

Preparing for a Lung Transplant



Ray, lung recipient (transplanted August 2021)



THE OHIO STATE UNIVERSITY
WEXNER MEDICAL CENTER

The Ohio State University Wexner Medical Center Comprehensive Transplant Center doctors and staff welcome you as a possible lung transplant candidate.

Our Comprehensive Transplant Center has one of the largest organ transplant programs in the nation and is a preferred provider for all major insurance companies. We perform more than 600 liver, kidney, pancreas, heart and lung transplants each year. Since our program began in 1967, we've performed more than 11,500 lifesaving transplants, including more than 1,000 thoracic (lung or heart) transplants.

As you begin this journey, you and your family may have many questions and concerns. We hope this information helps you to learn about the process of lung transplantation so you know what to expect.

The goal of a transplant is to allow you to live a more normal life, but there are changes you will need to make after transplant to have the best outcome.

For More Information

It is common to feel both concerned and excited as you consider a lung transplant. If you have any questions or concerns, please talk to your lung specialist or contact the Comprehensive Transplant Center.

Phone: 614-293-5822
Monday through Friday
8 a.m. to 4 p.m.

After regular hours, a phone tree will direct you to the right person to leave a message.

Lung Transplant Program
Comprehensive Transplant Center
410 W. 10th Ave.
825 Doan Hall
Columbus, OH 43210
Fax: 614-293-9820

Preparing for a Lung Transplant



Beverly, lung recipient (transplanted March 2020)



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About the Lungs



The lungs are air-filled organs located on either side of the chest and weigh about 5 pounds (2½ pounds each). The right lung is shorter and wider because it has to make room for the liver, which is just below it. The left lung is narrower to make room for the heart. Your lungs are protected by the rib cage, which is made up of 12 sets of ribs.

The inside of the lungs looks like sponges. When we breathe in, air that has oxygen moves down from the nose or mouth through the windpipe (trachea), into two large tubes called bronchus tubes. One bronchus goes into the left lung and the other into the right. The lungs then provide oxygen to our red blood cells to be carried throughout the body. When we breathe out (exhale), the lungs also help the body to get rid of carbon dioxide gas.

A reduced lung function means that the ability of the lungs to exchange oxygen and carbon dioxide is less than normal.

Because every cell of the human body needs oxygen to live, working lungs are needed for life.

Lung Transplant Process



Harold (center), lung recipient (transplanted June 2018), pictured with his family



Lung Transplant Process

We strongly encourage you to have a support person attend all your office visits, testing appointments and education sessions with you. Because of your lung disease, you may have problems remembering and thinking, so your support person can be a second set of eyes and ears to help you.

Transplant Process Steps:

The journey through the process of organ transplant requires several steps.

- 1. Referral for Transplant**
- 2. Testing**
- 3. Evaluation Day**
- 4. Transplant Education**
- 5. Other Testing and Consultations**
- 6. Patient Selection Committee (PSC) Review**
- 7. Transplant Wait List**
- 8. Getting the Call**

We will review each of these steps to help you know what you can expect. Please ask any questions you may have and let us know if there is anything that you do not understand.

Step 1: Referral for Transplant

Your doctor might have talked to you about having a lung transplant because of the amount of damage you have to your lungs.

Pulmonologist

If you want to consider a transplant, you will need to be seen by a pulmonologist, a doctor who treats lung disease patients. This doctor will review your records and may do other testing to check the amount of damage to your lungs and if transplantation may be a good treatment option for you.

If your pulmonologist thinks you might be a candidate for lung transplant, they will refer you to The Ohio State University Wexner Medical Center's Comprehensive Transplant Center for more information and testing. Your pulmonologist will manage your lung disease treatment and medicines, whether or not you become a transplant candidate.

Transplant Team

Once you have been referred to the Ohio State Wexner Medical Center's transplant center, you will be seen by many members of the transplant team to help you understand the process and what to expect. Some of the team includes:

- **Transplant pulmonologist** – lung doctor who will review all of your testing and talk with you about transplant
- **Transplant surgeon** – doctor involved in reviewing your history and doing an exam. This doctor or another transplant surgeon may do the transplant surgery
- **Pre-transplant coordinator** – registered nurse (RN) who will work with you through the process from your referral until transplant surgery. You will need to let this coordinator know about any hospital stays, changes in your health or any changes in your contact information or insurance. After surgery, you will have a post-transplant coordinator, who is also a nurse
- **Transplant financial coordinator** – works with you to help you understand the costs of transplantation and any benefits you may be eligible to receive
- **Transplant social worker** – checks that you have support and coping skills to deal with the transplant process. If you have a history of problems with drug or alcohol use, the social worker will also assist you with meeting transplant guidelines and may refer you to the psychologist if needed
- **Transplant psychologist** – doctor who will work with you, if needed, to be sure you have the support and coping skills to handle the stress of the transplant process or will coordinate alcohol or drug counseling
- **Transplant dietitian** – reviews your eating habits and diet and help you make adjustments to manage your health
- **Transplant pharmacist** – evaluates your current medications to manage your health

Step 2: Testing

You will be scheduled to have tests done to check your current health and whether you may be able to have transplant surgery. These tests will be scheduled at Ohio State Wexner Medical Center.

Tests could include:

- Chest imaging, including CT and lung perfusion scan
- Blood tests
- Electrocardiogram (EKG or ECG) to check your heartbeat patterns
- Cardiac echo to check the pressures in your heart and lungs and the blood flow through your heart
- Pulmonary function testing to check how well your lungs are working
- Arterial blood gas (ABG) to check oxygen levels in your blood
- 6-minute walk test to check your heart and lungs when you are active
- Chest X-ray

Pulmonary Rehabilitation

Pulmonary rehabilitation is a requirement for lung transplant evaluation. It is an exercise program that increases your strength and helps your muscles better use oxygen. The therapists can also help you with breathing techniques to help manage your shortness of breath.

Avoid Alcohol, Drug and Nicotine Use

Alcohol, illegal drug and nicotine use is strictly prohibited.

- If you drink alcohol or use drugs, you will be sent for counseling and three months of treatment to help you meet requirements for the transplant waiting list.
- If you test positive for nicotine, you cannot be on the lung transplant list for six months.
- If you are on the lung transplant waiting list and you test positive for alcohol, illegal drugs or nicotine, you will be placed on an inactive status or you may be removed from the waiting list.
- Random drug and alcohol screening is done for all lung transplant patients. If you are called to have drug or alcohol screening, you have 24 hours to complete the needed test, or it will be assumed that your results are positive and actions will be taken.

Step 3: Evaluation Day

After your testing is completed, you will have an office visit for evaluation. It may take **2 to 3 hours** for this appointment, so please **bring a snack and something to drink**. You are also expected to **bring at least one support person with you to this appointment**.

On evaluation day, you will meet:

- **Pre-transplant coordinator** – will be your main point of contact. The coordinator will assist you through the entire evaluation process.
- **Transplant pulmonologist** – will discuss all of the testing that you have had up to this point. This doctor will speak with you about your medical and social history and look at your testing to check if you may be a candidate for transplant. They will explain transplant and answer any questions you may have about the process.

Step 4: Transplant Education

If you are considering a lung transplant, you will be scheduled to attend a class at the Ohio State Wexner Medical Center's Comprehensive Transplant Center. **You are required to attend this class with your support person(s) to learn about the transplant process.** There is much to think about before a lung transplant. The class is scheduled through the transplant center office by your pre-transplant coordinator.

Step 5: Other Testing and Consultations

After the first appointment, if the doctor feels like you may be a candidate for transplant, you will be scheduled for appointments with the following:

- **Dietitian** – to review your current diet and nutrition status and create a plan to keep you healthy. Changes to cooking and food prep, and use of nutrition supplements may be discussed.
- **Social worker** – to check your living situation, mental health, social support system, work history, and any issues with drug or alcohol abuse. Based on this review, you may also need to meet with the transplant psychologist. You must have a support person with you for these appointments.
- **Surgeon** – will talk with you about the plan for lung transplant and review the results of your tests. You will have a physical exam, and the risks and benefits of the surgery will be reviewed with you.
- **Financial coordinator** – will talk about your health insurance benefits and other financial resources, including your income and savings. We will help you create a financial plan to cover the cost of the transplant and follow-up care, as needed.
- **Pulmonary Rehabilitation at Ohio State** – will check your exercise tolerance and give you goals to take back to your pulmonary rehabilitation program.

