

UW Medicine

Lung Transplant Recipient Handbook



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UW Medicine Lung Transplant Program

This handbook was written for lung transplant recipients and their caregivers. It contains reliable and detailed information about the lung transplant process at UW Medicine in Seattle, Washington. It explains what to expect after having lung transplant surgery and how to best manage your new lung(s) after transplant.

We understand that receiving so much information can be overwhelming. But, we hope that what you learn from this handbook, along with support from the UW Medicine Lung Transplant Team, will give you confidence to fully embrace life after your lung transplant surgery.

Our goal for you is a successful lung transplant and return to a fulfilling life. To reach this goal, the Lung Transplant Team will be your partner. We will work closely with you to monitor your progress over time.



University of Washington Medical Center – Montlake campus in Seattle, Washington

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The Immune System

Infection and rejection after a lung transplant

This handout explains how the immune system works, and why it must be suppressed after lung transplant surgery.

What is the immune system?

The *immune system* is a complex network of special cells and organs. When it is working well, it protects the body against “invaders” such as viruses, bacteria, fungi, and other infections.

To do this, the immune system must tell the difference between a person’s own cells and any invading “non-self” cells. If the immune system finds “non-self” cells, it will attack them. This is a type of *immune response*.

An immune response can be triggered when the immune system finds *antigens* in the body. Antigens are often “non-self” cells. They might be cells from bacteria, viruses, or other types of infection.

Antigens can also be cells from another person, such as blood used in a transfusion or an organ used for a transplant. The immune system sees these substances as “foreign” and tries to remove them. When this happens after an organ transplant, it is called *rejection*.

How does the immune system work?

When the immune system senses antigens, it activates *white blood cells* to fight the invader. The 2 main types of white blood cells are *lymphocytes* called *T cells* and *B cells*:

- **T cells** attack the foreign cells directly.
- **B cells** produce *antibodies* that attach to the foreign cells. These antibodies signal other immune cells to attack the foreign cell.



As a transplant recipient, you will take medicines to suppress your immune system, to keep it from rejecting your new lung(s).

What stops the immune system from rejecting a transplanted organ?

Transplant recipients are given medicines to suppress their immune system and keep it from rejecting the transplanted organ. These are called *immunosuppressants* or *immunosuppressive medicines*.

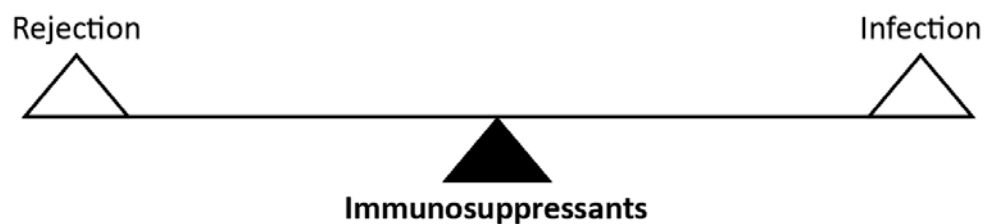
Lung transplant recipients start to receive these medicines when they go to the operating room for the transplant surgery, even before the donor lung(s) are placed in their body. After the transplant surgery, recipients must take immunosuppressants for the rest of their lives.

Challenges in Suppressing the Immune System

Your immune system must be suppressed to prevent rejection of the transplanted lung(s). But if your immune system is suppressed too much, it will not be able to fight infections. Both rejection and infections threaten your overall well-being and the health of your transplanted organ.

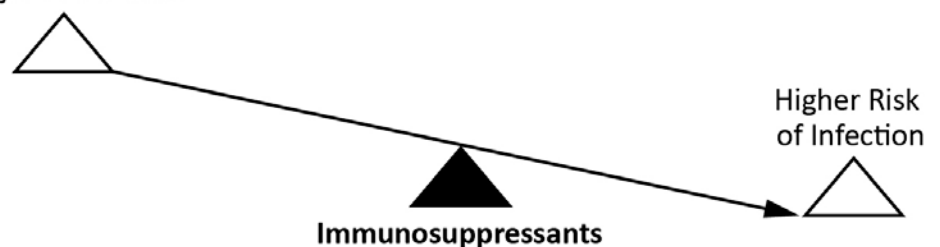
Once you have your new lung(s), we want to both keep your body from rejecting the new lung(s) and limit your risk of infection. We will do our best to adjust your immunosuppressant doses to find the right balance. This process takes time.

These drawings show the relationship between immunosuppressants, rejection, and infection:

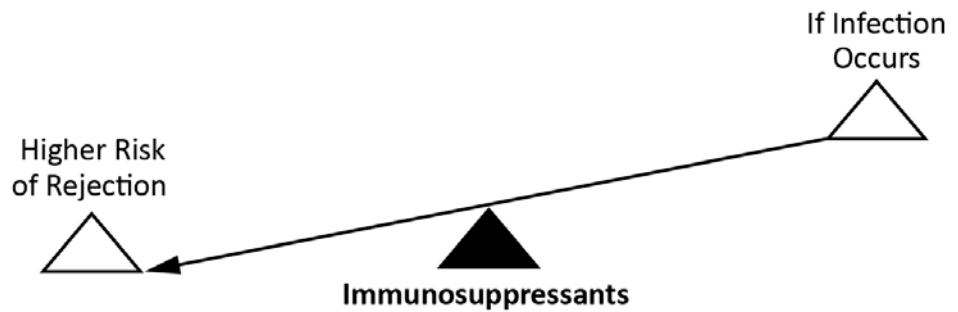


When well balanced, immunosuppressant medicines prevent rejection and infections are minimized.

