



Lung Transplant

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Lung Disease and Transplant: General Information

A lung transplant is surgery that removes a patient's unhealthy lung (or lungs) and replaces it with:

- a healthy lung from a donor (usually deceased).
- part of a healthy lung (from a living donor).

Most patients replace both lungs in a transplant surgery (double lung transplant). Some patients have:

- surgery to replace only 1 lung (single lung transplant).
- more than one lung transplant surgery.

Usually, patients need a lung transplant if they have:

- pulmonary fibrosis,
- chronic obstructive pulmonary disease (COPD),
- cystic fibrosis,
- pulmonary hypertension, or
- a different disease that affects their lungs.

Age guidelines

- Anyone (newborn to adult) can have a lung transplant.
- Some [guidelines](#)¹ say lung transplant patients should be younger than 65.
- Many patients over 65 do have lung transplants.
- Usually, patients over 75 do not qualify, but transplant centers make the final decisions.

Lung Transplant Waitlist

A patient is put on the transplant waitlist when their transplant team decides they meet requirements for lung transplant.

¹ <https://www.atsjournals.org/doi/full/10.1164/ajrccm.158.1.15812>

The treatment team gives the patient a **Lung Allocation Score (LAS)** to predict how long the patient:

- can live without a lung transplant.
- might live after lung transplant surgery.

A higher LAS score means the patient is higher on the lung transplant waitlist, so they will get a lung transplant sooner.

Learn more about LAS scores:

- United Network for Organ Sharing (UNOS) “A Guide to Calculating the Lung Allocation Score”: <https://unos.org/wp-content/uploads/unos/lung-allocation-score.pdf>
- Organ Procurement and Transplantation Network (OPTN) LAS Calculator: <https://optn.transplant.hrsa.gov/data/allocation-calculators/lung-cas-calculator/>

Donor Lungs

Transplant centers **use ex-vivo lung perfusion (EVLP)** so they have more donor lungs they can use for transplant.

EVLP is technology that circulates a solution (nutrients, proteins, and oxygen) through donor lungs to:

- evaluate their health,
- improve their health, and
- reverse lung damage.

Ask your transplant team about donor lungs from **increased-risk donors**.

- Patients who accept organs from increased-risk donors usually wait less time for an organ.
- An increased-risk donor is a deceased donor with higher risk of spreading one of the following undiagnosed diseases to a transplant patient (Abara et al., 2019):
 - human immunodeficiency virus (HIV),
 - hepatitis B, or
 - hepatitis C (HCV).
- Organs from increased-risk donors are not lower quality.

Before Lung Transplant: Caregiver Responsibilities

There are a lot of steps before a lung transplant. This is usually an overwhelming time for patients and caregivers.

The patient must:

- choose a transplant center,
- receive transplant education,
- complete the evaluation process,
- and, if approved, be listed for transplant.

To receive a lung transplant, the patient must complete an evaluation with the transplant team. This team can include:

- lung doctor (pulmonologist),
- transplant surgeon,
- nurse coordinator,
- social worker,

- psychologist,
- psychiatrist,
- pharmacist,
- dietician, and
- financial coordinator.

Evaluation includes many appointments and tests to evaluate the patient's lung and general health. The treatment team reviews test results to decide if the patient is eligible for transplant. If the patient is eligible, they are placed on the transplant waitlist.

Before the Transplant: Medical Tests and Terms

Patients must do many tests during transplant evaluation and while they wait for transplant surgery.

- **Pulmonary function test (PFT)** measures how well the lungs work.
- **Six-minute walk test (6MWT)** measures how far a patient can walk in 6 minutes.
- **Pulse oximeter** measures how much oxygen is in the blood (oxygen saturation).
 - If the patient has an electronic device to measure oxygen, you will help them use it.
 - Call the transplant nurse coordinator if you have questions.

These tests:

- show changes in how well the lungs work.
- Show if a patient needs to be on oxygen (to support breathing).
- may change the patient's position on the waitlist.

Most patients need **supplemental oxygen**.

- Work with the transplant nurse coordinator and social worker to help the patient.
- Be prepared for an emergency (if the patient needs oxygen immediately). Know the:
 - oxygen company's name and phone number
 - patient's prescription and requirements
- Help the patient use the oxygen correctly.
- Tell the transplant team about the patient's oxygen requirements.
 - Watch for changes in the patient's oxygen requirements.
 - Patients usually require more oxygen the longer they wait for transplant.
- Make sure the patient has enough oxygen tanks when traveling. Always plan ahead.

Some patients need **Extracorporeal Membrane Oxygenation (ECMO)**.

