

Lung Transplant

What to expect

This handout explains what is involved in having a lung transplant with the UW Medicine Lung Transplant Program.

Getting Started

We will give you a lot of information about having a lung transplant and the entire transplant process. Please read this information very carefully. Share it with your family and caregivers.

Having a lung transplant changes a person's life in many ways. Patients must think about everything involved before going forward with the transplant process.

It is normal to feel overwhelmed with all you are learning. Write down any questions you have and bring them to your clinic visit.



The UW Medicine Lung Transplant Program is the only lung transplant program in the Pacific Northwest.

What is a lung transplant?

A lung transplant is a treatment option for some people with end-stage lung disease. During the transplant surgery, the surgeon removes one or both diseased lungs. They are replaced with lungs from an organ donor.

A successful outcome after a transplant requires a full commitment from the patient, their family and caregivers, and the entire UW Medicine Lung Transplant Team.

What are the goals of transplant?

The main goals of a lung transplant are to improve quality of life and prolong life. After a lung transplant, most recipients:

- Can breathe better and do not need oxygen support
- Can be more active than they were before the transplant
- Enjoy a better quality of life

Who can have a lung transplant?

To be a candidate for a lung transplant, a patient must have:

- End-stage lung disease that affects their activities of daily living
- A lower life expectancy because of their lung disease
- Tried all other treatments for their lung disease, without success

All transplant programs have criteria for choosing transplant candidates. These criteria help us know if a patient will most likely benefit from a lung transplant. The criteria used by UW Medicine's Lung Transplant Program are included with this handout.

What is involved in having a lung transplant?

Screening

Patients must first have a full health screening before they are placed on the waiting list for a lung transplant. The purpose of the screening is to find any problems that could affect the success of the transplant surgery and the patient's recovery afterward.

Teamwork

Everyone involved in the transplant process works together as a team. This team includes the patient, their family and caregivers, and the entire UW Medicine Lung Transplant Team.

Commitment

Success depends on the patient's commitment to the process before, during, and after the lung transplant surgery. This commitment begins with the first clinic visit and continues for the rest of their life. Patients must commit to:

- Taking their medicines as prescribed
- Monitoring their health and new lung(s)
- Practicing healthy living
- Being faithful about visits and follow-up with the Lung Transplant Team

Family and Caregivers

Success also requires the ongoing dedication of the patient's family and caregivers. Their commitment must last for the rest of the patient's life.

Ongoing Monitoring

The recipient must be closely monitored after the transplant surgery and for the rest of their life. This lifelong follow-up is vital. It allows us to find any problems early so that tests and treatments can be started right away. All members of the Lung Transplant Team work together to provide the best possible care before, during, and after the transplant surgery.

Being Referred

For a patient to be considered for a lung transplant at UW Medicine, their local healthcare provider must refer them. The referring doctor is usually the lung doctor (*pulmonologist*) who has been treating the patient's lung disease. The Lung Transplant Team values input from the patient's other providers. We will involve them in both the screening process and long-term care.

Screening Process

The screening process begins over the phone. We review the patient's medical records and ask about their health history. If we do not find any issues that may affect their ability to have a good outcome after a lung transplant, we will set up a first clinic visit.

First Clinic Visit

A doctor who is an expert in lung transplant will review all the patient's health information. This doctor then meets with the patient to find out if a lung transplant is their best option. The doctor will explain the transplant process and talk about the risks and benefits of having a lung transplant.

A lung transplant is not the right option for every patient. If a lung transplant is not a good option for a patient, the doctor will explain why. We will also talk with the patient's referring provider about the decision and suggest other treatment options, if possible.

Evaluation

If the patient and the lung transplant doctor decide that a lung transplant may be a good option, the next step is the evaluation. During this process, we set up tests to assess the patient's lung disease. We also do other studies to make sure the patient does not have any problems with their heart, bones, kidneys, liver, or other organs.

Some of these studies and lab tests can be done by the patient's local providers. Others must be done at University of Washington Medical Center (UWMC). As each study is done, we review the results to be sure that the patient is still a possible candidate for a transplant.