If Rejection Occurs



If rejection occurs, we will increase the level of immunosuppression. This increases the risk of infection.



If an infection occurs, we may decrease the level of immunosuppression. This increases the risk of rejection.

We will closely monitor your lungs and overall health after surgery. If needed, we may adjust your doses of immunosuppressants at your follow-up visits. This is one reason you must have follow-up visits very often in the first few months after transplant surgery.

How long will I need to take immunosuppressants?

Every lung transplant recipient must take immunosuppressive medicines every day for the rest of their life. This is because the recipient's body will never accept the transplanted organ as its own. As long as the recipient is alive, there is always a risk of rejection. The amount of immunosuppressive medicines varies, depending on each lung transplant recipient's unique situation after the lung transplant surgery.

Does the risk of rejection change over time?

Most times, rejection occurs during the first 12 months after a lung transplant. But it can occur at any time, even many years after the transplant surgery.

Right after a lung transplant, the recipient receives high doses of immunosuppressants. This high dose is needed right away to keep the immune system from rejecting or damaging the new lung(s). As time passes, the immune system may become less aggressive in its attempt to reject the new lung(s). If this happens, we may be able to reduce the level of immunosuppressive medicines over time.

If rejection occurs at any time after a lung transplant, your level of immunosuppression will need to be increased. After we treat you for rejection, we may need to find a new balance of immunosuppressive medicines to keep you from having another rejection episode.

What are the symptoms of rejection?

It is not always easy to diagnose rejection after a lung transplant. Symptoms of rejection might include:

- Decrease in *spirometry* (breathing tests), particularly FEV1
- Shortness of breath
- Fever
- Changes in chest X-ray or *computed tomography* (CT) images
- Change in oxygen saturation
- New fatigue

These symptoms can also occur if you have an infection or other problems after a lung transplant. If you have any of these symptoms, we may ask you to have a test called a *bronchoscopy* to help us find the cause.

During a bronchoscopy, a scope is inserted into your lung(s) through your nose or mouth. This allows us to look at the new lung(s) and take samples to test for rejection, infection, or other problems.

What happens if rejection occurs?

Treatment of rejection depends on whether it is *acute* rejection or *chronic* rejection, also called *chronic lung allograft dysfunction* (CLAD).

Acute Rejection

There are 2 main types of acute rejection:

- *Acute cellular rejection*, usually triggered by T-cells
- *Antibody-mediated rejection*, usually triggered by B-cells

If we find rejection or we feel strongly that your symptoms are being caused by rejection, your level of immunosuppression will be increased until the rejection subsides. Treatment depends on the type of immune cell most likely causing the rejection.

After acute rejection is treated, the patient's lung function often returns to their former baseline. But sometimes the transplanted lung(s) are damaged by the rejection episode. This can mean that the lungs will never work as well as they did before the rejection. The patient's symptoms after treatment of the rejection will depend on how severe the lung damage is.

Acute Cellular Rejection

Acute cellular rejection occurs when T-cells attack the new lung(s) directly. Most times, the first treatment given for acute cellular rejection is a “pulse” (short-term treatment) with high-dose steroid medicines (*methylprednisolone*, then *prednisone*).

If the rejection does not respond to this first treatment, we will try other ways to get rid of the T-cells that are causing the rejection. These other treatments can include medicines like *anti-thymocyte globulin* (ATG) and *alemtuzumab*, both of which kill T-cells. These drugs strongly suppress the immune system for a while. Sometimes, they can cause severe, permanent suppression of the immune system.

Antibody-mediated Rejection

Antibody-mediated rejection requires treatments directed at B-cells and the antibodies that are triggering an attack on the new lung(s). These treatments can involve some combination of:

- *Plasmapheresis*, a process that removes antibodies from the blood, much like dialysis removes toxins for patients with kidney failure
- *Rituximab*, a medicine that kills immature B-cells
- *Bortezomib*, a medicine that kills the mature B-cells that produce antibodies
- *Intravenous immunoglobulin* (IVIG), a medicine that inactivates circulating antibodies and decreases the production of new antibodies

Chronic Lung Allograft Dysfunction

Chronic lung allograft dysfunction (CLAD) is also called *bronchiolitis obliterans syndrome* (BOS) or *chronic rejection*. CLAD is defined as a *sustained* decline in spirometry (FEV1 and/or FEF 25% to 75%), without another cause.

