

Getting A New Lung: Facts About Lung Transplants

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WHY IS IT IMPORTANT TO HAVE HEALTHY LUNGS?

Your lungs play an important role in the overall health of your body. Your lungs will help to bring oxygen to your other cells and allow them to function. Your lungs will also remove carbon dioxide from your body.

WHO CAN GET A LUNG TRANSPLANT?

People get a lung transplant when their lungs stop working well (respiratory failure) and other treatments haven't helped.

WHAT CAUSES THE LUNGS TO STOP WORKING?

Many diseases can harm your lungs and cause them to stop working well. Some diseases can damage the lungs in weeks or months, while others can take years.

If you're physically active and fit, you'll know when your lungs aren't working well. If you're not active and are out of shape, it'll be harder for you to notice a problem. You may have:

- · A cough, sometimes with mucus or phlegm
- · An infection in your lungs
- · Tiredness, dizziness, and feeling lightheaded
- · Shortness of breath

To learn more about common diseases that can cause lung failure, click on these links:

- · Pulmonary Fibrosis
- COPD
- Cystic fibrosis
- Bronchiectasis
- Sarcoidosis
- Alpha 1 Antitrypsin Deficiency

HOW DO DOCTORS TREAT LUNG DISEASE?

There are many treatments for lung disease. Your doctors will use the best treatment for your type of lung disease:

- At first, doctors will give you medicines, such as antibiotics to fight infections or steroids to lower inflammation (swelling) in your lungs
- You may need to use a machine that gives you extra oxygen to help you breathe
- Doctors will ask you to eat healthy foods and be active every day — especially walking to keep your muscle strength. This will help you be able to get dressed, do things around your house, and other daily activities.

Your regular doctor may refer you for a lung transplant, even while treating your lung disease. Some lung diseases get worse very slowly and others get worse quickly. You may want to be evaluated (checked) for a lung transplant early in your disease, even though you may not need a lung transplant for many years. Your regular doctor or the lung transplant center can explain your disease and if it will likely get worse slowly or quickly.

WHAT HAPPENS WHEN YOU DECIDE TO GET A LUNG TRANSPLANT?

When you and your doctors decide that a lung transplant may be right for you, they'll help start your journey to getting a new lung. Your doctor or their staff will send your medical records to the transplant center and help you schedule a visit there.

The health care team at the transplant center will guide you through a 5-step process to:

- Decide if you need a new lung and what kind of transplant you need
- · Decide if you are strong enough to get a lung transplant
- Search for a new lung this can take a long time and there is no guarantee of a lung that is a good match
- · Do lung transplant surgery
- · Stay healthy after your lung transplant

Step 1: Decide if you need a new lung and what kind of transplant you need

Many lung diseases worsen slowly or get better with different treatments. The transplant team will first see if a new medicine can improve your lung disease. They want to give you every chance to get better with your own lungs before they recommend a lung transplant.

The team will look at tests and treatments you've already had, such as:

- Lung biopsy small samples of lung tissue that doctors look at under a microscope
- · The pattern of your breathing tests over time
- Imaging tests such as x-rays of your chest and other organs

 this helps them check your lung disease and make sure
 you don't have other health problems that might prevent a
 successful transplant

There are 4 main types of lung transplant. Your doctors will decide which type of lung transplant is best for you:

Single lung transplant

Doctors usually do single lung transplants for patients with emphysema, pulmonary fibrosis, and some other diseases. They don't do them for patients with cystic fibrosis or pulmonary hypertension.

Although people have 2 lungs, people can live a normal, healthy, and active life with just one good lung. When doctors do a single lung transplant, they remove one bad lung and put a new healthy lung in its place. This will give you 50% to 90% (half or more) of normal lung function.

50% is probably more normal lung function than you've had for years. 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 extra oxygen.

· Double lung transplant

Patients with emphysema, pulmonary fibrosis, cystic fibrosis and pulmonary hypertension may get this type of transplant. In this surgery, doctors take both lungs out and replace them with new lungs. They replace both lungs at the same time, usually from the same donor. Lung function is usually 60% to 90% (more than half) of normal after a double lung transplant.

Heart-lung transplant

Doctors take out the heart and both lungs at the same time and put in a new heart and 2 new lungs—all from the same donor. This is the rarest type of lung transplant because most donor heart organs are given to patients who only need heart transplants first. Thus, it is difficult to find all three organs (one heart and two lungs) for one recipient. Usually the wait

for a heart-lung transplant is much longer than for a double lung transplant.

