Lung Transplant Surgery

Congratulations! You have been added to the lung transplant waitlist at Northwestern Memorial Hospital.

If you have any questions, please ask any member of the transplant team.

This is an exciting and challenging time. An organ transplant can make a very positive change in your life. This handbook provides important information. It will help you know how to take care of yourself before and after your transplant. It describes:

- Your hospital stay
- Follow-up care after your surgery
- Returning to the routines of daily life

It is impossible to know when your transplant will happen. So it is very important to prepare yourself now for the surgery, the recovery, and care after a lung transplant.

Please review this handbook as often as you need to. Keep it as a reference. We want you to go home with the confidence to care for yourself.

We encourage you to write down your questions and bring them with you to clinic. We will be happy to answer them then, or you can call the transplant nurse coordinator at any time.

Remember, you are a very important part of the transplant team. Your well-being and the success of your transplant depends on your involvement during the entire transplant process. We are honored to be a part of your medical team.

Preparing for your transplant

Based on your transplant evaluation, your pulmonologist (lung physician) and transplant surgeon will decide whether you should receive 1 or 2 lungs. Some patients can be listed for both. Then the decision will be made at the time of the lung offer. This is discussed with you prior to being placed on the waitlist.

Lung allocation score (LAS)

The LAS was developed to ensure that all people on the transplant waitlist are judged fairly. It considers the “net benefit” of the patients listed. It looks at:

- How sick a patient is before transplant
- How well he or she will recover after the transplant
To be a good candidate, you must be physically and mentally ready for a transplant. Your LAS is based on clinical information about you and includes:

- Lab values
- Test results
- Disease diagnosis

These results are used to calculate a score ranging from 1 to 100. Those who have the most urgent need for a transplant have the highest score. They are given first priority when a donor organ becomes available. In other words, the sicker you are, the higher on the list you are placed. However, if you are too sick, you may lose points. We want you to have the best possible outcome and be able to recover from surgery.

**Organ allocation**

The United Network for Organ Sharing (UNOS) is responsible for transplant organ distribution in the United States. This includes many different organs including hearts, lungs, kidneys, livers and more.

UNOS uses a national database for organ distribution. The transplant team at Northwestern Memorial Hospital updates your information in UNOS as your condition changes. A lot of information goes into UNOS, including your:

- Age
- Sex
- Blood type
- Lung allocation score (LAS)

UNOS then uses this information to match you with a possible donor. Organs are offered to patients on the waitlist based on their LAS and time on the waitlist. In each blood group, the patient who will be called first has met the following criteria:

- The highest LAS
- A negative crossmatch with the donor tissue
- The longest wait time on the list

UNOS works closely with the regional Organ Procurement Organizations (OPOs). These OPOs help coordinate the donor and the recipient when placing an organ. At the time of transplant, your nurse coordinator will be in contact with the OPO coordinating the donation. The Gift of Hope (GOH) is the OPO in the greater Chicagoland area.

You will have blood samples drawn every 2 months while you are on the waitlist. The GOH uses your stored blood samples to make sure that your body will not reject your new organs right away. The test between donor tissues and your stored blood sample is called a crossmatch. The crossmatch must be negative for the lungs to be offered to you.

**Waiting time and other factors**

The length of time a patient is on the list is one of the last factors to be considered by the OPO. The only time waiting time will be used is when there are 2 candidates on the list who happen to have the exact same LAS and negative crossmatches.
If this happens, the candidate with the longest waiting time will get the lung offer first. Remember, a patient with a higher LAS will be called before you, no matter how long he or she has been waiting on the list.

It is hard to know how long you will wait for your transplant once you are listed. On average, candidates wait between 6 months and 3 years for a lung transplant. However, it is important to know that as soon as you are placed on the waitlist, you could get your transplant at any time.

Age also plays a role in when you will receive a lung transplant. Lungs from children and teenagers will be offered to children and teenage candidates first, before they are offered to adults.

**Lung sources**
The person giving the organs is known as the **donor**. The person receiving the new organ(s) is the **recipient**.

Lung transplants are always done from deceased donors who have had a fatal injury to the head (brain death). But their heart is still beating and carrying oxygen to the rest of the body. Therefore, the organs remain healthy and can be removed for transplantation.

Once a patient is determined to be brain dead, the OPO is contacted. They, in turn, discuss organ donation with the donor family. If the family agrees, a full medical and social health evaluation is done to make sure the organs are acceptable. Tests include:

- Chest X-ray
- Sputum culture
- Arterial blood gases (ABGs)

The donor is also tested for several diseases and infections, including hepatitis B, hepatitis C, HIV and cancer. If the patient has any of these diseases, he or she will be considered an increased-risk donor. The risks and benefits to transplanting these lungs will be discussed with you at the time of the transplant.

If the patient is an acceptable donor, the OPO will contact the United Network for Organ Sharing (UNOS) and match the donor to a recipient on the waitlist. The recipient is matched to the donor’s:

- Blood type
- Height
- Weight
- Age (if possible)

Organ donation is confidential. That means the transplant team at Northwestern Memorial Hospital will never provide you with any information about your donor.

However, we strongly encourage you to write an anonymous letter to your donor’s family. See Appendix B for more information.
Before your surgery

Planning ahead
To be ready for a lung transplant at any time, it is important to focus on 4 things:

Keep yourself healthy
Work with your physician and the rest of the transplant team to prevent your lung disease from getting worse. Some tips on keeping yourself healthy include:

- Take only your prescribed medicines.
- Be sure to talk to your physician before taking any other medicines, such as over-the-counter medicines, herbal supplements or vitamins.
- Keep up-to-date on your appointments and lab work.

Stay fit
We know that this might be hard for you. But it is very important that you be in good shape before surgery. Exercise regularly or as much as you can. Take part in pulmonary rehabilitation. This exercise program is designed just for patients with lung disease. You will learn special exercises that help you breathe and keep your body strong.

Review this booklet
Ask questions so you know what steps you need to take before and after surgery.

Set a plan
It is best to start thinking now about your surgery and life afterwards.

- Start to gather resources, such as family members and friends who can drive you to your appointments.
- Plan your travel route to the hospital so that you know where to go and how long it will take you.
- Keep a suitcase ready to go to the hospital.

The transplant team is here to help you. We will discuss specific plans with you along the way. Please contact us by phone if you ever have any questions or concerns.

Making the most of your waiting time

Short-term plans

- Make healthy choices.
- Put yourself on a schedule that allows for exercise and rest.
- Make sure it is easy to contact you by phone at all times.
- Call your transplant team contact as soon as there is a change in your health.
- Complete all tests, procedures and blood work as requested by your physician, transplant nurse coordinators and patient liaisons.

Every 6 months

- Have your teeth cleaned and checked. Your physician or dentist may want you to take antibiotics before and after your dental treatment, so check on this before your appointment.
**Long-term plans**

Arrange for your time away by planning for:

- An extended absence away from home, work and other scheduled activities
- Care for your children, pets and others who require care
- Household chores and housekeeping
- Mail pick-up
- Financial matters, such as paying your bills and banking

**Considering advance directives**

At Northwestern Memorial Hospital, we honor your right to make your healthcare wishes known.

The Illinois Power of Attorney Act was created so that you have a voice in your medical treatment even if you are unable to speak for yourself. The law allows you to complete a power of attorney for health care to designate someone to make healthcare decisions if you cannot.

It is easy to complete a power of attorney for health care:

- There is no cost.
- You do not need a lawyer.
- You can prepare it at home or at the hospital.

See Appendix A for more details.

**Finding support**

We have asked you to name 2 caregivers who will be able to take turns caring for you at home after your surgery. You should have one caregiver with you 24 hours a day, 7 days a week for the first 8 weeks after you are discharged.

