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Getting A New Lung

Facts About Lung Transplants



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Getting a New Lung

Facts About Lung Transplants

When you have a lung transplant, there is a lot to do before and after the operation. Before the operation, you will work with the transplant team to complete an evaluation. After the operation, you will need to see your transplant team to make sure your lung keeps working well and you stay in good health. How long a new lung lasts depends on many factors. Some of these factors you can control. Some you cannot control.

You and the transplant team will work together to keep you and your new lung healthy.

What Happens When Your Own Lungs Fail?

Different diseases can harm your lungs and cause them to work poorly. Some of these diseases can damage the lungs very quickly—sometimes in just weeks or months. Other diseases can take years to do damage. If you are really fit and physically active, you will know when your lungs are not working well. If you are not active and are out of shape, it will be much harder for you to notice something is wrong with your lungs.

Some lung diseases start with a cough. You may cough up mucus or phlegm. Some start with an infection. Others may start with feeling really tired, being dizzy and lightheaded, or you may feel short of breath. The signs will depend on the reason your lungs are failing.

Here are some common diseases that can cause your lungs to fail, meaning you need a transplant:

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

There are other diseases that cause lung failure. Some are very rare. Your regular doctor or your transplant doctor can tell you more about which lung disease you have.

What are Some Ways to Treat Lung Disease?

There are many treatments for lung disease. How your doctors treat your lung disease depends on which disease you have.

Some diseases will require you to use oxygen and/or medications to fight off infections. Many diseases will require you to be on steroids (a pill or intravenous form of prednisone). If you have pulmonary fibrosis, emphysema, or cystic fibrosis, your doctor

may put you on steroids to reduce the inflammation in your lungs. Steroids are also an important part of your treatment after the transplant.

Sometimes transplant centers offer new therapies that can help your disease.

Good nutrition is a very important part of your treatment. You need to eat right so your muscles will be strong.

Exercise will also make your muscles stronger. If your muscles are weak, it will be harder for you to walk, get dressed, and be able to help yourself, even if there is no change in your lung condition. This is why you need to walk on a regular basis—with your oxygen if the doctor orders it. Walking will help you maintain and strengthen your muscles.

Depending on which disease you have, your regular doctor may refer you for a lung transplant, even while treating your lung disease. This is because some lung diseases do not respond to medicine and can get worse quickly. It is important for you to be evaluated for a lung transplant early in your disease. Other lung diseases get worse very slowly, so you may not need a lung transplant for many years.

Your doctor or the lung transplant center can explain your disease and how it will likely progress.

What Happens During a Lung Transplant?

There are five steps involved in getting a lung transplant. Your team of health care professionals will:

1. Decide if you are sick enough to need a new lung.
2. Decide if you are strong enough to undergo lung transplantation.
3. Search for a new lung that is the right match. This can take a long time and there is no guarantee a lung will be found.
4. Perform a lung transplant.
5. Help you stay healthy after your lung transplant.

Step 1. Decide if You are Sick Enough to Need a New Lung

Because many lung diseases worsen slowly, or respond to different therapies, the transplant center may want to review any lung biopsy samples that were done earlier. They may look at the pattern of your breathing tests over time. They will also review imaging or x-ray studies of your chest and other organs to evaluate your lung disease and be sure you do not have other health conditions that might prevent a successful transplant.

They will also want to know if the therapy you have had for your condition was the right one for you. Sometimes a new medicine can make a big difference in how you feel and the condition of your lung. The transplant center wants to make sure you have every

chance to get better and live longer with your own lungs before they recommend you have a transplant.

Step 2. Decide if You are Strong Enough to Undergo Lung Transplantation

Before you can have a lung transplant, a team of health care professionals will talk with you about what may happen if you get a new lung. This can depend on your physical health, your mental health, and how easy it will be for you to get the transplant medicines you will need.

There are four parts to this phase.

First you will visit a transplant center.

You, your doctor, a nurse, or a social worker can schedule this visit. Your doctor's office will send your medical records to the transplant center before your appointment so your transplant team can:

- Learn about your current lung disease
- Learn about your overall health
- Make sure you take your medicine properly
- Make sure you have no other illness that would prevent you from receiving a transplant
- Make sure you will have enough help at home after you get transplanted

During this visit, your physical health will be evaluated.

The transplant team will do a complete evaluation of your physical health. You may need to have tests to evaluate your:

- heart
- kidneys, gallbladder, and liver
- stomach, esophagus, and intestines
- bladder
- teeth and gums
- prostate, if you are a man
- breasts and cervix, if you are a woman
- bones
- nutritional status
- fitness level

The transplant team may order other tests as well.

