

CAREGIVER GUIDE GETTING THROUGH A LUNG TRANSPLANT TOGETHER

You may not be the one getting a new lung — but you are experiencing a transplant all the same. As a caregiver, spouse, adult child or other loved one of a lung transplant patient, you're likely to be going through many difficulties yourself.

There are emotional, physical and financial tolls to caring for a loved one who is undergoing a transplant. Your ability to care for them and yourself is key to getting through this difficult time.

At Temple Lung Center, we not only want to meet the needs of our patients, but their support people as well.

"There was not a better place for us to be. Temple really cares about how everybody's doing — not only the patient who had the transplant, but their family too."

— Mary Beth, daughter of Betsy

"We were going in blind and feeling hopeless; and [the surgeons] gave us some comfort and strength and faith that we could get through this with their help."

— Lori, wife of Bob

"Temple's staff — including everyone from [...] the nurses, to the doctors, to the technicians — I mean, everybody went out of their way to help us."

— Ashley, wife of Bobby

Temple Lung Center is here to help you and your loved one. In this guide, you'll find tips on arranging support for yourself, a description of the lung transplant journey and details on what makes Temple different.

Thank you for all you do.

THE LUNG TRANSPLANT PROCESS

A single appointment could be the first step in a life-changing process for you and your loved one.

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. You or your loved one can schedule an appointment at Temple by calling **(888) 748-3818** between the hours of 8 a.m. and 5 p.m., Monday through Friday.

During the first appointment, a Temple Lung Center pulmonologist will evaluate the patient's physical and mental health and medical history. If these preliminary questions determine potential eligibility for a lung transplant, then your loved one will be referred for a lung transplant evaluation. During the evaluation, they'll need to undergo several medical tests. You're encouraged to attend alongside the patient to act as an emotional support and to stay up-to-date on their condition.

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.

The patient 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, your loved one will meet with members of the Temple lung transplant team. Support people are encouraged to attend so they can ask questions as needed. The transplant team will discuss test results, inform the patient of their eligibility and outline the risks and benefits of transplantation.

Temple Lung Center takes 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 waiting for the team's decision, your loved one should spend time with family and friends to keep up a positive attitude. It's also wise to keep them physically active (if possible) so they can be in their best possible shape for the potential transplant surgery.

If your loved one is eligible for a lung transplant, they'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). Your loved one's wait for a donor lung will vary based on availability and on their current condition. The wait can be understandably difficult, but there is much that can be done in the meantime.

First, you and the patient should 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 medical expenses.

The patient should also stay healthy and active while waiting for a transplant and find ways to reduce stress. Temple's lung transplant team can help find a diet and exercise plan that works for your loved one. You can provide additional support by ensuring the patient is keeping up with their exercise program.

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

When a donor lung becomes available, you and the patient will be called and need to come to the hospital immediately. Because time is critical, it's important that you both keep your phones charged, turned on and nearby at all times. Have bags packed and ready so you can both quickly leave for the hospital. You'll also want to plan a driving route to the hospital, with a few alternate routes in mind should there be problems with traffic.



3. TRANSPLANT SURGERY AND WHAT COMES AFTER

Upon your loved one's arrival at the hospital, they'll be evaluated to make sure they'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; however, your loved one's place on the waiting list will remain the same.

Surgery can take approximately 6 to 12 hours, so it can be helpful to have another adult who will commit to joining you in the waiting room.

After surgery, your loved one will 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, they'll recover and begin education and physical rehab. This will continue after leaving the hospital.

When the patient arrives home, they'll need 24-hour support for approximately two weeks. You will need to help with administering medication in addition to cooking, cleaning and other everyday tasks. The Family Medical Leave Act

(FMLA) may help protect your job if you take time off from work to help.

Recovering from lung transplant surgery can take six to eight weeks. Your loved one will not be able to drive themselves during this time. The recovery 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 need to help monitor the patient closely for signs of organ rejection and infection. Because of your regular interactions with the patient, you are the most likely to catch warning signs of issues early. Before discharge, you'll be taught what signs to look for.

Once they've recovered, it's time for life to begin again. Following a successful lung transplant, your loved one will get to breathe easily without the aid of an oxygen tank. They'll be able to keep up with you and other friends and family. And they'll be better able to enjoy the little moments in life.



CARING FOR YOURSELF

As a support person to a lung transplant patient, you might feel a responsibility to be the rock who is always there and ready to provide help. But the fact is that unless you're able to care for yourself first, you won't be able to give your all when helping your loved one.

Try following these tips on practicing self-care and lightening the load on yourself:

- **Plan for the journey.** Many caregivers feel they have to put the patient's needs before their own. But it's actually better for you and your loved one if you address your needs first. It's the same principle as during an airplane emergency: You need to put on your own oxygen mask before helping others put theirs on. So don't be afraid to get the sleep, food and exercise you need to be at your best physically and mentally.
- **Keep track of medical information and instructions.** Reduce your long-term workload by recording names of health professionals, medications, care instructions, medical milestones and other relevant information related to your loved one's journey. This way, whenever there's a change in their care team or medication, there's reference material immediately available.
- **Create a communication system.** Many patients depend on their support person to relay information to the transplant team as well as friends and family. This means you will want to regularly ask your loved one how they're feeling and then pass along relevant information as needed. You may decide to write regular emails to a list of people, make phone calls to select individuals or create a Facebook group.
- **Don't be afraid to ask for help.** Who can you lean on when times are toughest? Think about who you can depend on to help when you feel overwhelmed by caregiving. Your friends, family, church network or support group might be options. If somebody volunteers to help, be specific in how they can provide assistance. For example, you could ask them to prepare some food or give a ride to an appointment.
- **Be patient.** The lung transplant journey can be filled with many ups and downs. Couple this with the side effects of medication, and the person you're caring for can seem unpredictable in a way that's hard to handle. As emotional as the situation is, try to remain calm and patient as the emotions run their course. If outbursts become especially worrisome, please contact a mental health professional.



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 the patient 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 the patient before the transplant through the time that they'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 patient's hospital stay.
- **Financial coordinator** — Helps to ensure medical services are covered and approved by insurance.
- **Social worker** — Helps you and the patient coordinate the miscellaneous needs of the patient and family, including lodging, transportation, financial and mental health needs.
- **Family doctor** — Acts as the patient's source for primary care throughout the lung transplant process and coordinates with the transplant team to stay updated on the patient's status.
- **Clinical immunologist** — Diagnoses and treats any diseases caused by a disordered immune system.
- **Psychologist** — Conducts the patient's psychological evaluation if they are referred to a psychologist prior to their approval for a transplant. The psychologist can also provide therapy services as a form of post-transplant support.
- **Dietitian** — Creates a plan on how the patient's nutritional needs can be met before and after surgery.

To learn more about our program or to make an in-person or telemedicine appointment for a loved one, call (888) 748-3818.

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.