Living donor lobar transplant

In this surgery, 2 healthy living donors each give one of their 5 lobes (lung parts). Doctors have used this type for very sick young patients, but rarely do it now because of possible risks to healthy donors.

Step 2: Decide if you are strong enough to get a lung transplant

Before you can have a lung transplant, a team of health care professionals will talk with you about a lung transplant and what it requires physically, mentally, and financially.

There are 4 parts to this step.

· Your first visit to the 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 visit so your transplant team can:

- · Learn about your lung disease and your overall health
- · See if you are taking your medicine the right way
- Make sure you don't have other health problems that could prevent you from getting a transplant
- Make sure you'll have enough help at home after you get a transplant

· Physical health check

The transplant team may do many tests, including on 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 to make sure that you are not too underweight or overweight
- · Fitness level

· Mental health check

A social worker, psychologist, or other member of the transplant team will:

- Make sure you are not dependent on alcohol or drugs
- If you used to smoke, see if there's a chance you
 might start smoking again. To even be considered for
 a transplant, you must show that you have given up
 tobacco in all forms and you will never use them again.
- See if you have emotional problems that could interfere with your health or your ability to manage medicines, doctor visits, and other health needs after a transplant
- Make sure you have support from a caregiver someone to help you in the first few months after transplant with medicines, travel to the transplant center, and other needs

· Financial check

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

Once you have undergone all the testing and clinical visits listed above, your transplant team will determine if the benefits outweigh the risks of lung transplant for you. Once it has been decided by your entire lung transplant team that you are a good candidate for lung transplant, you will be placed on the lung transplant list.

You will receive a score called the Lung Allocation Score while you are on the lung transplant wait list. This score is determined by how sick you are before transplant and how likely you are to survive after one year. The higher the score, the higher you are on the transplant list.

Step 3: Search for a new lung

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 transplant you need.

When donor lungs become available they are matched with people who need a transplant based on:

- Blood type
- How close or far away the new lungs are
- How severe their lung disease is to estimate how severe your lung disease is, your transplant team will use the results of your physical tests to decide on your <u>Lung Allocation Score</u>

Step 4: Do the lung transplant surgery

When a new lung is found for you, a member of your transplant team will call you to come to the hospital. To prepare for your transplant surgery, the transplant team will:

- Do a final check to make sure you're strong enough for the surgery
- Check the donor lung to make sure it's the right match for you

Next, doctors will take you to the surgery room. They'll give you an anesthetic to put you to sleep and medicines to prevent your body from rejecting the new lung.

During surgery, the transplant surgeon will make an incision and remove one or both of your lungs. They'll place the new lung(s) through an incision (cut) between your ribs.

After the surgery, doctors will take you to a recovery room. You'll stay in the hospital until your doctor feels you are ready to go home. How long you stay will depend on your health, how well the new lung is working, and how quickly you learn to take care of your new lung.

Step 5: Stay healthy after your lung transplant

Your health and the health of your new lung transplant depend on you doing your part to stay healthy. In the weeks and months after your transplant surgery, you can help your new lung work its best by doing these **4 important things**:

- Take your transplant medicines exactly the way the doctor tells you to
- Go to all of your visits at the transplant center and your regular doctor's office tell them if you have trouble taking your medicines or getting to visits. They will need to watch for signs that your body may be rejecting the new lung. They'll do an exam and test your blood to know for sure. They will also do breathing tests and chest x-rays.
- Take care of your health. This includes eating healthy foods, being active most days of the week, and resting when needed.
- You will also need to check your blood pressure, temperature, and weight at home every day. Many transplant centers give a home spirometer, which is a special machine that can measure how well your lung is working. Use your home spirometer often — your transplant team will tell you how often.

Take your transplant medicines

After your surgery, you will need to take strong medicines to keep your body from rejecting your new lung. Your body's immune system protects you from germs and other foreign things, like viruses, that can make you sick. Your immune system will think the new lung is foreign and will try to reject it. This can damage your new lung and cause it to fail.

For reasons doctors don't fully understand, rejection is more common and is often more severe after lung transplants than after other organ transplants.

To protect your new lung, you will take immunosuppressant (i-mu-no-su-pres-ant) medicines, also called anti-rejection medicines. These medicines suppress (calm) the immune system enough to keep your new lung healthy. Your immune system will always treat your lung as foreign, so you'll need to take anti-rejection medicines for the rest of your life.

