



JOHNS HOPKINS

M E D I C I N E

INTRODUCTION

For many patients, having a lung transplant is the most serious health challenge they have faced. It is natural to be frightened, overwhelmed, anxious and uncertain as you complete the evaluation process and await lung transplantation. Our entire team is committed to providing you with the best care and chance for a successful transplant.

Following transplant, your recovery and return to a good quality of life is our teams' priority. We ask that you join us in making a lifelong commitment to keep you and your new lung(s) healthy.

This book is designed to help you learn about these new responsibilities and changes. It will answer some of your questions as you recover. Please share this information with your family, loved ones, and support persons.

There is a lot of information in this book and at first, you may find it overwhelming. As time goes on, much of this material will become second nature. The transplant team will help you, and your caregivers, learn what you need to know. When you have questions, write them down, and contact a member of the transplant team. We are here to help you!

This book, does not replace the relationship you will have with the transplant team and your doctors. When you have a question, or change in your condition, please notify the transplant team immediately. It is our pleasure to be a part of your care team, and we look forward to your recovery.

The Johns Hopkins Hospital
Comprehensive Transplant Center
Lung Transplant Office
1800 Orleans Street
Halsted 667
Baltimore, MD 21287

Phone: 410-614-4508
Fax: 410-614-7008
On-Call Pager: **410-283-0249**

You are the most important caretaker of your transplanted lung(s). To have the best outcome, please: CONTACT your transplant team anytime there is a concern or question.

- ✓ Know all of your medication doses, times and why you are taking them.
 - ✓ Take your medication exactly as directed by your transplant team.
 - ✓ Do not let your medicines run out.
 - ✓ Attend all clinic appointments.
 - ✓ Complete all labs, tests and procedures on time.
 - ✓ Check your lung function, weight, blood pressure, temperature every day.
 - ✓ Exercise every day and make healthy food choices.
-

CONTACTING THE TRANSPLANT TEAM

Your transplant team has many team members including your doctors, surgeon, nurses, pharmacist, social worker, and receptionists. It can be confusing to know who to reach out to when you have a question. Your transplant coordinator is a nurse or nurse practitioner who will be your primary contact as issues arise. He/she will address questions, follow up on test results, work closely with your doctors, and reach out to specialty staff as needed.

Your transplant coordinator can be reached through the numbers below:

Lung Transplant Office

Monday through Friday

8:30 am – 4:30 pm

Phone (410) 614-4508

Option 2: pre-transplant

Option 3: post-transplant

Option 4: medication refills

Routine calls for prescription refills, laboratory results, and appointments should be made during regular office hours.

If you get the voicemail, leave a message and we will return your call as soon as possible.

Include:

- Your Name
- Reason for calling
- Call-back number

Evenings/Weekends/Holidays

After 4:30 pm & before 8:30 am

Page the On-Call Lung Transplant Coordinator:

(410) 283-0249

1. Wait for the 3 beeps,
2. Enter your 10 digit phone number,
3. Followed by the # sign.

Do NOT leave a verbal voicemail or a TEXT.

PATIENTS AND FAMILY MEMBERS

SAVE THESE NUMBERS TO YOUR PHONE:

Transplant Office: (410) 614-4508 opt 3

Transplant Pager: (410) 283-0249

If there is no response and your concern can not wait until morning, call the Hospital Operator:

(410) 955-6070.

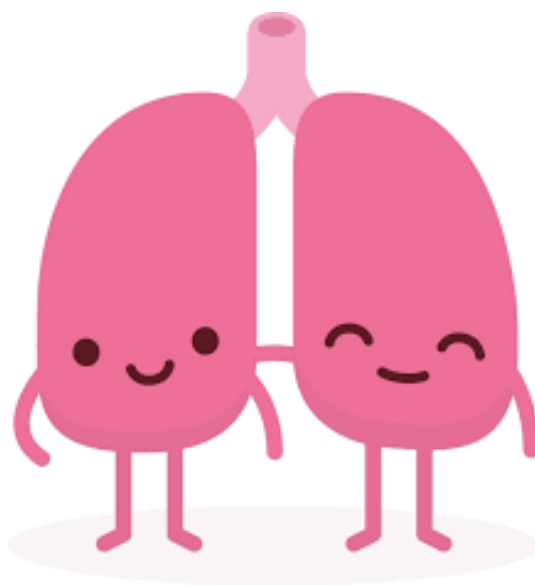
Ask the hospital operator to contact the: Lung Transplant Coordinator or Pulmonary Fellow On-Call.

