunately. Your own doctor or your transplant doctor can talk to you more about the nature of your disease.



HOW TO TREAT LUNG DISEASE

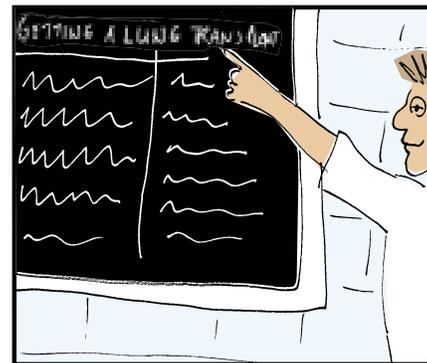
- There are many treatments for lung diseases. These treatments all depend on what the specific lung disease is. However, many patients eventually will require oxygen; some will require frequent antibiotics; many will require "steroids." "Steroids" is the name for the pill or intravenous form of prednisone—a treatment to reduce inflammation in the lung due to many diseases such as pulmonary fibrosis, emphysema, asthma, and sometimes cystic fibrosis. "Steroids" are also an important part of the treatment after a transplant. The many other treatments for specific lung diseases can be discussed with your doctor or with the transplant center. Sometimes transplant centers have special protocols—new experimental therapies—that *may* be useful in your specific disease.
- No matter what sort of lung disease you have, it is very important that good nutrition be part of your treatment. Without this the muscles will become undernourished and weak. You need your muscles to walk, to work, and **to breathe**.
- It is important to keep your muscles strong—not just by feeding them but also by exercising them to keep them efficient. If muscles become weak it is harder to walk, to dress, and to generally stay independent even if there is no change in the lungs. Because of this it is very important to try and include regular walking, with your oxygen if the doctor orders it, in an effort to maintain or improve muscle strength.
- Depending on what your lung disease is, your doctor may decide to refer you for lung transplantation even while he or she is treating your lung disease. This is because some lung diseases don't respond to medicine and can get worse quickly. It is important for you to know about, think about, and be evaluated for a lung transplant early not late. Other lung diseases get worse very slowly, and a lung transplant may not be necessary for many years. Your doctor or the lung transplant center will explain to you the usual pattern of your disease.



GETTING A LUNG TRANSPLANT: WHAT'S INVOLVED

There are five steps involved in getting a lung transplant.

A team of health-care professionals will do the following:



1 Find out if you are healthy enough to receive a new lung.

2 Find out if you are sick enough to need a new lung.

3 Prepare you for your operation. This can take a long time, and there is no guarantee a lung will be found.

4 Perform a lung transplant operation.

5 Help you stay healthy after your lung transplant.

STEP 1. FINDING OUT IF YOU ARE A GOOD CANDIDATE FOR LUNG TRANSPLANT

Before you can have a lung transplant, a team of health-care professionals will want you to think about what is likely to happen if you do get a new lung. This depends on your physical health, your mental health, and your ability to get the transplant medicines you will need.

There are four parts that determine how long this evaluation and preparation phase can take.



1. Visiting a transplant center

- This visit can be arranged by your doctor, a nurse, or a social worker. You can also make an appointment on your own.
- Your doctor or his/her staff will be asked to send your medical records to the transplant center to make sure you currently
 - take your medicine properly
 - have no medical conditions that will prevent you from receiving a transplant

2. Having your physical health evaluated

- At the transplant visit, you will have a very thorough evaluation of your medical condition by a transplant doctor and nurse coordinator.
- The transplant team may require further testing to evaluate
 - your heart
 - your kidneys and gallbladder
 - your stomach, esophagus, and intestines
 - your bladder
 - your teeth and gums
 - your prostate if you are a man
 - your breasts and cervix if you are a woman

There may be other tests and examinations that the transplant team may need.

3. Having your mental health evaluated

- You may need to see a social worker or psychologist to make sure that
 - you have no alcohol or drug addiction
 - you have no emotional problems that may interfere with your health

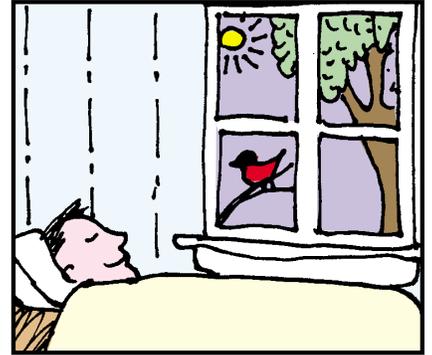
4. Seeing an insurance specialist

You will see an insurance specialist to evaluate your insurance to make sure you have enough coverage for medication after your transplant.