The evaluation includes visits with everyone on the Lung Transplant Team. Team members include the transplant pulmonologist, the lung transplant surgeon, social worker, financial counselor, and nutritionist. There may be visits with other providers as well.

Evaluation appointments and tests are usually done as outpatient visits. They do not require an overnight stay in the hospital. We do our best to group as many tests or visits as possible into one day to reduce travel time. If the patient cannot do many tests or visits in one day, we can spread them out over more days.

Most evaluations take a few weeks. The process may take longer for some people. The findings from the studies and visits will help us decide if the patient is likely to benefit from a lung transplant.

Caregivers

The potential recipient must name at least 2 people who will be their caregivers before the transplant, while they are on the waiting list, and for the rest of their life after transplant. These caregivers must be adults, be able to drive, be nonsmokers, and be able to stay all day at the hospital while the patient is recovering from the transplant surgery.

We do **not** advise depending on paid caregivers. Paid caregivers are:

- Not covered by most insurance after transplant
- Not available for care 24 hours a day, 7 days a week
- Not committed to the lifelong follow-up needed

As part of preparing for a transplant, the patient and their family or caregivers must attend our lung transplant education class. The class explains more about the transplant process, being on the waiting list, the transplant surgery, and what to expect after a lung transplant.

Decision by the Lung Transplant Recipient Selection Committee

After the evaluation is done, the UW Medicine Lung Transplant Recipient Selection Committee reviews the results from all the tests and clinic visits. This committee includes all members of the Lung Transplant Team, including the Program Director, Surgical Director, Medical Director, transplant pulmonologists, lung transplant surgeons, lung transplant nurse coordinators, social worker, nutritionist, financial counselor, pharmacist, and other providers as needed. The committee may also review input from the patient's primary providers and other consultants.

After their review, the committee may decide to:

- Accept the patient as a lung transplant candidate and put their name on the lung transplant waiting list
- Not accept the patient as a lung transplant candidate, and suggest other treatment options, if available
- Ask for more visits and tests before they make their decision

If the committee decides that the patient is not a candidate for a lung transplant at UW Medicine, the lung transplant doctor or lung transplant coordinator will talk with the patient and explain the reasons for their decision. The patient may wish to contact other transplant centers and ask to be evaluated. They can also request that we send their medical records to other centers.

If the committee needs more visits or tests to make their decision, they will meet again to talk about the results after those visits and tests are done. They will then make their final decision about the patient's candidacy for a lung transplant at UW Medicine.

Double-Lung or Single-Lung Transplant

The Lung Transplant Recipient Selection Committee decides if the patient is best suited to receive a double-lung (*bilateral*) transplant or a single-lung transplant. This decision is based on many factors, including the organs that are available. A double-lung transplant may be the only option if the patient has certain types of lung diseases.

Confirming Insurance Benefits

After the patient is approved for the waiting list, we must confirm their insurance benefits with their insurance company or designated payer. If needed, the Lung Transplant Program will submit all required information to the payer. We will ask for final approval of benefits for the lung transplant surgery, all follow-up care, and medicines needed after transplant.

Financing a Lung Transplant

The UW Medicine Lung Transplant financial counselor will contact the patient and their family or caregivers during the evaluation to go over insurance information. Before moving forward with a lung transplant, the patient should ask their insurance provider if these costs are covered:

- Organ acquisition fee
- The transplant surgery and hospital stay
- Lifetime medicines (including immune-suppressing medicines)
- Home *intravenous* (IV) therapy
- Rehabilitation (inpatient and outpatient physical, occupational, and speech therapy)
- Travel or relocation and housing

The patient should also ask about "lifetime maximums" for any benefits that are paid.

Sometimes, a patient finds out that their insurance will not cover all the costs of a lung transplant. If this happens and the patient cannot afford to cover the costs, the patient and their family may need to do fundraising before being placed on the waiting list.

