

BEFORE LUNG TRANSPLANT

What is Lung Transplantation?

Lung transplantation is the surgical replacement of either one (single) or two (double) badly diseased lungs with healthier lungs from a human organ donor. Lung transplant may be appropriate when, despite all medical treatments, your lung disease continues to get worse. Lung transplant recipients can have normal lung function and activity with a single lung transplant. The decision whether you will need a single or double lung transplant will be based on your specific lung disease, your current medical condition, and medical history.

Why You May Need a Lung Transplant

Lung transplant may be necessary for people with permanent, severe low lung function that can't be treated with other effective medical therapy. People with severe stages of the following lung conditions may benefit from lung transplantation:

- Alpha-1 antitrypsin deficiency-related emphysema
- Bronchiectasis
- Chronic obstructive pulmonary disease (COPD)
- Cystic fibrosis
- Emphysema
- Eosinophilic granuloma
- Idiopathic bronchiolitis
- Lymphangioleiomyomatosis (LAM)
- Pulmonary hypertension (Idiopathic pulmonary arterial hypertension)
- Pulmonary fibrosis
- Sarcoidosis
- Other conditions may also be considered

Some Patients Cannot Be Listed for a Lung Transplant

Some of the following conditions prevent patients from being listed for lung transplant at Michigan Medicine as it is considered not in the best interest of the patient:

- Actively smoking persons are not candidates for consideration. Candidates must be nicotine free (no smoking, no nicotine gum, no nicotine patches, no chewing tobacco, no e-cigarettes, no vaping, no marijuana or other products) for a minimum of six months before evaluation
- Hospitalized elsewhere other than Michigan Medicine
- Extended care facility or nursing home dependent
- Unable to walk 450 feet during a six minute hall walk (oxygen use is permitted for this test)
- Lung cancer
- History of cancer (within the past five years, except skin cancer)
- Active infection
- Active hepatitis infection
- HIV infection
- Body weight - BMI (Body Mass Index) above 32 or too low (< 18) to tolerate the surgery (<http://www.bmi-calculator.net>)
- Advanced heart, kidney or liver disease
- Advanced coronary artery disease
- Active alcohol or other substance abuse
- Significant mental illness or lack of social support
- Active systemic disorders such as certain connective tissue disease or demyelination disorders
- Lack of insurance coverage, resources to cover the transplant, medicines and follow up required after transplantation

Lung Transplant Medical Evaluation

The First Appointment

People with lung disease are generally under the care of a doctor specializing in lung disease, known as a pulmonologist. As your lung disease gets worse, your pulmonologist may refer you to a pulmonologist specializing in lung transplant. The **transplant pulmonologist** will evaluate whether you are a candidate for lung transplant. The transplant pulmonologist will also discuss the extent of your lung disease, lung transplantation, the risks, the benefits, timing of transplant listing, and other alternatives to transplant. The transplant pulmonologist will decide with you if and when to move forward with lung transplant evaluation. You will complete the following testing during your appointment with your transplant pulmonologist:

- Pulmonary function test (PFT)
- Six-minute hall walk
- Arterial blood gas
- CT (computed tomography) scan of the chest

You will also meet a pre-lung transplant coordinator who will be your primary contact throughout the lung transplant evaluation process and listing. Your pre-transplant coordinator may have you complete blood and urine testing and possibly schedule other required testing on the day of your surgical evaluation.

Lung Transplant Education Class

You and a support person **MUST** attend a Lung Transplant Education Class before you can be listed for a lung transplant. Your **pre-lung transplant coordinator** will schedule the class for you. The class includes:

- A lung transplant **nurse** will discuss the process of having a transplant, including the surgical procedure with you and your support persons. Information about life after transplant and a lifetime of follow-up care is provided.
- You will learn about the lifelong medicines that lung transplant patients must take after transplant. Side effects of these medicines and medication monitoring also are discussed.



Lung Transplant Evaluations

- A **financial coordinator** will meet with you to address insurance and financial planning for your transplant.
- A **social worker** will meet with you and your caregiver(s) to evaluate your coping ability and available support throughout the transplant process. Resources for emotional and mental wellbeing, family and caregiver support, financial concerns, substance abuse and employment or disability concerns are then recommended for each individual case.
- A **registered dietitian** will meet with you to evaluate your current nutritional health, and help you establish a healthy diet both before and after transplant. Some patients need to gain or lose weight before they are listed for transplant. If this is the case for you, the dietitian will coach you to reach your goals.