You may also need to see these other doctors based on your testing:

- **Cardiologist (heart specialist)** – will review the results of some of your tests to determine if you have any heart issues
- **Infectious disease doctor** – will review your vaccination history and recommend vaccines that may be needed before transplant
- **Transplant psychologist** – will work with you, if needed, to be sure you have the support and coping skills to handle the stress of the transplant process, or to coordinate alcohol or drug counseling
- **Transplant pharmacist** – will talk with you about the medications you are currently taking and medications needed after transplant

You also will need these tests:

- Cardiac catheterization to look at the blood flow through the heart and the blood pressure of your lungs
- Carotid duplex, an ultrasound of your neck to look at the blood supply to your brain
- Gastric emptying to look at the amount of food your stomach empties in a set amount of time
- Esophagram and/or esophageal manometry and 24-hour pH probe to look at your esophagus and test for acid reflux
- Bone density to measure the strength of your bones
- Dental clearance (within 1 year)

- Cancer screening that may include:
 - Colonoscopy if older than 45, or younger if you have a family history of colon cancer
 - Mammogram for women older than 40
 - PSA for men
 - Pap test for women

Some of these tests can be done at your home facility. Your pre-transplant coordinator will discuss this with you.

Based on the findings from your evaluation, you may need other tests, or you may be given other guidelines that you need to meet before your case is able to proceed to the committee review process.

If your evaluation is complete, your case will be presented to the Patient Selection Committee.

Step 6: Patient Selection Committee (PSC) Review

This committee meets weekly to review new patients and to discuss updates for those patients who are either on or waiting to be placed on the transplant wait list. Many members of the transplant team are on the committee. They determine if you are a good candidate for transplant or if there are other treatment options for your care.

All aspects of your health, testing and evaluations will be discussed, and a decision will be made about your case. There are three possible decisions:

1. You are an acceptable lung transplant candidate.
2. More testing is required to decide whether it is safe for you to have a transplant.
3. You are not a candidate at this time. This may be a permanent or temporary decision. Continue your care with your lung specialist doctor.

The pre-transplant coordinator will contact you to let you know the decision from the PSC about your case.

If you are an acceptable candidate, the transplant center will work to get your insurance approval for the surgery. They will also contact the Ohio Solid Organ Transplantation Consortium (OSOTC) to get approval to have you added to the lung transplant wait list.

Step 7: Transplant Wait List

You will receive a letter and a phone call when you have been placed on the lung transplant list. There are several factors that determine your rank or placement on the wait list:

- Blood type
- Height range
- Lung allocation score (LAS)

Blood Type

There are four blood groups on the list: A, AB, B and O.

- O and A are the most common blood types and have a longer wait list, but they also have more donors available.
- AB and B groups have shorter lists, but there are fewer donors in these groups.

Height Range

The donor lung size can determine which recipient is selected. Each patient on the waiting list will have a height range based on their body size.

Lung Allocation Score (LAS)

Lung allocation score (LAS) is a useful tool for both you and your health care team as you plan for a transplant. It is a numbered scale that estimates how well your lungs are working.

The scores range from 0 to 100. Your transplant team will talk to you about your score.

The score is calculated by a formula using:

- A number based on your lung disease
- The results of your pulmonary function tests
- The results of your 6-minute walk test
- Blood test reports for your kidney and liver function
- Measure of your arterial blood gases (ABG)
- Measure of the blood pressure of your lungs

Testing will be done no less than every three months while waiting on the lung transplant list. This is both to check your lung disease and maintain an accurate lung allocation score. You may need testing more often based on the type and severity of your lung disease.

While Waiting

- **Make sure that you are available by phone. Check your messages and respond right away. You need to return the call within one hour** to determine if you are well enough to transplant. If you do not return the phone call in that time, the coordinator will contact the next person on the transplant list and you will miss the opportunity.

- **Be sure to stay in close contact with your transplant coordinator.** Let the coordinator know right away if you have:
 - Changes in your health, especially if you are seen in a hospital outside of Ohio State Wexner Medical Center.
 - Changes to any of your medicines.
 - Changes to your contact information or your family contact information if you listed them as a contact for you.
 - Plans to leave the state on vacation or for other reasons. You may be placed on hold if you are out of range.
 - Any changes to your support system or caregiver plan.
 - Any changes in your insurance.
- You should have plans ready for child and pet care, if needed, as well as transportation arranged, so you are ready if you get a call for transplant.
- You are required to avoid using drugs, alcohol and nicotine while you are on the transplant list and for life. You may be required to get random drug screenings done while you are on the transplant list.
- You will need to have ongoing lab work.
- You also need to have yearly dental exams, heart testing or other imaging tests, and keep all cancer screenings current.
- Be sure to keep all of your appointments with your primary care doctor and lung specialist and have your needed lab work completed.

