



# Health Facts for You



Your lung transplant  
evaluation

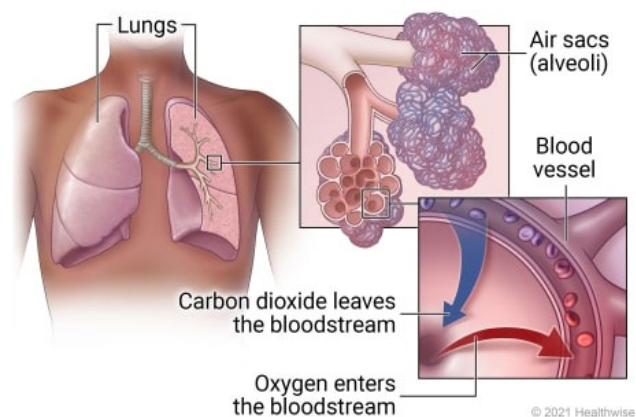
**UW**Health



Welcome to the UW Health Lung Transplant Program. The team takes pride in building a care plan tailored to your needs. We are committed to your success. UW Health is a national and international leader in the field of transplantation.

## The Lung

It is good to have basic knowledge of how the lungs work. When you breathe in air, it goes to tiny air sacs called alveoli. Oxygen moves from the air into the blood. This blood leaves the lungs and goes to the heart. The heart pumps the blood to the rest of the body. This is how all your tissues and organs get oxygen. The lungs also remove gases, such as carbon dioxide.



When lungs are damaged, oxygen cannot get into the blood as well. The lungs also may not expand properly. These lung problems get worse despite medical treatment. This is when someone may consider a lung transplant. Some of the diseases that can be treated with a lung transplant include:

- Emphysema/COPD
- Pulmonary fibrosis
- Cystic fibrosis
- High blood pressure that affects your lungs (pulmonary hypertension)
- Alpha-1-antitrypsin deficiency
- Bronchiectasis
- Congenital disease
- Sarcoidosis

## Evaluation Testing

During your evaluation, you will have many tests and meet many team members. Some tests might include:

- Cardiac catheterization:- A test to check heart function and blood flow and to look for blockages in the arteries.
- Echocardiogram: A type of ultrasound to view the heart.
- Lung imaging
- Sinus computed tomography (CT) scan: This test uses x-rays of your sinuses and mouth to look for signs of infection.
- Bone density scan: An x-ray to measure the strength of your bones.
- Walking tests: Tests to see how much oxygen you need at rest and with activity.
- Swallowing tests
  - pH test to check for esophageal reflux. A small flexible tube is passed through your nose into your esophagus to measure the acid in your esophagus. You will have the tube in your nose for about 24 hours.
  - Manometry to measure how the esophagus works. It tests the valve muscle between the stomach and esophagus.

## After Your Evaluation Testing

When your evaluation testing is done, the transplant team reviews and discusses your results. There are three possible decisions:

1. You are approved to be added to the waitlist. Or,
2. The team feels transplant is NOT the best option for you. Or,
3. The team needs additional testing or information to make the decision.

You will be told of the decision and next steps.

## Where My New Lung Will Come From

### **The Organ Shortage**

There is a severe shortage of organs for transplant. This means that the wait for a lung transplant can be unpredictable. You will be given our recent waiting times to help you better understand your wait. Patients may die while they wait. The UW Transplant Program is a leader in finding new ways to increase the number of good organs for transplant. You have options about where your new lung will come from. It is vital that you explore these options fully.

### **Donation After Brain Death (Deceased Donor)**

The most common type of organ donor is a person who has suffered a head injury causing brain death. "Brain death" occurs when the brain doesn't get enough oxygen and the brain stops working. This is often due to trauma or a stroke. Tests are done to tell when someone is brain dead.

People who are brain dead are on a breathing machine. The breathing tube and medicines keep the heart beating and supply the organs with blood and oxygen until a transplant team arrives. Once the liver is removed, it should be transplanted within 12 hours. Livers from these types of donors are called "standard donor" livers.

### **Donation After Circulatory Death (DCD)**

Sometimes a patient's trauma is so bad that doctors can't save their life, but they are not brain dead. The doctor meets with the family to decide if life support should be stopped. If the family chooses to remove life support, the machines are turned off. Patients may or may not be able to donate. When the patient's heart stops beating, they are declared dead by the doctor. The transplant

teams can remove the organs. This is called donation after circulatory death (DCD).

The lungs may have some damage due to lack of blood flow. This can cause problems for the recipient. This could include primary graft failure, ischemia/reperfusion injury, and shorter long-term graft survival.

Long-term graft survival means how long a lung works. A standard lung has a graft survival of about 50% at 5 years. The graft survival of a DCD lung is similar to standard donor lungs.

A DCD lung can help you get a transplant sooner. This increases your chance of staying alive longer. This could be most helpful for patients who have many health concerns and those with worsening health.

At UW Health, you will automatically be included in DCD organ offers, which may increase your chance of getting a transplant sooner.