Lung Transplant Evaluation Testing

Required testing for lung transplant evaluation at Michigan Medicine may include:

- Pulmonary function test
- Chest CT
- Heart catheterization (right and sometimes left)
- Echocardiogram 2D Surface
- EKG
- Quantitative VQ Scan
- Chest X-Ray
- Esophagram
- Carotid Doppler
- Occasionally, an evaluation and input from other specialties (e.g., infectious disease, nephrology, gastroenterology) will be required
- Additional testing unique to your individual case

Additional testing that you will need to complete locally includes:

- Bone densitometry
- Dental clearance
- Mammogram (females 40 years and older)
- Pap smear (females)
- Colonoscopy (50 years and older)
- Guaiac stool test (not needed if colonoscopy is normal)
- Additional testing unique to your individual case

Additional requirements for listing:

- Current Durable Power of Attorney
- Tobacco, Alcohol and Substance Abuse Contract
- Patient and Caregiver Agreement

Lung Transplant Surgical Evaluation

A lung transplant thoracic surgeon will meet with you and evaluate your case. The surgeon will discuss lung transplant surgery, the risks, benefits, survival rates, and conditions special to your case. The surgeon you meet at the surgical evaluation may or may not be the surgeon who performs your transplant surgery, if you are a candidate.

Lung Transplant Outcomes

It is hard to predict how any one individual may tolerate a lung transplant. There is data available to help you understand how the average patient may respond, but it cannot predict how you will do after lung transplantation.

These survival rates can change over time. For current information on lung transplant and outcomes you may visit the following websites:

- United Network for Organ Sharing (UNOS) - www.UNOS.org
- Scientific Registry of Transplant Recipients (SRTR) - www.srtr.org

Lung Transplant Multidisciplinary Team

Once all testing is complete and all the requirements for lung transplant consideration are met, your individual case will be reviewed at the multidisciplinary lung transplant meeting. You are not present at this meeting but will be aware when your case is being presented. You and your referring doctor will be notified of the team's decision after the meeting. The multidisciplinary team will fully review your case and make a recommendation for lung transplant listing for your individual case.



The multidisciplinary team may determine some patients are **too well** for lung transplant listing. The transplant pulmonologist will continue to medically manage these patients. If the patient's lung condition gets worse, they may reconsider listing for lung transplant at a future date.

The multidisciplinary team may determine a candidate is **not eligible** for lung transplant due to their medical condition or other factors that prevent the team from recommending lung transplant. In these cases, the risk of the lung transplant exceeds the expected benefit.

The multidisciplinary team may recommend **referral** to another lung transplant center with expert knowledge in a particular area. A referral and test results will be forwarded to the lung transplant center with your permission.

The multidisciplinary team may determine that you are a **good candidate** for lung transplant and recommend lung transplant listing at this time. The team also will determine how you will be listed for lung transplant (single or double lung transplant) based on your diagnosis and results of your evaluation.

You and your referring doctor will be notified of the decision in writing. If you have any questions or concerns, you may contact our center.

Listing for a Lung Transplant

Eligible persons are listed for lung transplant through the United Network of Organ Sharing (UNOS). Your lung transplant listing will include the type of transplant, your blood type, your height, and your composite allocation score (CAS). The lung(s) for you will need to come from a donor with a compatible blood type and size. The lung(s) may come from a donor of a different gender or race. If you receive a double lung transplant, both lungs will come from the same donor. Factors determining lung transplant offers are:

- Your Composite Allocation Score (CAS) on the wait list
- Your blood type (the donor must have a compatible blood type)
- Your height (the donor must have a compatible size)
- Listing for a left lung, right lung, either lung, or double lung transplant

Multiple Lung Transplant Center Listing

You can be actively listed for lung transplant at more than one lung transplant program. There is no guarantee that multiple listing will shorten wait time, although it is possible. You will need to complete an evaluation at the other programs and meet criteria for listing at each program. Each lung transplant program has unique selection criteria. Aspects of multiple center listings that you may want to consider include: insurance coverage, transportation to each center, and follow up care after transplant at the center.

Composite Allocation Score (CAS)

The composite allocation score (CAS) is a calculation that determines which people on the lung transplant waiting list need a lung transplant the most and have the

$$S_{WL,i}(t) = S_{WL,0}(t) e^{\beta_1 X_{1i} + \beta_2 X_{2i} + \dots + \beta_p X_{pi}}$$

greatest expected benefit from lung transplant. Many factors go into the lung allocation score, which you cannot control. Lung disease diagnosis, cardiac catheterization pressures, pulmonary function testing, oxygen requirement, laboratory testing, age, and additional results are part of the lung allocation score calculation. A high CAS reflects an urgent need for lung transplant while the expected benefit is higher than the risk of the lung transplant. Additional information on the Lung Allocation Score is available at <https://optn.transplant.hrsa.gov/patients/by-organ/lung/lung-allocation-based-on-the-composite-allocation-score-cas-questions-and-answers-for-patients-and-caregivers/>.