Once it is determined that you are a good candidate for transplantation, the transplant team will work with you to find the best transplant for you.

STEP 2. FINDING OUT IF YOU ARE SICK ENOUGH TO NEED A LUNG TRANSPLANT

Because many lung diseases worsen slowly, or respond to different therapies, the transplant center may wish to review any lung biopsy samples that have been done earlier. They may wish to look at the pattern of your breathing tests over time. They will also want to know if you have had the best possible therapy for your condition. Sometimes a new medication can make a big difference to how you feel and to the worsening of your lung disease. The transplant center does its best to make sure that you have had every chance to get better and live longer with your own lungs before they will recommend that you have a lung transplant.



STEP 3. PREPARING FOR YOUR OPERATION

This next part involves finding a lung for you. This sometimes can take a long time. How long it takes depends on the type of lung transplant you are able to get.

There are three main types of lung transplants.

1. Single lung transplantation

Even though you have two lungs normally, one good one is more than enough to let you live a normal, healthy, active life. When a single lung transplant is done, one of your bad lungs is removed and a new healthy lung is put in to replace it. This will give you 50% to 90% of normal lung function. Remember it has probably been many years since you had 50% of normal lung function. If you look after yourself, and if the transplant goes well, with just one lung you will be able to live a nearly normal life and you won't need oxygen. Single lung transplantation is done usually for emphysema, pulmonary fibrosis, sarcoid, and sometimes pulmonary hypertension (as well as other diseases). It is not done for people who have lung disease associated with infection.



2. Double lung transplantation

This operation involves taking each lung out and replacing it with a new lung. This is all done at the same time using two good lungs usually coming from the same organ donor. This operation is usually done on people who have infection in their lungs. Sometimes it is also done for emphysema or for pulmonary hypertension. Again lung function is usually 60% to 90% of normal after a double lung transplant. The difficult part about a double lung transplant is that it is sometimes hard to get two perfect lungs from an organ donor. Often one lung has been damaged or injured. Because of this, patients often wait longer for double lung transplants than for single lung transplants.

3. Heart-lung transplantation

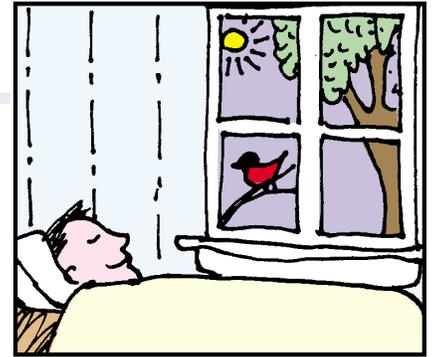
This operation involves taking out the heart and both lungs at the same time and putting in a whole new heart and two lungs—all coming from the same donor. This is the rarest form of lung transplantation. This operation is even more difficult if, in addition to bad lungs, you have a heart that is either damaged by heart disease or abnormal from birth. This is the most difficult transplant to do because it is very hard to find three very good organs—a heart and two lungs—in the same donor. Usually you have to wait at least twice as long for a heart-lung transplant as you do for a double lung transplant.

STEP 4. THE OPERATION

The Operation

The lung transplant operation has been perfected over many years. Here is what will happen:

- When an organ that meets your requirements is donated, you will be called into the hospital by the nurse coordinator.
- The transplant doctors will be checking the donor organ while you are being evaluated and started on medications in preparation for transplantation. If the donated organ is good, then you will be taken to the operating room, put to sleep with an anesthetic, and one of the transplant surgeons will begin the process of removing one of your lungs. Meanwhile the new lung will be removed and transported to you. The new lung (or lungs) will be placed in your chest through a big incision between your ribs. This incision is called a *thoracotomy*. You will be given medications both before and during the operation to prevent you from rejecting the new lung.
- After the operation, you will be taken to a special unit and hospital floor for recovery.
- You will stay in the hospital until your doctor believes you are ready to go home. How long you stay in the hospital will depend on the following:
 - your health
 - how well the new lung is working
 - your ability to learn to take care of your new lung transplant



Transplant Medicines After the Operation

After your operation, you will begin to take strong medicines to keep your body from rejecting the new lung.

- Your **immune system** protects you from foreign invaders, and your body will consider the new lung a foreign invader.
- The immune system will try to reject your new lung. This can damage the lung.
- The medicines you will take will help to suppress the immune system enough to keep your lungs healthy. That's why these medicines are called *immunosuppressants* (*im-u-no-su-pres-ants*) or antirejection drugs.
- In lung transplantation the organ is not matched to you except by a blood type match. In other words the organ is very different from your own tissue. This means that rejection is more common and is often more severe than in some other organ transplants such as kidney transplantation. This is OK, as long as you take your immunosuppressive medication.
- **Because your body will not "forget" that the lung once belonged to someone else, you will have to take immunosuppressive medicines for as long as you have the transplant.**

For more information on transplant medications, please visit the AST website: www.a-s-t.org under the Patient Care Section.