Your support person can expect to help you with:

- **Transportation** – driving you to and from clinic appointments, testing procedures, pulmonary therapy and other places you may need to go
- **Medication assistance** – helping to keep up with your medication schedules, refilling prescriptions and helping with changes in dosing
- **Home health monitoring** – helping you measure and record your daily weights, blood pressures and spirometry

To assist, we ask that your support person:

- Attend at least one of your pre-transplant clinic appointments with you.
- Be present at our pre-transplant patient education session, which occurs before you are placed on the waiting list.
- Review the contents of this handbook.
- Know how to contact members of your transplant team.
While most patients will have a better quality of life and manage well after transplant, it can be a difficult course. You may feel depressed and worry about your health. You may feel anxious and even guilty about depending on others for help. It is important to have support systems at home and people to:

- Help you understand what is happening and what you need to do
- Allow you to share what you are feeling
- Arrange any treatment you might need

“The call”

The transplant team must know how to get in touch with you **24 hours a day, 7 days a week**. The transplant nurse coordinator will have to work quickly to find you when a lung becomes available. **It is essential that you are easy to reach.** Many people find that a cell phone makes them easiest to reach. An added help is a list of phone numbers where you can most often be reached and a list of contact people. This includes family members, friends, neighbors and their phone numbers.

Please give the transplant nurse coordinator or patient liaison a list of all of your phone numbers, and update them as needed, including:

- Home
- Work
- Cell phone
- Close family, friends and neighbors
- Places you frequently attend, such as school or place of worship

We suggest that you pay extra attention to your cell phone. Be sure that it is always fully charged and always on. If you think somebody from the transplant team was trying to reach you, please call the transplant office at 312.695.5864.

*Once you are offered an organ, your transplant team has an hour to accept or turn down the organ. If we cannot reach you or you are unable to have the transplant at that time, the next potential candidate will be offered the organ.*

The waiting time can be a time of hope, uncertainty and stress for you and your family. Keep yourself busy. You may want to join one of the transplant support groups to meet with others going through the same experience. The transplant social worker can help you with this.

**Preparing for surgery**

You will receive a phone call when a suitable donor has been found. The organ bank asks the transplant nurse coordinator to find you and verify that you are healthy and available for surgery. The transplant nurse coordinator will talk to you about the donor organs, including any special circumstances, so that you will have all the information you need to choose to accept or turn down the offered organ(s). This is known as informed consent. The physician will also join the call to answer any questions you may have.
If you choose not to accept the lung, you will not lose your place on the waitlist. We can only tell you our best estimate of your chances of getting another offer soon.

Once you get the call, you need to prepare for surgery. This means you must:

- Tell the transplant nurse coordinator right away if you are ill or having any new symptoms or problems.
- Tell the transplant nurse coordinator if you are taking any new medications.
- Stop eating and drinking because you could be going to surgery by the end of the day.

The transplant nurse coordinator will tell you how to prepare for the transplant. You may be told to come to the hospital right away or in several hours. This depends on how far away our team has to travel to get the lung(s). In most cases, our procurement team will go out to obtain the donor lung before you even arrive at the hospital. The organ is checked carefully to make sure it is suitable for transplant. While the donor’s lung is being checked, you will be in the hospital waiting for the results.

The stay in your pre-surgery room will more than likely be short, but it could take as long as 6 hours. An IV (into the vein) line will be placed in your arm or hand. During that time, you will have many tests such as:

- Blood tests
- EKG
- Chest X-ray

Members of the surgery team and the anesthesia team will come in and talk to you about what to expect before and after surgery.

Please know that up to 50 percent of the time, a person may be called in and admitted to the hospital only to find out that a potential lung or lungs are not suitable for transplant. Sometimes, we do not know this until the surgeon actually looks at the lung(s). These “dry runs” are frustrating for everyone, but we do not want to give you lungs that will not work well or that may contain an infection.

As soon as we know that the organ is suitable, you will be taken to surgery. The operating room (OR) will have a lot of equipment in it. This equipment is used to monitor your condition throughout the surgery.

Once the donor team calls the recipient team to let them know that the lung(s) will be suitable, your surgery will begin. This means that your surgery will begin before the donor lung(s) arrive(s) at Northwestern Memorial Hospital. However, a lung is not removed before a new one arrives. This happens because once a lung is removed from the donor, it needs to be transplanted within a certain period of time.
Your hospital stay

The transplant surgery
After you receive general anesthesia and fall asleep, the transplant team begins their work. The surgery will take several hours. The length of the procedure depends on:

- Your lung disease
- Previous chest surgeries
- Whether you are getting 1 lung or 2 lungs

You will be placed on a breathing machine (ventilator). Sometimes a heart and lung machine is needed. This machine does the job of your heart and lungs during surgery. You will be weaned off this machine slowly as your new lung(s) begin to work. Often this takes place in the OR, but sometimes we have to wait until you are in the intensive care unit.

Single lung transplant
For single lung transplant, the surgeon will make an incision on the side of your chest (thoracotomy). Your diseased lung will be removed and the donor lung will be placed (Figure 1).

Figure 1

There will be 3 connections (anastomoses) from you to the donor lung:

- First, the donor lung’s main airway (bronchus) is attached to your bronchus.
- Second, the donor pulmonary artery is attached to your pulmonary artery.
- Third, the donor’s pulmonary veins are attached to the left side of your heart where the oxygen-rich blood will pass from the heart to the rest of your body.

Once these connections are made and the lung is working well, your incision is closed with either surgical glue or staples.
Double lung transplant
For a double lung transplant, a “clam shell” incision will be made across your chest, right under your breasts (Figure 2).

Figure 2

If you have had chest surgery in the past, the surgeon may make 2 chest incisions – one on each side, just like in a single lung transplant.

Each lung is replaced separately, just like in a single lung transplant. Sometimes, we can complete the first lung transplant without using the heart and lung machine, but we will need to use it during the second lung transplant.

Once both lungs are replaced, your incision will be closed, just like in a single lung transplant. You will go straight to the Cardiothoracic Intensive Care Unit (CTICU) after surgery.

Family waiting area
There are two areas for your family to wait during your surgery. If your transplant occurs:

- During the day (7 am to 5 pm), your family will use the Surgery Family Waiting Area located on the 7th floor of the Feinberg Pavilion. Volunteers are available to answer any questions.
- At night (5 pm to 7 am), your family will be in the Intensive Care Unit (ICU) Family Waiting Area located on the 8th floor of the Feinberg Pavilion. This area is right next to the CTICU, allowing easy access to your room. Family members should register with the unit secretary, or the nurses’ station, when they get to the waiting area. Family members can decide to wait here regardless of the time of your transplant, if they would like.

The surgeon will come to the waiting room to talk to your family after the surgery.

After surgery
After surgery, once you are settled in your room in the CTICU, your family may visit. Visiting hours in the CTICU are limited and begin at 7 am and end at 9 pm. Only 2 family members are allowed in the room at one time. Please have your family talk with your nurse to coordinate visiting time, as there may be some times that are better than others.
Cardiothoracic Intensive Care Unit (CTICU)
You will not remember the first hours after the transplant. Gradually you will become more alert and responsive. You will feel weak, tired and sore after the surgery. The nursing staff will be at your bedside often to check on you and keep you comfortable. The nurses will ask you to do simple tasks, such as squeezing their fingers or moving your toes.

You will have many tubes and wires attached to your body (Figure 3).

Figure 3

A heart monitor will record your blood pressure, heart rate and heart rhythm.

An endotracheal (ET) tube in your throat is connected to a ventilation machine (vent) to help you breathe. You will remain on the vent and have the ET tube in place for about 1 to 2 days. This allows your lungs to rest and helps them heal.

There will be a thin, flexible tube inserted through your nose (nasogastric) or mouth (orogastric) into your stomach. It is used to provide needed medicine and fluids/nutrition.
A pulmonary artery (PA) catheter is an IV line inserted into a large vein in the neck. The end of this line has many ports or openings. One port is connected to the heart monitor and shows the pressures in your heart. Other ports are used for medicines and fluids. The PA line will stay in place for a few days.

An IV pump regulates the amount of IV fluids and medicines being given.

An arterial line (A-line) is a special IV tube that is placed in an artery and connected to the heart monitor. The A-line displays your blood pressure on the monitor. It also allows the nurses to draw your blood easily through a special port.

A pulse oximeter checks the oxygen levels in your blood. It is most often worn on the finger, but can be placed on other areas such as your toes or earlobes.

