Waiting for Your Lung Transplant

Waiting on the Transplant List

- What is the process for being placed on the transplant list?
- What is my lung allocation score?
- What happens while I wait for a lung transplant?
- When should I call my transplant coordinator?

The United Network for Organ Sharing (UNOS) oversees all organ donation programs in the United States. UNOS handles the waiting list and matching donor organs to recipients 24 hours a day, 365 days a year. You will be listed by blood type, body weight, and how sick you are (lung allocation score or “LAS”).

Your transplant team will review all of the findings from your evaluation. The surgeons, pulmonologists, and all other team members meet and decide if you meet the standards to be placed on the transplant list. If you do, and if you agree, you will be listed.

The LAS is used to rank potential recipients ages 12 and over. It measures medical need and life expectancy of patients on the waiting list. Health information for each transplant candidate is entered into UNOS. Each person is given a score from 0 to 100. This score depends on the results of these tests.

- **Forced vital capacity** – This is a lung function test. It measures the amount of air you can breathe out after you breathe in as deeply as you can. This number may be lower in patients with lung disease.

- **Pulmonary artery pressure** – This is the pressure the heart must produce to pump blood through the lungs. This may be high in some people with severe lung disease.

- **Oxygen at rest** – This is the amount of oxygen needed at rest to maintain oxygen levels in the blood. People with severe lung disease may need more oxygen.

- **Age** – This is the person’s age at the time lungs are offered.

- **Body mass index** – BMI is a ratio of a person’s weight to height. When used with other test results, it helps to assess health status.

- **Diabetes** – This may predict future problems in some people with lung disease.
• **Functional status** – The New York Heart Association’s ratings measure how a person’s lung disease affects their ability to function in daily life.

• **6-minute walk distance** – In the 6-minute walk test, patients are asked to walk as far as they can in 6 minutes. The distance walked is a measure of how well you can manage your daily life.

• **Assisted ventilation** – The use of a ventilator, BiPAP, or CPAP to assist breathing may be a measure of how severe the disease is and may affect success after a transplant.

• **Pulmonary capillary wedge pressure** (PCW or “Wedge Pressure”) - Blood that returns to the heart from the lungs must get by this pressure. This can become higher when the heart is not pumping as well as it could.

• **Serum creatinine** – This measures how well your kidneys work. High creatinine levels reflect impaired kidney function.

• **Diagnosis** – Research has shown that urgency among people needing a lung transplant and success after a lung transplant varies among people with different lung diseases.

• Other lab tests – Bilirubin, blood gases, cardiac index, etc.

The LAS may change daily due to age and other factors that affect how well-matched the donor and the recipient are. Because the LAS changes daily, we do not provide the LAS to patients. Your score can be revised if your health status changes.

**Status 7** is for patients who are not candidates for transplant at the moment, but may need a transplant in the future.

While on the wait list, you will be seen in the Lung Transplant Clinic every 3-6 months. We will update your LAS with each visit. Follow-up testing and a teaching session will be done to help you prepare for transplant. It is helpful to bring a family member or friend with you to your visits. It is vital that you call your transplant coordinator or a member of the transplant team if there is a change in your health status or how well you can function. Be sure to call if you

- Start a course of antibiotics.
- Are transfused with blood or blood products.
- Are hospitalized locally or at UWHC.
- Have a major change in your health status.

If there is a major change in your health status, we will update your LAS and the lung transplant team will want to schedule you to be seen in the Lung Transplant Clinic.

Always follow the instructions given to you by your local doctor or the transplant team.

Waiting on the transplant list can be stressful for you, your family, and friends. Be sure that you talk with your support people about your clinic visits, your health status, and your plans/wishes.
Your local pulmonologist will stay involved in your care before and after you receive a lung transplant. Be sure that you let your coordinator know if your local pulmonologist makes changes in your medicines.

**Intro to Medicines**

- What types of medicines will I need to take and why?
- Will there be side effects from them?
- How will I pay for them?

After your lung transplant you will be on many kinds of medicine each day, such as:

- Medicines that prevent rejection (anti-rejection). You will take these for the rest of your life.
- Medicines that prevent infection (anti-infective). You may take these for the rest of your life.
- Supplemental medicines. These may include vitamins and medicines to control your blood pressure or cholesterol.

It is vital that you take all the medicines ordered by your transplant team.

There can be many side effects caused by the medicines you will be taking. These can include

- Diabetes
- High cholesterol
- High blood pressure
- Weight gain
- Tremors
- Mood changes
- Headache
- Nausea
- Diarrhea

Medicines can be given to help with some of the side effects. Other side effects may improve over time. It can be very hard to cope with the new medicines, side effects, and lifestyle changes. You should never stop a medicine or change a dose without talking with your transplant team.