STEP 5. HELPING YOU STAY HEALTHY AFTER THE LUNG TRANSPLANT

What You Will Need to Do

The most important part of the lung transplant is keeping yourself healthy after the transplant. Here is what you will need to do after you are discharged from the hospital:

- Make many visits to the transplant center, and keep all of your appointments. These frequent visits will only last for the first few (6 to 8) months.
- **Take your medicines properly. This is extremely important.**
- **Let the staff at the transplant center know about any problems you may have that may prevent you from keeping your appointments or taking your medicines.**
- It is up to you to watch your weight, to exercise regularly, and to check your breathing tests at home. You will receive a special testing machine to allow you to do this.



Your health and the health of your new lung transplant are dependent on your doing your part.

Why You Will Need to Keep Your Appointments

- Your body may begin to reject your new lung, and YOU may not be able to tell. Although the signs of rejection are experienced by some patients, most patients are not able to tell when their bodies are starting to reject the new lungs.
- If your body is rejecting the new lung, your doctors and nurses CAN tell. Your doctors and nurses will watch you closely, looking for signs of lung rejection and side effects of the medications that you are taking.

How Your Doctor and Transplant Team Can Help You

Your doctors will only be able to tell whether you have rejection by examining you and taking blood tests. Here are the things your doctor and transplant staff will be watching for:

1. Rejection

The risk of rejection never goes away. You will always need to stay on your antirejection medications. The dose of the medications will be decreased, but you should never skip or stop your medications. Your doctors will monitor your breathing tests, your chest x-rays, and some blood tests to try and prevent lung damage due to rejection.

2. Infections

Immunosuppressant medications can increase your chances of certain types of infections. These infections can be treated, but you will need to be aware of fevers, unusual pains, or any other new feelings. As the doses of the antirejection medications are decreased, the risk of infections will also decrease.

3. High Blood Pressure

High blood pressure is a common problem after transplant. The treatment of high blood pressure is important because high blood pressure can damage not only the lung transplant, but can also cause strokes and heart attacks.

STEP 5. HELPING YOU STAY HEALTHY AFTER THE LUNG TRANSPLANT (CONT.)

4. Diabetes Mellitus

Even if you've never had diabetes, the antirejection medications used to suppress your immune system can cause diabetes. If you had diabetes before the transplant, the control of your blood sugar may be more difficult.

5. High Cholesterol

Just like diabetes, the medication used to suppress the immune system can cause the blood cholesterol to go up. High cholesterol is not entirely due to diet high in fatty foods.

6. Reappearance of Lung Disease

Some forms of lung disease can come back in the transplanted lung. Your doctor and transplant staff will monitor your blood, your breathing tests, your lung biopsies, and your chest x-rays for signs of this problem.

7. Cancer

Patients with lung disease are at higher risk for lung cancer. The antirejection medications may increase the risk. In addition the antirejection drugs increase the likelihood of skin cancer and blood cancer. The blood cancer, called *lymphoma*, occurs because of the transplant medications and can cause death or require that your antirejection medicines be decreased. If the antirejection medications are decreased, rejection may occur.

8. Osteoporosis

Osteoporosis is thinning of the bones due to illness, poor diet, poor activity, prednisone, and other antirejection medicines. Your doctor will monitor your bones with a study called a "bone density" test. You will be placed on medications to help prevent or reduce the possibility of bone thinning.

9. Cataract

Prednisone, and perhaps some of the other medications that you will be or were on, can increase the possibility of cataracts in the eyes. These are spots of tissue within the eyeball that block sight. They can be surgically removed. They cannot really be prevented. Your doctor will ask you to see an ophthalmologist (eye specialist) at least once a year to check for cataracts and also for glaucoma (high pressures in the eyeball that can damage your vision).

10. Kidney Disease

The main medicines used for rejection, and also many of the medicines used to treat infection, can hurt your kidneys. Your doctors will try to make sure you have enough medicine to prevent damage to your new lung but not so much that it hurts your kidneys. Sometimes this is hard to do. If you are older or if your kidneys have already been injured by illness or medications, sometimes permanent kidney damage occurs. This can cause swelling in your feet, fluid retention in your body (and in your new lung), and a feeling of fatigue and of being unwell. This can be a very serious problem. So it is very important to have the regular blood tests your doctor may order to check that the levels of your rejection medications are not too high or too low.

