

Lung Transplant: After-Hospital Care

The following provides helpful information to assist you as you recover from lung transplant surgery. Be sure to follow any added guidelines provided by your physician or nurse.

If you have any questions, ask your physician or nurse.

Contact information

You may contact us 24 hours a day, 7 days a week.

- During business hours (8 am to 5 pm Monday through Friday), please call the transplant office at 312.695.5864.
- For urgent issues during non-business hours, please call 844.639.5864 (844.NEW.LUNG) and ask for the “lung transplant coordinator on call.”
- If unable to reach anyone at the above numbers listed, please call the Northwestern Memorial Hospital operator at 312.926.2000 and ask to have the “lung transplant coordinator on call” paged with your name and contact information.

When to call the physician

Call your physician or transplant nurse coordinator if you notice any of the following:

- Fever greater than 100.4 degrees F (call the coordinator before taking any medicine to reduce the fever)
- New cough or change in sputum color
- Flu-like symptoms, such as fatigue, muscle aches, chills or sore throat
- Bleeding or bruising from any site
- Ankle swelling
- Feeling dizzy, tired or “just not right”
- Feeling like you did before you had your transplant
- Any wound or area of swelling, redness, discharge or warmth to touch.
- Burning when you urinate
- Nausea, vomiting, constipation or diarrhea (this may decrease the effect of your immunosuppressive medicines)
- Weight gain of more than 2 pounds in 1 day or 5 pounds in a week
- Headaches

Call 911 or go to the nearest emergency room if you have:

- Shortness of breath
- Chest pain

Activity

For the first 6 weeks

It is important to protect yourself from infections and illnesses.

- Avoid public places. Wear a mask if you are unable to avoid a crowded area.
- It is OK to be around children unless they are sick or have just received a live vaccine. If you are unsure whether it is a live vaccine, please call your transplant nurse coordinator.
- Avoid people with illnesses, such as colds, flu, cough or chickenpox. If you have been exposed to someone who was sick, please notify your transplant team.
- Avoid anyone who has received a live vaccination for at least 1 week.
- Do not change diapers or cat litter.

You may gradually increase your activity. Rest if you get tired. Avoid moderate to heavy activity until you talk with your physician.

- Do not drive.
- Do not perform any abdominal exercises, such as sit-ups.
- Avoid heavy household activities, such as vacuuming, laundry, home repairs and yardwork.
- 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).
- Always wear a mask when in the hospital or around sick people.
- Do not travel out of the state without discussing with your transplant team.

Keeping you healthy

When your physician feels it is safe to do so, you may resume your daily activities. It is important to take certain precautions to protect yourself from infections and illnesses.

Food preparation

- Avoid fresh salads, buffet-style restaurants, raw fish or raw meat. You may eat prepared foods, but avoid canned soups that have high salt content.
- Avoid drinking grapefruit juice to avoid interactions with immunosuppressant medications.

- Avoid unpasteurized products.
- Practice good hand-washing at all times.

Bathing

- Do not take tub baths for 2 weeks after discharge, or until you are seen at the clinic and the chest tube sutures are removed.
- You may shower and gently wash incisions with mild soap and water.

Dentist

Speak with the lung transplant team before any dental or surgical procedure. (You will need to take antibiotics before the procedure.)

Outdoors

- Avoid gardening for the first 3 months. After 3 months, wear a mask and gloves when doing gardening near plants and soil.
- Wear a mask on windy days or around construction sites.
- Always wear shoes when walking outside or in public places.
- Clean and bandage any cuts, and report signs of infection.
- Wear a hat and sunscreen with at least 25 SPF when in the sun.

Pets

- Pets should be checked by a veterinarian, and vaccinations should be kept up to date.
- Do not have a bird in the household.
- Do not change cat litter.

Self-monitoring

Be sure to report even minor changes in your condition to your physician. This will allow us to promptly treat problems and complications that may occur after your transplant. To assist with this, it is important that you keep a daily record of your:

- Temperature—Take it the same time each day. Wait at least 20 minutes after eating or drinking.
- Blood pressure
- Heart rate
- Weight—Weigh yourself at the same time each day, on the same scale, with the same amount of clothing.
- Spirometer readings—Measure at the same time each day before a meal.

Contact the transplant coordinator at 312.695.5864 between 8 am and 5 pm or the lung transplant hotline at 844.639.5864 (844.NEW.LUNG) 24 hours a day if:

- Your temperature increases more than 1 degree F above your normal temperature. This may be a sign of infection or rejection.

- Your blood pressure (BP) is 20 mmHg above or below your normal systolic (top number) reading. BP changes may be due to medications, fluid retention or fluid loss. If you are unsure of what your normal BP is, check with the transplant nurse.
- Your heart rate is higher than 110 or lower than 60.
- You gain 2 or more pounds in 1 day or 5 pounds in a week. This may mean you are retaining fluids, and your medicine may need to be adjusted.
- You have a drop in your usual spirometer reading for 2 or 3 days. This means a drop of 10 percent or more in the FEV1 (forced expiratory volume in 1 second). This could mean rejection, infection or narrowing of the airway. If you are unsure about how to measure a drop in your spirometer reading, please feel to call us.

Please bring this record and a list of your current medications to each clinic visit for your physician and nurse to review.

Diet

Make sure you eat nutritious foods low in sodium, cholesterol and fats. Do not eat large amounts of sweets. Transplant patients are at a greater risk for heart disease (coronary artery disease), so it is important that you reduce your risk by maintaining your ideal weight and getting regular exercise.

Clinic visits

You will receive a list of all of your follow-up appointments before your discharge. It is extremely important that you go to your follow-up appointments even if you feel well. Over the next 6 months, your visits will be:

- Once a week for the first month (appointment schedule attached).
- Every 2 weeks for the next 2 months.
- Monthly for the next 3 months and then at the physician's discretion.

Follow-up testing

Blood work

- Complete blood count (CBC with differential), comprehensive metabolic panel (CMP), Prograf® levels and cytomegalovirus (CMV) tests are drawn every clinic visit.
- Prograf level will also be drawn 1 week after any dosage change.

Transbronchial biopsy

- Done with every bronchoscopy. The first one will be done at 1 month after transplant.

Spirometry

- Checked at every clinic visit.

Spiral CT

- Done 1 month after transplant to check for a blood clot.

After-transplant medications

Before you are discharged from the hospital, both a pharmacist and your transplant nurse coordinator will explain your medications to you in detail. This will include:

- What the medications do.
- How and when to take them.
- Side effects and when to call the physician.

We are here for you

We want to address your health concerns quickly to prevent any problems and avoid any hospital stays.

We are available 24/7 and are here to assist you! Please contact us if you have:

- Any concerns and questions.
- An onset of new signs or symptoms, or changes in how you feel.

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.

Para asistencia en español, por favor llamar al Departamento de Representantes para Pacientes al 312.926.3112.

The entities that come together as Northwestern Medicine are committed to representing the communities we serve, fostering a culture of inclusion, delivering culturally competent care, providing access to treatment and programs in a nondiscriminatory manner and eliminating healthcare disparities. For questions, please call either Northwestern Memorial Hospital's Patient Representatives Department at 312.926.3112, TDD/TTY 312.926.6363 or the Northwestern Medical Group Patient Representatives Department at 312.695.1100, TDD/TTY 312.926.6363.

Developed by: NMH Lung Transplant Team