Chest tubes will drain air and fluid from around your lungs. These tubes are attached to a container to measure the amount of fluid draining, as well as to check for increased air around your lungs. There will be a lot of fluid the first few days after surgery. One by one, each tube will be removed as drainage slows down and your lungs begin to heal.

A urinary catheter or tube will drain urine from your bladder. The ET and the urinary catheter are often removed at the same time.

Sequential compression devices (SCDs) are cloth and plastic sleeves applied to the legs. They are attached to a machine that gently squeezes your calves. SCDs promote blood flow and help prevent blood clots from forming in your legs.

Once the ET tube is removed, your nurse will have you begin deep breathing and coughing exercises. You should take 10 deep breaths every hour while awake. Your nurse will show you how to do this and how to support your incision with a pillow when coughing. This, along with turning in bed, helps prevent mucus and fluid buildup in your lungs and avoid complications, such as pneumonia.

To be sure you are taking deep breaths, you will use an incentive spirometer (Figure 4).

To use the incentive spirometer correctly:

- Put the mouthpiece in your mouth and close your lips around the mouthpiece.
- Breathe in slowly and deeply as you watch the disc in the device rise toward the top of the column.
- Hold the disc at the top for 2 to 3 seconds and then breathe out slowly.

A respiratory therapist will be working with you several times a day. You will also learn to use other devices to help break up secretions and keep your new lungs as healthy as possible. The nurse will also keep a close eye on your pain level and will give you medicine as needed. At first, your pain medicine will be given through your IV. Later you will take pain medicine by mouth.
Good pain relief can help you become more active and speed your recovery. Let your nurses know how your pain medicine is working. Rate your pain on a scale of 0 to 10, with 0 meaning no pain and 10 being the worst pain. It is best to take medicine before pain becomes severe. Otherwise, it is more difficult to control.

Your expected stay in the CTICU is 1 to 3 days, but may be longer depending on your progress.

**Hospital and medical staff**

You will meet many members of the healthcare team during your hospital stay.

- Anesthesiologists and the critical care team will monitor your care during surgery and in the CTICU.
- Respiratory therapists help you with your breathing exercises and breathing treatments.
- Physical therapists and occupational therapists will help you increase your physical activity and strength. They will also help you to perform your activities of daily living more easily.
- Dietitians will work with you and the physicians to create the best diet for you – for your healing and for the long-term.
- Social workers assist you with your insurance needs and help you get ready for home.
- Staff nurses who are specially trained in transplantation will help you learn about your post-transplant care and medications.
- Patient care technicians assist staff nurses in meeting your daily care needs.
- Pharmacists will teach you about your medications and how to take them.
- Transplant nurse coordinators are important members of the care team. You will get to know them well during the entire transplant process – evaluation through post-hospital care. They will do the following:
  - Review your chart every day
  - Monitor your laboratory results
  - Assist you in obtaining your discharge medicines
  - Help plan your care with the medical staff
- The medical staff includes the transplant surgeons and pulmonologists (lung specialists). They work with the nurse practitioners as well as fellows, residents, interns and medical students to:
  - Monitor your progress
  - Develop a plan of care just for you
  - Change your plan of care based on your needs

**The step-down unit**

As you progress, you will be transferred to the step-down unit. Here you will:

- Continue to recover from your surgery
- Learn about your new medicines
- Get ready to take care of yourself at home
Each day you will get stronger and be able to increase your activities. When you are in bed, you will continue to wear your SCDs. You will be able to walk in the hall without help, but it is still very important to make sure someone is with you during your walks.

Continue to take your pain medication. To help prevent pain before it starts, many people find it helpful to take pain medicine before walking or before doing other activities that may trigger pain. Be sure to let your nurse know how well your pain medicine is working. Your chest tubes and other devices will begin to come out and this will help with the pain.

You will begin to learn about your new medicines. These medicines lower your body’s normal immune response, help your body accept the new organs and prevent rejection. The donated lungs will always retain their original identity. You will need to take anti-rejection medicines for the rest of your life. Failure to do so will always lead to rejection and organ failure. You will begin to take your anti-rejection medicines in pill form.

**Preventing infections**
Germs and infections can be passed from person to person at home or in the hospital. You will be at a greater risk for infection due to your anti-rejection medications.

It is very important that:
- Everyone who comes into your room washes their hands before entering. This is true for medical staff, family members and friends.
- Friends and family who are sick should not visit at all.
- You wear a mask whenever you leave your room.

Your expected stay in the step-down unit is 5 to 7 days but can change based on your progress.

**Preparing to go home**
Knowing what to do will ease your transition to home. The transplant team members are here to help you. We welcome your questions and those of your family.

Your nurse, therapists and transplant coordinator will review your discharge guidelines with you and your family including:
- Medicines
- Diet
- Activity
- Wound care
- When to call the physician
- Signs of infection and rejection
- Follow-up care and appointments
**Home health care**
Some patients require home health care after they are discharged.

If you need home health care, your social worker will set this up before you leave the hospital.

Home health agencies allow you to return home and back to your daily routine, but still receive some services offered in the hospital, such as:

- IV therapy
- Wound care
- Monitoring equipment

A representative from the home health agency may visit you while you are in the hospital. If you have any questions about home health care, you can ask your transplant nurse coordinator or the home health agency representative.

Some home health services will be needed later in your recovery as well. If you get an infection or have signs of rejection, your transplant physician may order IV antibiotics or steroids. These can be given by a home health nurse instead of having you come into the hospital. If this type of care is needed, your transplant nurse coordinator will discuss this with you at that time.

**Home monitoring/medical equipment**
To take care of yourself at home, you will need the following equipment. Be sure to have these on hand before you leave the hospital.

These items may be purchased at your local drug store:

- Weighing scale
- Blood pressure device
- Thermometer

You can also purchase a medical alert bracelet. It should indicate that you have had a lung transplant.

The transplant nurse coordinator will help you obtain a microspirometer and a nebulizer before you go home.

Be sure to take your incentive spirometer home with you.

The physical therapists and occupational therapists will work with you while you are in the hospital. You should be able to perform most activities of daily living by the time you go home. This includes:

- Bathing
- Dressing
- Walking and stair climbing

You will be given a sheet of exercises to do daily while at home. You will be asked to continue pulmonary rehabilitation. These 2 exercise routines will help you get stronger and resume daily routines.
Caring for yourself at home

After you are discharged, you will visit the transplant clinic frequently. Please call our team with any questions or concerns. You can reach us 24 hours a day, 7 days a week by calling 312.695.5864 or toll-free at 844.639.5864 (844.NEW.LUNG).

Wound care/bathing
You will have a large incision on your chest and several smaller incisions where your chest tubes were inserted. Any sutures at the tube sites need to remain in place for 2 to 3 weeks after the chest tubes were removed. They will be taken out at your first clinic visit with the surgeon.

Your incisions do not need a bandage. If there is some drainage, or if the area rubs against your clothes, you can apply a sterile gauze dressing or a Band-Aid®. To care for your incisions, follow these steps:

- Wash your hands before and after cleaning your incision.
- Clean the incision 2 times a day (morning and evening) with a mild soap and warm water.
- Gently pat dry. Do not use any lotions, oils or creams around the sites unless instructed.
- If you need a dressing for your incision, be sure to change it daily.
- Call the transplant nurse coordinator with any concerns or if there is any redness, swelling or new drainage.

You may shower even with the sutures still in place. But do not soak the wounds or take a tub bath for at least 1 month after surgery. You may want to get a chair for your shower as showering right after transplant can be tiring.

Activity
Be sure to do the exercises daily as instructed by your physical therapist. Also, continue with your pulmonary rehabilitation program.

For the first 6 weeks
- Do not drive.
- Do not do any abdominal exercises, such as sit-ups.
- Do not do any strenuous activity like vacuuming, household repairs or gardening.
- Sexual activity may be resumed, but be sure to avoid strain across your incision sites.