### **Organs Meeting Risk Criteria for possible transmission of HIV, Hepatitis B and Hepatitis C**

You may be offered an organ from a deceased donor thought to be at more risk for spreading certain infections.

Donors are deemed to meet risk criteria for possible transmission of HIV, Hepatitis B, and Hepatitis C based on national guidelines. This may include risk factors such as prostitution, intravenous (IV) drug use, or those with same sex partners. Potential donors have blood tests done to look for viruses such as HIV, Hepatitis B, and Hepatitis C. You will also be tested for HIV, Hepatitis B, and Hepatitis C before your transplant. No test is perfect, and false negative results can happen.

There is a small chance (at most, 1 organ in 10,000) that an infection could be passed on. After your transplant you will be tested for HIV, Hepatitis B, and Hepatitis C. These infections all have good treatment options. We believe that the risks of getting this type of lung are very small.

### **Hepatitis C Positive Donors**

Hepatitis C is a virus that can damage the liver. It does not affect the lungs. We now have medicines to treat this virus. This means that we can often use lungs from donors who have had or have hepatitis C.

Donors who have had hepatitis C and do not have an active infection are very low risk. If the donor has had hepatitis C, we will do tests to check for signs of this virus. You likely would not need other medicines.

If the donor had an active hepatitis C infection, you need to take medicine to treat the virus. When placed on the waiting list, the transplant team asks if you are willing to accept a hepatitis C donor lung. If you agree, you will be required to sign a consent. If you choose not to accept this type of lung, you will not lose your place on the waiting list.

### **What will I be told about my donor?**

Privacy laws limit how much we can tell you about your donor. We can't tell you the donor's age, gender, or personal health history. The United Network for Organ Sharing (UNOS) distributes the organs. The Organ Procurement Organization (OPO) tells the UW Health transplant team when a lung is found and who is first on the UNOS list to get the lung.

The OPO carefully screens all would-be donors for any illness that could affect the transplant organ or the patient who gets it. This screening can be limited by time constraints between the time that the donor was injured and when the organ is obtained. The donor's evaluation and screening results may impact your care after transplant. This may include the need for other tests or medicines. We believe the risk of these treatments outweighs the risk of waiting for another organ. We use our best knowledge and judgment to make sure every organ we transplant will work and will not harm the person who gets it.

### **How do I choose?**

There are risks and benefits of each type of lung transplant. Members of the transplant team can tell you more about this topic. They can help you choose the option that may be best for you.

## The Transplant Waitlist

Completing a transplant evaluation does not guarantee being put on the waitlist. If you are approved for transplant after your evaluation, you will then be put on the waitlist.

### The Waitlist

The United Network for Organ Sharing (UNOS) manages the waiting list, matching donor organs to recipients, 24 hours a day, 365 days a year. You will be listed based on a lung Composite Allocation Score (CAS). The CAS is unique for each patient and each organ offer. CAS point values represent each of the factors used to match organ offers with transplant candidates. The people who have the highest number of points for that organ offer will have the highest priority.

Factors that make up the lung CAS:

- Candidate medical urgency
- Likely survival greater than 5 years
- Blood type match
- Immune system matching (CPRA)
- Height match
- Listed younger than 18
- Prior living donor
- Travel efficiency
- Proximity efficiency

A computerized matching system will give the highest priority to the candidates with the highest total CAS for each lung offer. If the offer is not accepted for the person with the highest CAS, it will then go to the candidate with the next highest score. The offers will be made in that order until a transplant program accepts the offer, or until, for whatever reason, the lung(s) cannot be transplanted. Because travel and proximity efficiency are dependent on the donor, you will not have the same score across all organ offers.

## Factors Used to Determine Urgency and Expected Survival

- **Pulmonary artery pressure:** The pressure the heart generates to pump blood through the lungs.
- **Oxygen at rest:** The amount of oxygen needed at rest to maintain enough oxygen in the blood.
- **Age:** Age at the time lungs are offered.
- **Body mass index:** A measure of body fat based on height and weight.
- **Functional status:** A way to measure the effects that lung disease has on doing routine daily tasks.
- **6-minute walk distance:** How far you can walk in 6 minutes is a measure of functional status.
- **Assisted ventilation:** A device to help move air into and out of the lungs. The use of a ventilator is a measure of disease severity.
- **Serum creatinine:** A measure of kidney function. High levels reflect impaired kidney function, which may happen with severe lung disease.
- **Diagnosis:** Different kinds of lung diseases vary in how effective a lung transplant is in treating them. Therefore, diagnosis is part of the composite allocation score.
- **PCO<sub>2</sub> and change in PCO<sub>2</sub>:** The amount of carbon dioxide in the blood. PCO<sub>2</sub> level may increase with lung disease.
- **Bilirubin:** High bilirubin is a marker for right heart failure that can occur with lung disease.
- **Cardiac index:** A measure of how well the heart is pumping blood. This is used in calculating the post-transplant portion of the score, not for waitlist urgency.