Other Staff (Monday – Friday 9-4pm)

Transplant Pharmacist	1-888-264-0393 Option 2, then Option 1, then Option 5, and Option 5
Home Care Coordinator	(410) 955 -1930
Social Worker	(443) 287 -2986

MyChart Use

MyChart is a useful tool for communicating with your health care team. Do not use MyChart to send urgent messages or sick calls/concerns. **Mychart is ONLY for communicating stable test results, or issues that do NOT require a same day response.** If you do not receive a response after 3 days of sending a message, please call the lung transplant office.



EMERGENCIES

If you have a **MEDICAL EMERGENCY**, call **911** or go to the nearest emergency room. Once help is on the way, please contact the transplant office AND ask the ER to call the transplant office or Johns Hopkins Access Line for hospital transfers. If you are at an outside hospital, we may ask for you to be transferred to Hopkins for further management of your transplanted lung(s). The Hopkins Access Line is for health care professionals only. **Always carry a list of your transplant medications and your yellow transplant card, which has our contact information.**

Hopkins Access Line/Transfer Line: (800)-765-5447

For health care professionals ONLY

Call 911 or go to the closest hospital immediately if you have:

Difficulty breathing, heavy bleeding, chest pain, seizures, one-sided weakness, slurred speech, facial droop, or hit head with fall

Examples of MEDICAL emergencies:

- Sudden weakness
- Quick onset of numbness
- Sudden shortness of breath
- Sudden ONSET chest pain
- Passing out
- Low blood pressure
- Nausea and vomiting that does not go away after 6 hours
- Rectal bleeding, or vomiting blood
- Lower belly pain that does not go away
- Bleeding that cannot be stopped

When you are at home or an outside hospital please remind all doctors:

- ✓ **AVOID "NSAID" MEDICATIONS, such as ibuprofen and Toradol.**
- ✓ **AVOID IV DYE/CONTRAST, UNLESS APPROVED BY TRANSPLANT Team.**

When something changes, or feels different, CALL the TRANSPLANT TEAM promptly.

Call the transplant office for the follow concerns after transplant, OR if anything changes in your health. Please note, symptoms that would not have been considered urgent before transplant, may be very important after transplant.

- ✓ **Delaying diagnosis or treatment can cause a minor problem to become a serious one!**
- ✓ **Call early for quicker treatment!**

Call with INFECTION or LUNG symptoms:



- ✓ New or changed cough
- ✓ ANY shortness of breath
- ✓ Great than 10% drop in home lung function or decreasing trend
 - Ex: FEV1 drops from 3.0 to 2.6 or from 2.0 to 1.7
- ✓ Fever over 100°F or chills
- ✓ ANY sore throat/runny nose
- ✓ Swelling, redness, or green/yellow leakage from incision or line site
- ✓ Nausea/vomiting OR diarrhea
- ✓ Unexpected weight loss of more than 5 pounds
- ✓ Blood in stool

Call with HEART or BLOOD PRESSURE issues:



- ✓ Heart rate more than 140 or less than 50
- ✓ High blood pressure (more than 180/95) or low blood pressure (less than 95/50)
- ✓ Weight gain more than 3 pounds in /day

Call with MEDICATION issues:



- ✓ Whenever you get new medication from another doctor.
- ✓ Any new symptom that happens after a change in your medication
- ✓ If you missed a medication dose
- ✓ Trouble getting your medications from pharmacy

FIFTEEN THINGS I WISH I KNEW BEFORE TRANSPLANT
From patient S.P., transplanted in 2004