For the first 3 months
- Do not resume activities such as golf, bowling, tennis, jogging, swimming, skiing, rigorous cycling or contact sports.
- Do not mow or rake the lawn.
- Do not go scuba diving, hang-gliding, skydiving or mountain climbing.
- Do not lift anything heavier than 10 pounds (a gallon of milk weighs 8 pounds).
Tips for taking care of yourself at home

Health
At the same time each day, be sure to check and record your:
  ■ Blood pressure
  ■ Weight
  ■ Pulse
  ■ Temperature
  ■ Microspirometry reading

Use the health monitoring record (given at discharge) to record the readings. Remember to bring your health monitoring record with you to every clinic appointment.

These readings are extremely important. They help your transplant team watch for medication side effects, signs of rejection, and signs of infection. You should get into a daily routine. We suggest taking these measurements as soon as you wake up. But you can do them any time of day that feels right for you.

Call your transplant team if:
  ■ Your temperature is 1 degree F higher than it usually is.
  ■ Your blood pressure is higher than 160/100 mmHg or lower than 90/60 mmHg (unless otherwise instructed).
  ■ Your pulse is higher than 100 beats per minute or irregular (unless otherwise instructed).
  ■ You have an increase in weight of 2 pounds or more in 1 day, or 5 pounds in 1 week.
  ■ There is a decline of 10 percent or more in your microspirometer readings for 2 to 3 days.
  ■ You have any dizziness, unexpected weakness or fatigue, or swelling in your hands or feet.

Always notify your transplant physician or transplant nurse coordinator before you have any dental or surgical procedures. Let your dentist or surgeon know that you have had a lung transplant. You may need to take antibiotics before the procedure.

If you are taken to the emergency room or admitted to the hospital, please let us know right away. Be sure to let the physician at the admitting hospital know you have had a lung transplant, and ask him or her to call us at 844.639.5864 (844.NEW.LUNG) and ask for the transplant coordinator to be paged right away.

Clean and dress cuts and scrapes right away. Check for signs of infection a few times each day. Monitor for:
  ■ Redness
  ■ Warmth
  ■ Swelling
  ■ Drainage
  ■ Pain
Notify your transplant physician or transplant nurse coordinator if you have any of the following symptoms:

- Shortness of breath
- Fever
- Chills
- Cough
- Increased sputum
- Vomiting
- Diarrhea
- Unusual blisters, sores, growths or lumps

For the first 6 months after transplant, wear a mask whenever you return to the hospital or are on an inpatient unit.

**Beauty**

- Always wear a sunscreen of SPF 30 or greater when outside. You are at higher risk for skin cancer because of the anti-rejection medications. Never use a tanning bed.
- Never wear artificial fingernails or tips, as this increases your risk of fungal infections. You can wear nail polish.

**Lifestyle**

- Avoid crowds for the first 3 to 6 months after transplant. This is the time when you are at the greatest risk for infection. Stay away from places such as theaters, malls and restaurants, and avoid using public transportation.
- Avoid people who may be sick. This includes those with a cold or the flu.
- Be sure to wash all dishes in hot water. You may use the same dishes or linen used by family members.
- You may sleep in the same bed as your partner.
- Do not use humidifiers with standing water reservoirs.
- Do not change birdcage paper or cat litter.
- If you have pets, make sure they have all of their immunizations and are healthy. You may not have birds as pets after a transplant. Do not adopt or purchase any pets before talking to your transplant physician or transplant nurse coordinator.

**Outdoors**

- Avoid construction sites or buildings under construction. Be sure to wear a mask when walking by these places.
- Do not swim in lakes, ponds or stagnant bodies of water.
- You may swim in chlorinated pools after 6 weeks after surgery.
- Wear gloves when you are doing light gardening or handling dirt.
- Always wear shoes when walking outside.
- Wear a mask when you are outdoors on windy days.
Nutrition

Good nutrition plays an important role in your recovery after an organ transplant. Your meal plan should be well balanced and contain items from all food groups: milk, meat, fish, poultry, legumes, fruit, vegetables, cereals and grains. Feel free to discuss your meal plan with your dietitian if you have questions.

Protein

A high-protein diet:
- Aids wound healing and helps fight infections
- Replaces protein breakdown due to high doses of some medicines, such as prednisone

Complete proteins contain all of the essential amino acids that your body needs. Incomplete proteins are missing at least 1 of these amino acids (see chart below). If you choose foods that contain incomplete proteins, be sure to eat other protein-rich foods (either incomplete or complete) during the day.

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<tr>
<th>Protein Sources</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Complete Proteins</strong></td>
</tr>
<tr>
<td>Lean meats</td>
</tr>
<tr>
<td>Poultry</td>
</tr>
<tr>
<td>Fish</td>
</tr>
<tr>
<td>Eggs</td>
</tr>
<tr>
<td>Low-fat or nonfat dairy products</td>
</tr>
<tr>
<td><strong>Incomplete Proteins</strong></td>
</tr>
<tr>
<td>Dried peas</td>
</tr>
<tr>
<td>Soy products</td>
</tr>
<tr>
<td>Tofu</td>
</tr>
<tr>
<td>Nuts and nut butters</td>
</tr>
<tr>
<td>Seeds</td>
</tr>
</tbody>
</table>

Carbohydrates

Carbohydrates (CHOs) are the foods that we use for energy. While all foods may affect your blood sugar, carbohydrates may have the biggest impact. Your blood sugar is more likely to increase if you have diabetes, or are taking certain medications, such as Cyclosporine™, Tacrolimus™ or other steroids like prednisone.

A consistent carbohydrate diet can help control your blood sugar. This means that you eat the same amount of CHO at each meal. Here are some basic guidelines that will help you control your blood sugar.

Know your carbohydrates
Keep a close eye on portion sizes.
<table>
<thead>
<tr>
<th>Sources of 1 Serving of Carbohydrate</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Starches</strong></td>
</tr>
<tr>
<td>• 1 slice bread</td>
</tr>
<tr>
<td>• 1 tortilla (6-inch)</td>
</tr>
<tr>
<td>• 1/4 large bagel</td>
</tr>
<tr>
<td>• 1/2 hamburger/hot dog bun</td>
</tr>
<tr>
<td>• 3/4 cup ready-to-eat cereal</td>
</tr>
<tr>
<td>• 1/2 cup cooked cereal</td>
</tr>
<tr>
<td>• 1/3 cup pasta or rice (cooked)</td>
</tr>
<tr>
<td>• 4 to 6 small crackers</td>
</tr>
<tr>
<td>• 1/2 cup beans, peas, corn, potatoes, winter squash (cooked)</td>
</tr>
<tr>
<td>• 2 cups popcorn (popped)</td>
</tr>
<tr>
<td><strong>Fruit</strong></td>
</tr>
<tr>
<td>• 1 small fresh fruit</td>
</tr>
<tr>
<td>• 1/2 cup canned fruit</td>
</tr>
<tr>
<td>• 1/4 cup dried fruit</td>
</tr>
<tr>
<td>• 1 cup melon or berries</td>
</tr>
<tr>
<td>• 1/2 cup fruit juice</td>
</tr>
<tr>
<td><strong>Dairy products</strong></td>
</tr>
<tr>
<td>• 1 cup milk</td>
</tr>
<tr>
<td>• 1 cup soy milk</td>
</tr>
<tr>
<td>• 2/3 cup (6 ounces) fat-free yogurt with sugar-free sweetener</td>
</tr>
<tr>
<td><strong>Sweets and desserts</strong></td>
</tr>
<tr>
<td>• 2-inch square cake (unfrosted)</td>
</tr>
<tr>
<td>• 2 small cookies</td>
</tr>
<tr>
<td>• 1/2 cup ice cream or frozen yogurt</td>
</tr>
<tr>
<td>• 1/4 cup sherbet or sorbet</td>
</tr>
<tr>
<td>• 1 Tablespoon syrup, jelly, table sugar, honey</td>
</tr>
</tbody>
</table>

**Eat 3 meals a day**

- Plan to eat your meals at about the same time each day.
- Do not skip meals.
- Limit fruit to one serving per meal. Eat fresh or water-packed canned fruit (no syrup or sugar).
- Eat a variety of foods at each meal.