## Lung CAS Calculator

### Multiple Listings and Transferring of Waiting Time

Multiple listing is when you are listed for transplant at two (2) or more transplant centers. Multiple listing can increase your chances of getting an organ offer. It does not assure that you will have a shorter wait time.

UW Health allows multiple listing. You need an evaluation at each transplant center. Each transplant center then decides whether to accept you on their waiting list. You should check with your insurance to see if they cover more than one evaluation. You will need to keep current health information and contact information at each transplant center where you are listed.

There are many reasons that affect how long you wait for transplant. Your transplant care will be done at the center where you have your transplant. To learn more about multiple listing or transferring waiting times, contact the transplant center where you are listed or want to be listed. For more information: [https://unos.org/wp-content/uploads/unos/Multiple\\_Listing.pdf](https://unos.org/wp-content/uploads/unos/Multiple_Listing.pdf)

## When to Call

While you are waiting, you may have many health changes. It is vital to tell the transplant team about any changes in your health status. Examples of things that you should call about include:



- Taking antibiotics or having an active infection
- Being started on a new medicine
- Getting a blood transfusion
- Being hospitalized
- An increase or decrease in your weight (5 pounds or more)
- Having a significant change in your health status
- Having a change in insurance coverage
- Changes in contact information (such as phone number or address)
- Changes in your support people or plan
- Planning to travel away from home

The transplant team needs to know about these changes. This ensures that you are in the best condition for your transplant. Some new medicines or hospitalizations could change your status on the waitlist. It is vital that you contact the team with any health changes.

### Re-evaluation While Waiting for Transplant

To stay active on the UNOS waiting list, your medical information needs to be updated. These should be updated anytime you have a significant change in your health or every 6 months. If you are using some treatments your information must be updated at least once every 28 days. This will ensure your score reflects the most timely information about your condition. If these tests are not done, you may be made inactive on the waitlist until they are done.

While on the wait list, you will be seen in the Transplant Clinic often. How often depends on how sick you are. This may be anywhere from weekly to every six months. At these visits testing and teaching will be done to help you prepare for transplant. It is helpful to bring at least one of your support people to your visits.

Our goal is that when an organ becomes available for you, you will be ready. Knowing about changes in your health helps to assure us that it is safe for you to have surgery when the time comes.

### **Staying Healthy Before Transplant**

Taking care of your health is very important while waiting. It is expected that you will take all medicines and vaccines as directed by your doctor and attend all appointments. You must also follow your plan for diet and exercise. Continue to follow the instructions from your lung transplant team. Contact them with any new or worsening symptoms.

Waiting on the transplant list can be stressful for you and your support people. Be sure that you talk with your support people about your appointments, your health status, and your plans.

### **Nutrition**

Nutrition plays a key role in the transplant process. Eating well and exercising before transplant may help you recover faster after surgery. After surgery, your body needs enough nutrition to promote healing, fight and prevent infection, and gain back weight you may have lost. In the long-term, good nutrition plays a key role in keeping you healthy.



### **Frailty**

You may be frail if you have lost weight without trying, feel weak or tire easily, walk more slowly, or need help for daily activities. This could include bathing, dressing, eating, getting out of bed and moving around on your own.

Causes of frailty include aging, being less active, chronic diseases, and malnutrition. People who get a transplant when they are frail stay longer in the hospital and get more infections. They are less likely to go home from the hospital and more likely to need rehabilitation.

### **Improve Your Strength With Exercises**

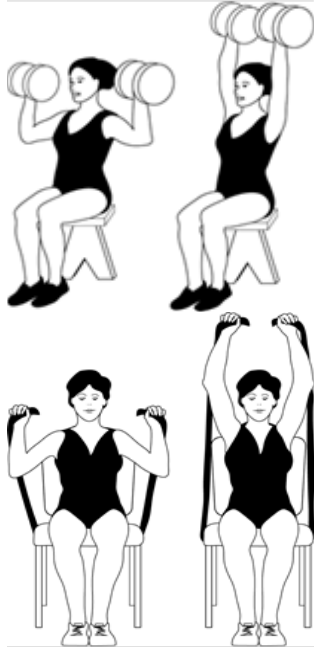
You can improve your strength if you add 30 minutes of exercises daily. This could be walking, weightlifting, or sitting chair exercises. If you cannot exercise on your own, you may need physical therapy (PT) or pulmonary rehab. Let your nurse or doctor know if you think you need PT.

It is important to exercise even if you have physical limitations. You can do these exercises at home sitting down with either resistance bands or light weights. You can use common household items that have some weight to them. Examples could be filled water bottles, canned goods, or rocks. To gain strength, do these exercises daily. For each exercise, complete 3 sets of 10-15 repetitions. Do not rush. Go slowly.