Be sure to talk with the financial counselor and social worker about medicine coverage after transplant. These medicines are very costly. You will want to have a plan to cover the costs in case your insurance does not.
Financial Planning

- **What do I need from my insurance company to plan for a transplant?**
- **What questions about finances do I need to have answered?**

As you get ready for transplant, you will need to learn more about your insurance plan.

- Transplant patients are required to take medicines for the rest of their lives. In fact, you may need over 15 different transplant drugs. As a result, you must learn now about your **drug co-pays or deductibles**.

- Know your **co-pays and deductibles for clinic visits and procedures**. Transplant patients receive lifelong follow-up care. Knowing your co-pays and deductibles will ensure that you are prepared to budget for this expense.

- Many insurance plans have a **yearly limit for co-pays or deductibles**. Once you have reached the limit, your insurance may pay 100%. To know your plan, refer to your insurance booklet and keep track of your healthcare expenses.

- Contact your insurance agent to find out how much you have left before you reach your lifetime and transplant limits. This helps you to plan for **secondary coverage** or other options to cover any further expense. Once you reach the limit, insurance will not cover any further expense. Transplant patients often reach their limit.

- Know the **referral guidelines** of your health plan. UWHC is a hospital-based clinic. You will get separate bills from the hospital and the doctors for their services. If you fail to follow the guidelines, you may need to pay for the cost of a service which may have been covered.

- **You may need to stay in Madison for some time** after your transplant. Since most insurance plans require patients to only fill prescriptions in certain drugstores, know where you can get them filled both in your hometown and in Madison. Plan ahead for monthly bills as well.

- Also, check with your insurance to see if you have any coverage for housing.
Once you have received your benefit summary from the financial coordinator, you may have even more questions. Below are some common questions which other transplant patients have found helpful.

- What would be my monthly total co-pay if I were prescribed 15 medicines?
- What are the co-pays and deductibles for clinic visits and procedures that I need to pay out of pocket?
- How would this expense fit into my budget?

\[
15 \times \$\text{_____} \text{ (the co-pay amount per prescription)} = \$\text{______}
\]

Monthly clinic and procedure co-pays: $\text{______________}

- My lifetime insurance maximum is: ______. How will I obtain coverage if I reach my lifetime max?
- What would I do if my insurance was changed or dropped? Call a financial coordinator and tell your transplant coordinator right away!

My health plan referral guidelines

________________________________________________________
________________________________________________________
________________________________________________________

It is also vital to understand how Medicare may affect your transplant. Review your Medicare benefits handbook for more complete information. If you have Medicare and other health insurance coverage and have questions about who should pay first, check with your insurance company or your Medicare coordination of benefits contractor at 800.999.1118.

- Lung transplant will be a covered cost under Medicare part A (inpatient hospitalization). However, patients are responsible for a deductible of about $992.00. This may change every year. You are responsible for paying the deductible if you do not have a supplemental insurance plan to Medicare or alternative insurance coverage.
- Patients enrolled in Medicare part B have outpatient clinic benefits that will pay for 80% of costs for:
  - Doctor’s services
  - “Special Practitioner” services
  - Home Health services, ambulance services (if medically needed)
  - other items such as outpatient testing, diagnostic tests, and labs

For a complete listing, review your Medicare benefits handbook. Patients are responsible for paying the portion not covered by Medicare if they do not have a supplemental insurance plan or alternative insurance coverage.
• Medicare part D Prescription Drug Plan (PDP) varies for each person.
  o If a transplant patient has Medicare B at the time of his transplant, Medicare B pays for 80% of the cost of immunosuppressant and antiretroviral medicines. Patients are then responsible for the remainder of the cost if they do not have a medicine benefit from their supplemental insurance plan or an alternative insurance coverage. Medicare D will NOT cover any cost related to the immunosuppressant or antiretroviral medicines if a patient had Medicare B at the time of his transplant. You will need to check with your Medicare D PDP to figure out what medicines they will cover. Each plan is different so be careful in choosing the best plan to fit your needs.
  o If a transplant patient does not have Medicare B at the time of the transplant, Medicare D will cover some of the cost of the immunosuppressant and antiretroviral medicine. Patients still need to be aware of the “doughnut hole” and how that will affect their medicine costs.
  o Be careful in choosing your Medicare D PDP as you will need to purchase medicines in the Madison area as well as in your hometown if you need to stay here after transplant.
  o The hospital financial planner or social worker will be able to answer questions you have about Medicare.

❖ The Call

• How will I be reached?
• What do I need to have ready ahead of time?
• What will happen after I get the call?

Once you are listed for a lung transplant, we must be able to reach you at all times. You must inform your transplant coordinator if you are going to be out of the area or can’t be reached for any reason. You must always have a cell phone with you. Be sure your phone is always on and fully charged.