Wait List Hold

You may be placed on a wait list hold for many reasons. You are not able to receive organ offers while on hold, but you are still on the list. Some of the reasons to be placed on hold include:

- You are too sick to safely have transplant surgery.
- You are traveling more than three hours away from the Ohio State Wexner Medical Center.

You may be removed from the list if you:

- Had a positive drug screen, including nicotine.
- You are not following through with required care.

If you are removed from the transplant wait list, you will receive a phone call and a letter of notification.

Contact the Transplant Team

Your transplant coordinator is available if you have any questions or concerns. All calls are routed to the coordinators and prioritized based on urgency. Calls are most often returned the same day.

If you have an emergency, **do not drive yourself to the emergency room. If you go to the emergency room, please call or have a family member call the office at 614-293-5822 or 866-204-3411.** After hours, please ask to be put through to the nurse.

Step 8: Getting the Call

Call from Coordinator

- A transplant coordinator will call you when a potential donor lung is available.
- Organ offers come at all hours of the day and night. Be sure to keep your phone on at night.
- The phone number that the coordinator is calling from will not always show as an Ohio State number on your caller ID. Please do not screen calls, as you might miss the call for an organ offer.
- You have one hour from the time the coordinator first called you to return the call. You do not have to be at the hospital in an hour, but you do need to return the call.
- The coordinator will keep trying to call you and anyone listed as a contact for you during the hour.
- When the coordinator reaches you, you will need to provide information about any changes to your medical history, infections, fevers and the distance you are away from the hospital.
- You might be asked to come to the hospital and then be sent home if the organ does not appear to be a good match for you or if the organ is of poor quality. This would not change your position on the wait list. You could also be sent home if you have an infection, test positive for drugs, alcohol or nicotine, or you have a new health problem that would make surgery unsafe for you.

Coming to the Hospital

- Be sure to bring these items with you to the hospital:
 - Photo ID
 - Insurance card(s)
 - Current list of all medicines
 - Power of attorney or living will documents
 - Medical history and list of past surgeries
 - List of important phone numbers
 - Personal hygiene items
- Do not bring jewelry, large amounts of money or other valuables with you to the hospital.
- For the safety of all patients on the transplant unit, children age 12 or younger are not permitted to visit. In addition, live plants (that are planted in soil) are not permitted in the transplant unit.

Organ Offers with Risk Criteria

You may be offered an organ that has risk criteria present, based on test results or behavior of the donor. The transplant team would only offer an organ that they feel would benefit you.

- A general reason why the organ has risk criteria present will be discussed at the time of the call. The doctor will explain this more to you when you are admitted to the hospital for transplant.
- You would need to sign another consent after talking with the doctors at the hospital.

Lung Transplant Surgery



April, lung recipient (transplanted January 2014)



Transplant Surgery

After you receive the call from your transplant coordinator, you will be admitted to the Richard M. Ross Heart Hospital at The Ohio State University Wexner Medical Center.

Upon arrival, you will have lab tests done to be sure you are ready for transplant. You will be given a number of medicines, including antibiotics, antifungals and immunosuppression medicines.

Possible Risks or Problems from Surgery

The doctor will talk with you about risks and benefits of transplant surgery before you sign the surgery consent form. There may be other risks, based on the donor organ and other factors. Ask questions if you do not understand the risks as the doctor explains them to you. The major risks include:

- Bleeding
- Infection
- Pneumonia
- Heart complications
- Kidney complications
- Blood clots
- Death

Surgery Takes 4 to 12 Hours

You will have general anesthesia, so you will not be awake during the surgery. The doctors will cut an incision based on the kind of lung transplant you are getting. You may get one or two lungs based on your lung disease, age and your functional status.

You will have a breathing tube and several IV lines in place after the surgery is done. You will also have several drains in place for fluid to drain out to help with healing.

You will likely be on oxygen and a heart monitor after surgery. You will also wear sleeves on your legs that are connected to a pump, called a sequential compression device or SCD. The compression device is used to prevent blood clots from forming in your legs while you are on limited activity.

Care After Surgery



Cheryl, double lung recipient (transplanted October 2017)



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Care After Surgery

Most transplant patients spend a few days in the intensive care unit. When you are able to breathe on your own, the breathing tube will be removed. You will then be transferred to the step-down unit to continue your recovery.