CLAD occurs in most lung transplant recipients over time. We do not know why it occurs. There may be many factors that play a role, including:

- Episodes of acute rejection
- Episodes of infections, including respiratory viruses (colds and flu)
- Gastroesophageal reflux (GERD)

Sometimes, there does not seem to be a specific event that has caused CLAD to occur. And even when we manage and treat issues that could cause CLAD, we might not be able to keep it from occurring in lung transplant recipients.

It is very hard to diagnose CLAD. We do not have a test that clearly points to CLAD as the cause of a patient's symptoms or permanent decline in spirometry.

Studies show the most likely end-result of CLAD is damage to the *bronchioles* (very tiny airways in the lungs) and scarring of the lung tissue. The bronchioles become inflamed, causing them to be distorted, narrowed, and plugged with scar tissue. After the bronchioles are destroyed, the patient can develop severe *obstructive airway disease* (cannot get air out). When a lot of scar tissue forms, the patient can develop severe *restrictive lung disease* (cannot get air in).

We do not have medicines that can restore lung function after the bronchioles are destroyed. The best we can do is to try to keep more damage from occurring. We do this by treating any known underlying problems such as acute rejection, infection, or gastroesophageal reflux.

For lung transplant recipients, the best way to try to prevent CLAD is to:

- Take your medicines **exactly** as prescribed.
- Closely monitor your breathing with your home spirometry machine. Call the Lung Transplant office **right away** if you have a decline in FEV1 of more than 10% from your baseline.
- Keep in close contact with the UW Lung Transplant Team. Call the Lung Transplant office **right away** if you have any new symptoms.

Infections

After a transplant, the recipient takes immunosuppressants to prevent rejection. But suppressing the immune system lowers the body's ability to fight off infections. This means bacteria, viruses, or fungi can cause infections that don't often affect people with a normal immune system.

The air we take into our lungs may contain *infectious pathogens* (organisms that cause infection). This can be dangerous for someone whose immune system is suppressed.

Viruses

Viruses cause about 40% of infections (40 out of 100 infections) that occur in transplant recipients. Some infections are more common early after the transplant surgery, but others can occur at any time after a transplant.

Herpes Viruses

The *herpes virus* family is one of the most common causes of viral infections in transplant patients. By age 25, more than 80% of people (80 out of 100 people) have been infected by a herpes virus (cold sores, chicken pox, etc.).

When someone gets a herpes virus, the virus lives in their body for the rest of their life. These “latent” infections usually do not cause problems. But, when the immune system is suppressed, the herpes virus can reactivate or “wake up” and cause problems.

There are 4 types of herpes virus:

Herpes Simplex Virus (HSV)

HSV Type I (HSV-1) outbreaks often cause cold sores. Type II (HSV-2) outbreaks often cause genital herpes.

HSV outbreaks most often occur in the first 6 months after a transplant or up to 3 weeks after treatment for rejection. At these times, the patient is on higher doses of immunosuppressants. As the level of immunosuppression decreases over time, the number of HSV outbreaks also goes down.

Other factors which may reactivate HSV are stress, anxiety, other illness, friction, or chafing. Rarely, HSV infections can involve internal organs such as the lungs, liver, and brain. For patients who keep having HSV outbreaks, we may prescribe a daily anti-viral medicine.

Varicella Zoster Virus (VZV)

VZV causes both chicken pox and shingles. The first time you are exposed to VZV, you develop chicken pox (the *primary illness*). The reactivation of VZV is called shingles (the *secondary infection*).

Rarely, VZV infections can affect other organs such as the lungs, eyes, or brain. For patients who keep getting shingles, we may prescribe a daily anti-viral medicine.

Cytomegalovirus (CMV)

CMV is a common herpes virus that occurs in immunosuppressed patients. The risk of CMV infection after a lung transplant depends on the status of the donor (D) and recipient (R).

- A lung transplant recipient who has been infected with CMV (R+) can receive an organ from a donor who had also been infected with CMV (D+), or from a donor who had NOT been infected (D-).
- Likewise, a lung transplant recipient who has NOT been infected with CMV (R-) can receive an organ from a donor who had been infected with CMV (D+), or from a donor who had also not been infected (D-).

CMV infection can occur in any transplant patient. But, lung transplant recipients who have not had CMV infection (R-) who receive an organ from a donor who has been infected with CMV (D+) are at the highest risk of reactivation. This is because their bodies have not developed immunity to CMV, and the immunosuppressants often keep these patients from developing immunity to CMV. This makes it harder for their immune system to keep the CMV under control.

If either the lung transplant recipient or their donor has a history of CMV infection (R+ or D+), the recipient will receive a *prophylaxis* (preventive) dose of an anti-viral medicine such as *valganciclovir*. How long they receive this prophylactic medicine depends on the CMV status of the donor and recipient and whether a CMV infection occurs after transplant.

A blood test to check for CMV is done often during the first year after a lung transplant. Many times, we find CMV in the blood before the patient has any symptoms. CMV can also cause symptoms such as fever, severe fatigue, shortness of breath, abdominal pain, nausea or vomiting, or diarrhea.

If CMV is found, we will start treatment right away. If you have symptoms from CMV, we might do tests to see if the CMV is causing problems in your lung(s) or stomach and *gastrointestinal*

(digestive) tract. Treatment will continue until the CMV is gone. This can take 3 weeks to several months.