**Read food labels**

- Avoid foods with sugar, honey sucrose, dextrose or corn syrup listed as the first or second ingredient.
**Sodium (salt)**

A diet high in salt:
- Makes the body retain extra fluid
- Causes the heart to work harder
- Increases blood pressure

It is important to avoid excess salt after your transplant. Surgery and medications, such as prednisone, can cause you to retain sodium and water.

The “no added salt” diet is often prescribed. This means you:
- Limit salt when cooking.
- Avoid adding salt at the table.
- Stay away from salty foods.

A healthy diet should contain no more than 2,300 mg per day of sodium. Do not forget to read your food labels. Lower-sodium foods have no more than 140 mg of sodium when eating 1 serving.

<table>
<thead>
<tr>
<th>High-Salt Foods to Avoid</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Canned and dried soups</td>
</tr>
<tr>
<td>- Homemade soups where ingredients can be controlled are best</td>
</tr>
<tr>
<td>- Processed meats</td>
</tr>
<tr>
<td>- Ham, bacon, sausage, cold cuts, pepperoni, smoked meats</td>
</tr>
<tr>
<td>- Canned meats and cheeses</td>
</tr>
<tr>
<td>- Frozen packaged meals</td>
</tr>
<tr>
<td>- Onion/garlic/celery salt</td>
</tr>
<tr>
<td>- Pickled vegetables</td>
</tr>
<tr>
<td>- Canned vegetables</td>
</tr>
<tr>
<td>- Salted snacks</td>
</tr>
<tr>
<td>- Buttermilk</td>
</tr>
<tr>
<td>- Tomato and vegetable juices</td>
</tr>
</tbody>
</table>

**Fluids**

You are encouraged to drink adequate amounts of fluids following transplant. This can be hard if you were on fluid restrictions prior to transplant. A general goal is about 1.5 to 2 liters of water per day depending on your size. If you have questions about specific amounts, talk to your dietitian or physician.

**Calcium**

Calcium is needed to maintain healthy bones. Steroids interfere with your ability to absorb calcium. Eat foods high in calcium including nonfat or low-fat (1 percent) milk, milk products and cheese, or use calcium supplements. Your calcium intake from food and/or supplements should total 1,500 mg per day.

**Potassium, phosphorus and magnesium**

After transplant, you may have periods of:
- High or low levels of potassium
- Low levels of phosphorous and magnesium

Your physician will let you know if you need to increase or decrease potassium, phosphorus or magnesium in your diet. As needed, refer to the following food lists.
### Potassium

<table>
<thead>
<tr>
<th>Lower-Potassium Foods</th>
<th>Higher-Potassium Foods</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Some vegetables (bell peppers, cabbage,</td>
<td>• Some vegetables (potatoes, tomatoes, cooked broccoli, spinach, collard greens,</td>
</tr>
<tr>
<td>carrots, raw celery and onions, green beans,</td>
<td>sweet potatoes, winter squash)</td>
</tr>
<tr>
<td>lettuce)</td>
<td>• Some fruits (oranges, bananas, prunes, dried fruits, fresh apricots, kiwi, nectarines)</td>
</tr>
<tr>
<td>• Some fruits (apples, pears, peaches,</td>
<td>• Legumes (lentils, pinto beans, black-eyed peas)</td>
</tr>
<tr>
<td>watermelon, berries, grapes, pineapple,</td>
<td>• Milk, ice cream, yogurt</td>
</tr>
<tr>
<td>lemons, limes)</td>
<td>• Nuts, seeds, coconut, bran</td>
</tr>
<tr>
<td>• White rice</td>
<td></td>
</tr>
<tr>
<td>• White bread</td>
<td></td>
</tr>
<tr>
<td>• White pasta</td>
<td></td>
</tr>
<tr>
<td>• Cooked rice and wheat cereals</td>
<td></td>
</tr>
<tr>
<td>• Rice milk</td>
<td></td>
</tr>
</tbody>
</table>

### Phosphorus

<table>
<thead>
<tr>
<th>Lower-Phosphorus Foods</th>
<th>Higher-Phosphorus Foods</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Fresh fruits and vegetables</td>
<td>• Liver, bologna, hot dogs, organ meats</td>
</tr>
<tr>
<td>• Corn and rice cereals</td>
<td>• Canned salmon or herring, sardines, oysters</td>
</tr>
<tr>
<td>• Rice milk (not enriched)</td>
<td>• Dairy</td>
</tr>
<tr>
<td>• Breads</td>
<td>• Colas</td>
</tr>
<tr>
<td>• Pasta</td>
<td>• Beans, lentils, nuts</td>
</tr>
<tr>
<td>• Rice</td>
<td>• Bran</td>
</tr>
</tbody>
</table>

### Higher-Magnesium Foods

- Dark green leafy vegetables, potatoes, okra, tomato products
- Nuts, seeds
- Legumes
- Soy milk

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**Maintaining a healthy weight**

Some post-transplant medicines may cause you to gain weight. Here are some tips to maintaining a healthy weight:

- **Limit snacking.** If you are feeling hungry between meals, choose low-fat and lower-calorie foods such as vegetables, fruits and fat-free yogurt.

- **Monitor portion sizes.** Start by using a smaller plate. Fill half your plate with colorful vegetables and the rest with whole grains and lean proteins.

- **Limit sweets.** Avoiding calorie-dense desserts, juices and soda can help you reach and maintain a healthy weight.
Stay active. Start slowly, and ask friends and family to join you.

Reduce fat intake and choose healthy fats. Healthy fats include vegetable oils, unsalted nuts and seeds, and avocados.

Keeping your heart healthy
Some of your medicine may also increase your cholesterol and triglyceride levels. A heart-healthy diet will help prevent heart disease.

- Read food labels carefully to avoid foods that are high in saturated fat and cholesterol.
- Bake, broil, steam or boil foods.
- Choose fish, chicken, turkey and lean meats. Remove the skin and visible fat from meats before cooking.
- Try using dried beans, peas and lentils instead of meat as a protein source.
- Choose nonfat or low-fat (1 percent) milk, yogurt and cottage cheese.
- Choose cheese made from skim milk, but limit cheese intake due to the high sodium content.
- Increase fresh fruits and vegetables in your diet. Avoid adding sauces.
- Choose whole grain breads, cereals, pasta and brown rice.
- Choose vegetable oils and tub margarine without trans fats.
- Include healthy fats in your diet like vegetable oils, unsalted nuts and seeds, and avocados. Monitor serving sizes, as these healthy fats are high in calories.

Patients who need to gain weight after transplant
Some patients lose an excessive amount of weight during the transplant process.

Below are some tips for healthy ways to gain weight.

- Eat more often. Choose to eat 5 to 6 small meals per day.
- Set a reminder to eat every 2 to 3 hours. Use friends or family to help you remember.
- When you are cooking a meal, make extra! Use leftovers as a quick and easy snack.
- Keep high-calorie and high-protein snacks on hand at home, such as:
  - Peanut butter and banana sandwich
  - Pita and hummus
  - Bagel and cream cheese
  - Tortilla, beans and cheese
- Include liquid supplements like Ensure™, Boost™ or Carnation Instant Breakfast™ as needed. Choose the “plus” versions of these products for added calories.

Food safety
Food safety is an important part of your care. Your anti-rejection medicines put you at a greater risk for infection. The following guidelines will help you avoid foods that are more likely to contain infection-causing organisms.
**Food handling**

- Wash your hands with warm, soapy water for 20 seconds before and after preparing food, and before eating. Dry hands thoroughly with a clean, dry towel. Disposable paper towels are a good option.
- Choose fresh fruits and vegetables that can be washed and peeled when eaten raw. Wash fresh fruits and vegetables thoroughly under running water before peeling or cutting. Use a clean vegetable scrubber. Do not wash produce with soaps, detergents or chlorine bleach solutions.
- Do not purchase produce that has been cut at the grocery store.
- When you are at the grocery store, keep raw meat separate from all other foods. At home, keep raw meat at the bottom of the refrigerator.
- Keep hot foods hot and cold foods cold. Refrigerate leftover foods within 1 hour.
- Thaw meat, fish or poultry in the microwave or refrigerator in a dish to catch drips. Do not thaw at room temperature. Use defrosted foods right away and do not refreeze them.
- Put perishable foods in refrigerator within 1 hour of serving. Egg-, cream- or mayonnaise-based foods should not be left unrefrigerated for more than 1 hour.
- Never place cooked food back on the same plate that previously held raw food.
- Always marinate foods in the refrigerator. Sauce that is used to marinate raw meat should not be used on cooked foods.