1. *Being intubated is not as scary as you think. And you can ask to sleep if it gets to be too much.*
2. *The first year will be rough, but there will be times of incredible joy that will take your breath away (in the best way possible). So many happy firsts occur during this time. Breathe them in.*
3. *Don't forget to live your life the best you can as you wait for your transplant.*
4. *You're trading a terminal illness for a manageable one. Knowing this one truth has kept me grounded and sane when things go wrong. And things will go wrong sometimes. Do the work to get better, be an informed patient, and trust your team.*
5. *That said, you are a key member of your own team. Be involved, ask all the questions, and don't be afraid to speak up if you feel uncomfortable about a treatment plan.*
6. *There will be days that you forget you've had an organ transplant, at least until it's time to take your meds.*
7. *It's a huge gift and a huge responsibility, so do your part and take care of yourself, alright?*
8. *Wait for the transplant team to wean you off your pain meds - even if you feel much better. Trust me on this one.*
9. *The transplant community is huge, supportive, and kind. It is also opinionated and has lots of conflicting information. Be sure to always follow your team's recommendations.*
10. *Becoming a transplant recipient is your job, but it does not have to become your identity. You are a unique and amazing individual, not only a solid organ recipient.*
11. *Always breathe as deeply as you can. After surgery and bronchoscopies inhale until it hurts, then do it some more.*
12. *Ask for the frozen mouth swabs dipped in Coke when you're in the ICU – game changer.*
13. *Make sure you maintain open and honest communication with your doctor and coordinators. You guys are in this together for the long haul. Getting to know each other helps them develop better treatment plans and makes visits more fun and effective.*
14. *Stay as physically active as you can. It will help you immensely in the long run.*
15. *Your transplant is probably the biggest surgery you will ever have. Recovery will be hard work. That said, you will be supported by the most talented, caring humans, I've had the privilege to know.*

CLINIC VISITS AND TESTING SCHEDULE

Clinic Follow-up Schedule

Below is a typical schedule for stable patients. If there is a change in your health, we may ask you to have additional tests and/or clinic visits.

	Schedule			
	Month 1	Month 2-3	Month 3-12	More than 1 year
Routine Follow-up for Stable Patients				
Transplant Clinic Visit	Weekly	2x/month	Monthly	4/x year
PFT/Lung Function Tests	Weekly	2x/month	Monthly	4x/year
Local Labs	Weekly	Weekly	2x/month	Monthly
X-Rays	Twice		At year 1	Yearly
Special Lab Testing at Hopkins	Once	Once	Every 3 months	Yearly
Surveillance Bronchoscopy	Once	Once	Every 3 months	Twice in year 2
Home Monitoring	Daily	Daily	Daily	Three times a Week

Clinic Visits

When you leave the hospital after transplant, your first 4 clinic appointments will be scheduled for you. **Please keep the list in your binder!** After that, you will need to schedule the rest of your appointments at check out or by calling the office.

- ✓ Pulmonary Function Tests (PFT's) will be done before **EVERY** clinic visit.
- ✓ Bring your transplant binder, medication list, blood sugar and vital signs logs to all clinic visits.
 - Your coordinator will review these results with you
- ✓ Bring a list of your questions
- ✓ We often adjust your medications in clinic. If this is confusing for you to do when you get home, bring your pill bottles with you.
- ✓ Additional tests may be ordered if needed
 - Some may be scheduled same day, please plan for extra time
- ✓ If you are ill and we need to treat you urgently, you may be admitted to the hospital.



Blood Work

Blood tests need to be checked after transplant to monitor your recovery, to check for side effects from your medication, and to be sure that you are receiving the correct dose of medications for your body. You must have your blood tests performed as instructed in order to prevent serious complications from your medications.

The Lung Transplant team recommends that you have your labs drawn at either a Hopkins facility, LabCorp or Quest so that the tests will be directly reported into our electronic medical record. This usually takes 2-3 days.

- ✓ Please have labs drawn on Monday mornings, if possible.
- ✓ Your blood will be tested for:
 - Tacrolimus/Cyclosporine drug level
 - Magnesium level, Complete Blood Count (CBC)
 - Comprehensive Metabolic Panel (CMP)
 - Anti-fungal drug levels (if applicable)
 - CMV and EBV levels (if applicable)
- ✓ Anti-rejection medications (tacrolimus) and antifungal medications (voriconazole, posaconazole) involve drawing drug levels.
 - **Go to the lab 11-12 hours after your evening dose of tacrolimus/cyclosporine**
 - **DO NOT TAKE** you morning tacrolimus/cyclosporine or antifungal medication **until AFTER your labs are drawn**
- ✓ Annual labs will be done each year around the time of your transplant. They may include, but are not limited to:
 - Thyroid screen
 - Cholesterol levels
 - Vitamin levels
 - Urine sample, including drug screen
 - Immune levels
 - Diabetic screening
- ✓ If you **DO NOT SEE** your labs results in MyChart within 1 week, please notify the office.