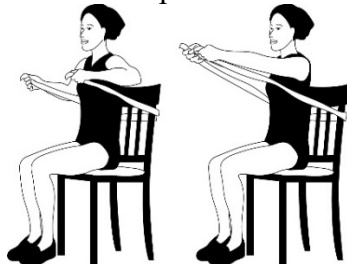
### Overhead Press

Sit on edge of a chair with your feet planted flatly on floor. Grab light dumbbells or a resistance band. Take a deep breath and tighten your core. Push the weights or band evenly over your head. Keep your neck and back in a neutral position. Bring the weights or band back down to the level of your ears and repeat. You can also do this activity standing with your feet evenly spaced apart. Keep your feet firmly on the ground.



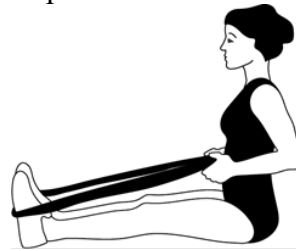
### Seated Press

Wrap your band around the back of your chair and make sure it is secure. Sit with your weight evenly distributed. Take a deep breath. With a flat back and even posture, push your arms straight out in front of you. Make sure you are using your chest to push out your arms. Try not to move the position of your back. Bring your hands back to your chest and repeat.



### Horizontal Row

Sit on the floor with your back straight. Place your band around your feet at the halfway point on the band, so the sides are even. Pull the band towards your chest. Squeeze your shoulder blades together. Slowly release the band back to the start. Repeat.



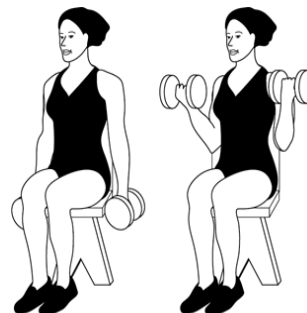
### Triceps Extension

This movement can be done with a band or light weights. Squeeze your arms up so they line up with your ears and bring them back down to the start. If you are using a band, make sure it is secure before you begin.



### Biceps Curl

Take a deep breath and exhale. Without changing your posture, curl the weights or band up to your shoulders and push back down. Repeat.



## Getting the Call

When on the list, the transplant team should be able to reach you at any time of the day, any day of the week. If the transplant team contacts you and you are not available to return the call up to 30 minutes from the first phone call attempt, the team will move on to the next potential recipient.



You need to have a plan ready for when the call comes.

- How will you get to UW Health?
- Who will come with you?
- Who will take care of things at home while you are in the hospital, such as your children, pets, etc.?
- Where will your support people stay while they are in Madison?

## Getting to the Hospital Quickly

When you get the call, you have a short amount of time to gather your things and make final arrangements. You will be directed when you should come to the hospital. It is important to arrive when instructed. Your safety when traveling is important, so be careful on your way here. The transplant is often done within 12-24 hours of the call.

The Organ Allocation Specialist will call you if an organ becomes available. You may be asked:

- To stop eating and drinking.
- To stop taking one or more of your medicines.
- About your current health status.
- About your recent immunizations, illnesses, infections and medicines
- To come to UW Health **or** to keep a phone available, but to wait at home until you are called again.

It is vital that support people are involved in the planning process. Be sure they know that

you need to be reachable at all times. They should also know the plan for getting you to the hospital when you get the call. Make plans for the care of your pets, children, work duties, and other responsibilities ahead of time. Being prepared will help to lower your stress.

There may be times when the donor organ becomes unsuitable for transplant. In an event of one of these “dry runs” you will be discharged home to wait until another donor becomes available.

## What to Bring to the Hospital

You need to be prepared when you get the call. This call can come anytime, day or night. Be sure your cell phone is on and ready to call in case of delay or questions (**608-263-6400** or **1-800-323-8942**).

Plan to bring these items:

<input type="checkbox"/> Copy of Advanced Directives/Health Care Power of Attorney if it has changed
<input type="checkbox"/> <b>All</b> medicine bottles and list of medicines
<input type="checkbox"/> Form of payment for medicines at discharge
<input type="checkbox"/> Name of local pharmacy
<input type="checkbox"/> Loose clothing (sweat pants or something with elastic or drawstring waist bands), T-shirts, socks and supportive shoes for walking and therapy.
<input type="checkbox"/> If you use them, bring your glasses, hearing aids, dentures, CPAP machines/mask, blood pressure cuff, diabetes supplies
<input type="checkbox"/> Personal comfort items (electronic devices, phone, chargers, and blanket or pillow)

**Please do not bring jewelry, large amounts of cash or valuable items.**

## Surgery

### Day of Surgery

When you are taken to surgery, your support people may stay in the surgical waiting area. The nurses will provide them with updates.

Once you are in the operating room (OR), you will meet nurses and other staff. They answer questions, make sure you are comfortable, and explain what is happening. There will be ECG (electrocardiogram) patches on your chest to check your heart rhythm, a blood pressure cuff on your arm, and a plastic clip on your finger to check your heart rate and oxygen levels. The anesthesiologist will ask you to breathe oxygen through a soft plastic mask. Medicines will be given through your IV. After you are asleep, a breathing tube will be placed in your windpipe. Other lines and monitors are added after you are asleep.