Epstein-Barr Virus (EBV)

EBV causes *mononucleosis*. It is also involved in *post-transplant lymphoproliferative disorder* (PTLD). This is a type of *lymphoma* (cancer of the lymph nodes) found in people who are taking immunosuppressants. PTLD is rare but most times can be treated.

Respiratory Viruses

Respiratory infections (colds) can occur after a lung transplant. Colds can be the same as they are for people who are not taking immunosuppressive medicines. But, lung transplant recipients might notice their symptoms are a little worse and last a little longer than in other people.

Sometimes respiratory viruses can cause major damage to the transplanted lung(s). They can even trigger acute rejection. If you get cold or flu-like symptoms after transplant surgery:

- Call the UW Lung Transplant Team **right away**.
- Watch your symptoms closely and use your home spirometry to monitor your lung function.

We do not have treatments for most respiratory viruses, but it is still important to tell us about any symptoms as soon as you can.

Bacterial Infections

About 40% of infections (40 out of 100 infections) that occur after a transplant are caused by bacteria. These infections can occur at any time after a lung transplant and may affect any part of the body. Watch yourself closely for any signs of infection.

If you notice any signs, call the UW Lung Transplant Team **right away**. We might do tests to help tell us what bacteria may be causing the infection. Once we know if bacteria are involved, we can decide the best treatment.

Fungal Infections

Fungi cause about 10% to 20% of the infections (10 to 20 out of 100 infections) that occur after an organ transplant. *Fungal spores* (pieces of the fungus) are normally found in the air. There are

usually more spores in areas where the soil has been disturbed, such as building sites, farming areas, and compost piles. If a transplant recipient is exposed to these areas often, and does not wear a mask or other protection, it can increase their risk of getting a fungal infection.

It is always a good idea to wear a mask and other gear to protect yourself when you are around areas where soil has been disturbed. This includes wearing long sleeves and long pants if your arms or legs might come in contact with the soil.

Aspergillus

The most common fungal infection after a lung transplant is *Aspergillus*. *Aspergillus* is a mold that is all around us. We all breathe in a few *Aspergillus* spores all the time. When there is a lot of dirt in the air, we may breathe in a large amount of *Aspergillus* spores at one time. This raises the risk of getting an *Aspergillus* infection.

Symptoms of *Aspergillus* infection can include fever, shortness of breath, or cough. We can also sometimes find it on a chest X-ray or *computed tomography* (CT) scan before symptoms appear.

Treatment for an *Aspergillus* infection can involve taking an anti-fungal medicine for at least 3 to 6 months.

Preventing Infections

Preventing infections is a good way to protect your health. Most of the things that help prevent infections make good sense.

Washing Your Hands

Simply washing your hands might be the very best way to prevent the spread of infection! Most people pick up respiratory viruses by touching things such as door handles, sink faucet handles, and grocery store carts and then touching their *mucus membranes* (eyes, nose, and mouth). It's easy to carry hand sanitizer and clean your hands when you are out in public and around objects that other people have touched.

Wearing a Mask

We advise transplant patients to wear masks at certain times to lower the risk of getting some types of infections. Remember to wear a mask:

- Whenever you return to the hospital or clinic. There are many sick people in the hospital who may cough or sneeze, so wear a mask!
- Anytime you are around building sites or any place where you can see dust or debris in the air.
- When you are digging soil in the garden or doing other yard work.

There may be other times we advise wearing a mask, such as during the outbreak of a disease such as COVID-19. Please talk with your transplant team to find out what to do during these times.

Tips to Prevent Infection

- Avoid being around anyone who is sick.
- Wash your hands often, especially when you are in public places.
- Use common sense if you do not feel well. Give yourself time to rest, eat healthy foods, and drink plenty of fluids. Call the UW Lung Transplant Team and tell them your symptoms. They could have other ideas of ways you can take care of yourself.

Vaccines

Before you receive a lung transplant, we will make sure you are up to-date on your vaccines.

Vaccines may include shots to prevent:

- Hepatitis
- Pneumonia
- Flu
- Tetanus and whooping cough (Tdap)
- Measles, mumps, and rubella (MMR)
- Shingles

After your lung transplant, we advise you to get a flu shot every year. It is also important to update your pneumonia vaccine. Ask the UW Lung Transplant Team how often you need to do this.

Warning About Live Virus Vaccines

Some vaccines contain live viruses. **After transplant, you must NEVER receive an immunization that contains a live virus.**

With your suppressed immune system, you may get the infection instead of being protected against it.

The most common live vaccines are for:

- Shingles
- MMR (measles, mumps, and rubella)

Other live vaccines include:

- *Intranasal* (nasal spray) flu vaccine
- Smallpox vaccine
- Oral polio vaccine
- Yellow fever vaccine

Questions?

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

Weekdays from 8 am. to 4 p.m.: 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.

Health Basics

Ways to stay healthy after a lung transplant

Now that you have had your lung transplant, we want you to resume a normal and active lifestyle. This chapter gives important information to help you stay healthy as you get back into your life.