BRONCHOSCOPY

Bronchoscopy (bronch) is a procedure performed often after transplant to examine the connection between the old and new lung airway, and test for infection and/or rejection. In this procedure, you are sedated while a thin flexible tube with a camera is placed in your lung airway. Bronchoscopies are scheduled routinely for the first two years, and may also be performed if you have changes in your breathing or drop in lung function. Routine bronchoscopies will be done at: 1 month, 3 months, 6 months, 9 months, 12 months, 18 months, and 24 months.

During the procedure we usually obtain the following samples:

- A transbronchial biopsy removes a tiny piece of lung tissue that can be examined under the microscope for signs of **rejection or other injury**.
- Bronchial alveolar lavage (BAL): A small amount of fluid, is rinsed through a lung and then collected back. BAL fluid is sent to the lab to test for **infection**.
- The procedure takes about 60 minutes, plus additional time for monitoring until you are fully awake.

Bronchoscopy Instructions

Bronchoscopies are performed at the Johns Hopkins Hospital Endoscopy Suite, Main Floor of the Zayed Tower. Park in the Orleans Street Garage, cross the bridge, and the Endoscopy Suite is on the main level.

- ✓ **Do not eat or drink anything after midnight the night before your scheduled bronchoscopy.**
- ✓ Stop taking aspirin five (5) days before the day of your procedure.
- ✓ On the morning of the procedure, only take your anti-rejection medications (tacrolimus, prednisone, mycophenolate), and any antifungal medication with a sip of water. Take the rest after your procedure.
- ✓ You may need to have bloodwork at Hopkins the morning of your bronchoscopy
- ✓ Arrive at endoscopy suite 90 minutes before start time.
- ✓ If you are on a blood thinner or insulin please talk to your transplant coordinator at least 5 days before the procedure so that they can provide further instructions.

Because you will be sedated for the bronchoscopy, you cannot drive after the procedure. Please have someone drive you home afterwards. It is not uncommon to have a slight fever or cough-up a small amount of blood the day after the procedure. Please contact the Lung Transplant Office if this continues more than 1-2 days, but do not be alarmed.

Call the Lung Transplant Office **immediately** if you experience any of these symptoms following bronchoscopy:

- Difficulty breathing, or cough that does not go away
- More than 3 teaspoons of blood in your sputum
- Chest pain
- Chills and fever greater than 100°F
- Nosebleed



DAILY CARE AT HOME

Showering

- Once you are home shower **daily** using mild, unscented moisturizing soaps (such as DOVE or IVORY).
 - Avoid body wash or soap with dyes, deodorant and fragrances
- Cover any IV lines, tubes or wound drains as instructed by home care nurse (*see page 19*)
- Use a plastic chair in the tub or shower to sit.
- Place a non-skid mat on the shower floor.
- Water should be warm, avoid water that is too hot.
- Gently wash your incision with mild soap using fingertips. Do this area last and separately from rest of your body to keep this area as clean as possible. Allow water to wash over area to rinse.
- At first, limit your shower to 3-5 minutes. Sit down while drying off to prevent falls or dizziness.

Wound Care

- DO NOT RUB, just PAT the surgical site dry and then leave area uncovered except for clothing
- A small amount of watery yellow-pink drainage is normal; cover lightly with gauze
- **Never** apply any type of cream or lotion to the healing incision
- Wait at least 12 weeks after surgery before soaking in a bath tub
- Wear loose clothing to avoid irritating the surgical site while it is healing
- Women should wear a comfortable but supportive sports bra, avoid wires

Chest Tube Stitches will usually be removed 4 weeks after surgery.

- ✓ Check your surgical site daily
- ✓ **Contact your lung transplant coordinator** if you notice any:
 - Redness
 - Tenderness
 - Swelling
 - Warmth
 - Increased drainage
 - Pus-like, yellow, green, or bright red drainage
 - Bleeding
 - Odor



Hygiene

- It is recommended that you throw away the toothbrush that you used prior to transplant. New lungs, new toothbrush.
- It is not necessary to buy a completely new mattress. A mattress encasement is a cheaper alternative to trap allergens.
- The purchase of new pillows helps reduce irritants and allergens.

