



Life after lung transplant

WHAT TO EXPECT



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Contact the PFF Patient
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A new phase of life—with new responsibilities

After your lung transplant—major surgery for which you prepared carefully—you'll likely enjoy a significantly improved quality of life. Most patients who have a transplant due to the effects of pulmonary fibrosis (PF) breathe better, increase their activity, and can discontinue supplemental oxygen. Some people continue to work and travel.

But even when surgery results are positive, life after a transplant has its own challenges. To maintain the best possible health and reduce the chance of complications, you'll need to carefully follow your care team's instructions throughout your life. This booklet provides an overview of what to expect.



THE RECOVERY PROCESS

Once you've left the hospital, your early recovery process continues at home. You should have at least two caregivers available so that someone can be with you 24 hours a day for the first several months after surgery. Most lung transplant programs caution against driving in the early recovery period to avoid strain on the incision site from turning the steering wheel. Many programs caution against lifting more than five pounds for similar reasons.

In the early stages of recuperation, you should carefully avoid crowds and anyone who is sick. Your transplant team may also ask you to wear a mask when you leave the house. It's best to restrict visitors to your home while you're recovering. Frequent hand washing is an important way to prevent the spread of infection.

Keep the incision clean and dry, following your care team's instructions for bathing. Contact your care team if you have any of the following worrisome symptoms:

- Redness or swelling of the incision
- Blood or other fluid leaking from the incision
- Pain around the incision that gets worse
- Fever
- Shortness of breath or trouble breathing

In the hospital, you probably began a pulmonary rehabilitation program of exercise and education designed to improve your breathing and daily functioning. Your care team will want you to continue pulmonary rehabilitation once you return home. A structured exercise regimen will be prescribed by your transplant team to avoid excessive motion or strain of the torso that may impair healing of the incision.



Encouraging survival stats

Approximately 89% of lung transplant patients survive at least one year after their surgery. After three years, approximately 74% of individuals receiving lung transplants are still alive. Many factors contribute to survival post-transplant, including age, disease type, severity of illness at the time of transplant, and procedure type. Survival rates have continued to improve over recent years.

Source: Organ Procurement and Transplantation Network and Scientific Registry of Transplant Recipients 2018 Annual Data Report



POTENTIAL COMPLICATIONS AFTER TRANSPLANT

The two major issues facing transplant patients after surgery are rejection and infection. Because your risk of rejection or infection is highest in the first few months after surgery, you'll need to remain close to your transplant center for a period of time defined by your transplant team—often two to three months.

During the first several months, you'll have frequent follow-up visits. You'll likely be seen in the outpatient clinic setting once a week for the first few months to ensure your lung function is improving. After that, your follow-up visits are usually less frequent. Tests performed during these visits may include:

- Blood tests
- Pulmonary function tests
- Electrocardiogram (EKG)
- Chest X-ray
- Bronchoscopy
- Biopsy of lung tissue

For brief descriptions of some of these tests, see the glossary on the inside back cover.

Rejection

Your body perceives a transplanted lung as a foreign object. To help prevent your immune system from rejecting the new lung, you'll need to take immune-suppressing medications for the rest of your life. Your transplant team will determine which medications are appropriate for you and may change dosages depending on your body's response. The goal is to find the lowest possible immunosuppressant dose that will prevent rejection and minimize medication side effects.

Despite taking these immune-suppressing drugs, up to one-third of transplant patients will develop acute cellular rejection (ACR). This is a condition diagnosed by biopsy in which a transplant recipient's immune system recognizes a donor lung as foreign and attacks the blood vessels of the donor lung. The peak time to develop ACR is around six months post-transplant, with the highest risk of ACR occurring in the first year. Because patients with ACR may be asymptomatic, most centers will perform regular "surveillance" bronchoscopies (viewing the inside of your lungs with a small scope) with transbronchial biopsies (taking small samples of lung tissue) to assess for rejection for the first year after transplant. Surveillance bronchoscopies are performed as outpatient (ambulatory) procedures.

Since acute rejection is the biggest risk factor for developing Chronic Lung Allograft Dysfunction (CLAD) or chronic rejection (scarring of the transplanted lungs), most

lung transplant programs are vigilant about monitoring for acute rejection. Fortunately, when detected early, ACR is readily treatable with augmented immunosuppression.

In addition to ACR, you'll be monitored for the development of antibody-mediated rejection (AMR). Your body's immune system makes proteins called antibodies to help fight infections. However, a lung transplant recipient may generate antibodies that instead target the transplanted lung and cause an inflammatory reaction, leading to lung injury. Many lung transplant centers will routinely perform blood screens to detect these types of donor-specific antibodies that recognize a donor lung as "foreign." Care teams may recheck for these antibodies after times of stress, such as infection, major surgeries, or receiving blood product transfusions.

