Lung Transplant

What to expect

UW Medicine
UNIVERSITY OF WASHINGTON
MEDICAL CENTER

This handout describes the process of having a lung transplant with the UW Medicine Lung Transplant Program. It explains what to expect before, during, and after your surgery.

Getting Started

As you prepare for your lung transplant, we will give you detailed information to help you understand the process. Please read this handout very carefully. Share it with your family and caregivers.

Having a lung transplant will change your life in many ways. You must think about everything involved before starting 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. We will be here to answer all your questions and concerns.

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 patients with end-stage lung disease. During the transplant surgery, the surgeon removes one or both diseased lungs. These are replaced with lungs from an organ donor.

What are the goals of a transplant?

The main goals of a lung transplant are to improve your quality of life and help you live longer. After a lung transplant, **most** patients can:

- Breathe better and do not need oxygen support
- Be more active than before the transplant
- Enjoy a better quality of life

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Who can have a lung transplant?

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

- End-stage lung disease that affects 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* (guidelines) for choosing transplant candidates. This helps us know if you are likely to benefit from a lung transplant.

What does a successful transplant require?

- **Teamwork**: Everyone involved in the transplant process works together as a team. This team includes you, your family and caregivers, and the entire UW Medicine Lung Transplant Team.
- **Commitment**: A successful transplant depends on your commitment to the process before, during, and after surgery. This commitment begins with the first clinic visit and continues for the rest of your life. You must commit to:
    - Taking your medicines as prescribed
    - Monitoring your health and new lung(s)
    - Practicing healthy living
    - Going to all appointments with the Lung Transplant Team
- **Caregiver support:** Success also requires the continuous dedication of your caregivers. Their commitment must last for the rest of your life.
- **Ongoing monitoring:** You must be closely monitored after the transplant surgery and for the <u>**rest of your life**</u>. Your lifelong follow-up care is extremely important. It will help us 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

To be considered for a lung transplant at UW Medicine, your current healthcare provider must refer you. The referring doctor is usually the lung doctor (*pulmonologist*) who has been treating your lung disease. Our team will use information from your other healthcare providers during the screening process and your long-term care.

Screening Process

The screening process includes a review of your medical records and health history. We will check for any issues that may affect your ability to have a good outcome after a lung transplant. If we do not find any issues, we will call you and discuss the next steps.

Caregivers

You must name at least 2 people who will provide support throughout your entire transplant process. Your caregivers **must** be:

- Adults
- Able to drive
- Nonsmokers

At least 1 caregiver must attend **all** appointments with you before and after your transplant. **All** caregivers must attend certain appointments, such as meetings with the lung transplant social worker, and the transplant education class. This class will explain more about the transplant process, being on the waiting list, the transplant surgery, and what to expect after a lung transplant.

When you are getting ready to leave the hospital after your transplant, at least 1 caregiver must be at the hospital for 3-5 days. During that time, we will teach them how to care for you.

- We do **not** accept paid caregivers for this role. Paid caregivers cannot be available for care 24 hours a day, 7 days a week or for the lifelong follow-up needed after your transplant surgery.

Financing a Lung Transplant

A lung transplant is a significant medical procedure that involves various costs, including:

- **Pre-transplant evaluations and testing:** You will have many tests and appointments to determine if you are eligible for a transplant.
- **Transplant surgery:** There are costs for the transplant surgery and hospital stay.
- **Post-transplant medications:** You must take special medications to prevent problems after the transplant and to manage your health.
- **Follow-up care**: You must go to many appointments and tests after the transplant to monitor your health.

You will have an appointment with a *transplant financial coordinator* (TFC) during your transplant evaluation. The TFC will help you understand the costs and financial planning of your lung transplant. They will work with your insurance provider to understand your coverage and out-of-pocket responsibility. Then they will talk with you about the expected costs of your transplant. The TFC can also give you information about financial assistance programs and payment plans.

Clinic Visit

A lung transplant doctor will meet with you and review all your health information. The doctor will explain the transplant process and talk about the risks and benefits of having a lung transplant.

If a lung transplant is not a good option for you, your doctor will explain why. We will also talk with your referring provider about the decision and suggest other treatments that may work for you.