- Catheters (small tubes) in a patient's neck, groin, or chest pump oxygen into their blood.
- To put the catheters in, patients are sedated and on a ventilator.
- When the catheters are in place, sedation usually stops, so patients can do physical therapy.
- Patients on ECMO stay in the hospital.
- Visit the patient as much as you can.

Tobacco

You and the lung transplant patient must stop using all smoking products, including:

- cigarettes,
- cigars,

- vapes,
- e-cigarettes,
- hookahs, and
- cannabis in smoked form.

The patient will have drug tests during the transplant evaluation.

- The patient can be removed from the transplant waitlist if they show **any amount of**:
 - nicotine,
 - tobacco, or
 - illegal drugs (even from secondhand smoke).
- **Drug tests can detect secondhand smoke.**
 - If family or friends smoke near the patient, they might not be eligible for transplant.

Ask your doctor for help quitting. [There are many resources that can help².](#)

Supporting the Patient

As a caregiver, you can help the patient navigate this overwhelming process. You can:

- learn about the patient's diagnosis (there are many reasons they may need a transplant).
- go to the evaluation and follow-up appointments with the patient.
- take notes and ask questions during the evaluation and follow-up appointments.
- pack lunches and snacks to get through the full day of evaluation appointments.
- help the patient follow recommendations from the transplant team.
- work with the transplant team's financial counselor and social worker to make sure the patient has insurance for treatment and access to medication.
- help the patient follow good health habits.
- listen to the patient.
- offer comfort and encouragement to the patient.
- make plans if you and the patient must move closer to the transplant center while on the waiting list. (Ask your center about their requirements.)
- visit the patient in the hospital. If they are very sick or on ECMO, they might stay in the hospital to wait for transplant.
- Help the patient with their daily nebulizer treatments, breathing treatments, and physical exercise.
 - Completing the daily treatments shows the transplant team the patient can take care of their new lung after transplant.

The waiting period before transplant can be stressful. Ask the transplant social worker for support.

While waiting for transplant, many patients experience:

- worsening health,
- anxiety,
- depression,
- panic, and
- lower quality of life.

² <https://power2save.org/caregiver-toolkit-chapter-3/>

As a caregiver, [you must take care of yourself during this time³](#). You might feel:

- fatigue,
- anxiety, and
- depression.

During Lung Transplant: Caregiver Responsibilities

When the transplant team accepts lungs for the patient, they will:

- tell the patient (if they are already at the hospital).
- call the patient and tell them to come to the hospital (if they are at home). This can happen any time during the day or night. The team will call you if they need help contacting the patient.
- **not** give information about the donor to the patient, caregivers, or family (due to federal law).

When the patient is admitted to the hospital they will:

- have blood tests. Most heart surgeries require blood transfusions.
- not be able to eat or drink before surgery (NPO, or nothing by mouth).
- meet with the intake nurse.
- sign consents before starting surgical preparation.
- have an X-Ray.
- go to different places in the hospital for testing and surgery preparation. Staff will update you as they can.
- receive anesthesia 1-1.5 hours before surgery. They will not be awake during the surgery or feel any pain.
- will be on a ventilator. A tube that goes down their throat connects to a machine to help them breathe.
- might be connected to a machine that helps circulate blood during the surgery.

Important! Sometimes, transplant surgery is canceled because the organ might not be a good match for the patient. This is disappointing, but it means the patient is at the top of the waitlist. They might get another call soon.

A lung transplant can take many hours.

- The surgeon might tell you how long surgery could take. This is an estimate and can change.
- The medical team will update you as often as they can.
- During surgery, The surgeons will:
 - make a cut in the patient's chest.
 - remove the damaged lung.
 - put the new lung in the patient's chest.
 - attach the patient's blood vessels and airway to the new lung.
 - close the chest with stitches or staples.

³ <https://power2save.org/caregiver-toolkit-chapter-3/>

- put a bandage over the cut.
- put tubes in the patient's chest so extra air and fluids can leave their body.
- After surgery, the patient will go to a recovery room then the Intensive Care Unit (ICU).
- As the patient recovers, they will move from the ICU to a different hospital unit. Patients spend different amounts of time in ICU.

When you see the patient after surgery, they might be asleep. They will have:

- tubes in their chest to remove extra fluid from their body. Tubes are removed before discharge.
- stitches (sutures) in their chest, around the chest tube. Sutures are removed at the 1st follow-up visit.
- machines monitoring them, so the transplant team can see how well they are recovering.
- a breathing tube. Breathing tubes are usually removed 6-24 hours after surgery).