The surgery will take about 6-12 hours.



### After Surgery

You will go to back to your room on the transplant unit for recovery. The nurses on the unit will let your support people know when they can come to the room to see you. Time to visit may be limited. Nursing staff may ask them to leave the room if needed for patient care.



You and your support people will hear beeps and alarms of the equipment. The noises you hear are normal. Many patients who have had lung surgery tell us that they recall little of the first hours after surgery. This is normal.

### Equipment and Other Changes to Expect

You may need tubes, lines, and monitors after surgery. Tubes remove fluid from your body. Lines give you fluid and medicine.



Monitors tell us how your heart and lungs are doing. Removal of tubes and lines is based on your progress. This is a list of common tubes, lines, and monitors:

- Intravenous catheter (IV)
- Chest tube
- Breathing tube
- Stomach tube
- Foley catheter
- Pulse oximeter (pulse ox)
- Safety equipment and restraints
- Sequential stockings
- Telemetry

The breathing and stomach tube are removed once you are awake enough to breathe on your own. You will sit up in a chair shortly after the breathing tube is removed.

You will have an incision down the center of the chest at your sternum. The incision will have a dressing over it.

Your doctor will order pain medicine for you. When you are unable to eat or drink, you will get pain medicine through your IV. Later, you will take pain pills. Pain medicine should be taken to lessen incision pain. You will stop taking the pain medicine as you recover from surgery.

You will be coughing, deep breathing and using the incentive spirometry device 10 times each hour while awake. Deep breathing helps air to reach your lower lungs. Coughing helps clear out secretions. Coughing and deep breathing are an important part of recovery and help to prevent pneumonia.

You will wear sequential compression devices (“SCDs” or leg pumps) during and after surgery when you are in bed. This improves blood flow and helps prevent blood clots. Walking helps the most. Once the breathing tube is removed, we will help you to the chair at least 3 times each day. The goal is for you to walk 3-4 times each day.



While in the hospital you will have blood tests daily or more often if needed. The results keep you and your health care team aware of how you are doing. You will learn about and track these tests too.



Your blood sugars will be checked during and after surgery. You may need insulin as you recover even if you have not needed insulin in the past. Well-managed blood sugars lower your risk of infection.

As your condition improves, the nurses will not be at your bedside as often. This is a good sign. You are on the road to recovery.

### **How will I know my transplant is working?**

Your vital signs, spirometry, and ability to breath without supplemental oxygen will be monitored closely. The transplant team will talk with you daily and answer any questions you have about your progress.

You will have bronchoscopies in the hospital. During this test a camera goes down your nose or through your mouth to look at the inside of the new lungs, the incision, and to remove secretions if needed. This usually happens before the breathing tube comes out and again before discharge.

### **Education After Transplant**

You must learn about the care of your new organ. Education sessions are **required with you and both of your support people**



in order to be discharged. This may start any time based on how your recovery is going. You may have education sessions with your transplant coordinator, transplant pharmacist, transplant dietitian, physical and occupational therapists (PT and OT), and diabetes care and education specialists.

You and your support people will review all materials with your coordinator before leaving the hospital.

### **Guidelines for Visitors**

Visitors should check at the information desk or nursing unit before visiting. The main hospital phone number is 608-263-6400.

### **What will happen after I am discharged from the hospital?**

You will have to stay within 60 minutes of UW Health for a minimum of 4 weeks after discharge from the hospital. At least one of your support people will need to stay with you 24 hours a day during this time. Patients and support people may be asked to relocate for an additional period of time depending on the patient’s unique care needs and access to a larger volume hospital (in case of emergency).

### **Finding Area Lodging**

UW Health Guest Services may offer discounts at local hotels. Many area hotels have shuttles available. The phone number to call Guest Services to make lodging arrangements is **(608) 263-0315**. If you live within 60 minutes of the hospital, you may return home after surgery.

## Commitment to Follow-Up Care

Your care after a transplant is for your entire lifetime. This long-term care includes:

- Biopsies
- Labs and other tests
- Medicines
- Transplant clinic visits

### Keeping the Commitment

For a transplant to be a success, you need to commit to the following things:

- Follow the treatment plan, including biopsies and hospital stays.
- Call the transplant office about any new problems or symptoms related to your transplant or about any new medicines or tests you have.
- Take all prescription medicines as directed.
- Follow the diet and exercise plan advised by your doctor and dietitian.
- Go to your clinic visits.
- Get your labs drawn
- Follow up primary care doctor for routine health maintenance
- Follow recommendations for mental health or alcohol/substance use treatment
- Plan transportation for at least 8 weeks after surgery or until you are approved to return to driving.

### Appointments

The follow-up schedule is intense for the first few months.



Labs and biopsies are done to check for rejection. This can happen when your body's immune system attacks your new organ. During a biopsy, pieces of tissue are taken from the inside of your organ. If a biopsy is done because your organ is not showing normal function, it may be somewhat urgent. You may need to make plans to come to UW Health without much warning.