Traveling to and Staying in the Seattle Area

Since a transplant surgery cannot be “scheduled,” a patient may be called any day of the week and any time of the day or night. When they are called, they must be able to arrive at UWMC within 3 to 4 hours.

As part of the evaluation, the Lung Transplant Recipient Selection Committee will review the patient’s plans for:

- Getting to UWMC within 3 to 4 hours of being called for a lung transplant
- Housing in the Seattle area after the transplant

We want to make sure that there are no issues that might keep the patient from arriving at UWMC in time. We also want to be sure they have a place to live after the transplant surgery.

If the patient:

- **Does not live within driving distance of Seattle:** They may need to plan for air travel. This will allow them to keep living at home and still arrive at UWMC within 3 to 4 hours of “the call.”
- **Cannot travel to UWMC within 3 to 4 hours, either by ground or air:** They must move to Seattle or to a place within 3 to 4 hours’ travel time while they wait for a lung transplant.

For **at least 3 months** after the transplant, the patient and their family or caregivers must live within 1 hour of UWMC. Some patients must stay in the Seattle area for 6 months or longer.

Most insurance providers do not pay for non-emergency travel, caregiver costs, or local housing. Housing is not directly provided by the UW Medicine Lung Transplant Program, so the patient and their family must make these plans if they need to relocate. The Lung Transplant social worker will provide information and resources about travel and housing options.

Waiting List

After the Lung Transplant Recipient Selection Committee accepts the patient as a lung transplant candidate and we receive final approval from their insurance provider, we contact the patient and place them on the waiting list for a lung transplant. If the patient needs to relocate to be closer to Seattle, we will place them on the waiting list after they have relocated.

The United Network for Organ Sharing (UNOS) maintains the waiting list for patients in the United States. The list matches patients waiting for a transplant with a compatible organ donor. Most times, organs are allocated based on how sick a patient is and how long they can expect to live after a

transplant. UNOS uses the *Lung Allocation Score* (LAS) for this process. To learn more about UNOS and the Lung Allocation Score, visit www.unos.org.

Waiting for a Transplant

A patient may wait a few days or a few years before the right donor organ is found. The most recent Scientific Registry of Transplant Recipients (SRTR) report is included in this packet. This report includes the UW Medicine Lung Transplant Program's *median* waiting time for a lung transplant. The median is the middle number in a range of numbers. A median waiting time of 6 months means that half of the patients wait less than 6 months and half wait more than 6 months.

While the patient waits for a lung transplant:

- Their primary care provider and a pulmonologist must continue to manage their medical issues and lung disease.
- They must see a UW Medicine Lung Transplant Program pulmonologist at least **every 2 to 3 months**. At these visits, we review any changes in their health and update studies or tests as needed. We may also set up other visits with the social worker, dietician, and other providers as needed.

Being Removed from the Waiting List

While waiting for a transplant, a patient may become more ill, develop new health problems, or have other issues. These changes may affect whether a lung transplant is still the best treatment option. If it is not, the patient may be removed from the waiting list.

Patients may also be removed from the waiting list if they lose their insurance, lose their caregivers, or no longer meet our criteria for a lung transplant in some other way. We will talk with the patient and their family or caregivers about any problems that arise. We will do our best to help resolve these problems, if possible.

If a patient is removed from the waiting list and is no longer a candidate for a lung transplant, the Lung Transplant Team and the patient's other providers will help them explore other treatment options, or end-of-life care and comfort measures as needed.

Donor Lung(s)

The donor lung(s) may come from the Seattle area or a surgical team may drive or fly to another city or state to get the lung(s). When a potential donor is found, the Lung Transplant Team does a full assessment of the donor lung(s) to see if they are suitable for transplant. This process can involve hours or days of tests and review.



The patient must provide us with phone numbers where they can be reached at any time of day or night.

Getting “the Call”

If the donor lung(s) seem to be suitable, we call one or more potential recipients to come to UWMC. If we call more than one potential recipient, usually one is a “back-up” recipient. A back-up is needed in case there are any reasons the lung(s) are not a good fit for the first recipient.