During the Transplant Hospitalization

The patient will probably stay in the hospital for at least several weeks after surgery. The patient will be monitored closely by:

- the lung transplant team,
- the critical care team, and
- other specialty teams, for “consults” to make sure other organs are adjusting well.
 - nephrology (kidney)
 - cardiology (heart)
 - hepatology (liver)
 - psychology or psychiatry (mental health)

Many different providers will go in the patient's room throughout the day. You should spend most of the day at the hospital, so you can:

- meet the providers,
- learn about the different medical teams,
- know the patient's daily schedule,
- hear all the updates,
- ask questions, and
- attend educational sessions to learn about post-transplant care:
 - signs of rejection,
 - potential activity limitations,
 - environment exposure risks to be aware of,
 - nutritional needs,
 - hygiene,
 - signs of infections,
 - and lifestyle changes.
- You will learn how to care for the patient at home (wound care, wound vac, medication management, etc.).

Nurses are a great resource. They know a lot about the patient's condition and treatment, so ask them questions and learn from them. Their first priority is caring for the patient, so remember to ask if it's a good time to talk. Make a list of your questions, so you are ready.

While recovering in the hospital, the patient:

- will start immunosuppressant medications to help their body accept the new lung(s). They will take these medications at the same time every day.
- might hear a heartbeat in their ears for the first time. They might need to adjust to the sound.
- might be confused, delirious, forgetful, or even hallucinate. New medications, stress, and recent anesthesia cause these symptoms. **Tell the transplant team if you see a big change in the patient.**
- might move to an acute rehabilitation unit (acute rehab) to build strength through physical therapy, before going home. Acute rehab might be in the same hospital or a different facility.

While the patient is in the hospital:

- Put the patient's oxygen company **on hold**.
- **Do not cancel** the oxygen.
- The transplant team will tell you if the patient needs oxygen after transplant (or if you can cancel it).

Before and after transplant surgery, the patient might have the following procedures:

- **bronchoscopy:** When a medical provider puts an endoscope (a thin tube with a camera) through a patient's nose or mouth to see their lungs.
- **ventilator:** A machine that helps a patient breathe. A tube is put down the patient's throat and then hooked to a machine that will help them breathe.
- **tracheostomy:** When a provider cuts a small hole in the patient's neck and puts a tube through the hole into the windpipe (trachea). Tracheostomy helps patients breathe temporarily so the:
 - ventilator tube can be removed (after 7 days on a ventilator) to stop pressure on the trachea.
 - lungs get back to their normal working strength.
 - patient can slowly stop taking sedatives.
 - patient can participate in physical therapy.

You will learn how to take care of the "trach".

Preparing for Discharge from the Hospital

Some patients discharge, or leave, the hospital and go to a rehab hospital for intensive physical therapy before they can go home.

The inpatient case manager will help you arrange supplies and services the patient needs at home, like:

- a walker,
- a tracheostomy and related supplies,
- a feeding tube and nutrition supplies,
- suction machine,

- home health,
- compound medications for a nebulizer,
- scale to track the patient's weight,
- thermometer,
- spirometer,
- blood pressure cuff,
- pill box,
- shower chair and handheld shower attachment, or
- glucometer to test for blood sugar levels.

When you are not at the hospital with the patient, use the time to:

- disinfect and clean the home.
- go grocery shopping so there is enough food and drink when the patient arrives,
- learn about transplant food safety with the transplant team and the nutrition providers, and
- ask the pharmacist about food-drug interactions.

Caregiving for a lung transplant patient is a big job. You must also take care of yourself.

- Go home and rest. Do not sleep at the hospital.
- Trust the hospital staff to care for your patient and call you with any needs.
- Talk to the transplant social worker if you are feeling overwhelmed.
- Talk about how you are feeling.
- Ask for help. [Don't try to do everything alone](#)⁴.

After Lung Transplant: Caregiver Responsibilities

Taking care of a new lung is a big job.

After discharge from the hospital, the patient will need a lot of help. Ask your transplant center how close you and the patient must stay to the center. If the patient lives far from the center, you might have to make plans to stay close.

You will take care of the patient at home until they improve enough to take care of themselves (usually 3-4 months). You will:

- learn about the patient's new medications (dosage, mixing, specific instructions, side effects).
 - help the patient take their medications **exactly** as prescribed.
 - mix specific medications.
 - use a pill box to help the patient organize their medication.
 - look for side effects (hand tremors, shakiness, etc.).
 - understand what medications interact with other medications or with food.
- track blood pressure, blood sugar, temperature, weight, and spirometry readings at the same time every day.
 - Steroids might affect the patient's mood, blood sugar, and appetite.
 - A spirometer measures how much they breath in and out.
 - Pay attention to detail.
 - Tell the transplant team if there are changes, especially in spirometer readings.