DAILY HEALTH MONITORING

After your transplant, we watch your health closely so that we can treat minor changes before they become serious. We will teach you to measure vital signs before you leave the hospital and write down values every day in your Daily Monitoring Log. This log will be reviewed at every clinic visit, and over the phone if you have any sick symptoms.

- **Equipment – provided at discharge**

- ♥ Blood pressure cuff with heart rate monitor
- ♥ Thermometer
- ♥ Blood glucose meter (if needed)
- ♥ Home Spirometer
- ♥ Bathroom Scale – you must purchase



- **Lung Function (PFT)** – We will provide a home spirometer for you to monitor lung function, which can change during an infection or rejection before you notice any symptoms. This is one of the most important things to check daily.

- FEV1 = Forced Expiratory Volume in 1 Second = the amount of air which can be exhaled from the lungs in the first second. This number will be smaller than the FVC.
- FVC = Forced Vital Capacity = the amount of air which can be exhaled from the lungs after taking the deepest breath possible. This is the same as the **FEV6**.



- **Blood Pressure** – Anti-rejection medications can increase your blood pressure even if it was normal before. This is in addition to other causes such as too much sodium in your diet.
- **Heart Rate** – You can get a high heart rate as a side-effect of medications, dehydration, infection, or due to a heart/lung condition.
- **Temperature** – A fever can be a sign of infection or rejection. You should take your temperature twice daily, more often if you are feeling ill. Take temperature before taking Tylenol, if needed.
- **Weight** – Weight can change quickly due to nutrition changes, eating habits and fluid loss. Take your weight under the same conditions every day; for example, wearing the same clothing/use the bathroom before, etc.
- **Blood Glucose/Sugar** – You may need to check blood sugars after transplant, even if you did not check them before transplant. High doses of steroids and anti-rejection medications can increase your blood sugar, requiring you to check sugars before meals and at bedtime, and give yourself insulin injections.

Check your vital signs and weight every day at the same time and record in your Daily Monitoring Log.

DAILY HEALTH MONITORING

Type of Test	How often to check	CALL THE OFFICE IF YOU HAVE:
Lung Function (PFT)	TWICE A DAY	More than 10% decline in 3 home PFT checks (ex: from 3.0 to 2.7, or 2.0 to 1.8)
Blood Pressure		Systolic blood pressure (top number) is more than 180 or less than 90
		Diastolic blood pressure (bottom number) is more than 100 or less than 50
Heart Rate		Heart rate is more than 140 or less than 50
Temperature		Temperature is more than 100° F
Weight	ONCE A DAY	Weight changes by more than 3 pounds in one day or 5 pounds in a week
Blood Sugar	4X/DAY	Your blood sugar is more than 350 or less than 60



HOME CARE

Home Care Services

Some patients will need home care services for IV antibiotics, or physical therapy after transplant. If needed, the transplant team will order home care services before you leave the hospital.

The home care nurse will:

- ✓ Visit once a week, usually in mornings
- ✓ They will teach you how to give yourself IV antibiotics if needed
- ✓ Draw weekly blood work
- ✓ Teach you and your family how to care for any IV lines, tubes, , wounds, or drains
- ✓ Change dressings
- ✓ Remind you to check your vital signs every day

The Home Physical Therapist will:

- ✓ Work on strength and safety until you are ready for outpatient pulmonary rehab

Once you leave the hospital, if you are ordered home care:

- ✓ Your home care company should contact you within 2 days
- ✓ If no home care company contacts you:
 - Call Johns Hopkins Home Care Group at **(410) 955 -1930**
 - AND**
 - Call the transplant office at **(410) 614 4508**

My Home Care Agency is _____ phone number _____

My Home Infusion Company is _____ phone number _____

IV LINE CARE

Why do I need home IV access?

- ✓ Some patients will need home infusion of intravenous medications, to treat or prevent infections. This is usually temporary, and your line will be removed once it is no longer needed.