Then your mental health will be evaluated.

You may need to see a social worker or psychologist to make sure you are not addicted to alcohol or drugs. You will also be evaluated with regards to your risk

of smoking relapse if a previous smoker. It is critical that you demonstrate sustained abstinence from all tobacco products to be considered a candidate and remain so after transplantation. It is also important to make sure you have no emotional problems that can interfere with your health.

Finally, you will see an insurance specialist.

An insurance specialist will review your insurance to make sure your policy covers the transplant operation and the medicines you will need after your transplant.

If the transplant team decides you are a good candidate for the operation, they will work with you to find a new lung.

Step 3: Prepare You for Your Operation

This step involves finding a new lung for you. Sometimes this can take a long time. How long it takes depends on how sick you are and the type of lung you need.

There are four main types of lung transplants.

The first three depend on finding the right donor who has just died but has a healthy lung. The fourth type depends upon finding two healthy living donors. Your doctors will determine which type of lung transplant is best for you and your condition.

Single lung transplantation

Although you have two lungs, certain patients can live a normal, healthy, and active life with just one good lung. When a single lung transplant is done, one of your bad lungs is removed and a new healthy lung is put in its place. This will give you 50% to 90% of normal lung function. It has probably been years since you had 50% of normal lung function. If you take good care of yourself, and if the transplant goes well, you should be able to achieve a good quality of life with just one new lung. And you won't need oxygen.

Single lung transplants are usually done for patients with emphysema, pulmonary fibrosis, sarcoid, and sometimes pulmonary hypertension. They are also done for other diseases too. They are not done for people who have lung disease caused by infections.

Double lung transplantation

This operation involves taking both lungs out and replacing them with new lungs. Both lungs are replaced at the same time with two good lungs usually coming from the same organ donor. People with lung infections usually have this kind of transplant. Patients with emphysema or pulmonary hypertension may also have this kind of transplant. Lung function is usually 60% to 90% of normal after a double lung transplant.

The difficult part about a double lung transplant is it can be hard to get two perfect lungs from one donor. Often one lung has been damaged. Because of this, patients often have to wait longer for double lung transplants than for single lung transplants.

Heart-lung transplantation

This operation involves taking out the heart and both lungs at the same time and putting in a new heart and two new lungs—all from the same donor. This is the rarest form of lung transplantation. It is the most difficult transplant to do because it is very hard to find three good organs from one donor. Usually you have to wait at least twice as long for a heart-lung transplant as you do for a double lung transplant.

Living donor lobar transplantation

In this operation, two healthy living donors each give you one lobe (out of five normally present). Although previously performed in very sick young patients, with the change in lung allocation in the U.S. the volume of live donor transplants has decreased dramatically and the operation is rarely performed because of the potential risks to healthy donors.

Step 4: Perform a Lung Transplant Operation

When a new lung is found for you, the nurse coordinator at the transplant center will call you to come to the hospital. While you are being evaluated, the new lung will be removed from the donor and sent to the transplant center where doctors will check it to make sure it is the right match for you. You will be started on medications that will keep your body from rejecting the new lung. If the donated lung is the right match, you will be taken to the operating room and put to sleep with an anesthetic.

During surgery, the transplant surgeon will remove one or both of your lungs. The new lung(s) will be placed in your chest through an incision made between your ribs. This incision is called a thoracotomy.

After the operation, you will be taken to a special hospital unit to recover. You will stay in the hospital until your doctor feels you are ready to go home. How long you stay will depend on your health and how well the new lung is working. It will also depend on how quickly you learn to take care of your new lung.

Transplant Medicines

After your operation, you will take strong medicines to keep your body from rejecting your new lung. Your immune system protects you from foreign invaders. Your immune system will think the new lung is a foreign invader, so it will try to reject it. This can damage the lung. Because of this, you will take immunosuppressants (i-mu-no-su-pres-ants), also called anti-rejection medicines. These drugs slow down the immune system enough to keep your transplanted lung healthy. Your immune system will always know that the lung once belonged to someone else, so you will need to take these drugs for the rest of your life.

Your donor lung will be compatible with your blood group (but not necessarily identical to your blood group). Because of complex immunological factors that are not fully understood, rejection is more common and is often more severe after lung transplantation than in other organ transplants. You can help prevent this process by taking your immunosuppressive drugs.

For more information on transplant medications, please visit the Patient Education section of the AST website at www.myAST.org.