The appointment schedule following your hospital discharge is roughly as follows:

- Weekly for 4 appointments
- Every 2 weeks for 4 appointments
- Monthly through the first year

Bronchoscopies and biopsies are done regularly:

- They are scheduled at 6 weeks, 3 months, 6 months, 9 months, and one year from your transplant date.
- More often as needed based on symptoms.
- After your first anniversary, only as needed.

With each bronchoscopy you will also have labs, imaging, and other tests as directed by your doctor.

### Primary Care Visits

You must have a primary care provider to address routine health issues. This might include diabetes, minor infections and illnesses, and regular health care needs. Plan to see your local doctor shortly after your transplant.

We want you to live a healthy life after transplant. We will work closely with your primary care provider to give you the best care. We work together to advise you about your diet, exercise, and other health needs. Your primary care doctor will continue to manage chronic opioid and benzodiazepine medicines if you take them. The transplant team will manage your transplant medicines and address any transplant issues.

## Types of Medicine After Transplant

After your transplant, you will be on many medicines. You will be on most of them for the rest of your life. These medicines are important in the success of your transplant. You will need to know what medicines you are taking, why you are taking them, and the dose prescribed. Some of your medicines may need to be taken at the same time every day. Never stop or adjust medicines on your own. Not taking your medicines correctly can lead to rejection and other health problems.



### Immunosuppressive Medicines (Anti-rejection Drugs)

These medicines block or suppress your immune system. They are used to prevent rejection of new organs. All transplant patients take these medicines for the **rest of their lives**. There are different kinds. You will be on more than one kind. Your doctor will decide which ones you will need. You will need to take these multiple times a day. These will include:

- Tacrolimus (Prograf<sup>®</sup> or generic)
- Mycophenolate mofetil (Cellcept<sup>®</sup> or generic) or mycophenolic acid (brand name Myfortic<sup>®</sup> or generic)
- Prednisone

### Anti-infection Medicines

Anti-infection medicines prevent common infections after transplant. You may need other medicines too based on the type of donor. You will need medicines to prevent:

- Posaconazole (Noxafil<sup>®</sup> or generic)
- Sulfamethoxazole-trimethoprim (Bactrim<sup>®</sup> or generic) or atovaquone (Mepron<sup>®</sup> or generic)
- Valganciclovir (Valcyte<sup>®</sup> or generic) or valacyclovir (Valtrex<sup>®</sup> or generic) or letermovir (Prevymis<sup>®</sup>)
- Amphotericin B Liposome injection (AmBisome<sup>®</sup> or generic)

Supplies for inhaled Amphotericin will need to be paid with cash or using a MyRx Card to lower the cost. The medicine is usually for 90 days after transplant but could be longer. The cost for these supplies is usually about \$100-200 per month.

### Other Medicines

- Rosuvastatin (Crestor<sup>®</sup> or generic)
- Magnesium
- Multivitamin
- Pantoprazole (Protonix<sup>®</sup> or generic)
- Vitamin D
- Calcium
- Rapid-acting insulin – common types are insulin lispro (Humalog<sup>®</sup> or Lyumjev<sup>®</sup>) or insulin aspart (Novolog<sup>®</sup> or Fiasp<sup>®</sup>)
- Long-acting insulin – common types are insulin glargine (Lantus<sup>®</sup> or Basaglar<sup>®</sup>) or insulin degludec (Tresiba<sup>®</sup>)

Vitamins/supplements such as magnesium, multivitamin, vitamin D, and calcium may be bought over the counter.

### Other Medicines

Many patients have high blood pressure after their transplant. You may require medicine to treat this. Sometimes transplant patients get diabetes after their transplant. You may need insulin or other medicines to manage blood sugar levels.

Some of these medicines are temporary but many are life-long. You may need opioid pain medicines for a short time after the transplant. You will not be able to take NSAID medicine after transplant. Some medicines may be managed by your primary care provider.

## Vaccines

Timing of when you receive a vaccine can impact when you can receive a transplant. You must be screened for conditions or medicines that might make the vaccines unsafe for you because of your immune system. No one who is waiting for or has had a transplant should be given a live vaccine.

The list below includes general guidelines. Your situation may be different. **Always talk with your coordinator before getting any vaccines.**

### Vaccines to Get Before and After Transplant

- Inactivated influenza, injected
- COVID-19 boosters
- Hepatitis B
- Hepatitis A
- Diphtheria/Tetanus/ Pertussis (Tdap, DTaP, Td or DT)
- Polio, inactivated
- Pneumococcal polysaccharide or conjugate
- Human papillomavirus (HPV) (for ages 9-26)
- Varicella zoster (Shingrix®)

### Vaccines NOT Recommended After Transplant

- Varicella (Varivax®)
- Measles, Mumps, Rubella
- Rotavirus

### Other Vaccines to Discuss With Your Provider

- Quadrivalent meningococcal conjugate or polysaccharide
- Haemophilus influenzae type b
- Measles, Mumps, Rubella (MMR)
- Travel vaccines

## Health Concerns After Surgery

After transplant, people can live a healthy life. The main issues are the **increased risks of infection and rejection**. To prevent infections, wash your hands often. If you are at risk for exposure to fungal, bacterial, or viral infection you will need to wear a mask. You should always wear a mask in clinics or hospitals. Sometimes, it is best to avoid crowded places, areas with poor ventilation, or people who may be contagious.