Types of IV access:

- ✓ PICC (Peripherally Inserted Central Catheter) inserted in a vein in the upper arm
- ✓ Tunneled IV line (such as a Hickman) inserted under the skin into vein in the upper chest area
- ✓ Implanted port

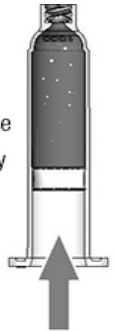
Caring for your line:

- ✓ Soreness at insertion site for 1-2days is normal
- ✓ Completely cover dressing and tubing while in the shower, do not let it get wet.
- ✓ If dressing is loose or getting dirty, you must change it immediately
- ✓ Secure tubing if dangling
- ✓ Light exercise, sexual intercourse, and light housework is fine
- ✓ Ironing, vacuuming, sports, and weightlifting are **NOT** allowed

How to flush your line:

- ✓ Supplies
 - Alcohol wipe
 - Saline and heparin flushes
- ✓ Directions
 - Wash your hands with soap and water or a hand sanitizer
 - Wipe end of port with alcohol wipe back and forth for 15 seconds
 - Unscrew cap of flush, turn syringe with tip facing up and tap to let air bubbles rise, if there are any
 - Push the piston of the syringe up until air is removed
 - Screw tip of flush onto the port and turn clockwise until attached
 - Unclamp tubing and flush line
 - Re-clamp tubing first, unscrew flush, then replace the cap
 - Throw away the syringe – do not reuse!

1. Tap syringe
2. Let air bubbles rise
3. Push piston slowly



Call the transplant office if you have:

- ✓ Fever greater than 100°F, or shakes after you flush the line
- ✓ Hard knot or redness along vein where line is inserted
- ✓ Redness, soreness, bleeding, or drainage at line insertion site
- ✓ Arm swelling on the same side with the line
- ✓ Difficulty flushing catheter (never force it to flush)
- ✓ Catheter moves out of place or comes out completely
 - If this happens, cover site with gauze and hold pressure to stop bleeding before calling
- ✓ Leaks, or tears in tubing
 - If this occurs clamp the line between the damaged area and your body and then call us



FEEDING TUBES

Sometimes a patient may need a temporary feeding tube for nutrition.

Why would I need a feeding tube?

- ✓ You may be at high risk for food and drink going into your new lungs while eating. This can cause serious lung infections or even lung rejection.
- ✓ You may need extra calories to help you gain weight.

How is a feeding tube placed?

- ✓ A specialty doctor will place a tube through your abdomen into your stomach
- ✓ The tube is called a percutaneous endoscopic gastro-jejunosomy tube, or PEG-J

How do I use my feeding tube?

- ✓ Your home care nurse will teach you how and when:
 - To give yourself your tube feedings
 - To check for feeding that did not get digested (This is called RESIDUAL)
 - To flush your feeding tube so the line does not clog
 - Do this before AND after all feedings and medications
- ✓ You should be upright in a chair or angled bed when the tube is being used



What supplies do I need and how do I take care of them?

- ✓ Tube feed formula
 - Store room temperature or lower than 75°F
 - Cover and refrigerate any leftover tube feeding formula
 - Throw away tube feeding formula if not used within 24 hours
- ✓ Bag for formula
 - Wash bag and allow to air dry after use
 - Replace the bag as directed by your home care nurse
- ✓ Sterile water or normal saline for flush
 - Flush your feeding tube per your home care nurse or team's directions
- ✓ Syringe
 - Take apart, wash parts, and allow to air dry after use
 - Replace syringe as directed by your home care nurse
- ✓ Stopcock
 - Change as directed by your home care nurse



Feeding tube site care:

- ✓ Always wash your hands before touching the site of the feeding tube
- ✓ Gently wash with soap and water, and pat dry. The site should be cleaned daily.
- ✓ You may not soak in water or take a bath with the feeding tube
- ✓ If you have a small amount of drainage, you may cover the site with gauze

Call the lung transplant office if:

- ✓ You have a fever, redness, soreness, odor, or yellow/green drainage at the exit site
- ✓ Your residual is greater than 200mL
- ✓ Persistent nausea, vomiting, or diarrhea
- ✓ You cannot flush your feeding tube, or flushing has become sluggish. Do not try to force a flush!
- ✓ Your feeding tube has become dislodged or come out. If this occurs cover the site and hold pressure until otherwise instructed by your team



When can my feeding tube come out?

