

PATIENT GUIDE

LUNG TRANSPLANT: A LAST RESORT, OR A NEW LEASE ON LIFE?



The thought of getting a lung transplant can come with a flood of emotions. While it gives hope to imagine a life with easier breathing and more mobility, it can also be frightening to consider replacing the worries of lung disease with the worries of a transplant.

Many people have been in your shoes before. And many who chose to pursue a transplant found that the risks were worth everything in the end:

“I can’t explain what it means to be able to just breathe again. It’s a blessing. The freedom I now have ... it’s a new lease on life.”

— Sharon

“Since my surgery, I am back to myself. Temple gave me back my life and we are able to continue our life together.”

— Bobby

“I feel blessed. If I hadn’t done this, I don’t know where this journey would have ended.”

— Jim

A lung transplant can be a life-changing experience with many quality of life benefits. But you might still be unsure if it’s right for you.

That’s what this guide is for. We hope it will help you understand the lung transplant process here at Temple Lung Center and help you decide if pursuing a lung transplant makes sense.

WHEN IS A LUNG TRANSPLANT NEEDED?

Lung transplants are reserved for patients with the most severe lung diseases. You must have difficulty accomplishing daily activities and have a poor outlook for long-term survival. In most cases, other medical and surgical treatment options are no longer viable.

Conditions that may lead to transplant include:

- **Interstitial Lung Disease (ILD)** — ILD is a group of conditions that cause scarring of the lungs, called fibrosis. This scarring makes the lungs stiff, which makes it hard to breathe. Exposure to chemicals or certain drugs and medical treatments can cause ILDs. Examples of ILDs include idiopathic pulmonary fibrosis (IPF), hypersensitivity pneumonitis, sarcoidosis and asbestosis.
- **Chronic Obstructive Pulmonary Disease (COPD)** — COPD consists of two diseases: chronic bronchitis and emphysema. COPD causes less air to flow in and out of the lungs, making it hard to breathe. The most common cause of COPD is smoking.
- **Pulmonary Hypertension** — Increased pressure in the arteries that supply blood to the lungs is called pulmonary hypertension. It can be inherited or caused by certain drugs or medical conditions.
- **Bronchiectasis** — With bronchiectasis, chronic inflammation and/or infection causes the walls of your airways to thicken. Mucus then fails to drain normally and causes repeated infections. As this cycle continues, lung function is lost over time. You're more at risk for bronchiectasis if you have a condition such as cystic fibrosis, immunodeficiency disorders, allergic bronchopulmonary aspergillosis or primary ciliary dyskinesia.
- **Cystic Fibrosis** — This condition affects the cells that produce mucus, making them sticky and thick. The mucus clogs airways and traps germs, leading to infections and other complications. Cystic fibrosis is inherited and most people are diagnosed by 1 year of age. However, there is a small percentage of people who are not diagnosed until they are teens or adults.



WHAT TO EXPECT

Here's what to expect from the lung transplant process, one step at a time:



1. CALLING AND TRANSPLANT APPROVAL

In order to schedule an in-person or telemedicine appointment with Temple Lung Center, a referral from a medical professional is necessary. Schedule a lung transplant consultation at **(888) 748-3818** between the hours of 8 a.m. and 5 p.m., Monday through Friday.

During your first appointment, the pulmonologist will evaluate your physical and mental health and ask questions about your medical history. If these preliminary questions determine you may be eligible for a lung transplant, then you'll be referred for a lung transplant evaluation. During the evaluation, you'll need to undergo several medical tests.

Possible preliminary tests include:

- Blood test.
- Chest X-ray.
- Echocardiogram.
- CT scan.
- Cardiac catheterization (right- and/or left-heart catheterization).
- Pulmonary function test (may include a six-minute walk test).
- Urine test.
- Ventilation perfusion scan.

You may also need these general health tests:

- Colonoscopy.
- Dental exam.
- Pap test (for women if they haven't had a test within a year).
- Mammogram (for women over 40 who haven't had a test within a year).
- PSA blood test (for men over 40).

During the evaluation, you'll meet with members of the lung transplant team. You're encouraged to invite family members to meet the team so they can ask questions as needed. The transplant team will discuss your test results, inform you of your eligibility and outline the risks and benefits of transplantation.