To alert the patient about the potential transplant, we call them by phone at the numbers they provided when they were placed on the waiting list. This means that the patient **must**:

- Tell us right away if their phone numbers change
- Answer all incoming calls or voice messages right away

If the patient does not answer the phone or reply to a voice mail within a short time, we may call another patient to come to UWMC for the transplant.

When the patient arrives at UWMC for the transplant, they are admitted to the hospital. When everything is ready and we confirm that the donor lung(s) are suitable for use, we take the patient to the operating room.

Donor lung(s) that appeared suitable at first may turn out to be not suitable for transplant. Sometimes, the surgical team finds this out when they arrive to get the lung(s). This may happen before or after a potential recipient is called to come to UWMC.

If the donor lung(s) turn out not to be suitable for use, the transplant surgery is canceled. The patient(s) who were called in for transplant are sent home. We call this a “dry run.” Most patients have at least one “dry run” while waiting for a lung transplant.

Hospital Care After Transplant

In the hospital, teams of providers care for lung transplant recipients. These teams follow the recipient during recovery and talk with each other about the recipient’s progress. The names of the providers on the UW Medicine Lung Transplant Team are listed on page 15 of this handout.

- The **Cardiothoracic Intensive Care Unit (CT ICU) Team** provides care while the patient is in the Intensive Care Unit (ICU).
- The **Thoracic Surgery Team** is in charge of the patient’s care in the Thoracic Surgery Unit.
- The **Pulmonary Transplant Team** helps care for the recipient during the entire hospital stay.
- Nurses, nutritionists, physical therapists, occupational therapists, respiratory therapists, and pharmacists also care for the patient.
- Some patients may also need to see other providers. These may be specialists in *endocrinology* (diabetes), *nephrology* (kidney), *gastrointestinal* (stomach and intestines), and *infectious diseases*.

In the CT ICU

A basic single lung transplant surgery takes about 4 to 6 hours. Right after the surgery, the patient goes to the CT ICU. Nurses, doctors, and respiratory therapists assess the patient's status right away. They begin treatments as needed and get the patient settled into their room. This may take 1 to 2 hours. During this time, we ask family or caregivers to wait in the waiting area just outside the CT ICU.

In the CT ICU, the patient is on a *ventilator* (breathing machine). This machine provides air through a breathing tube in the mouth. It is used until the patient can breathe on their own.

Sometimes, we can remove the breathing tube a few hours after the surgery, as soon as the patient recovers from the *anesthesia* (sleeping medicine). Most times, the patient can breathe on their own about 24 to 48 hours after the surgery. If problems arise, they may need to use the ventilator for many days or even weeks.

After a lung transplant, the patient has *catheters* (tubes) in their arms and neck, a catheter to drain their bladder, and drains in their chest to remove any fluid from around the new lungs. They may also have an *epidural* catheter for pain medicine. As their condition improves, we remove the catheters and drains.

Most patients stay in the CT ICU for about 3 to 5 days. If there are any problems, they may stay there longer.

In the Thoracic Surgery Unit

Once the patient can breathe on their own and their condition is stable, they move to the Thoracic Surgery Unit. One of our goals on this unit is to prepare the recipient and their family or caregivers for going home. A recipient may stay in this unit a few days to a few weeks, depending on their recovery. The average stay in the hospital is 14 to 20 days.

Some recipients have issues that arise during their recovery. These recipients may need to be in the hospital for several months.

Safety

After the transplant surgery, the recipient has a higher risk of getting infections. To keep the recipient safe, we:

- Ask visitors to wear gloves, a mask, and perhaps a gown
- Ask all adults and children with symptoms of a cold or an infection to wait until they are well to visit the patient.



Care after a lung transplant includes many medicines that the patient must take several times a day.

Getting Ready to Go Home

All members of the Lung Transplant Team help the patient get ready to leave the hospital. We give many teaching sessions about care at home. The recipient and their family or caregivers must attend all of these teaching sessions. This means that the family or caregivers must be with the recipient on the Thoracic Surgery Unit all day, every day, until the recipient leaves the hospital.