Waiting for Your Lung Transplant

Wait time for lung transplant depends on an adequate donor lung(s) offer. Deceased donors, whose family members agree to organ donation, sometimes are able to donate organs. Only a small percentage of these donors will have suitable lung(s) for transplant because lungs have a higher risk of injury and infection. Donor lung offers are matched with possible recipients and then offered to transplant centers by the United Network of Organ Sharing (UNOS). The lung(s) transplant offer depends on your Composite Allocation Score (CAS), the lung(s) you need for transplant, as well as a compatible blood type and donor size. Wait time for lung transplant varies greatly. Some patients have received a lung transplant offer after a day on the list while others have waited months or years. The length of time a patient may wait for a suitable lung(s) organ offer cannot be estimated.

You must keep our transplant center updated with a list of current telephone numbers. When a donor lung(s) becomes available, we are required by UNOS to speak with you within **one hour** of accepting a lung organ offer. This means the transplant coordinator has only one hour to reach you. If the coordinator is not able to reach you, the next transplant candidate will receive the lung offer. The lung transplant coordinator may call you from a cell phone, the hospital or other phone, so calls cannot be screened. The coordinator will not leave a message. If you have privacy manager on your telephone we recommend that you remove it while on the transplant list. You will also need to remain in an area with reliable phone service.

While on the transplant list, we require our patients to stay within a **four-hour range** of Michigan Medicine. If patients live or are traveling further, transportation arrangements need to be made ahead of time or patients will temporarily be placed on hold or not eligible for transplant.

While waiting for lung transplant you will need:

- To be **reachable any time day or night** within **one hour** as required by UNOS. If we are unable to reach you within one hour, we are required to move on to another potential recipient.
 - *This includes not screening phone calls, turning off phones, or traveling to areas without phone service.*
- Have an **available driver/transportation** at any time, day or night, to bring you to the hospital for transplant and stay with you through your surgery.
- **Stay within four hours** of Michigan Medicine or have a transportation plan arranged in advance. Please keep the coordinator updated with travel plans even within the four hour range.

While on the lung transplant wait list, it is extremely important to remain in contact with our center. Your **pre-transplant coordinator** will be your main contact with our program while waiting for lung transplant.

While on the lung transplant list you MUST contact us with:

- Your current phone numbers and address – a way to reach you any time, day or night, within one hour as required by UNOS
- Any change in oxygen requirement
- Any new medications
- Any illness or need for an antibiotic
- Prednisone dose changes
- Any hospital stays or Emergency Room visits
- Any change in medical condition
- Any blood transfusions
- Travel plans
- Any insurance changes
- Any situation or condition that may cause you to not be eligible for a lung transplant

Hold Status or Removal from the Lung Transplant List

Persons on the lung transplant list may need to be placed **on hold or temporarily ineligible** for lung transplant for a number of reasons. Proceeding with transplant is not safe or possible at this time. **You will remain on the lung transplant wait list but not receive lung(s) offers while on hold.** Once the condition for the hold status is no longer an issue, you can usually return to active status and receive lung(s) organ offers. New medical issues or operations will require your status to be on hold. Non-medical reasons may also result in hold status for transplant.

Sometimes new medical, surgical, or non-medical issues that occur may result in people no longer being a candidate for lung transplant. If the issues are not reversible or it is determined in your best interest not to proceed with lung transplant then you will be **delisted or permanently removed** from the lung transplant list.

Random checks of tobacco and substance abuse will be performed while you are listed for lung transplant.

Some conditions that will require you to be placed **on hold or removed** for lung transplant include:

- A new active infection
- Hospital stay at another institution
- A steroid burst - Prednisone taper
- Any tobacco product use or positive cotinine test
- Travel outside of a four hour range unless transportation is arranged
- Cancer except skin cancer
- A new medical condition or operation
- Loss of insurance
- Compliance issues
- Social support issues
- Substance abuse issues
- Untreated psychiatric issues
- Weight gain or loss with BMI (Body Mass Index) too high (above 32) or too low (below 18) to tolerate the surgery. (<http://www.bmi-calculator.net>)
- Not able to walk 450 feet during a six minute hall walk (oxygen use is permitted for this test)

You must keep the lung transplant team informed of any changes in your health, insurance, or personal situation. Please contact your **pre-lung transplant coordinator** right away with any of these changes. A transplant social worker and financial coordinator are available to help remove barriers to transplantation and will work with you and your family towards this goal.