Vital Signs

Right after your transplant, you will need to start taking and recording your *vital signs*. This means taking your heart rate (pulse), blood pressure, and temperature 2 times a day. You will also need to weigh yourself every morning. As time goes on, if you are doing well, you may only need to check your vital signs and weight as needed, or if you aren't feeling well.



After your transplant surgery, you will need to take your pulse and other vital signs 2 times a day.

Spirometry

At first, lung transplant recipients must check their *spirometry* (breathing test) **every day**. Small changes in your lung function can be an early warning sign of rejection, infection, or other problems. It is important to remember: If your FEV1 goes down 10% or more from your baseline, call the Lung Transplant Team **right away**.

After the first year, if you are doing well and your lungs are stable, you may check your spirometry less often – once a week instead of once a day. Always remember that changes in your lung function may be slow and subtle, and you may not have any symptoms. This is why it is so important to keep checking your spirometry. Otherwise, you may not catch changes that need treatment.

Medical Identification (ID)

We advise all lung transplant recipients to carry a list of their current medicines and contact information for the UW Medicine Lung Transplant Team in case of emergencies. If you choose, you may also wear a medical ID bracelet or necklace.

Returning to Your Activities

We strongly encourage you to be active and take part in physical exercise after your lung transplant. But, you must follow some restrictions in the first few months after your transplant surgery so that your body can heal.

Upper Body Restrictions

You will need to follow “upper body restrictions” to allow your *sternum* (breastbone) and other tissues to heal. Before you leave the hospital, we will tell you which activities you may not do, and how long you will need to follow these restrictions. Most patients are on upper body restrictions for about 8 to 12 weeks.

Walking

Walking is the best way to exercise and rebuild your strength after the lung transplant surgery. We encourage you to walk often and try to walk more each time. We also strongly advise you take part in a Pulmonary Rehabilitation program after you leave the hospital.

At first, you may feel short of breath with fast walking, walking up hills, and walking upstairs. Some patients worry that this means their lungs are not working. But most times, these problems are due to muscle weakness caused by a lack of exercise while waiting for a lung transplant.

Activities

You can resume most activities when you feel ready. Use your common sense as you go through each day. If something hurts, if you are too tired, or if you feel an activity is too much for you, back off for a while and try it again later. Be sure to give yourself plenty of time to recover from the transplant surgery.

Exercise

After your lung transplant, exercise **must** become a regular part of your life. Exercise will help keep you strong and keep your lungs healthy. Having a daily exercise routine, getting enough rest, and eating balanced meals will increase your strength and stamina, and will make you feel better overall.

Once the Lung Transplant Team tells you that you can return to all your activities, increase your exercise slowly. Your muscles may be very sore if you push yourself too hard, too quickly. Your goal is to do exercise that helps you get stronger, but does not cause you pain.

Call the Lung Transplant Team if you have any of these issues during exercise:

- *Systolic* blood pressure (upper number) higher than 190 mmHg
- *Diastolic* blood pressure (lower number) higher than 110 mmHg
- Feeling lightheaded
- Feeling a lot of pain

Driving

You cannot drive until the Lung Transplant Team tells you it is ok. Steering the car and getting in and out of the driver's seat:

- Will put strain on your wounds
- Can dislodge the tip of your sternum
- May delay healing of your other tissues

You also may not drive if you are taking *opioid* pain medicines. Opioids may cause sleepiness and impair your judgement.

Once you are cleared for driving, start slowly. You may be a little stiff and sore.

Travel

- Do not travel long distances from Seattle or your home until the Lung Transplant Team tells you it is OK. Once we lift this restriction, we still advise you to tell us if you plan any long-distance trips or travel to other countries. If an emergency arises, we need to know where you will be so we can direct you to the nearest lung transplant center. If you plan to be gone for a long time, we will need to work together to find a lab for blood tests as needed. We will also need to make sure you can get refills of your medicines.
- Anytime you travel, take a good supply of your medicines with you. It may be very hard to get more medicines if you are away from your pharmacy or out of the country.
- If you travel by airplane, we advise that you carry your medicines on the plane with you and not in your checked bags. This will protect you in case your bags are lost. We also advise all lung transplant recipients to carry a list of their current medicines, along with contact information for the UW Medicine Lung Transplant Team, in case of emergencies.



It is vital that you do not smoke, and that no one who is around you smokes.

- If you plan to travel to other countries:
 - Tell the Lung Transplant Team which countries you plan to visit. We can tell you if those countries require any vaccines or other precautions, such as treatment to prevent infections.
 - Before you leave the U.S., check your health insurance to see if you are covered while out of the country.
 - Think about buying travel insurance that will provide coverage for emergencies.

Alcoholic Drinks

In general, we advise that you do **not** drink alcohol after your lung transplant. Alcohol may affect the strength and potency of your immunosuppressive medicines. This may cause rejection of your new lung(s).

Smoking

Smoking is very harmful to your lungs. It can also increase your chance of infection. Because of this:

- The Lung Transplant Team insists that you **never** smoke.
- We also insist that your caregivers and other people who live with you or are around you do **not** smoke.
- Avoid places where people are smoking or the air is smoky.