**Cooking**

- Never eat undercooked eggs, raw meat or raw seafood such as sushi.
- Be sure to cook meat, poultry, eggs and seafood thoroughly. Use a meat thermometer.

<table>
<thead>
<tr>
<th>Minimum Internal Temperature</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Ground turkey or chicken</td>
<td>165°</td>
</tr>
<tr>
<td>Fresh or ground beef, veal or lamb</td>
<td>160°</td>
</tr>
<tr>
<td>Whole chicken, turkey, duck or goose</td>
<td>165°</td>
</tr>
<tr>
<td>Fresh pork</td>
<td>145°</td>
</tr>
<tr>
<td>Egg dishes</td>
<td>160°</td>
</tr>
<tr>
<td>Leftovers and casseroles</td>
<td>165°</td>
</tr>
</tbody>
</table>
Foods to avoid

<table>
<thead>
<tr>
<th>Dairy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unpasteurized milk, cheese and other dairy products</td>
</tr>
<tr>
<td>Aged cheeses made with raw or unpasteurized milk</td>
</tr>
<tr>
<td>Cheeses from deli unless contained in a cooked dish</td>
</tr>
<tr>
<td>Blue cheese, including Roquefort, Gorgonzola and Stilton</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Meats</th>
</tr>
</thead>
<tbody>
<tr>
<td>Raw or undercooked meat, fish, poultry, eggs and egg substitute</td>
</tr>
<tr>
<td>Cold smoked fish (salmon), lox and pickled fish unless contained in a cooked dish</td>
</tr>
<tr>
<td>Packaged deli meats or cold cuts from a delicatessen unless heated until steaming</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Fruits and Vegetables</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unwashed raw fruits and vegetables</td>
</tr>
<tr>
<td>Raw fruits and vegetables when eating out</td>
</tr>
<tr>
<td>Salad bars or pre-cut salad ingredients sold in the store</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Beverages</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unpasteurized fruit/vegetable juices unless homemade with well-washed fruits/vegetables</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Miscellaneous</th>
</tr>
</thead>
<tbody>
<tr>
<td>Raw honey</td>
</tr>
<tr>
<td>Raw, uncooked brewer’s yeast</td>
</tr>
<tr>
<td>All moldy and outdated food products</td>
</tr>
<tr>
<td>Raw tempeh and miso products</td>
</tr>
<tr>
<td>Buffets and street vendors</td>
</tr>
</tbody>
</table>

Nutritional side effects of transplant medications

Medications used to prevent rejection of your new organ are the main reason diet changes are needed after a transplant. Following is a list of commonly used medicines and some of their side effects that may impact your nutrition. For specific questions about your medicines, always talk with your physician and pharmacist.

With transplant medications, it is recommended to avoid grapefruit and grapefruit juice.

Steroids (prednisone)

- Impaired wound healing
- Increased blood glucose with post-transplant diabetes
- Increased fluid retention possibly causing high blood pressure
- Increased cholesterol and triglyceride levels
- Increased appetite leading to weight gain
- Osteoporosis
**Tacrolimus (Prograf™)**
- Increased blood pressure
- Increased blood potassium levels
- Decreased blood magnesium levels
- Possible nausea, vomiting and diarrhea
- Increased blood glucose levels
- Decreased appetite

**Mycophenolate sodium (Myfortic™) or mycophenolate mofetil (Cellcept™)**
- Nausea, vomiting and diarrhea

**Sirolimus (Rapamune™)**
- Increased blood glucose levels
- Possible nausea, vomiting and diarrhea
- Increased blood lipids levels
- Impaired wound healing

**Cyclosporine**
- Possible nausea, vomiting and diarrhea
- Increased blood potassium levels
- Increased blood glucose and lipid levels
- Decreased blood magnesium levels
- Increased blood pressure

**Follow-up care (appointments and testing after transplant)**

**Clinic visits**
You will be given a calendar with your transplant clinic appointments. Keep this calendar in your transplant binder.

For the first few weeks after discharge, you will be seen frequently in the clinic. Over time, your visits will be less often. It is important that you arrange for transportation to these clinic visits until you can start driving again. You should plan to be in the clinic for 1 to 3 hours. It is also helpful to have your support person with you.

To get the most out of each clinic visit, remember to do the following:
- Keep all appointments and show up on time.
- Call the clinic as soon as possible if you need to reschedule an appointment.
- Have your blood work done as instructed by your transplant nurse coordinator.
- Bring all of your medications, medication lists and your transplant binder with you to every appointment.
- Write down any questions you may have and bring them to clinic.
- Confirm your next appointment date and any tests you may need before you leave clinic that day.
Parking is available for patients and visitors in the garage at 222 East Huron Street, across from the Feinberg and Galter pavilions. For discounted rates, please bring your parking ticket with you. Tickets can be validated at the customer service desks on the 1st and 2nd floor of the Feinberg and Galter pavilions and the 1st floor of Prentice.

Worcester House guest rooms are for patients of Northwestern Memorial Hospital and their family members. To make a reservation, guests need to have a current appointment or a family member staying at the hospital. Reservations can be made for a maximum of 7 nights. If rooms are available, extensions can be made for up to an added 7 nights. For reservations, call 312.926.2566.

You will have several tests done before coming to the clinic. We will help you schedule a chest X-ray, lab work and spirometry reading if it is necessary. It is very important that you get these tests done before coming to clinic so that we can discuss the results with you.

During your clinic visit, you will have a brief exam. You will meet with your transplant nurse coordinator, nurse practitioner and the physician. We will talk about how you are feeling and go over your test results. There will be plenty of time to ask the physicians and transplant nurses any questions that you may have.

We are concerned with your whole health—not just the health of your new lungs. Share with us any questions or concerns. Your support person can be with you in the exam room.

**Note:** If you are having your lab work done, do not to take your tacrolimus until after you have had your labs drawn.

**Outpatient testing**
Along with your clinic visits, you will have frequent testing done to check how your new lungs are working. We will schedule these tests for you. Be sure that you follow any testing guidelines and keep these appointments.

Write all of your appointments on the calendar in your transplant binder. If you are unsure or have questions about your appointments, contact your transplant nurse coordinator.

**Blood work**—done before every clinic visit and on an as-needed basis:
- Tacrolimus levels test the amount of anti-rejection medication in your system
- Kidney functions tests, including blood urea nitrogen (BUN) and creatinine levels
- Blood sugar (glucose) test

If you are getting your blood drawn at Northwestern Memorial Hospital, please check in at the Outpatient Diagnostic Center on the 2nd floor of the Arkes Pavilion. Your blood work orders should be in the computer system.
To properly monitor the levels of certain drugs in your blood, we need to make sure that we draw blood when the drug levels will be at the lowest (trough) level. Please do not take your tacrolimus on the morning of your blood work. Instead, bring your tacrolimus with you and take it right after your blood is drawn. This is very important because we adjust your medication dose based on this level.

**Bronchoscopy** – done to check for infection, rejection and your airway suture line. Post-transplant, you will have a bronchoscopy at your:

- 1-month visit
- 3-month visit
- 6-month visit
- 9-month visit
- 12-month visit
- 18-month visit

A bronchoscopy may be done more often if your spirometry reading or other tests are showing signs of rejection.

During the exam, a thin, flexible tube is inserted into the throat to the lungs. It allows the physician to view the:

- Airways to the lungs
- Inside of the lungs

If needed, a small tissue sample (biopsy) may be taken. The exam itself takes about 15 to 30 minutes. Since medicine is given to relax you:

- Your visit will last about 4 to 5 hours.
- You will need a responsible adult to take you home.

It is very important that you remember the following for your bronchoscopy:

- Please report to Same Day Surgery on the day of your appointment, located on the 5th floor of the Galter Pavilion.
- Do not eat or drink anything after midnight the night before.
- Discuss with your coordinator whether to take your medications before your bronchoscopy—this depends on the scheduled time of your bronchoscopy.