To learn more about transplant medicines, visit the Patient Education section of the AST website at www.myAST.org.

Go to your medical visits

After you get a new lung, it's very important to go to all visits with your regular doctor and the transplant team. This is because your doctors:

- Will recognize signs that your body is rejecting your new lung
 — signs that you may miss
- Will watch for side effects from the medicines you take
- Must examine you, test your blood and breathing, and do chest x-rays

Your doctor and transplant team will watch for these warning signs and side effects:

Rejection

To help prevent rejection:

- · Never skip or stop taking the medicines
- Go to all of your appointments so doctors can do breathing tests, chest x-rays, and blood tests to prevent lung damage caused by rejection

There are 2 kinds of rejection:

 Acute rejection — this type of rejection occurs quickly usually in the first year. This type of rejection may be treated with added immunosuppressants, including high doses of steroids. It usually gets better with the right treatment. • Chronic rejection — this type of rejection occurs more gradually usually after the first year. This type of rejection may also be treated with changes in immunosuppressants, but this does not always work. If the rejection continues, your lung may not work as well and you may get infections often. In some patients, rejection will slow down, but in others it may limit how active they can be and how long they live. This is a problem that researchers keep trying to solve.

Infections

Immunosuppressant medicines can raise your chance of getting infections. 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 chance of infection will go down when it's safe enough for your doctor to lower the dose (amount) of medicines you take.

· High blood pressure

This is a common problem after transplant. It can cause strokes and heart attacks and damage to your kidney.

Diabetes

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

· High cholesterol

Your anti-rejection medicines can also cause high cholesterol. Doctors may give you medicines called statins to lower your cholesterol. These medicines may help prevent rejection because they also lower inflammation (swelling) in your body.

· Lung disease

Some forms of lung disease can come back in your new lung. Your doctor and transplant staff will check for signs of this problem.

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 raise your risk of getting cancer. It is important to wear sunscreen and get a skin check-up every year. Tell your doctor about any new moles or marks on your skin.

Osteoporosis

Anti-rejection medicines can cause osteoporosis, which is thinning of the bones. Your doctor will order a bone density test and may have you take medicines that help prevent bone thinning.

· GERD (gastroesophageal reflux disease)

Lung transplant patients have a high chance of getting GERD, which is bad heartburn. If you have an upset stomach, throwing up, and stomach pain, let your doctor know right away. GERD can sometimes lower your lung function. It can often be treated with medicines you take by mouth, but you may need surgery.

· Cataracts and glaucoma

Your doctor will ask you to visit an eye doctor at least one time a year to get checked for eye problems such as:

Cataracts

Cloudy spots on the lens of your eye. Anti-rejection medicines can cause these. You can't prevent cataracts, but an eye doctor can remove them.

Glaucoma

Pressure in the eye that can damage your vision

Kidney disease

Anti-rejection medicines and infection medicines you may take after a transplant can damage your kidneys. Doctors will try to give you enough medicine to prevent rejection of your new lung, but not so much that it hurts your kidneys. Sometimes this is hard to do.

Tell your doctor if you have these symptoms, because kidney disease is a serious problem. You will need to get regular blood tests to make sure your anti-rejection medicine levels are not too high or too low.

Depression and anxiety

Having lung disease and getting a transplant can be stressful and even scary. It's normal to feel overwhelmed, excited, anxious, scared, or depressed before and after a lung transplant.

Every patient getting a transplant needs a strong support system. It's important to tell your transplant team how you're feeling and adjusting after your surgery. Many patients find it helpful to reach out to other patients who are waiting for a transplant or are living with a new lung.

Living with a lung transplant

After surgery, you must be closely checked at the transplant center. For most patients, the transplant can mean they're trading in one set of problems (their lung disease) for a new set of problems (rejection, immunosuppression, and its risks).

Ideally, your lung will work better after a transplant, and you will enjoy life and live longer. Most lung transplant patients can be active, travel, go to school or work, and share daily life with friends and family.

ADDITIONAL LUNG TRANSPLANT RESOURCES

- SRTR Website
- UNOS Facts about Lung Transplantation
- Find and Compare Lung Transplant Programs
- AST Guide to Anti-Rejection Medicines
- <u>Lung Transplant Foundation</u>
- American Lung Association Lung Transplant Fact Sheet