Sexual Activity

You may resume sexual activity as soon as you are physically able and you feel good about doing so. But, be sure to follow all upper body restrictions until the Lung Transplant Team tells you otherwise.

If you have a new sexual partner, be sure to ask them if they have been exposed to sexually transmitted diseases or other infections. If they have been exposed, please call the Lung Transplant Team. We will talk about any testing or treatments you may need, and how to best prevent getting an infection.

We also strongly advise you use barrier protection such as a condom to prevent possible infection.

Pregnancy and Birth Control

Medicines you are taking can harm an unborn baby. They can cause birth defects and developmental delays. Talk with your primary care provider (PCP) if you are thinking about getting pregnant.

Women can get pregnant even if they are not having regular menstrual periods. This is why it is so important to use reliable birth control methods after transplant. Please talk with the Lung Transplant Team or your gynecologist to decide which birth control method is best for you.

Basic Healthcare

Health Screenings

- Suppressing the immune system increases your risk for cancer, so it is important to have routine cancer screenings. Stay current with mammograms and colonoscopies, and all the health screenings your PCP advises.
- Side effects of your transplant medicines include high blood pressure, diabetes, high cholesterol, and *osteoporosis* (thinning of the bones). Be sure to get regular screenings for these conditions.

Eye Care

- You may have blurry vision or changes in your eyesight in the first several months after your transplant. This can be related to your medicines. If it is severe, we may suggest that you see an *ophthalmologist*, a doctor who specializes in eye care.
- Over time, the medicine *prednisone* may cause *cataracts* or *glaucoma* (high pressure in the eye). We suggest that you have an eye exam every 1 to 2 years or as advised by your eye doctor. See an ophthalmologist for all your eye care, not an *optometrist*.

Skin Care

- You may have skin changes after your transplant. This can be a side effect of immunosuppressants. You may have acne, oily skin, dry skin, easy bruising, or skin tearing. You may need to see a *dermatologist* (skin doctor) if your skin changes cause problems.
- If you see any unusual sores, lumps, bumps, or rashes, contact the Lung Transplant Team **right away**.
- If you get a cut or scratch, wash the site well. Keep it clean and dry. Watch for redness, tenderness, or swelling. Call the Lung Transplant Team if you see any of these signs of infection.
- Some transplant medicines make your skin more sensitive to the sun. This means that you will sunburn more easily than before

your transplant. Immunosuppressants also increase your risk of skin cancer. Be sure to stay covered and use sunscreen when you are outside.

- We advise lung transplant patients to see a dermatologist at least once a year. This doctor can check for skin cancers or other skin problems.

Dental Care

- We advise you to practice good oral hygiene every day. This includes brushing your teeth and flossing. Infections in your mouth can cause infections in other parts of your body.
- Regular dental visits are important to keep your teeth and gums healthy and prevent infection. See your dentist every 6 to 12 months, or as often as your dentist advises.
- Unless you have other health problems that require antibiotics before dental work, you do not need antibiotic therapy for routine teeth cleanings or minor dental work. Follow your dentist's advice if they feel a planned treatment puts you at risk for infection.

Hair Care

You may notice some changes in your hair after the lung transplant surgery. Your hair may seem weaker or may fall out. Or, you may have an increase in hair growth, often on your face.

Most issues with hair get better with time. You may want to see a dermatologist if your symptoms cause you problems.

Your Staying Healthy “To Do” List

Because you are taking immunosuppressants, it is very important to:

- Stay current with all cancer screening as advised by your PCP.
- See a skin doctor (dermatologist) at least once a year.
- Have regular checks for high blood pressure, high cholesterol, diabetes, and osteoporosis.
- Visit the eye doctor (ophthalmologist) every 1 to 2 years to check for glaucoma and cataracts.
- Use your spirometer to check your lungs as directed. Call the Lung Transplant Team if you see any changes.

Questions?

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

Weekdays from 8 am. to 4 p.m.: 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.

Social Work Services

For UW Medicine lung transplant patients

This chapter explains how the UW Medicine Lung Transplant Social Worker can support you during all stages of the transplant process.

A lung transplant may help you have a better quality of life and even allow you to live longer. But you, your family, and your care providers will deal with many challenges before and after your transplant surgery. A social worker can be of help with many of the issues you will face.

What does a social worker do?

The Lung Transplant Social Worker is a vital member of the UW Medicine Lung Transplant Team. The social worker can help you, your family, and your care providers cope with stress and resolve many of the issues that arise during the transplant process.



The Lung Transplant Social Worker is here to support you, your family, and your care providers.

Assessment

Patients, their families, and their care providers will meet with the Lung Transplant Social Worker during the first part of their evaluation. During your visit, the social worker will ask many questions about your situation. Your answers will help us know what help you might need as you prepare for a possible lung transplant. The social worker will also explain what the Lung Transplant Team needs from you and your care providers.

You may meet with the social worker more than one time. It may take weeks or months before the assessment is complete.