Evaluation

If you and our team decide that a lung transplant may be a good option, the next step is the evaluation. During this process, we will set up tests to assess your lung disease. We will also check to make sure you do not have any problems with your other organs, such as your heart, bones, kidneys, liver, or esophagus.

Some of these tests can be done by your local providers. Others must be done at UWMC-Montlake (University of Washington Medical Center - Montlake).

Your evaluation process will include visits with everyone on the Lung Transplant Team. Our team members include:

- Lung transplant doctor (transplant pulmonologist)
- Lung transplant surgeon
- Social worker
- Financial counselor
- Nutritionist
- You may also have visits with other providers

Evaluation appointments and medical tests are usually *outpatient* visits, meaning you will not have to stay overnight in the hospital. We do our best to do multiple tests during your appointments to reduce the number of trips you must take to UWMC-Montlake. If needed, we can also spread your tests and transplant team visits out over more days.

Your evaluation will likely take a few weeks, but it may take longer. The results from your tests and visits will help us decide if a lung transplant will be the right treatment for you.

Decision by the Lung Transplant Recipient Selection Committee

After your evaluation, the UW Medicine Lung Transplant Recipient Selection Committee will review the results from all your tests and clinic visits.

This committee includes all members of the Lung Transplant Team. It includes the Program Director, Surgical Director, Medical Director, transplant pulmonologists and surgeons, nurse coordinators, social worker, psychiatrist, nutritionist, financial counselor, pharmacist, and other providers as needed. The committee may also review input from your primary providers and other consultants.

After their review, the committee may decide to:

- **Accept you as a lung transplant candidate.** If you are accepted, we will contact you to discuss the steps needed before you are placed on the waiting list.
- **Defer making a decision**. Additional visits or medical tests may be needed. After these tests, the committee will meet again to review and make a new decision.
- **Not accept you as a lung transplant candidate.** In this case we will contact you to explain the reasons for the committee's decision. We will suggest other available treatment options. You may ask your primary *pulmonologist* (lung doctor) to refer you to other transplant centers for evaluation.

Bilateral-Lung (Double) or Single-Lung Transplant

The Lung Transplant Recipient Selection Committee will decide if you should have a bilateral-lung (*double*) transplant or a single-lung transplant. This decision is based on many factors, including the organs that are available and the type of lung disease you have.

Confirming Insurance Benefits

After you are placed on the waiting list, we will confirm final approval of your insurance benefits for your lung transplant.

Traveling to and Staying in the Seattle Area

Transplant surgery cannot be scheduled for a specific date. We may call you any day of the week, and any time of the day or night to let you know when it is time for your surgery. When we call, you **must** be able to arrive at UWMC-Montlake in a reasonable amount of time.

- **If you do not live within driving distance from UWMC-Montlake**: You may be required to relocate to the Seattle area or have a flight plan before you can be placed on the waiting list.
- **If you do not live within an hour of UWMC-Montlake:** You and your caregiver must stay within 1 hour of the hospital for a minimum of 3 months **after** you discharge from the hospital.

Most insurance providers do not pay for non-emergency travel, caregiver costs, or local housing. The UW Medicine Lung Transplant Program does not provide housing.

The lung transplant social worker will give you information and resources about travel and housing options.

Waiting List

After you are accepted as a lung transplant candidate and we receive final approval from your insurance provider, we will contact you to confirm that you are ready to be placed on the waiting list.

The United Network for Organ Sharing (UNOS) manages the waiting list for transplant patients in the United States. The list matches patients waiting for a transplant with a compatible organ donor. Patients are usually selected to receive an organ based on how sick they are and how long they can expect to live after a transplant.

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

Waiting for a Transplant

You may wait a few days or a few years before the right donor organ is found. The Scientific Registry of Transplant Recipients (SRTR) updates a report every 6 months that includes the UW Medicine Lung Transplant Program's *median* waiting time for lung transplant.

The median is the middle number in a range of numbers. For example, a median waiting time of 5 months means that half of the patients wait less than 5 months and half wait more than 5 months.

While you wait for a lung transplant:

- Your primary care provider and a pulmonologist will continue to manage your medical issues and lung disease. You **must** tell the UW Lung Transplant Team about any changes in your health.
  - Changes in your health may require updating your information so you have a higher score on the waiting list.
  - Sometimes a change in your health may mean it is not safe for you to have a lung transplant at that time.
- You are **required** to come to UWMC-Montlake for follow-up visits while you are on the waiting list. Most patients have visits every 2 to 3 months but you may need to come in more often.
  - Follow-up visits usually take 1 day but may sometimes take several days. Your visits make sure that the Lung Transplant Team has current information about your health.