- ✓ Your transplant team and/or speech therapist will reassess your ability to eat and drink safely
- ✓ Once you can safely eat and drink on your own, have gained weight, and are on less than 10mg of prednisone a day, your feeding tube may be able to be removed
- ✓ Feeding tubes are removed in a special procedure area

My tube feeding formula is _____

My tube feeding rate is _____ mL/hour

My tube feeding frequency is _____

My feeding tube should be flushed with

every _____ hours or with medications/feedings

PHYSICAL ACTIVITY

Physical Activity

- Exercise improves your overall health. It makes you feel better and can help control stress. Regular exercise can help maintain a weight that is right for you. Most importantly, staying active is key to living a full and healthy life.
- It is common to feel tired or weak as you recover from lung transplant. If you have been in the hospital for a long time, you may have lost some muscle strength from prolonged rest.
- Your lung function and strength will improve with physical activity. This means you need to get out-of-bed every day and exercise to help you become independent with your daily routine (bathing, getting dressed, shopping, cleaning etc.).
- We recommend frequent activity with rest periods when you first go home. The best activity in the first few weeks after transplant is **walking**.
- If you feel steady on your feet, you may walk up and down the stairs after transplant. You should practice this with your physical therapist or nurse before you leave the hospital.
- You may return to your normal level of activity as soon as you feel up to it. **You should find that your endurance improves week by week. If not, please notify the transplant team!**

NO LIFTING MORE THAN 10 pounds for 12 WEEKS after surgery.

NO DRIVING for first 12 WEEKS after surgery.

Stop exercising immediately and call your doctor if you have any of the following:

- Pain pressure in your chest, neck, or jaw
- Intense tiredness that is not related to a lack of sleep
- Unusual shortness of breath
- Dizziness or feeling faint during or after exercise
- Heart rate more than 180 during exercise.



Getting Out of Bed

- After surgery, it may be more difficult to get out of bed due to pain or weakness.
- Please ask your nurse and physical therapist to assist you with these activities in the hospital.
 - To Sit Up:

- Bring the head of the bed to an upright position.
- Roll over onto your side (if you have had a single-lung transplant, roll toward the non-operative side).
- Lower your legs over the edge of the bed while using the arm beneath you to push the side of your chest up, off of the bed.
- Push up from your side into a sitting position (stay in the sitting position for a few minutes prior to trying to stand).
- To Stand Up:
 - When you are ready, stand up. Do not use your arms to push yourself up!
 - Use the side rail of the bed to steady yourself. Give your body a few minutes to adjust to standing before taking any forward steps.
- To Sit in Chair:
 - Walk to your chair. Turn around and reach back with both hands and feel the armrests of the chair. Hold the armrests as you bend your knees and gradually lower yourself into the chair. Move your hips to the back of the seat.

Exercise & Pulmonary Rehabilitation

- Your physical therapy will teach you exercises you can do at home after you leave the hospital.
- Sometimes a short stay in an inpatient rehabilitation center is needed to improve strength and safety before going home. Your social worker will work with your family to arrange this if needed.
- DO NOT lift or carry anything heavier than **10 pounds for 12 weeks**.
- No upper body work-outs; this includes push-ups, pull-ups, pushing a vacuum or carrying laundry baskets.
- Avoid contact sports and strenuous exercise until you have permission from your transplant team.
- We will discuss pulmonary rehabilitation at your first clinic visit.

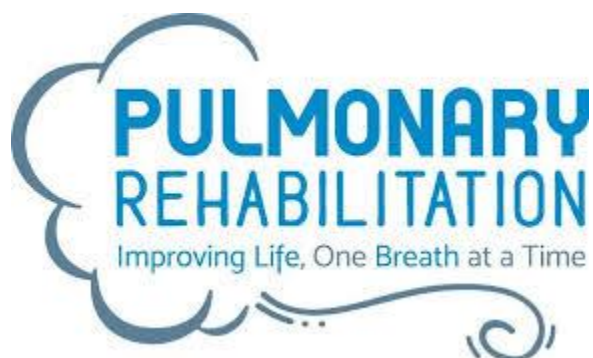
Driving

- For the first few weeks after transplant do not sit in the front seat.
- You may not drive for **12 weeks** or until approved by your transplant team.
- Do not drive if you are still taking pain medication.
- When driving or in a car, always wear a seat belt. You can use a pillow between the chest and seat belt to protect chest.
- Practice driving in an open lot away from traffic when you first start driving again.
- Have another licensed driver in the car with you for the first few times that you drive.