Temple Lung Center follows an individualized approach when it comes to approving patients for transplants. In some cases, this has meant patients who have been turned away elsewhere were approved for a transplant at Temple.

While you wait for the team's decision, spend time with family and friends to keep up a positive attitude. It's also wise to stay physically active (if possible) so you can be in good shape should you receive a transplant.

If you're eligible for a lung transplant, you'll need to finish all requirements to be placed on the national organ transplant waiting list.



2. THE WAITING LIST PROCESS

The lung transplant waiting list is administered by the United Network for Organ Sharing (UNOS). Most patients wait between three to six months for a donor lung, but the time varies based on many factors. The wait can be understandably difficult, but there is much you can do in the meantime.

First, prepare a financial plan. Some costs are covered by private insurance or Medicare/Medicaid. Others, such as child care, lost wages and lodging near the hospital, must be paid for out of pocket. Temple Health's social workers can help you find financial resources that may be able to help you to cover your medical expenses.

You should also stay healthy and active while waiting for a transplant and find ways to reduce stress. Temple's lung transplant team can help you find a diet and exercise plan that works for you.

Please note that you're required to stay in close contact with the Temple lung transplant team during the waiting period. Let the team know about any health changes or out-of-town trips. This information will help the team know how to find you if a lung becomes available.

When a donor lung becomes available, you will be called and need to come to the hospital immediately. Because time is critical, it's important that you keep your phone charged, turned on and have it on you at all times. Have a bag packed and ready so you can quickly leave for the hospital.



3. TRANSPLANT SURGERY AND WHAT COMES AFTER

Upon your arrival at the hospital, you'll be evaluated to make sure you're able to handle transplantation. At the same time, the donated organ will be examined to make sure it's in good shape. If the organ passes inspection, the transplant surgery will begin. If the organ fails inspection, the transplant will be canceled. Please be assured that your place on the waiting list will remain the same.

After surgery, you'll stay in the hospital for about two to three weeks, first in the ICU and then a special unit for lung patients. Some stays can be longer. During this time, you'll recover and begin education and physical rehab. This will continue after you leave the hospital.

When you go home, you'll need help from a nurse or physical therapist. You will also need a family member or friend to help with care. The Family Medical Leave Act (FMLA) may protect the job of a family member who decides to take time off from work to help.

Recovering from lung transplant surgery can take six to eight weeks. This process includes exercise, home testing/monitoring, follow-up appointments for chest X-rays and possible screening bronchoscopies at 1, 3, 6 and 12 months after transplant.

You will be monitored closely for signs of organ rejection and infection. Due to the drugs you'll need to protect your new lungs, you may develop other health conditions like diabetes, high blood pressure and kidney problems. If caught early, these conditions can be managed.

Once you've recovered, it's time for your life to begin again. You'll get to breathe easily without the aid of an oxygen tank. You'll be able to keep up with friends and family. And you'll be more likely to be there for the big moments in your life.

WHAT MAKES TEMPLE DIFFERENT?

Established in 1994, the Temple Lung Transplantation Program is one of the most experienced and well-respected in the Mid-Atlantic region. Our team has performed over 950 lung or heart/lung transplants since the program's founding and in 2018, we performed more lung transplants than any other program in the nation.

Thanks to our experience, we've been able to accept patients who are considered challenging and complex, including some who may not have qualified for a transplant at other hospitals. Patients seeking a lung transplant are advised to reach out to Temple Lung Center for a second opinion.