Being Removed from the Waiting List

While waiting for a transplant, your lung disease may get worse, or you may develop new health problems. These changes may affect whether a lung transplant is still the best treatment option. If it is not, you may be removed from the waiting list.

You may also be removed from the waiting list if you:

- Lose your insurance
- Lose your caregivers
- No longer meet our criteria for a lung transplant in some other way

If this happens, we will talk with you about the change. We will do our best to help resolve these problems.

If you are removed from the waiting list and are no longer a candidate for a lung transplant, the Lung Transplant Team and your other providers will help you understand your options. This may include other treatments, or end-of-life care and comfort measures.

Donor Lung(s)

Your donor lung(s) may come from anywhere in the country, but they are usually from a nearby area. When a potential donor is found, the Lung Transplant Team does a full assessment of the donor lung(s) to see if they are appropriate for transplant. The review process and tests can take hours or days.

Getting "The Call"

If the donor lung(s) are a good option for you, we call you to come to UWMC-Montlake. We will call you at the numbers you provide when you are placed on the waiting list. This means that you **must**:

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

If you do not answer the phone or reply to a voice message quickly, we may call another patient to come to UWMC-Montlake for the transplant.

When you arrive at UWMC-Montlake for your transplant, you will be admitted to the hospital and be prepared for surgery.

Sometimes, donor lung(s) that initially seem like a good match may later be found *unsuitable*. This means they cannot be used for a transplant. The surgical team might learn this when they arrive to get the lung(s). This may happen before or after we take you to the operating room.

If we are not able to use the donor lung(s) for your transplant, the surgery will be canceled, and you will be discharged from the hospital. We call this situation a "dry run." Many patients have 1 or more "dry runs" while waiting for a lung transplant.

You must provide us with phone numbers where we can reach you at any time of day or night.

Hospital Care After Your Transplant

Many different teams will manage your care together during your surgery and recovery in the hospital. These teams include:

- The **Cardiothoracic Intensive Care Unit (CTICU) Team** provides care while you are in the Intensive Care Unit (ICU).
- The **Thoracic Surgery Team** manages your care in the Thoracic Surgery Acute Care Unit (sometimes called "the floor").
- The **Pulmonary Transplant Team** helps care for you during the entire hospital stay.
- Nurses, nutritionists, physical therapists, occupational therapists, respiratory therapists, social work, and pharmacists also care for you.
- You may also need to see other providers. These may include specialists such as:
  - *Endocrinology* (diabetes),
  - *Nephrology* (kidney)
  - *Gastrointestinal* (stomach and intestines)
  - Infectious diseases

In the Cardiothoracic Intensive Care Unit (CTICU)

Lung transplant surgery usually takes about 4 to 6 hours. Right after the surgery, you will go to the Cardiothoracic Intensive Care Unit (CTICU). Nurses, doctors, and respiratory therapists assess your status right away. They will give you any needed treatments and get you settled in your room. This may take 1 to 2 hours. During this time, we will ask your family or caregivers to wait in the waiting area just outside the CTICU.

In the CTICU, you will be on a *ventilator* (breathing machine). This machine helps you breathe until you can breathe on your own.

Sometimes we can remove the breathing tube a few hours after the surgery, as soon as you recover from the *anesthesia* (sleeping medicine). Most times, patients will be able to breathe without a ventilator 24 to 48 hours after surgery. However, it is possible that you may need to be on the ventilator for many days or even weeks if there are problems after surgery.

After your surgery, you will have *catheters* (tubes) in your arms and neck, a catheter to drain your bladder, and drains in your chest to remove any fluid from around your new lungs. You may also have an *epidural* catheter in your spine for pain medicine. As you recover, we will remove the catheters and drains.

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

In the Thoracic Surgery Acute Care Unit

Once you can breathe on your own and your condition is stable, you will move to the Thoracic Surgery Acute Care Unit. In this unit one of our goals is to prepare you and your caregivers for discharge from the hospital. You may stay in this unit for a few days to a few weeks, depending on your recovery. The average stay in the hospital is 14 to 20 days.