Step 5. Help You Stay Healthy After Your Lung Transplant

It is very important that you keep yourself healthy after your transplant. Here are a few important reminders:

- After you leave the hospital, make sure you go to the transplant center often. Also be sure you go to all of your doctors' appointments. **This is very important!**
- Take your medicines properly. **This is extremely important!**
- Watch your weight and be sure to get some exercise on a regular basis.
- Be sure to tell the staff at the transplant center if you have problems keeping your appointments or taking your medicines.
- You need to also check your blood pressure, temperature and weight at home. Many centers provide a home spirometer, which is a special machine that can measure how well your lung is working. You should use your home spirometer frequently, as directed by your transplant team.

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

Your Appointments

If your body begins to reject your new lung, you may not know it. Some patients may have the signs, but most do not recognize them. If your body is rejecting the new lung, your doctors and nurses will know it. **This is why it is so important to go to all your medical appointments.** Your health care providers watch closely for signs of rejection and side effects from the medications. But, they must examine you and test your blood to know for sure. They will also do breathing tests and chest x-rays.

Your doctor and transplant team will watch for these signs:

1. Rejection

The risk of rejection never goes away. You will always need anti-rejection drugs. Your doctor may lower the dosage, but you should never skip or stop taking the drugs. Your doctors will monitor your breathing tests, chest x-rays, and blood tests to prevent lung damage due to rejection. There are two kinds of rejection: acute and chronic.

- Acute rejection may be treated with added immunosuppression drugs, including high doses of steroids. It usually gets better with the right therapy.
- Chronic rejection may also be managed with changes in immunosuppression drugs, but this does not always work. If the rejection continues, your lung function may decline and you may get infections often. In some patients, this will stabilize, but in others it may limit how active the patient is able to be and affect how long they live. This is a problem that medical research scientists keep trying to solve.

2. Infections

Immunosuppressant drugs can increase your chances of getting infections. These infections can often be treated, but you need to tell your doctor right away if you get a fever, cough, are short of breath, or have other new symptoms. The risk of infection will go down when your doctor lowers the dosage.

3. High Blood Pressure

High blood pressure is a common problem after transplant. If you have high blood pressure, you need to be treated because high blood pressure can cause strokes and heart attacks. It can also damage your kidney.

4. Diabetes Mellitus

Anti-rejection medications can cause diabetes. If you had diabetes before your transplant, you may find it harder to control your blood sugar level after your transplant.

5. High Cholesterol

Your anti-rejection medication can also cause high cholesterol. There are some medications called statins that control cholesterol and may help prevent rejection because they also control inflammation.

6. Lung disease

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

7. Cancer

Lung transplant patients are at risk for different types of cancer like lung cancer, skin cancer, or lymphoma (a blood cancer). Anti-rejection drugs can increase your risk of getting cancer. It is important to wear sunscreen and get a skin check-up on a regular basis. Any new skin lesions should be evaluated by a skin doctor.

8. Osteoporosis

Osteoporosis is thinning of the bones due to illness, poor diet, poor activity, prednisone (a steroid medication), and anti-rejection drugs. Your doctor will check your bones using a bone density test. You will be placed on medications to help prevent or reduce the possibility of bone thinning.

9. GERD (gastroesophageal reflux disease)

Lung transplant patients are at high risk for developing GERD, or bad heartburn. Some symptoms of GERD are nausea, throwing up, and stomach pain. If you start to have these symptoms, let your doctor know right away. GERD can sometimes lower your lung function after transplantation. It can often be treated with oral medicines, but surgery may be needed.

10. Cataract

Prednisone and other drugs can cause cataracts, which are cloudy spots on the lens of your eye. You cannot prevent cataracts, but they can be surgically removed. Your doctor will ask you to see an eye doctor (ophthalmologist) at least once a year to get checked for cataracts and glaucoma. Glaucoma is pressure in the eye that can damage your vision.

11. Kidney Disease

The main medicines used to treat rejection, and 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 rejection of your new lung, but not so much that it hurts the kidneys. Sometimes this is hard to do. If you are older, or if your kidneys have already been injured by illness or medications, you may have permanent kidney damage. This can cause your feet to swell and your body to retain fluid. You may feel very tired and not feel well overall. Kidney disease is a serious problem. So be sure to go for regular blood tests. These tests make sure the levels of your anti-rejection medications are not too high or too low.

Living with a Lung Transplant

A lung transplant is the last option for people with advanced lung disease. To have a successful transplant, a patient must be carefully evaluated before their operation. After the operation, the patient must be monitored closely at the transplant center. For most patients, the transplant can mean they are trading in one set of problems (their lung disease) for a new set of problems (rejection, immunosuppression and its risks). Ideally, the transplant patient's lung will function better and the patient will enjoy life and live longer than they would have if they did not get the transplant. Most patients are able to enjoy being active, traveling, going to school or work, and sharing responsibilities with friends and family.