Contact your transplant team immediately if you have signs of rejection (ACR or AMR), including:

- Fever
- Weight gain
- Flu-like symptoms, such as body aches, nausea, or diarrhea
- Tenderness over the transplant site
- Swelling
- Unusual fatigue
- Shortness of breath
- Cough or chest pain
- A decrease in oxygen saturation as measured by your pulse oximeter
- Decline in spirometry values (if you have a home spirometer)



PF after transplant

Many PF patients ask whether their new lungs will develop fibrosis (scarring). Medical research suggests that most forms of PF will not return in the transplanted lung.

Infections

Because immunosuppressant medicines affect the way your immune system works, you're more likely to have certain infections while taking them. These include oral yeast infections (thrush), herpes, respiratory viruses, and bacterial infections. You can do a lot to prevent infections by following the advice of your care team. If you practice good hand washing and avoid people when they're ill, you can prevent many respiratory illnesses.

Your transplant center may recommend that you wear a mask in high-risk public spaces as an extra safety measure. Other preventive measures may include staying away from crowded areas; not consuming raw seafood and unpasteurized foods; and avoiding dirt, soil, and dust (where fungi reside). Your care team will closely monitor you for infection and teach you to recognize signs of infection yourself.

Your transplant team will go over very specific instructions with you and your caregiver to ensure you know how to take your medications and understand the importance of taking them at the right time and in the correct dose. Be aware that your team is adapting your medication regimen to the way your body reacts to these medications. They'll use your lab results to modify the dose, and you'll need to be careful to make the changes they recommend immediately.

Most patients are started on three different immunosuppression medications. In addition, patients are prescribed antimicrobials to prevent common infections in people who are immunosuppressed. Because immunosuppression can increase your risk of high blood pressure, coronary disease, diabetes, and osteoporosis, you might be prescribed medications to control these conditions. Most patients are also given antacid medications, since gastroesophageal reflux can lead to injury of a transplanted lung.

Patients generally leave the hospital with at least six to eight new medications. Your transplant team understands that this can be overwhelming and will help you and your caregivers learn about each medication. Be sure to ask lots of questions—and follow these precautions:

- Keep your medications away from heat and moisture. Do not store in your bathroom.
- Talk with your team if you're having side effects.
- Do not stop taking any of your medications without talking to your team.

- Don't add any medications (including over-the-counter medications and herbal drugs) without discussing with your transplant team. These can significantly alter immunosuppression levels.
- Do not take non-steroidal anti-inflammatory drugs (NSAIDs) such as ibuprofen (Advil, Aleve, etc.). These medications can damage the kidneys when taken with immune-suppressing medications.
- Don't use marijuana and other THC-containing drugs, which can alter the metabolism of your immunosuppression and put you at risk of rejection.
- Don't eat or drink grapefruit, pomegranate, or papaya in fruit or juice form. These fruits contain compounds that can affect immunosuppressant drug metabolism.



Medication reminders

Set a timer on your phone so that you won't forget a single medication dose. Forgetting doses can increase the risk for rejection.

Other complications

Transplant patients are at greater risk of other complications, including tumors and cancers. Be sure you're up to date on your age-appropriate cancer screenings, such as colonoscopies, mammograms, Pap smears, and prostate screenings. Skin cancer is the most common cancer in transplant patients, so use sunscreen, wear a hat and protective clothing, and see your dermatologist yearly or more often if needed.

Approximately 3% of transplant patients develop lymphoma. Alert your care team if you experience fever, tiredness, weight loss, poor appetite, or sweating.

Over time, you may develop side effects from immune-suppressing drugs, including:

- Kidney problems
- Digestive problems
- Blood count problems
- Nerve damage
- High blood pressure
- Weight gain
- Diabetes

CAREGIVER RESPONSIBILITIES

You'll need a lot of help as you recover from surgery. Although patients are encouraged to take on as much care for themselves as is appropriate, your caregivers are there to support the following:

- Make sure you take medications as directed.
- Help you record information your care team needs.
- Drive you to and from follow-up appointments.
- Watch for unusual signs and contact your care team if anything seems wrong.
- Shop for food and prepare meals, avoiding meals from buffets in restaurants or grocery stores.
- Run errands, pick up prescriptions, and do household chores.
- Provide support, encouragement, and companionship.
- Stay in touch with family and friends.
- Assist you with daily activities like dressing and bathing, following the transplant team's guidelines for preventing infection.