Some patients have problems during their recovery. If you have complications, you may need to be in the hospital for a long time, possibly for many months.

Safety

After the transplant surgery, you have a higher risk of getting infections. To keep you safe, we will:

- Ask visitors to wear a mask in your room, and sometimes a gown and gloves.
- Ask all visitors with symptoms of a cold or an infection to wait until they are well to visit you.

Getting Ready to Leave the Hospital

All members of the Lung Transplant Team help you get ready to leave the hospital. We give many teaching sessions to prepare for your care after discharge.

You and your caregivers must attend all these teaching sessions. This means your caregivers must be available for teaching sessions with you in the week before we discharge you from the hospital. Not all teaching sessions can be scheduled. Your caregivers must be in your room every day for most of the day.

In the teaching sessions, you and your caregivers learn how to:

- Take all medicines correctly
- Check lung function (*spirometry*)
- Check vital signs (weight, blood pressure, pulse rate, temperature)
- Check blood sugar levels and give insulin injections if needed
- Monitor the surgical incisions and change dressings if needed
- Understand the symptoms of problems such as infection

You and your caregivers must complete all the teaching sessions. You will be ready to leave the hospital when you and your caregivers have completed your training and when your condition is stable.

After Your Transplant

Transplant Medicines

Every day for the rest of your life, you 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. You must also take medicines to prevent infection and other problems that may happen after your transplant.

You **must** take all your medicines as prescribed. If you do not, it may cause severe damage to your lungs, damage to your other organs, or even death.

Transplant medicines can be very expensive. The Lung Transplant Team will work closely with you to make sure you have enough insurance coverage or other resources to cover these costs.

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

Blood Tests

You must have frequent blood tests. These tests check the levels of the transplant medicines in your body. Blood tests can also show if there are any other problems that need treatment. Your doctor may adjust your medicine doses based on your test results.

Recovery

Your caregiver must stay with you **at all times** for at least the first 3 months after the transplant. You may need help with many daily activities including:

- Taking medicines
- Cooking meals
- Paying bills
- Doing chores like cleaning and laundry
- Taking care of surgery wounds
- Personal care including bathing, dressing, and using the toilet

The speed at which you can return to your usual activities depends on how your recovery goes. Most patients are able to do normal activities 4 to 6 weeks after transplant surgery. By then, you should be able to walk, bathe, and dress yourself. You may need ongoing physical therapy to help you fully regain your strength.

You must limit how much you use your arms for at least 8 to 12 weeks after surgery so that your chest can heal. The amount of time depends on whether you have a *bilateral* (double) or single-lung transplant.

Follow-up Visits

You will have many follow-up clinic visits after your surgery. The Lung Transplant Team will watch you closely for any signs of problems. Your caregivers must:

- **Provide transportation** to all follow-up visits. It will not be safe for you to drive for several months after your surgery.
- **Attend all follow-up visits** with you so they can learn about changes in your medicines and treatments.

Rejection and Infection After Transplant

Possible risks after a lung transplant include:

- Rejection of the new lung(s)
- Infection

Your *immune system* protects your body against infection and illness. It destroys 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 your body from rejecting your new lung(s), you must take medicines for the rest of your life that *suppress* (weaken) your immune system. When your immune system is suppressed, you can get infections more easily.

We will teach you and your caregivers about common signs of infection and rejection. It is important to notice these signs early and tell the Lung Transplant Team about them right away. You will have better results if you have an exam and begin treatment quickly.

Rejection

Different types of rejection can happen after a lung transplant. They include acute cellular rejection or antibody-mediated rejection. You may also develop chronic lung allograft dysfunction (CLAD), which is permanent damage to your transplanted lungs from rejection, infection, or other problems. Your provider will give you more information about different types of rejection.

If we are concerned that you may be having rejection of your new lung(s), we may schedule tests including:

- *Bronchoscopy* (exam where a tube with a camera is inserted into your lungs)
- *Lung biopsy* (removing a small sample of lung tissue)
- CT scans, blood tests, and other testing if needed

If you have rejection, your treatment will depend on the type of rejection and how severe it is. Your lung function may improve or stabilize with treatment.

Sometimes rejection can get worse, even with treatment. It is possible for rejection to cause lung damage, lung failure, or 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** can include respiratory viruses such as a cold, influenza, or COVID. These can damage your transplanted lung(s).
- **Fungal** or mold infections.