The risk of rejection is greatest the first 6 – 12 months after transplant. It is common to have a rejection. This is the body's normal immune response to "foreign" tissue. When rejection occurs, we need to adjust your medicines to further block your immune system. These medicines have side effects that can cause new health concerns. This can include high blood pressure, high cholesterol, diabetes, and osteoporosis (problems with your bones). Most of these side effects can be managed with medicines, diet, exercise, and how well you follow your treatment plan.

### Activity Levels

Over time, most patients can go back to their normal activity with minor changes. It will take some time to gain strength and endurance. Keeping up with an exercise routine is the best way to manage your weight and improve your well-being. You should exercise at least 30 minutes each day after transplant. You will be required to do pulmonary rehab for 12 weeks after transplant.

### Going Back to Work

We encourage patients to return to work after having a transplant. When you are ready to return to work depends on the type of work you do. Talk with your transplant team about returning to work. We will

complete medical leave paperwork for your job if needed.

### **Coping after Transplant**

During the transplant process, it is common to feel anxious, depressed, frustrated, and/or guilty. Stress can cause these feelings and so can your medicines. Talk with someone about your feelings. The transplant team is here to support you. If you want to see a mental health provider, you can contact your primary care provider or insurance company. Sharing your feelings with your loved ones and others may also be helpful. There may be support groups for transplant recipients and support people available.

### **Support People**

The transplant process can be very tough for support people. Many support people have anxiety during the process. It is important that they take care of their physical and mental health during this time.

### **Keeping Support People Updated**

It is a good idea to choose one person as the primary contact. This person can update family and friends about your status. Make sure the transplant team has that person's contact information.

## **Staying Prepared**

**Make sure your transplant team knows how to reach you.** Contact your transplant coordinator if contact numbers change for you or your support people. Have your cell phone on you at all times.



**Have your support people in place.** Support people can be family, friends, or guardians who are 18 years of age or older. Choose 2 people you feel close with who have the time, health, and flexibility to provide in-



person support as you prepare and recover from transplant. Contact your transplant social worker with any changes in your support plan.

**Allow others to help you.** Letting go of pride and your desire to be independent can be difficult. It is important though during the transplant process. Think about how you have felt when someone has had an illness, a death or even a new baby in the family. People are usually quite happy to help out but need to know best ways to help you. It could be picking up a few things at the store, bringing a meal, or helping with outdoor or household chores. When you are back to full speed, you can do small favors in return if you choose.



**Life preparations for surgery.** This means completing advance directive forms. Transplant social workers can answer questions about these forms. Consider a plan for the care of your pets, your bill payments, mail, and email while you are not able to do these things. Having a plan in advance will make it easier for someone to take over for you at any time.

**Arrange for your transportation needs** to and from appointments and testing.



**Learn about transplant and what to expect.** As you learn about what to expect you will feel more comfortable with the process.

- Review your transplant materials.
- Review resources on the next page.
- Join a transplant support group in person or online.
- If you have questions, contact your transplant coordinator.



**Take time each day to get exercise.**

Find an activity that you enjoy doing. Fresh air is good for the mind, body, and soul. It can be hard to make yourself walk or be active when you do not feel good. But the more you use your muscles before transplant, the quicker you will recover.



## Transplant Team Members

**Transplant Surgeons**

Transplant surgeons meet with you and your family during the evaluation. They review your record and test results and explain the surgery. They review the risks and benefits of transplant. The surgeon does the surgery and works with other doctors to manage your care after the transplant.

**Transplant Medicine Doctors**

These doctors help to decide if a transplant is the best option for you. They stay involved while you are on the waiting list and after the transplant.

**Pre-Transplant Nurse Coordinators**

These nurses coordinate your care before transplant. They are involved from the time of the first referral until a transplant is received. They arrange any tests needed to get you placed on the waitlist. This nurse helps you through the evaluation process. These nurses contact your local doctors and other healthcare facilities as needed.

**Post-Transplant Nurse Coordinators**

These nurses coordinate your care after transplant. They are involved from the time of transplant through long-term, post-transplant care. They serve as your link to the rest of the transplant team after surgery. They work with the doctors to coordinate your medical needs. They teach you and your family and advocate for you. These

nurses contact your local doctors and other healthcare facilities as needed.

**Transplant Social Workers**

A transplant social worker will meet with you at your evaluation. They will talk with you about your support system, your drug/alcohol use, how you cope, and how well you will be able to follow important instructions. They will do mental health assessments at evaluation. These questions help them learn more about your needs before the transplant. They can help with connecting you with community resources such as counseling, support groups, and financial support. They can also help you complete advance directives if needed. Social workers are also available for support after your transplant.