Support Group

The Lung Transplant Social Worker leads the UW Medicine Lung Transplant Support Group. Patients may attend support group meetings before and after their transplant surgery. Most times, these meetings are an “open forum” where everyone can share and ask questions.

These meetings are a great place to meet other lung transplant patients and their care providers. It can be helpful to connect with others who are going through an experience that is similar to yours.

Counseling and Referrals

The Lung Transplant Social Worker will talk with you about the lifestyle changes, reactions, and stresses that you will face before and after your transplant. If needed, the social worker can provide brief counseling. They may also refer you to agencies, community resources, or a mental health provider to help you cope with these challenges.

Resources

The Lung Transplant Social Worker can provide resources that explain the *psychosocial* (emotional, mental, or social) aspects of transplant. These resources include books from our lending library and other written materials. Some of these materials are about the transplant process, while others deal with more general subjects.

Coping After a Transplant

A transplant is a major event. It changes the lives of the patient, their family, and their care providers. The first few months after a lung transplant require a full commitment from everyone involved.

All Lung Transplant Team members, including the social worker, provide ongoing support and teaching for you and your care providers. Some of this occurs at clinic visits before the transplant. But we continue to support and teach you in the hospital after your transplant surgery, and at each clinic visit after you leave the hospital. Many patients and their care providers also find it helpful to attend the monthly Lung Transplant Support Group meetings at UWMC.

Work

Disability

Some patients can keep working while they wait for a lung transplant. Other patients qualify for Social Security Disability (SSD) or Supplemental Security Income (SSI) benefits.

At some point after a lung transplant surgery, recipients may no longer be considered disabled. The legal definition of “disability” under the SSD and SSI programs is:

“The inability to engage in any substantial gainful activity by reason of any medically determined physical or mental impairment which can be expected to result in death, or has lasted or can be expected to last, for a continuous period of not less than 12 months ...”

The Lung Transplant Team can help you determine if you are still legally disabled or if you are able to return to work.

Going Back to Work

Our goal is for each transplant recipient to lead a fulfilling and productive life. For some, this might mean returning to work. Going back to work can help financially and also provide access to health insurance.

Some recipients may be able to return to the job they had before their transplant surgery. Others might need to change some aspects of their job. Others may need re-training so that they can find a different job.

At times, transplant recipients can run into barriers when they try to return to work. An employer might be worried about hiring someone who has had a transplant. The Americans with Disabilities Act (ADA) provides some protection from this discrimination. The ADA law, and being better informed, can help an employer feel confident that transplant patients can be reliable employees.

Take Time to Recover

We encourage lung transplant recipients to go back to work if they choose to do so. But, it is important to give yourself plenty of time to recover from the surgery. Before you return to work after lung transplant surgery, please ask the UW Medicine Lung Transplant Team for a *medical release*.

Writing to Donor Families

Many patients ask about writing to the family of their organ donor. Most donor families are pleased to hear from the organ recipient.

It is your choice whether to write to the donor family. If you do write, it is helpful to talk about yourself, your family, your job or volunteer work, your hobbies, and your other interests. Donor families are often eager to hear about how having a transplant has changed your life. Be sure to thank the donor family for their gift.

To keep your letter confidential:

- Use **only** your first name.
- Do **not** include your address, phone number, email address, or other contact information.

Give your letter to the Lung Transplant Social Worker, who will help send it to the Organ Procurement Organization (OPO) for your donor. The OPO is a non-profit organization that manages organ donations. The OPO will then forward your letter to the donor's family.

When you give your card or letter to the social worker, include a separate piece of paper with your full name and the date of your transplant. This information is used to identify your donor's family. It will not be shared with them.

Questions?

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

Weekdays from 8 am. to 4 p.m.: 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.

Follow-up Visits and Tests

After your lung transplant surgery

This handout explains follow-up care after your lung transplant surgery.

After you leave the hospital, a team of transplant specialists will manage your care. Your Lung Transplant Team will include:

- *Pulmonologists* (lung doctors)
- Surgeons
- Transplant nurse coordinators
- Pharmacists
- Nutritionists
- Social workers
- Respiratory therapists
- And, most important of all, you!

Members of the Lung Transplant Team will work closely together to help you recover from the transplant surgery. We will also help promote your ongoing health.

Follow-up Visits

After you leave the hospital, you will need to return to UW Medical Center (UWMC) - Montlake campus often. You will have follow-up clinic visits and testing at least once a week for the first 4 to 6 weeks.

Right before each clinic visit, you will have a blood draw, a chest X-ray, and pulmonary function testing (spirometry). These tests will help tell us how you are doing after your lung transplant surgery.



You will come to the hospital for follow-up blood draws and clinic visits once a week for the first 4 to 6 weeks after you leave the hospital.

After 4 to 6 weeks, your visits may be less often, depending on how your recovery is going.

On the Days of Your Clinic Visits

On the days of your follow-up visits:

- Plan on being at the hospital for most of the morning.
- You may eat before your clinic visits.
- Do not take your morning medicines (except pain medicines, if needed) until after your blood draw.
- After your blood draw, take your morning medicines as usual.