We will provide more details about the test and how you should prepare for it.

**Spirometry** – also known as pulmonary (lung) function testing. This is done before every visit. It is a group of tests that check your lung function, such as:

- How easily the air moves in and out of the lungs
- The amount of air your lungs can hold
- How much oxygen the lungs send to the heart

We monitor your lung function very closely to look for signs of rejection. You also help by measuring your own breathing function every day with your microspirometer. If you notice a decrease in your readings, call your transplant nurse coordinator right away.
Chest X-ray – done to identify any changes in the lungs. We get a chest X-ray at every appointment to check for healing or any problems.

Computed tomography (CT) scan – sometimes referred to as a CAT scan. This is a special way of looking inside your body. The images produced are cross-sectional planes taken from a part of your body, much like slices taken out of a loaf of bread. A CT of the chest is done to check for disease, blood clots and cancer. It can also tell us if there is any rejection.

Other possible tests – see Appendix C.

Managing complications

Rejection
A major concern after transplant surgery is the risk of organ rejection. Rejection happens when your body stops accepting your new organ. When this occurs, your immune system attacks your new lung, as if it does not belong in your body. This triggers your body to make white blood cells (WBCs) and antibodies that can:
- Damage the new lung
- Limit how well the lung works

Signs of rejection
It is important to watch for signs of rejection:
- Fever – any temperature above 100 degrees F
- Shortness of breath – any difficulty or change in breathing pattern with rest or with exercise
- Fatigue – more tired than usual or lack of energy
- Loss of appetite – no interest in food or not wanting to eat
- Decrease in home spirometry readings – a decrease of greater than 10 percent that lasts for 2 to 3 days or more
- Decrease in ability to perform home exercises

If you notice any of these signs, you must call the transplant clinic right away. This allows treatment to begin quickly to help you have the best outcome.

Many times:
- Rejection can be detected only by biopsy
- Patients will not have symptoms at all

Thanks to recent advances in anti-rejection medications, patients today have a lower chance of rejection and infection following lung transplant than they did a few years ago. Even with these advances, rejection does occur.

There are several types of rejection.
**Hyperacute rejection**  
Hyperacute rejection is very rare in lung transplant and is a type of *humoral rejection*. It occurs when the organ recipient has antibodies against the donor organ. It results in immediate rejection of the organ. It is a life-threatening medical emergency.

We prevent hyperacute rejection by testing your blood for possible donor antibodies before placing you on the waitlist. This test is called an HLA matching and is done every 2 months while you are waiting for an organ.

**Acute Rejection**  
Acute rejection is the most common in lung transplantation. Almost every patient will have at least one episode of rejection within the first year after transplant. Since acute rejection is so common, you should prepare for an episode of rejection—but do not fear it. More than 95 percent of acute rejections can be successfully treated and reversed.

Sometimes you will note signs and symptoms right away. But often it takes a lung biopsy to detect acute rejection. This biopsy is done during a bronchoscopy.

The earlier acute rejection is treated, the better the chances of reversal. You can help us identify acute rejection early by:
- Measuring your spirometry daily. Call your transplant nurse coordinator with a decrease in the numbers of 10 percent or greater for 2 to 3 days.
- Calling your transplant nurse coordinator if you feel more tired than normal, or have increasing shortness of breath or fever.
- Keeping your bronchoscopy appointments.

Treatment of an acute rejection depends on the severity of the rejection. Sometimes, your transplant team will:
- Adjust your anti-rejection medications.
- Need to use more aggressive treatment, such as IV steroids. This may require a hospital stay.

While acute rejection is treatable, it is important to know that each episode does damage your lungs. The best way to avoid rejection is to take your medications as prescribed and to get your labs drawn regularly.

Most often, acute rejection occurs within the first year after transplant. If it occurs after the first year, the most common reason is non-compliance with medications. That is why it is important to **never** stop taking your medications unless your transplant physician or nurse coordinator tells you to do so.

> **Because the donated lung always retains its original identity, you will need to take anti-rejection medicines for the rest of your life. Not taking these medicines will always lead to rejection and failure of your new lung(s).**
**Chronic rejection**
The last type of rejection, chronic rejection, may become a problem months to years after your transplant. Chronic rejection is also called *bronchiolitis obliterans syndrome (BOS)*. This type of rejection develops slowly over months or years, and leads to scarring of the lungs. This causes the lungs to wear out and not work properly.

Chronic rejection is why some patients have lung transplants that work well for many years, but have a decrease in lung function.

The causes of chronic rejection are not well understood. We do know that:
- Patients who have several episodes of acute rejection are more likely to develop chronic rejection.
- The types of medications used to treat rejection may play a role in chronic rejection.

Physicians and researchers at Northwestern Memorial Hospital are working hard to understand the causes of chronic rejection.

Treatment for chronic rejection may be the same as for acute rejection. Sometimes you may also need to take IV antibiotics. Another treatment is called *photopheresis*. This is similar to dialysis, in which your blood is drawn out of your body and run through a machine. The machine treats your blood with special light beams to help prevent your cells from attacking your lungs.

If severe chronic rejection persists despite treatment, your physician will talk with you about the option for another lung transplant.

**Infection**
WBCs help your body fight infection. Anti-rejection medicines limit the action of WBCs, which puts you at an increased risk for infection. This risk is the greatest during the first 3 months after transplant when your dose of anti-rejection medicine is high. To help prevent infections during this time, your transplant physician will prescribe anti-viral medications, antibiotics and other medicines to help fight off infections.

Following is a description of the most common infections seen in patients after lung transplant.

**Cytomegalovirus (CMV)**
CMV is a virus that affects about half of the world’s population. Most people who are infected are carriers of the virus but do not have any symptoms. In patients with a suppressed immune system, the virus reactivates and can cause symptoms.

In patients who have had transplants, these problems can include:
- CMV pneumonia
- CMV hepatitis
- CMV GI (gastrointestinal) disease
Signs of CMV are:
- General weakness
- Decrease in spirometry readings
- Cough or shortness of breath
- Nausea and vomiting
- Fever
- Retinitis (inflamed retina of the eye)

CMV is treated with an anti-viral drug called Valtrex™ or Valcyte™. You will take this drug for 3 months, up to 1 year after your transplant.

To help prevent CMV, you will be tested for it before you are listed for transplant. Once we know your CMV “status,” we will seek to match you with a donor who has the same “status” as you. Based on the need for transplant, sometimes patients who are CMV-negative receive CMV-positive lungs.

**Fungal infections**
There are many types of fungal infections. The most common of these seen in transplant are candidiasis and aspergillosis.

To prevent these types of infections, you will take 2 anti-fungal medicines for up to 6 months post-transplant: voriconazole and amphotericin-B. Voriconazole is a pill that is taken daily. Amphotericin is taken twice a day via a breathing treatment (nebulizer).

**Bacterial infections**
There are many types of bacterial infections common in lung transplant. It is important that you contact your transplant nurse coordinator if you feel like you may be getting sick. You may need an antibiotic.

It is best to prevent bacterial infections before they start. You can help avoid a bacterial infection by doing the following:
- Use food safety guidelines (see page 23).
- Avoid crowds for the first few months.
- Practice good hand washing and hygiene.
- Wear a mask in public places.

You are at higher risk of getting a bacterial infection in the hospital. We try to keep your hospital stay as short as possible. You can help do this by staying motivated after your transplant.

**Protozoal infections**
The most common protozoal infection seen in transplant is pneumocystic pneumonia. To prevent this, you will be on an antibiotic called Bactrim for the rest of your life. It is important to never stop taking Bactrim, unless your transplant team tells you to do so.
**Risks of cancer, diabetes and osteoporosis**

Anti-rejection medications cause many side effects, including an increased risk of cancer. Skin cancer is the most common type in patients after transplant. Be sure to:

- Wear a sunscreen of SPF 30 or higher.
- See a dermatologist (skin specialist) every year so that any skin problems can be treated early.