Most lung transplant patients will be in the hospital about two to three weeks. Staff will teach you and your support person about your care with an organ transplant, such as:

- Medicines you will take to prevent rejection of the transplant, also called immunosuppression medicines.
- How to prevent infections.
- How to care for your surgery incision.
- Problems that you should watch for and whom to call.

Discharge Planning

Your transplant team will decide when you are ready for discharge. Some patients need continued rehab and may be transferred to an inpatient rehab facility or an LTACH (Long Term Acute Care Hospital). Inpatient rehab allows patients to have more therapy to gain strength to prepare them for life after transplant.

Any patient who lives farther than 30 miles from The Ohio State Wexner Medical Center will need to stay locally until released to home by the transplant team. The length of time you will stay locally is based on your progress, healing and test results. Time spent at an inpatient rehab or LTACH does not count toward your time spent locally before going home.

You will be responsible for costs incurred to stay locally, including hotel reservations, food and transportation. Patients are encouraged to fundraise before transplant in order to afford these expenses. Sometimes apartments are available near the medical center at no cost. Availability of these apartments is not guaranteed and should not be your primary or only plan after discharge. In addition, **you cannot stay alone** until you are physically released to drive. This often occurs six to 12 weeks after your transplant but may vary based on your condition.

Immunosuppression Medicines (also called anti-rejection medicines)

Your body's immune system helps protect your body from infection and fights off things that might be harmful to you. After transplant, your immune system will know the transplanted lung(s) is not part of you, so it may try to fight against it. Immunosuppression medicines must be taken after a transplant to reduce your immune system's ability to recognize the transplanted lung(s) as harmful. You will need to take these medicines two to three times each day, every day, for the rest of your life. As a transplant patient, you need to learn about your medicines and how to take them, including what side effects you may have.

You will need to have **lab work done often to check the levels of your medicines** to be sure they are in the right range to work best for you. You should **never stop taking these medicines, or change the dose, without first checking with your transplant doctor.**

Doses will change often and you will need to communicate closely with your post-transplant coordinator to be sure you understand your instructions.

Only an Ohio State Wexner Medical Center transplant doctor should be making changes to your transplant medicines.

Protect Yourself from Infections

Because these immunosuppression medicines weaken your body's immune system, you need to take extra steps to stay healthy. You will be taught about how to protect yourself:

- Good hand washing
- Wearing a mask
- Avoiding others who are sick

Post-Transplant Coordinator

Be sure to update your post-transplant coordinator with any changes in your condition. You can also call with any questions you may have about medicines, testing, restrictions or anything that involves your health.

Appointments After Transplant

You will have a number of appointments for follow-up after surgery. Be sure to keep all of your appointments.

You should plan to have appointments with your care team on a schedule that will progress like this:

- Once a week for two months
- Every two weeks for one month
- Once a month for nine months

Lab work:

- Twice weekly for 12 weeks
- Weekly for months 3 to 6
- Every two weeks for months 6 to 12
- Monthly after 1 year

Bronchoscopies:

- Months 1, 3, 6, 9 and 12 (this may change based on your condition and the results from the previous bronchoscopy)
- None after the first year unless you are having issues

Spirometry:

- You will also have spirometry every month for life

Pulmonary Rehabilitation

You will be expected to resume pulmonary rehabilitation after you are discharged from the hospital.

Contact with the Donor Family

This is your decision. Every donor family and situation is different. Some donor families want to share about their loved one while others find it too difficult.

Please call Lifeline of Ohio at 800-525-5667 to find out more about contacting your donor family.

Other Treatment Options



Michael, lung recipient (transplanted December 2020)



What if Transplant Isn't Right for Me?

Treatment Options

There is no cure for end-stage lung disease. If transplant is not for you for whatever reason, there are other treatments that may benefit you.

Here is some information about possible treatment options. Talk to your lung doctor about treatments to manage your disease.

- **Pulmonary rehabilitation** – Prescribed exercise sessions that increase your strength and help your muscles better use oxygen. The therapists can also help you with breathing techniques to help manage your shortness of breath.
- **Medical management** – Talk with your lung doctor to make sure you are taking the right medicines to manage your lung disease.
- **Palliative care** – Some patients decide that transplant is not right for them, and have different goals for their treatment. Palliative care can help you determine what you want to do, and how you want to have your disease treated for the rest of your life. Do you want treatments to prolong your life, or do you want to be kept comfortable until your death? Palliative care can help you control your pain and ease your symptoms. Hospice services may also be useful to you and your family.



Harold, lung recipient (transplanted June 2018)

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