Unless we tell you otherwise, you will **always** have these tests at UWMC - Montlake **before** you go to the clinic:

- Labs (“timed” blood draw) at Outpatient Blood Draw on the 3rd floor
- Chest X-ray (CXR) at Radiology on the 2nd floor
- Pulmonary function testing (PFT) at Lung Testing on the 5th floor

Blood Draw

Your blood should be drawn **11 to 12 hours after you take your evening dose of your immunosuppressant** (tacrolimus or cyclosporine). Timing of this blood draw is important for accurate results. For example, if you take your evening immunosuppressant at 8 p.m., you **must** have your blood drawn between 7 a.m. and 8 a.m. the next morning.

For your blood draw, go to Outpatient Blood Draw on the 3rd floor. The orders for your blood tests will already be in the computer.

Chest X-ray

For your chest X-ray, go to the Radiology department on the 2nd floor. Your X-ray order will already be in the computer.

Pulmonary Function Testing

For your spirometry test:

- Please be on time for your appointment.
- Go to Lung Testing on the 5th floor, across from the Pacific elevators, at your appointment time.

- Be sure to get a copy of your test results to take with you to the clinic.

To be on time for your Lung Testing appointment, you might need to delay your chest X-ray until after your spirometry. **But, you must always have your blood draw 11 to 12 hours after taking your evening immunosuppressants.**

Clinic Visit

When you are done with your tests, you will meet with the pulmonologist in the Medical Specialties Clinic on the 3rd floor. During this visit:

- Your doctor will examine you and evaluate your X-ray, labs, and spirometry results.
- The transplant pulmonologist or nurse coordinator will go over your medicine list.
- We will refill your prescriptions as needed.
- We will answer any questions you may have about your health.

What to Bring on Clinic Visit Days

- Bring your log of vital signs and your medicine list to all your clinic visits.
- **Bring your medicines with you.** If your tests or your visit take longer than you had planned, you must be able to take your medicines at the right times.
- Bring a list of your questions to ask the Transplant Team.
- If you have diabetes or high blood sugar, remember to bring:
 - Your glucometer
 - Your insulin
 - A snack

Warning Signs

After your lung transplant

This handout for lung transplant patients lists warning signs that require a call to the Lung Transplant Team.

Keep us posted about any changes in your health after your lung transplant. If you have any symptoms that concern you, **CALL!**

We want to catch any problems early. No issue is too small when it comes to caring for you and your new lung(s). Your well-being is important to us!

When to Call

Call the Lung Transplant Team if you have any of the symptoms listed here.

Lungs and Breathing

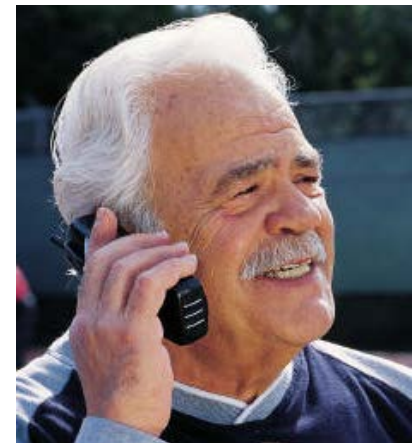
- Decrease in spirometry (FEV1 of 10% or more from your baseline)
- Shortness of breath
- Coughing or coughing more than usual
- Coughing up blood or green-colored mucus

Overall Health

- Big drop in your energy level
- Symptoms of a cold or flu
- Fever higher than 100.4°F (38°C)

Stomach, Bowel, and Urinary Tract

- Vomiting, or you vomited up your immunosuppressive medicines
- Diarrhea
- Pain in your belly
- Pain or burning when you urinate



Call the Lung Transplant Team if you have any symptoms listed in this handout, or any issues that concern you.

Skin and Incisions

- Redness or drainage from a wound
- New sores or rashes

Heart and Circulation

- Chest pain
- Sudden drop or rise in your blood pressure, with headache, feeling lightheaded or dizzy, or seeing spots
- Sudden change in your heart rate
- Heart rate goes higher than 130 (without exercise) or lower than 60 beats a minute
- Increased ankle swelling, along with weight gain

This list does not have every symptom that may occur. **If you are unsure about calling us, CALL!**

Who to Call

- Weekdays from 8 a.m. to 4 p.m., call the Post-Lung Transplant Coordinator at 206.598.5668. If you reach voicemail, leave a message. Include your name, number, and why you are calling.
- After hours and on weekends and holidays, call 206.598.6190 and ask for the Pulmonary Transplant Fellow on call to be paged. **Tell the person who answers that you are a lung transplant patient.**

Urgent Care Needs

If you feel you are having a health emergency:

- **Call 911 right away.**
- If you are in the Seattle area, ask the paramedics to take you to the Emergency Room at University of Washington Medical Center - Montlake.
- If you can, have someone call the Post-Lung Transplant office and tell us that you are on your way to the Emergency Room.

Questions and Concerns

For questions about clinic visits, medicine refills, or other concerns, call the Post-Lung Transplant office at 206.598.5668 weekdays from 8 a.m. to 4 p.m.

Questions?

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

Weekdays from 8 am. to 4 p.m.: 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.