There is also a small risk that you may develop a type of lymphoma (cancer of the lymph nodes). This type of lymphoma is often referred to as post-transplant lymphoproliferative disease (PTLD). This can occur months or years after transplant. Patients who need prolonged high doses of anti-rejection medications are at the greatest risk.

Another risk factor for PTLD is an infection called Epstein-Barr virus (EBV). EBV is more commonly known as mononucleosis (mono). About 9 out of 10 people have been infected with mono in their lives and, therefore, it is not a concern after transplant. However, if you have not been infected by EBV and you receive an EBV positive lung, your risk of getting PTLD is greatly increased. Therefore, EBV negative patients rarely receive EBV positive lungs.

PTLD is often treated by decreasing the dose of anti-rejection medications. If this does not work, chemotherapy may be an option. Your transplant team will monitor for PTLD after your transplant and discuss treatment options if it should occur.

Other health problems may occur after transplant.

- **Diabetes:** Anti-rejection medicines increase your blood sugar (glucose) levels, which can cause type 2 diabetes. You will see an endocrinologist (diabetes specialist) to help control high blood glucose. Regular exercise and a healthy weight can help control and prevent type 2 diabetes. However, medication may be needed.

- **Osteoporosis (bone loss):** We will check your bone density before transplant and may prescribe calcium and vitamin D supplements. This will continue after transplant. You will also need to get a DEXA scan (described in Appendix C) every year to check your bone density.

**Northwestern Medicine – Health Information Resources**

For more information, contact Northwestern Memorial Hospital’s Alberto Culver Health Learning Center (HLC) at hlc@nm.org, or by calling 312.926.5465. Health information professionals can help you find the information you need and provide you with personal support at no charge.

For more information about Northwestern Medicine, please visit our website at nm.org.
Appendix A: Power of Attorney for Health Care

A power of attorney for health care is a document that allows you to name a person who will act as your “agent.” Your agent can make decisions about medical treatment for you if you are unable to do so. You can also name one or more “successor” agents to step in if your agent is unavailable. Your agent must:

- Be at least 18 years old
- Be willing to assume this responsibility
- Know you well
- Be trusted to carry out your wishes
- Be able to remain calm in the stress of a medical crisis
- Not be a member of your medical care team

What is my agent’s role in making healthcare decisions for me?

- You may give your agent all the powers that you would normally have and the power to consent to, or refuse, any type of health care.
- You can place limitations on your agent’s power or can give your agent specific rules to follow.

The standard form of the power of attorney for health care contains blanks for you to fill in, if you choose, with instructions for your agent. It also contains 3 statements about life-sustaining treatment. You can select the statement that is closest to your own intentions or you can write your own. If you decide to write your own, we recommend you discuss it with your physician to be sure that it reflects your own medical situation.

How do I prepare a power of attorney for health care?

While you are a patient, the hospital staff can assist you in completing the power of attorney for health care. In the hospital’s Alberto Culver Health Learning Center, you can find educational videos and other resources about advance directives.

What do I do with the power of attorney for health care when I complete it?

Give copies to your primary care physician, your hospital physician, and close family members or friends. If you are admitted to the hospital, we will scan the documents into your electronic medical record so they are available to the clinical team. We encourage you to talk with your physicians, family and friends about how you want to be cared for if you can no longer speak for yourself. It is especially important to discuss the kind of treatment you would like to receive if you have a terminal condition or are unable to make your own decisions for an extended period of time. We also encourage you to talk to a trusted physician who knows you well as you think about these issues.

If you complete a power of attorney for health care and later change your mind, you can revoke the document by tearing it up or stating that it is being revoked. Each time you are admitted to the hospital, we will ask you if we have the most current copy.
**What happens if I do not specify a decision maker?**

If you decide not to designate an agent and if you cannot make your own decisions, under Illinois law, a limited range of healthcare decisions will be made by your legal “surrogate,” in this order of priority:

1. Court-appointed guardian (if any)
2. Spouse
3. Adult child
4. Parent
5. Adult brother or sister
6. Adult grandchild
7. Close friend
8. Court-appointed guardian of the estate

If more than one family member is in the same category, the majority must make the decision. For example, if there are 3 adult children, at least 2 must agree. In making healthcare decisions, the family members or friends must try to come to the same decision that the patient would have. However, a surrogate under Illinois law does not have the same authority or decision-making power that an agent has under the power of attorney for health care.

We recommend that everyone complete a power of attorney for health care to be sure that your wishes will be followed.

**Hospital resources**

We encourage you to discuss any questions about your care and treatment with your personal physician and the other physicians, nurses and caregivers who care for you during your hospital stay. The following individuals also are on staff at Northwestern Memorial Hospital and available to assist:

- Chaplains
  312.926.2028

- Patient representatives
  312.926.3112

**For more information:**

- Alberto Culver Health Learning Center
  Northwestern Memorial Hospital
  Galter Pavilion, 3rd Floor
  312.926.5465

- Northwestern Memorial Hospital
  www.nm.org/patients-and-visitors/patient-rights-website-policies
  Go to the “Advance Directives” page for more information.
Appendix B: Writing to the Donor Family

Many donor families have said that a message from the recipient has offered them comfort. Sometimes, donor families respond with personal information about the patient or about themselves. If you would like to write to your donor family, please contact your transplant nurse coordinator.

Tips for writing to your donor family

- Use only first names for yourself and others you may talk about in the letter.
- Include your family situation, such as marital status and whether you have children or grandchildren.
- Be sensitive about religious comments, as your donor family’s religion is unknown.
- Talk about your transplant experience.
- Explain what has happened in your life since the transplant, such as celebrating another birthday, getting married or becoming a grandparent.
Appendix C: Follow-up Testing

Your nurse coordinator will provide more detailed information about any of the tests that are ordered for you.

**Bone mineral density** or **DEXA** is a scan that can detect early bone mineral loss, such as calcium. This mineral loss may lead to osteoporosis. The exam is done in the Nuclear Medicine Department and will take about 30 minutes.

**Cardiac catheterization (cath)** is an X-ray exam of the heart and its arteries. It looks at how well the heart works. The test helps detect the area and extent of any artery blockage or narrowing. During the exam, a thin catheter (tube) will be inserted in the femoral artery (in the groin) and slowly passed to the heart. Dye (contrast) will be injected and X-rays will be taken. The contrast will allow the blood vessels to be seen. The exam will last 1 to 2 hours.

**Colonoscopy** is an exam used to detect disease of the lower digestive tract for early signs of colon and rectal cancer. This includes polyps, which can develop into cancer. It also is helpful in finding the cause of diarrhea, bleeding or changes in bowel habits.

The test takes about 30 minutes. During the exam, a small, flexible tube will be inserted into the rectum and to the colon. A tiny video camera with a light is at the end of the tube. This test may be more helpful than X-rays alone since the physician may:

- Directly view the area
- Remove polyps
- Take a small tissue sample (biopsy)

**2-D echocardiogram** is a test that uses high-frequency sound waves (ultrasound) to look at how the various parts of the heart work.

**6-minute walk test** looks at how far and fast you can walk before becoming short of breath. Your oxygen level and heart rate will be checked before you begin to walk, and then again after 6 minutes of walking. This test will be done in the clinic.

**Upper endoscopy** (EGD, gastroscopy or esophagogastro-duodenoscopy) is an exam that can detect diseases of the esophagus, stomach and duodenum (top part of the small intestine). An EGD is used to find the cause of:

- Persistent nausea or vomiting
- Heartburn or stomach pain
- Ulcers or bleeding
- Swallowing problems

The test takes about 15 to 30 minutes. During the exam, a small, flexible tube will be inserted into the mouth, down the throat, and into the stomach and duodenum. At the end of the tube (endoscope) is a tiny video camera with a light.
This exam may be more helpful than X-rays alone since the physician may do the following:

- View the area
- Take a small tissue sample (biopsy)

**Quantitative VQ scan/lung scan ventilation and perfusion** is a scan that shows air moving in and out of the lungs, and the flow of blood in the smallest blood vessels in the lungs. This test helps identify blood flow blockages within the lung. The exam, done in the Nuclear Medicine Department, takes about 1 1/2 hours. The amount of radiation used in this test is small and not harmful.