⁴ <https://power2save.org/caregiver-toolkit-chapter-3/>

- Changes to vital signs can be a sign of a complication.
- change wound dressings.
- prepare meals.
- complete (or ask for help with) household chores.
- help the patient with daily living and hygiene activities.
- help the patient report concerns or symptoms.
- monitor the patient's mental health.
- take the patient to frequent bronchoscopy, follow-up, and lab appointments (several times a week to start).
 - Bronchoscopies often require sedation, so the patient cannot drive.
 - Appointments decrease as they patient improves.
- help the patient with pulmonary rehabilitation, a medical program that teaches patients about lung disease and how to exercise their lungs.
 - Many patients start before transplant.
 - Patients can restart when the transplant team approves it.
 - Patients learn to exercise with less shortness of breath.
 - They become stronger and more active and usually feel better.
 - Classes are done in a group, usually 3 times per week.
 - Patients receive support from peers in the classes.
 - The financial coordinator will help you learn about insurance coverage for pulmonary rehab.

Recovery can take time. Talk often with the transplant team to monitor the patient's recovery. Make a list of all appointments, procedures, and medication changes to help you, the patient, and the transplant team.

Post-Transplant Medications

After surgery, the transplant team will prescribe many medications. Some will have very specific instructions. For example:

- Some immunosuppressant medication must be taken 12 hours apart.
- Other medication cannot be taken before laboratory blood draws.

If the patient does not take their medication correctly, their body can reject the new organ. This means that their immune system will attack the new organ because their body doesn't recognize it. Rejection is most common for transplant patients who miss medications.

As a caregiver, you must:

- help the patient take medication **exactly** when and how it is prescribed.
- order refills.
- make sure the patient takes the correct dose (doses change often).
- help the patient organize their medications.

Ask the transplant pharmacist or nurse to help you organize medications before the patient is discharged from the hospital. They might recommend you use a pill box.

Lab and Clinic Appointments

You will help the patient go to all lab and clinic appointments to monitor:

- the patient's general health.
- how the new organ is working.
- early signs of rejection.
- signs of infection.
- how the patient's body is handling anti-rejection medication.
- talk about any changes the patient should make.
- pain. Tell the transplant team immediately if the patient has pain. Pain over the incision area can be a sign of rejection.

Lifestyle Changes after Transplant

After transplant, the patient must change parts of their lifestyle.

They might have to avoid:

- fresh flowers and plants when inside.
- swimming.
- gardening.
- raw or undercooked food.
 - Learn about food safety.
 - Buy a meat thermometer.
- anything that can irritate or hurt the new lung.
- having certain kinds of pets in the home, such as birds.

They might have to start:

- washing raw vegetables carefully,
- wearing a mask in public (the first few months after transplant), and
- wear a mask on an airplane or during flu season.

The patient must adjust to life after transplant. They might:

- struggle with not using supplemental oxygen.
 - An oximeter will help monitor their oxygen levels.
 - It can be hard to learn to breathe with a new lung.
 - Some patients react emotionally to leaving home without oxygen. Tell the medical team if you see this.
- need more immunosuppressant medications than other organ transplant patients.
- worry their body will reject the transplanted lung.
 - Help watch for signs of rejection.
- see slow improvements in quality of life.
- struggle longer than they expected with mental and physical recovery from surgery.
- struggle to adjust to a more "normal and healthy" life.
- feel:
 - depression,
 - anxiety,

- PTSD,
- survivor's guilt, and
- caregiver dependence.

Other caregiver responsibilities

For the first 4-6 weeks (at least), you will need to:

- drive the patient to their clinic appointments,
- prepare meals,
- lift anything 10 pounds or more,
- and help the patient with the lifestyle changes needed to take care of their new organ.

Call the transplant center immediately if the patient has a fever or acts out of character.

Being a lung transplant caregiver is rewarding and challenging. [You must take care of yourself⁵](#).

- Remember to ask for help, to avoid caregiver burnout.
- Attend support groups for caregivers.
- Remember to take care of your own health.
- Go to your scheduled medical appointments.
- Don't stop taking your prescription medicine.
- Tell the transplant team if you are struggling with your caregiver responsibilities.
- Have a backup caregiver so you can have respite (a break).
 - Many centers require at least one backup caregiver.
 - Make sure the backup caregiver is prepared and understands caregiving responsibilities.