The Temple lung transplant team includes many doctors, surgeons and staff members who work together to help ensure that each lung transplant is as successful as possible. This team includes the:

- **Transplant nurse coordinator** — Organizes care before and after the transplant. They ensure you and your caregiver are informed about the transplant process and coordinate testing and follow-up care.
- **Transplant surgeons** — Specialize in transplantation and perform the surgery. They will work with you before the transplant through the time that you're discharged from our hospital.
- **Transplant pulmonologist** — Manages medical care, tests and medications in relation to the patient's transplant. They work closely with the transplant surgeon and coordinators.
- **Staff nurses** — Work in collaboration with the rest of the transplant team to manage and treat medical needs during the your hospital stay.
- **Financial coordinator** — Helps to ensure medical services are covered and approved by insurance.
- **Social worker** — Helps coordinate the miscellaneous needs of the patient and family, including lodging, transportation, finance and mental health needs.
- **Family doctor** — Acts as your source for primary care throughout the lung transplant process and coordinates with the transplant team to stay updated on your status.
- **Clinical immunologist** — Diagnoses and treats any diseases caused by a disordered immune system.
- **Psychologist** — Conducts a psychological evaluation if you are referred to a psychologist prior to your approval for a transplant. The psychologist can also provide therapy services as a form of post-transplant support.
- **Dietitian** — Creates a plan on how your nutritional needs can be met before and after surgery.

A DIFFERENT TAKE ON LUNG TRANSPLANTS

You might think that no matter where you go, the qualification process for a lung transplant is probably the same. But Temple Lung Center is different. We take an individualized approach when it comes to accepting patients for lung transplants. This means we are occasionally able to take patients who normally wouldn't qualify for a lung transplant.

How is this possible? Because our team has advanced levels of training and experience when it comes to lung transplants. We also evaluate each patient holistically and consider them on an individualized basis. So if you've put off making an appointment because you think you won't qualify, it might be time to try again. We've been able to accept patients who are considered challenging and complex. Whatever the reason you may have been turned away elsewhere, we may be able to help.

Come for a second opinion at Temple Lung Center. There's no commitment, and we'll help find the path that's right for your needs. You can make an in-person or telemedicine appointment by calling (888) 748-3818 or visiting our website at templehealth.org/schedule-appointment.

Temple Health refers to the health, education and research activities carried out by the affiliates of Temple University Health System (TUHS) and by the Lewis Katz School of Medicine at Temple University. TUHS neither provides nor controls the provision of health care. All health care is provided by its member organizations or independent health care providers affiliated with TUHS member organizations. Each TUHS member organization is owned and operated pursuant to its governing documents.

Non-discrimination notice: It is the policy of Temple University Hospital, Inc. that there shall be no exclusion from, or participation in, and no one denied the benefits of, the delivery of quality medical care on the basis of race, ethnicity, religion, sexual orientation, gender, gender identity/expression, disability, age, ancestry, color, national origin, physical ability, level of education, or source of payment.



How We Are Protecting You

SAFETY PRECAUTIONS AND PROTOCOLS DESIGNED TO PROTECT OUR PATIENTS AND STAFF

The safety of our patients and staff is our highest priority, especially now. Our team of clinicians have implemented numerous safety protocols to protect our patients and staff, based on the guidelines of the CDC, local and federal government, and leading medical associations. These include:

- Everyone must wear a mask while in the hospital. We encourage patients to wear their own mask. However, we will provide a mask to those who do not have one
- Patients and visitors will be screened at entryways for COVID symptoms
- Thorough cleaning and disinfecting at least several times per day, based on infection control guidelines
- Staff use appropriate PPE for each procedure and appointment, based on CDC guidelines
- The isolation of COVID patients into dedicated hospital units, separated from where your appointments and procedures are located
- Social (physical) distancing requirements including seat spacing in waiting areas, minimizing the number of people in lobbies, waiting areas and other public locations such as elevators
- Visitor restrictions are in place for both inpatient and outpatient services
- COVID testing on patients before procedures
- Employees are encouraged to participate in a daily symptom monitoring application, which is reviewed in real time by clinical staff



HEAR FROM DR. AMY GOLDBERG, SURGEON-IN-CHIEF, TO LEARN MORE ABOUT OUR SAFETY PRECAUTIONS:

or go to <https://bit.ly/34izoBl>



TELEMEDICINE APPOINTMENTS FROM THE COMFORT AND SAFETY OF YOUR HOME

In order to support patient and staff safety, many appointments are now available through telemedicine (also called virtual visits). When an in-office appointment is not medically necessary, we encourage our patients to participate in appointments using telemedicine.

Temple Health offers telemedicine appointments for both new and current patients for many of our specialty services. See a Temple doctor from the comfort of your home on your phone, tablet, or computer.