**Health Psychologists**

Health Psychologists provide care to our patients across the spectrum of care to support your mental health throughout the transplant journey. They work in partnership with our team to evaluate and provide recommendations for our patients pre-transplant, provide intervention for patients while hospitalized pre- and post-transplant, and conduct outpatient psychotherapy.

**Transplant Dietitians**

Clinical dietitians assess your nutritional status, your mobility, and your strength. They help you to make a plan for good nutrition and exercise.

**Physician Assistants and Nurse Practitioners**

These advanced practice providers care for you before and after your transplant. They check on you as you recover and help to manage your medicines. They also help to plan for your discharge needs. You will see them in transplant clinic before and after your surgery.

### **Surgical Residents and Transplant Fellows**

These doctors mainly assist with hospital care. This includes getting you ready for and assisting with surgery. They help to manage issues after surgery and prepare you for discharge. You may also see transplant fellows at transplant clinic visits.

### **Financial Counselors**

These staff work with you and your insurance company before and after transplant. They help to work through matters such as billing, deductibles, and drug coverage. They teach you about the financial aspects of transplant. They are the best resource for any questions about insurance.

### **Transplant Pharmacists**

Pharmacists work with the team to make sure the medicines are used correctly. They watch for side effects and try to minimize them. They also help to manage the timing of the medicines.

### **Inpatient Transplant Nurses**

These nurses care for you in the hospital. You will have a primary nurse. This nurse works with the rest of the team to get you ready for discharge.

### **Case Managers**

Case managers focus on the plan for leaving the hospital. Some patients need skilled nursing care, acute rehab or other services. The case managers can help arrange this care.

### **Transplant Clinic Nurses**

These nurses care for you during clinic visits. They provide care and support for you after procedures. They arrange follow-up care and provide education

### **Office Support Staff**

Support staff answer your phone calls and work with the coordinators and other staff. They help coordinators to manage lab results and patient issues and concerns.

### **Spiritual Care**

Chaplains help people find comfort and meaning from their faith during illness recovery. Our chaplains provide spiritual and emotional support. They also perform sacraments. Faith and medicine offerings are provided in the hospital chapel. Catholic and Protestant services are held on Sundays.

### **Other Expert Doctors**

Other doctors may be involved either during the evaluation or after transplant. UW Health has many specialized doctors who work with the rest of your team. Infectious disease, dental, endocrine, cardiology, hepatology, and urology are just a few of the teams that can assist in your care if needed.

### **Other Services**

Other services are available to help you and your family. For example, Interpreter Services help those who need translation. Housing assistance can help if you need short-term housing.

## Helpful Resources

The resources below may be helpful for transplant patients and their families.

### Know Your Rights

<https://autisticadvocacy.org/policy/toolkits/organs/>

Information to end discrimination in organ transplant.

### Scientific Registry of Transplant Recipients

<http://www.srtr.org>

Data on national, regional and center-specific success rates.

### Transplant Living

<http://www.transplantliving.org>

A patient education site developed by UNOS. Information on support groups and the costs of transplant can be found here.

### UNOS

<http://www.unos.org>

United Network for Organ Sharing (UNOS) is the private, non-profit organization that manages the nation's organ transplant system.

### UW Health Transplant

<https://www.uwhealth.org/transplant/transplant/10355>

Meet your transplant team, read patient stories, watch educational videos, and more. Information about mentor programs

### UW Health Transplant Peer Mentor Program

Program that connects transplant recipients for peer support. Contact [your transplant social worker for more information.](#)

### Lung Transplant Foundation

<https://lungtransplantfoundation.org/>

Information on life before and after lung transplant. Information about mentor programs.

### Caring Bridge

<https://www.caringbridge.org>

Free on-line resource to update your family and friends.

## Who and When to Call

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### Transplant Nurse Coordinator

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Name: \_\_\_\_\_

Call:

- If you are hospitalized or receive a blood transfusion
- When complete required evaluation testing

Contact:

- Monday-Friday, 8:00a.m.-4:30p.m.
  - 608-263-1384
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### Social Worker

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Call for:

- **Change in support plan**

Contact:

- Monday-Friday, 8:00a.m.-4:30p.m.
  - 608-263-1384
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### Financial Counselor

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Call for:

- Change in insurance

Contact:

- Monday-Friday, 8:00a.m.-4:30p.m.
  - 608-263-8770
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Your health care team may have given you this information as part of your care. If so, please use it and call if you have any questions. If this information was not given to you as part of your care, please check with your doctor. This is not medical advice. This is not to be used for diagnosis or treatment of any medical condition. Because each person's health needs are different, you should talk with your doctor or others on your health care team when using this information. If you have an emergency, please call 911. Copyright © 6/2024 University of Wisconsin Hospitals and Clinics Authority. All rights reserved. Produced by the Department of Nursing HF#8173.