The United Network for Organ Sharing offers the following tips for people caring for organ transplant patients:

- **Stay organized.** Make a checklist and set up a calendar to keep track of medical appointments, medications, diet, and exercise.
- **Communicate.** Keep an open dialogue with the patient, transplant team, friends, and family members.
- **Stay positive and patient.** To help the patient stay motivated, make note of recovery milestones. Provide encouragement to help the patient persist through the significant challenges of recuperation.
- **Rest and recover.** Be sure to get adequate rest, nutrition, and exercise. Caregiver fatigue is a real phenomenon; caregivers cannot be effective advocates for transplant patients if their own well-being is compromised.



Seek support

Recovery is a slow process, often with significant setbacks, and it's easy to feel overwhelmed. Both you and your caregivers may benefit from participation in a support group. Ask your transplant team if one is available—or join one of the PFF's telephone-based virtual support communities (see back cover for details).

KEEPING HEALTHY AT HOME

Each transplant program may have slightly different rules that you should follow in your early recovery. Your transplant team will not only review these rules with you before discharge, but will likely send you home with reference materials and contact information to use if you have questions. Besides following all instructions from your care team, here are some things you can do to take care of yourself while you're recovering and after you resume normal activity:

- **Eat right.** Stick with the personalized nutrition plan your care team will create for you. There are often dietary restrictions to reduce the risk of infection, such as prohibitions on eating raw seafood and undercooked meats. Certain fruits that can interact with your medications should also be avoided. Your transplant team will review the specifics of these restrictions with you.
- **Exercise.** You'll likely be referred to pulmonary rehabilitation to regain your strength and improve your exercise tolerance. With your care team's help, you'll formulate an exercise plan that slowly ramps up your activity as your recovery progresses.
- **Avoid all nicotine products—and stay away from smoke.** Try not to go to places where people smoke, and don't allow smoking in your home.
- **Avoid alcohol.** Alcohol consumption with immune-suppressing drugs can cause liver damage. Most lung transplant programs do not allow for the use of alcohol post-transplant.
- **Use care with pets.** Avoid baby birds, including chicks and ducklings; reptiles, including lizards, snakes, and turtles; and exotic pets such as monkeys. If you have cats, have another household member change the litter box.
- **Care for emotions.** In the early months after transplant, patients can experience a variety of emotions including anger, frustration, guilt, and depression. Treat your psychiatric health like all your other medical issues. Be open and honest with your care team so that they can provide you with optimal care.

GLOSSARY

Acute cellular rejection (ACR): A condition in which a transplant recipient's immune system recognizes a donor lung as foreign and attacks the blood vessels of the donor lung.

Antibody-mediated rejection (AMR): An inflammatory reaction, leading to lung injury and caused by the body generating antibodies (see separate listing) that target the transplanted lung.

Antibodies: Proteins produced by your body's immune system to help fight infections.

Biopsy: An examination of living tissue to discover the presence or extent of disease. During a lung biopsy, a very small piece of tissue is taken, usually through a bronchoscopy (see separate listing), to test for signs of rejection or infection.

Bronchoscopy: A procedure that allows a healthcare provider to examine the inside of the lungs. A thin tube containing a light and camera is inserted into the lungs through the nose or mouth.

Chest X-ray: An X-ray that produces images of the heart, lungs, airways, and blood vessels, as well as the bones of the spine and chest.

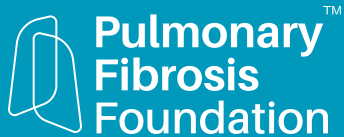
Electrocardiogram (EKG): A test that records the electrical signals in your heart and monitors its activity through sensors (electrodes) attached to your chest and sometimes your limbs.

Pulmonary function tests: A series of tests that show how well the lungs are working. The tests measure lung volume, capacity, rates of flow, and gas exchange (the delivery of oxygen from the lungs to the bloodstream and elimination of carbon dioxide from the bloodstream via the lungs).

Pulmonary rehabilitation: A supervised program that includes exercise training, health education, and breathing techniques for people with certain lung conditions.

STILL HAVE QUESTIONS?

Contact the PFF Patient Communication Center at 844.TalkPFF (844.825.5733) or pcc@pulmonaryfibrosis.org.



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RESOURCES

To learn more about life after a lung transplant, visit:

- United Network for Organ Sharing at unos.org
- Organ Procurement and Transplant Network at optn.transplant.hrsa.gov
- Scientific Registry of Transplant Recipients at srrt.org

PFF VIRTUAL SUPPORT GROUPS

General PF community

Third Thursday of each month

11:00 a.m. PT, noon MT, 1:00 p.m. CT, 2:00 p.m. ET

pulmonaryfibrosis.org/zoomgroups

Lung transplant community

Fourth Tuesday of each month

11:00 a.m. PT, noon MT, 1:00 p.m. CT, 2:00 p.m. ET

pulmonaryfibrosis.org/zoomgroups

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