In the teaching sessions, the recipient and their family or caregivers learn how to:

- Take all medicines correctly
- Check vital signs (weight, blood pressure, pulse rate, and temperature) and lung function (*spirometry*)
- Know the signs and symptoms of possible rejection or infection

The recipient is ready to leave the hospital when their condition is stable, they can walk, and they have completed all the teaching sessions.

After Transplant

Transplant Medicines

Every day for the rest of their life, the transplant recipient must take many medicines. Some of these must be taken several times a day. Medicines that help prevent rejection of the transplanted lung(s) are called *immunosuppression* or *immunosuppressive* medicines. The recipient also takes medicines to prevent infection and other problems that may occur after the transplant.

The transplant recipient **must** take all their medicines as prescribed. If they do not, it may cause severe damage to their lungs, damage to their other organs, or even death.

Transplant medicines can be very costly. UW Medicine's financial counselors work closely with the patient to make sure they have enough insurance coverage or other resources to cover these costs.

Blood Tests

The transplant recipient must also have blood tests often. These tests check the levels of the medicines in their body. The tests can also show if there are other problems. The doctor may adjust the medicine doses based on these test results.

Recovery

Two caregivers must be able to help during the first stages of recovery. This is needed because a family member or caregiver must stay with the

patient **at all times** for at least the first 3 months after the transplant. Most recipients need help with taking their medicines, cooking meals, paying bills, and doing chores like cleaning and laundry. Some patients may also need help with taking care of the surgery wounds and with personal care like bathing, dressing, and using the toilet.

How soon a lung transplant recipient returns to their usual activities depends on how their recovery goes. Most recipients can resume a good level of activity 4 to 6 weeks after their transplant surgery. By then, they should be able to walk, bathe, and dress themselves.

Recipients must limit use of their arms for at least 8 to 12 weeks after surgery so that their chest can heal. They may also need ongoing physical therapy to help them regain their strength.

Follow-up Visits

The recipient has many follow-up clinic visits with the UW Medicine Lung Transplant Team. The team will watch them closely for any signs of problems. The recipient's family or caregivers must:

- **Provide transportation** to all follow-up visits. It is not safe for the recipient to drive for several weeks after the transplant surgery.
- **Come to all follow-up visits** with the recipient so they can learn about changes in the medicines and other treatments.

Rejection and Infection After Transplant

After a lung transplant, recipients face these ongoing risks:

- Rejection of the new lung(s)
- Infection due to the immune system being suppressed

The immune system's job is to protect the body against infection and illness. It does this by destroying germs and other substances that may be a threat. To a healthy immune system, a transplanted organ is an "invader" that must be rejected.

To keep their body from rejecting the new lung(s), the recipient must take medicines that suppress their immune system. They must take these medicines for the rest of their life. But, when their immune system is suppressed, the recipient can get infections more easily.

We teach recipients and their family or caregivers about the common signs of infection and rejection. It is vital to notice these signs early and tell the Lung Transplant Team right away. Most times, the recipient has better results if they get checked and begin treatment quickly.

Rejection

Different types of rejection can happen after a lung transplant. They include *acute rejection*, *antibody-mediated rejection*, and *chronic rejection*, also known as *chronic lung allograft dysfunction (CLAD)* or *bronchiolitis obliterans syndrome (BOS)*.

If we are concerned that the recipient may be rejecting their new lung(s), we may schedule a *bronchoscopy* with lung biopsies, blood tests, and other testing. If the recipient has rejection, they receive treatments based on the type of rejection and how severe it is.

Sometimes rejection can get worse, even with treatment. Rejection may result in lung failure and death.

Infections

Many types of infections can occur after a lung transplant. These can include:

- *Bacterial* infections such as pneumonia, skin infections, or infection of other parts of the body
- *Viral* infections such as respiratory viruses (like colds) that can cause damage to the transplanted lung(s)
- *Fungal* or mold infections

We will do our best to treat any infections that occur. Some infections cannot be treated or do not respond to treatment. This can result in lung failure and death.