Staying Healthy Before Lung Transplant

Staying as healthy as possible, physically and emotionally before lung transplant is very important. We encourage you to learn as much as possible about your disease, testing, medications, and the transplant process before your transplant. The stronger, healthier, and more prepared you are at the time of transplant, affects your speed of recovery and coping with life after transplant.

Staying Physically Healthy Includes:

- **Stay as active as possible.** Listed lung transplant patients must continue to be able to walk 450 feet during a six minute hall walk. Oxygen can be used for this walk.
- **Attend a pulmonary rehabilitation or physical therapy program.**
- **Maintain your weight.** Eating well is an important part to maintaining your best health. Listed patients need to maintain a weight with a BMI (Body Mass Index) below 32 or above 18 to tolerate lung transplant surgery.
- **Continue to see your transplant pulmonologist.** You will continue to see your lung transplant pulmonologist at least every three to four months with testing required to maintain your Lung Allocation Score on the lung transplant list.
- Continue to see your **primary care provider.** Your will need to continue recommended routine medical care and physicals with your primary care provider.
- **Do not smoke, use any nicotine replacement or abuse other substances.** Patients on the lung transplant list will continue to be monitored to guarantee compliance with the program's substance abuse policy, including monitoring for nicotine products and/or other illicit drugs.

Mental Health

For any patient who is dealing with depression, anxiety or any other mental health issue, the transplant team will discuss a plan for managing the symptoms. This may include a referral to a mental health professional for therapy or medication management.

Substance Use

All patients are tested for use of alcohol, nicotine, and other controlled substances including pain and anxiety medicines before listing for transplant. Some will be referred for further evaluation and treatment by a substance abuse specialist. We require all patients be nicotine free for at least six months. Patients may also be required to stop using alcohol, narcotics, and benzodiazepines before transplant listing

Social Support Plan

Patients must be able to identify a reliable support system: To ensure a successful transplant outcome, it is important to discuss the need for ongoing social support with your family and friends. Your transplant social worker will require you to have a plan for these specific tasks that you will need help with:

- **24/7 on-call driver:** You will need to identify a friend or family member who can bring you to Ann Arbor when you receive the call for transplant and stay at the hospital until your surgery is completed. The surgeon will talk with your support person about your surgery when it is complete. It is also important that the person who is at the hospital during the surgery is your Durable Power of Attorney for medical decisions. Please remember, this call can come anytime, day or night.
- **Main support person while in the hospital:** The transplant team will want to provide education and instruction to you and your main support person before you are discharged. The team will educate you and your support person regarding medication instructions, home care, follow up clinic appointments, and weekly labs. Having another person hear this information helps you to remember the team's instructions after you have returned home.
- **In-home support:** For at least two weeks after your discharge, you will need 24 hour support by a family member or friend. During this time, you will need help with cooking, shopping, laundry and cleaning. You may also need help with organizing and monitoring your medicines, administering IV and inhaled medication at home, and talking with the post-transplant staff if you have concerns.
- **Driver to clinic appointments and bronchoscopies:** You will have clinic appointments with your transplant pulmonologist and surgeon after you are discharged from the hospital. You will not be able to drive for about six weeks and whenever you have a bronchoscopy. Bronchoscopies are scheduled at three weeks, six weeks, three months, six months, one year, and whenever clinically required. You may also be referred to other specialists within Michigan Medicine, such as diabetes, kidney or infectious disease doctors. Please ask a friend or a family member to help you with transportation to Ann Arbor for these clinic appointments.

If you have difficulty identifying friends or family to help you with any of these areas of support, notify your Transplant Social Worker, so you can work on a plan together.

Staying Emotionally Healthy is Very Important

Transplant social workers are trained to help patients and their loved ones to cope with the challenges of long-lasting illness and the specific challenges of lung transplant and ongoing care. Here are some suggestions from our social work team about emotional health:

- **Attend the Lung Transplant Support Group.** The lung transplant support group is held once a month and is a way to receive support from others who are going through a similar experience. We also offer a Caregiver support group and Cystic Fibrosis group. Your lung transplant social worker can provide you with a schedule of the support meetings. Your lung transplant team requires you attend three to six support group meetings per year while you are listed for transplant.
- **Share your feelings.** The wait for a lung transplant can be very hard and it is common to have feelings of frustration, anxiety and sadness during your time on the waiting list. If you begin to feel overwhelmed by these or other emotions, we encourage you to talk to your transplant social worker. If these emotions are making it hard for you to function on a daily basis, individual counseling might be helpful for you.
- **Stay involved.** Keeping life as normal as possible helps maintain stability during the waiting period. You should try to stay involved in work and leisure activities as your health will allow. If your health limits your ability to continue to work or participate in some activities, be creative and find new outlets or interests to focus on.
- **Try to find outlets to relax.** You should identify those activities that you find relaxing and make a commitment to yourself to do at least one relaxing activity each day. Some activities that help reduce stress are taking a walk, listening to or playing music, reading, relaxation classes, talking with friends or family, writing, drawing, painting, cooking, as well as many other activities. Avoid unhealthy outlets of stress such as abusing drugs or alcohol, overeating, or separation from friends and family.
- **Participate in activities that promote your spiritual wellbeing.** For patients who turn to faith or spirituality as a source of strength, you may find that connecting with your spiritual community for prayer and comfort may ease your mind, body and spirit.
- **Participate in physical activities. The lung transplant team recommends most patients participate in a lung (pulmonary) rehabilitation program or physical therapy program before transplant.**

Contact your Transplant Social Worker if you need support coping with your wait time or any other concerns you have about your emotional health. If you are already followed by a local therapist or psychiatrist, the transplant social worker will talk with you about requesting a letter summarizing your care and treatment plan at your evaluation appointment.

Nutrition Before Lung Transplant

Nutrition Health

As lung disease progresses, the work of breathing can increase ten to twenty times that of a person with normal lung function. In advanced stages of pulmonary disease, both energy balance and protein balance are affected. Research shows that people with advanced lung disease may find their activities of daily living are harder. They may also have lower lung function measurements, hard and labored breathing, and may not want to eat as much. Eating can lead to changes in how your body uses oxygen which may require some people to increase their oxygen requirements during meals. Nutrition services can assist you in developing a plan to either maintain your weight or a weight loss plan that is healthy and balanced to improve your energy levels.

Nutrition Goals While Waiting for Lung Transplant

It is important to consider your nutritional goals as you wait for your transplant. You will want to be able to:

- Recognize symptoms that can interfere with eating, such as shortness of breath, nausea, vomiting, and an early feeling of fullness.
- Maintain your nutritional well-being by eating enough calories and protein to support a healthy weight.
- Follow a healthy weight loss diet to restore your nutritional health, if necessary.
- Prevent unplanned weight loss.
- Avoid eating for two hours before going to bed if you have gastroesophageal reflux or heart burn.
- If prescribed, use additional oxygen around mealtimes.

If you have been instructed to lose weight, the following are recommended for you:

- Increase your daily activity as it helps reduce body fat and improves your muscle mass.
- Eat smaller serving sizes.
- Eat five to seven servings of fresh fruit or vegetables daily.
- Eat only at your kitchen or dining room table.

- Avoid distractions while eating because your brain won't fully register that you have eaten. This can cause you to overeat. While eating don't:
 - Read the paper or a book
 - Watch television
 - Talk on the phone
 - Use the computer
- Restaurant meals are often larger and higher in fat and calories than meals you would make at home. Take home half your entrée to eat at another meal.
- Avoid all foods fried in fat.
- Avoid drinking soda.

If you have been instructed to gain weight, the following suggestions will help you:

- Drink high-calorie, high-protein beverages.
 - Milkshakes, whole milk, flavored milk, nutritional products and fortified milk (one tablespoon powdered nonfat milk added to one cup liquid milk).
 - Freeze beverages into popsicles or ice cubes.
 - Use nutritional beverages in cooking and baking and on cereals.
 - Choose milk-based or cream-based soups instead of broth based soups.
- Choose foods high in calories.
 - Add cream, margarine, butter, cheese sauce, olive oil or salad dressing to pasta or vegetables.
 - Avoid diet foods by choosing regular cheeses, salad dressings, dips, sour cream, ice cream and cold cuts.
 - Select yogurt and cottage cheese made from whole or 2% milk.
- Choose foods high in protein such as milk, eggs, cheese, meats, nuts or beans.
 - Use 2% or whole milk for drinking, cooking and baking.

Nutritional services are available to lung transplant patients before and after a lung transplant. Patients may be referred to an outpatient dietitian through their doctor before or after their transplant. An inpatient dietitian meets with you during your hospital stay to teach you about good nutrition following your transplant. Cystic Fibrosis (CF) patients see a nutritionist who specializes in CF patients in the CF Clinic.