The transplant coordinator will call you if an organ that may be a match for you becomes available. At this time you will be asked

• To stop eating and drinking.
• About your current health status.
• To keep a phone line open, but to wait at home until you are called again OR to come to UW Hospital.

You will need to bring your insurance information, a list of your medicines, and your nebulizer compressor (if you have one) when you come to the hospital. You do not need to bring other items. It is a good idea to leave all jewelry and other items of value at home.

It is recommended you have a friend or family member drive you to UW Hospital. You should not drive alone when you are coming for a transplant.

The transplant coordinator will tell you where to report when you get to the hospital. Keep in mind that your transplant could be cancelled at any time.
It is vital that family and friends are part of the planning process. Be sure that they are aware of the need for you to be reached at all times. They should also know the plan for getting you to the hospital when needed.

Once you arrive, you will be very busy getting ready for your transplant. This will include

- Signing consent forms.
- Having blood drawn.
- Washing your chest and abdomen.
- Getting a chest x-ray.
- Having an IV line placed.

You may be given medicine to help you relax during this time.

**Advance Directives**

- What is a Power of Attorney?
- What is a Living Will?
- How do I fill these out?

We strongly urge all patients over 18 years of age to complete a Power of Attorney for Health Care. This is not the same as a Living Will. It tells us who you want to direct your health care if you are not able to speak for yourself. These people should know your wishes about medical care. They will make choices based on your requests. Any special health care wishes you have should be written down on this form. You are the only person who can complete this form.

The person named as your health care agent would not be able to make choices for you right away. Two doctors or a doctor and a psychologist would have to first sign an incapacity statement to put your Power of Attorney for Health Care into effect. This would state that you are not able to be given and understand health care information or to share your health care wishes. When you are able to make your own health care decisions again, the Power of Attorney for Health Care will no longer be active, but it remains valid in the event you become incapacitated again.

A Living Will lists some of your end-of-life wishes. It does not allow you to choose a person to make decisions on your behalf.

Your social worker can help you fill out and sign these forms. We provide this service to patients free of charge.
Family Support

- What resources are available for my family members?
- How can family members stay updated on my status?

Waiting for lung transplant can be very tough for a patient’s support person(s) and family members. Many of them are anxious during this waiting period. There are many things that can be done to ease concerns. They include

- Talking about hopes and fears about the transplant.
- Talking about the patient’s wishes in regards to Advance Directives.
- Going to transplant support groups
- Talking with a counselor.

Your transplant social worker can help you find resources where you live.

At the time of transplant, family members will be taken to a waiting area. The nursing staff will provide updates every couple of hours during the transplant. Family members will be able to make a short visit to the intensive care unit after the transplant.

It is best to choose one family member as the main contact. This person can leave a cell phone number with the nursing staff so he or she can be called if needed. This person can update other family members and friends about your status.

There may be family and friends who wish to send flowers. Fresh flowers and live plants are not allowed in the rooms of transplant patients. Mylar balloons are a nice option.

Resources for Transplant Patients

One-on-one conversations with UWHC patients who have had a transplant can be arranged. Call the Lung Transplant Office at (608) 265-5658 if you would like this arranged.

Internet Resources
University of Wisconsin Hospital and Clinics Transplant information –
http://www.surgery.wisc.edu – Patients, Organ Transplantation
http://www.uwhealth.org – General health information
Pre & post-transplant support group information:

General transplant information: http://www.unos.org

General transplant information: http://www.transweb.org

National Transplant Society: http://www.organdonor.org

TransWeb: http://www.transweb.org

TRIO: http://www.trioweb.org
Important Phone Numbers

Lung Transplant Office (608) 265-5658
Toll-free (888) 522-2501
(Monday through Friday, 8:00am-4:30pm)
Fax (608) 263-0597

G7/105 Transplant Clinic (608) 262-5420
Nursing Staff-Cardiothoracic Surgery Unit (608) 263-8720

Lung Transplant Social Worker (608) 890-9209
Patient Housing (608) 263-0315
Financial Advisor (608) 228 - 4523

In a medical EMERGENCY, proceed to the nearest emergency room or call 911.

The UW Hospital paging operator (608) 262-0486
When you call this number be sure to

- Call this number after 4:30pm and on weekends and holidays for emergencies only.
- Tell the operator you are a lung transplant patient.
- Ask for the cardio-pulmonary transplant coordinator on call.
- Give your name and phone number with the area code.
- If you do not hear from someone in 20 minutes, call back.

Your Transplant Coordinator (608) 265-5658

For questions, prescription refills or other problems, please call and ask for your coordinator by name Monday through Friday, 8am-4:30pm. Please reserve the “after business hours” calls for urgent calls only. Prescriptions will only be filled during business hours, so please keep close track of your medicines.

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 ©7/2017. University of Wisconsin Hospitals and Clinics Authority. All rights reserved. Produced by the Department of Nursing. HF#6679.