Other Problems After Transplant

There are many other problems that can occur after a lung transplant. Some of these are:

- *Primary graft dysfunction* can occur. This is when the lung(s) do not work as they should right after the transplant surgery. If this happens, recovery may be slower. The recipient may also need to stay in the hospital longer. The recipient may die if the lung(s) do not begin to work.
- Surgical incisions may not heal fully: They also may come apart (*dehiscence*), or become infected. Treatments for incision problems include medicines to fight infection, more dressing changes to the wound, or surgery.
- Airway (*bronchial tube*) problems may occur. These problems include airway *stenosis* (narrowing) or airway *dehiscence* (airway falling apart). If these problems occur, the recipient may need a *bronchoscopy* (an exam where a tube with a camera is inserted into the lungs) or surgery to repair the airways, to *dilate* (widen) the airways, or to place a *stent*.

Over time, other problems may also occur. Many of these may be related to the immune-suppressing drugs. Side effects from these drugs include:

- Kidney problems that may require dialysis or a kidney transplant
- Digestive problems
- Blood count problems
- Nerve damage
- High blood pressure
- Weight gain
- Diabetes

Immunosuppressive medicines also increase the risk of getting cancer. Transplant recipients can develop cancers such as skin cancers and a type of lymphoma called *post-transplant lymphoproliferative disorder* (PTLD). Cancer after a lung transplant can be minor, but it can also be very serious or life-threatening. Patients may need surgeries or chemotherapy to treat these cancers.

Long-Term Follow-up

After a lung transplant, the recipient must have regular clinic visits with the UW Medicine Lung Transplant Team. These follow-up visits will be needed for the rest of the recipient's life.

If the recipient lives far away from Seattle, we work closely with their local doctors. But they still must come to UWMC for their regular clinic visits with the UW Medicine Lung Transplant Team.

After the first recovery phase:

- If the recipient is doing well, we do blood tests at least every 4 to 6 weeks. We will then see them for clinic visits several times a year.
- If there are problems, the recipient may need to have testing or clinic visits much more often.

Long-Term Outcomes

After a lung transplant, most recipients report that they are doing well. Most feel that their quality of life has improved. Some are able to return to work. Others are able to enjoy their retirement, travel, and spend time with their loved ones and friends.

Our goal is for every transplant recipient to improve their quality of life. This does not always occur. Patients who have problems after a lung transplant may need to be hospitalized many times. They may not be able to do normal activities, they may feel short of breath, and they may need extra oxygen. Very rarely, a patient may even feel worse than they did before the lung transplant.

Survival Rates

About 85% to 95% of patients (about 85 to 95 out of 100 patients) who receive a lung transplant are living 1 year after the transplant surgery. The *median survival* of all lung transplant recipients is about 5½ years. This means that half of lung transplant recipients live less than 5½ years and half live longer.

Recipients in the UW Medicine Lung Transplant Program meet or exceed these expected survival rates.

Survival rates for all transplant programs are on the Scientific Registry of Transplant Recipients (SRTR) website at www.srtr.org. This data is updated every 6 months. The most recent SRTR report is attached.

Commitment and Dedication

A lung transplant is a major event for everyone involved. The patient's life is changed in many ways. A successful outcome after a lung transplant demands great dedication from the patient, their family and caregivers, and the entire UW Medicine Lung Transplant Team.

The UW Medicine Lung Transplant Team stands with our transplant patients. We are dedicated to providing life-long support, medical care, and teaching for the patient and their family and caregivers.

Please see the handout "UW Medicine Lung Transplant Team" for a full list of providers and staff on our team.

Questions?

Your questions are important. Call the UW Medicine Lung Transplant Team if you have questions or concerns:

Weekdays from 8 am. to 4:30 p.m.: Call 206.598.5668.

After hours and on weekends and holidays: Call 206.598.6190 and ask for the Pulmonary Transplant fellow on call to be paged.