Questions to Ask Your Lung Transplant Center

- What are the risks and benefits of receiving a lung transplant?
- How long might the patient wait for a lung transplant?
- Will you need to move closer if the patient's health gets worse?
- Will the patient need to stay in the hospital while waiting for transplant?
- Will the patient need a ventilator or ECMO (machines that give the lungs oxygen when a patient can't breathe well) while waiting for transplant?
- How close must the caregiver and patient live to the transplant center before and after the transplant? How long must we live close to the transplant center?
- How often will the patient have appointments at the transplant center, both before and after transplant?
- Must the patient buy a spirometer, or will the center provide it?
- What is the patient's LAS score?
- How often will the LAS score be re-evaluated?
- What are the risks and benefits of accepting an organ from an increased risk donor?
- What lifestyle and food safety changes must the patient make after transplant?
- When (and for how long) must the patient wear a mask after transplant?

⁵ <https://power2save.org/caregiver-toolkit-chapter-3/>

- How do I learn if the patient has insurance coverage for pulmonary rehabilitation?
- How do we plan for disasters or emergencies?

A Lung Transplant Caregiver's Perspective: Peggy B.

Every Lung Transplant Caregiver should know: "This is a life altering event. The caregiver's life changes, emotionally, physically, and financially. The caregiver's life is no longer their own. Your tolerance of the unexpected will be tested. Be prepared to learn a lot of medical information and terminology. Take lots of notes. Buy some type of case to carry all the paperwork and medications with you at all times. I recommend a rolling suitcase or tote, a small one."

The most difficult aspect of being a caregiver: "The feeling of helplessness; the constant feel of doubt in the care that you are providing to your loved one; waking up to the fear of the unknown on a daily basis."

As a caregiver I wish I would have known: "Trust the experts, the entire continuum of care that is provided by the medical team. This team of professionals have had the opportunity to review every scenario and possible outcome of the prognosis to determine to the best of their ability and give you the honest truth about what is to be expected."

The most rewarding aspect of being a caregiver was: "Having the opportunity to see all the work provided to allow your loved one another chance at life is priceless. Looking back over all the hard work put in by caregivers, family, and the medical team. A caregiver's job is hard work. I personally worked harder as a caregiver than I have at any job in my life. To see the fruits of our labor is simply a blessing."

I was most surprised as a caregiver by: "The love and care provided by the pulmonary department medical team at the Mayo Clinic, Jacksonville, FL. As a team of professionals, they know that for most caregivers the knowledge for medical assistance is limited. The kindness shown by this group of professionals made life as a caregiver a little more tolerable. It did not matter, no matter what time of the day or night, someone was available to help, even with the simplest of questions, to answer with patience and understanding. I always believed that the ability for one to pay for anything in life mattered in which the way you would be treated, even by the medical field. Yet my son's medical team treated us with dignity and respect. Always attentive to his every need, and mine. I have never received the medical care that this medical team has and continues to provide for us."

How I would recommend other caregivers prepare and take care of themselves for this experience and take care of themselves: "Faith and spirituality. For me it was my prayer team. Every day I would get a text that said, "Trust God Always, no matter what..." Having a belief in your higher power, whatever it may be, provides a level of peace to know that all things are possible, including miracles. My belief in God was the power that helped me to prepare for all that was coming at me, even though I had no idea what it was, through my faith I was ready. You see in my faith he promises that "He would never leave me, nor forsake me," and I believe that; you see God had been preparing me for this life changing event long before it happened. I had recently started a new job with a military schedule, which allowed me to be able to take my son to the doctor, transporting him on my days off, and even arranging for the rehabilitation department to make the schedule to coincide with my work schedule. I was so blessed to have the ability to travel 5-6 times a month for his rehab services, traveling over 230 miles each way. I never had an issue with my car, or safety traveling to and from. My car's truck was filled with 8-10 oxygen tanks inside. His need for oxygen was very high, it was 2 1/2 hour drive each way. You see my faith helped to prepare me for what was to come, a life changing experience. This is only one example of the many events during this experience; I believe that God was there with me."

Resources

- UNOS “Lung” Information Page: <https://transplantliving.org/organ-facts/lung/>
- American Lung Association: <https://www.lung.org/>
- Lung Transplant Foundation: <https://lungtransplantfoundation.org/>
- International Guidelines for the Selection of Lung Transplant Candidates: <https://www.atsjournals.org/doi/full/10.1164/ajrccm.158.1.15812>
- Pulmonary Fibrosis Foundation: <https://www.pulmonaryfibrosis.org/>
- Cystic Fibrosis Foundation: <https://www.cff.org/>
- COPD Foundation: <https://www.copdfoundation.org/>
- International Society for Heart and Lung Transplantation (ISHLT): <https://www.isHLT.org/about/patient-resources>

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