If you get an infection, we will do our best to treat it. Some infections cannot be treated or do not respond to treatment. This can result in lung damage, lung failure, or death.

Other Problems After Transplant

There are many other problems that can happen after a lung transplant. Some possible problems are:

- ***Primary graft dysfunction:*** This is when the transplanted lung(s) do not work as they should after surgery. If this happens, your recovery may be slower and you may need to stay in the hospital longer. You may die if your transplanted lung(s) do not start to work.
- **Wound healing issues:** Surgical *incisions* (openings) may not fully heal. They may come apart (*dehiscence*) or become infected. Treatments for incision problems include medicines to fight infection, dressing changes to the wound, or surgery.

- **Airway (*bronchial tube*) problems:** *Stenosis* is a problem where your airway becomes narrow. *Dehiscence* is when your airway comes apart where it has been sewn together. If you experience one of these problems you may need a *bronchoscopy,* which is an exam where a tube with a camera is inserted into the lungs. During this procedure we will *dilate* (widen) the airways or keep the airway open by placing a *stent* (tube). You may need surgery to repair your airway.

There are other possible problems that may happen over time. Many problems can be related to your immunosuppressive medicines. Side effects from these medicines may include:

- Kidney problems that may require a kidney transplant or *dialysis* (a procedure to remove waste from your blood)
- Digestive problems (nausea, vomiting, diarrhea)
- Blood count problems
- Nerve damage
- High blood pressure
- Weight gain
- Diabetes

Immunosuppressive medicines also increase your risk of getting cancer. Transplant patients can develop skin cancers and a type of *lymphoma* (a blood cancer that affects your immune system) called *post-transplant lymphoproliferative disorder* (PTLD). Cancer after a lung transplant can be minor, but it could be very serious or life-threatening. You may need surgeries or chemotherapy to treat these cancers.

Long-term Follow-up

After a lung transplant, you must have regular clinic visits with the UW Medicine Lung Transplant Team **for the rest of your life**. Providers who take care of lung transplant patients must have special knowledge and training.

If you live far away from Seattle, we will work closely with your local providers. However, you still **must** attend regular in-person clinic visits with the UW Medicine Lung Transplant Team.

For lifetime after transplant:

- We will see you in person for clinic visits. You must travel to UWMC-Montlake to see the Lung Transplant Team.
  - You will have frequent visits for the first several years after a lung transplant, even if you are not having problems.
  - After the first several years, your visits to UWMC-Montlake may be less frequent.
  - You should expect to have these visits at least twice a year for the rest of your life.
- You will need blood tests at least every 4 to 6 weeks. Some blood tests can be completed close to home.
- You may need to have testing or clinic visits much more often if you have any health problems.

Long-term Outcomes

After a lung transplant, most patients report that they are doing well and feel that their quality of life has improved. Once the Lung Transplant Team says it is ok, many patients are able to go back to work. They are also able to do activities such as travel, sports, and spending time with family and friends.

Our goal for every transplant patient is to improve their quality of life, but this does not always happen. If you have problems after a lung transplant, you may need to have many procedures or stay in the hospital many times. You may feel short of breath, need extra oxygen, or may not be able to do normal activities. Very rarely, you may even feel worse than you did before the lung transplant.

Survival Rates

- About 85% to 95% of lung transplant patients (about 85 to 95 out of 100 patients) are living 1 year after the transplant surgery.
- The *median survival* of all lung transplant patients is about 6½ years. This means that half of lung transplant patients live less than 6½ years and half live longer.
- Patients in the UW Medicine Lung Transplant Program do as well or better than these expected survival rates.

You can learn more about transplant patient survival rates and see this data on the Scientific Registry of Transplant Recipients (SRTR) website at *www.srtr.org*. This data is updated every 6 months.

Commitment and Dedication

A lung transplant is a major event for everyone involved. Your life will be changed in many ways. A successful transplant requires dedication from you, your caregivers, and UW Medicine Lung Transplant Team.

We are here to support you every step of the way. We offer life-long support, medical care, and teaching for you and your caregivers.

For a list of all the providers on our team, please see the handout "UW Medicine Lung Transplant 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 pm: Call 206.598.5668.

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

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