PULMONARY REHABILITATION

Although you have new, working lungs, you need to complete a formal pulmonary rehabilitation program to regain muscle strength, endurance and to get the best possible lung function after transplant. **The goal of pulmonary rehabilitation is to help you to safely recover to the best possible level of independence without causing injury.**



While you are in the hospital, your physical therapist will start this process. Once you leave the hospital you will need to continue this therapy as an outpatient. Some patients will receive home physical therapy before going to the outpatient center for pulmonary rehabilitation. Your therapists and transplant team will let you know when you are ready to start pulmonary rehab. A good program will be monitored by nurses and/or respiratory therapists who will work with you 2-3 days per week in an outpatient center. The exercise program may include walking, stationary bicycling, treadmill, and light weight training. Patient and family education may include topics such as home exercise programs, diet, stress reduction, energy conservation, and healthy lifestyle. You may meet other transplant recipients to talk with and who can share common experiences.



BREATHING EXERCISES

Respiratory Therapy

Keeping your lungs clear of secretions and mucus may help you recover and breathe more comfortably after lung transplantation. A normal lung has two ways to protect it from filling with secretions and material that does not belong:

- Cough reflex – this helps to clear material (like food) that accidentally enters the lung
- Active cilia – microscopic hairs which line the large airways of the lung; their continuous movement pushes normal lung secretions up and out of the lung

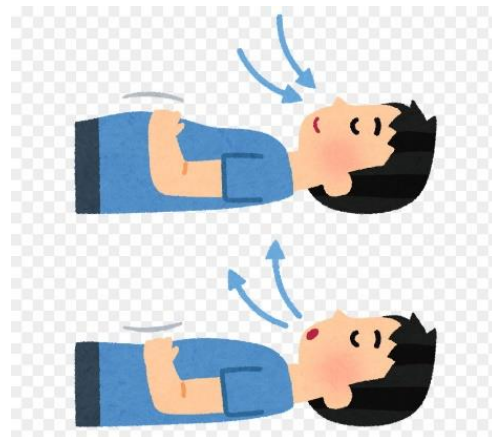
Nerves to the lung control both of these mechanisms. When a lung is transplanted these nerves do not work right away and you may not feel the need to cough as you would normally. Breathing and airway clearance exercises will help you bring up the secretions, breathe more comfortably, and help your lungs re-expand. **Do these exercises every day.**

Breathing Exercises

Diaphragmatic breathing:

The diaphragm is a muscle that does most of the work of breathing. When it is weak, it is assisted by muscles of the upper chest and neck, but your lungs will get tired when upper chest and neck muscles are used to breathe rather than the diaphragm.

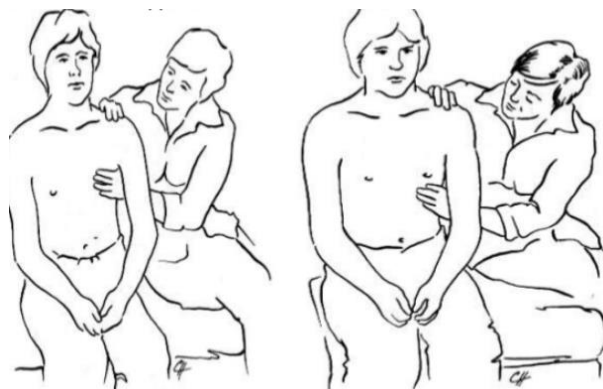
- ✓ Lie down on your back with one pillow under your head and your knees bent. Place one hand on your abdomen and the other hand on your chest.
- ✓ Breathe in slowly through your nose. Your belly should move the hand over your belly upwards. The hand on your chest should not rise
- ✓ Breathe out slowly through your mouth. Your belly should pull in. After you are able to do this exercise lying down, try it standing.



Basilar Rib Expansion (Segmental Breathing):

You may notice that you are breathing with one side of your chest more than the other. This may be due to incisional pain or muscle weakness. Segmental breathing will help you breathe with your entire lung.

- ✓ Place your hands on your sides so that you can feel your lower ribs. Exhale slowly through pursed lips. Inhale slowly through your nose as you expand your rib cage. Feel your ribs elevate as you inhale.



Incentive Spirometry:

Use this device to fully expand your lungs and strengthen your muscles.

- ✓ Sit up straight. Place the mouthpiece in your mouth and exhale completely. Then inhale slowly and deeply through your mouth. The large disc should move upward. The goal is to get the large disc to rise up as high as you can while keeping the smaller piece on the side “floating” in the “best” range at the same time.
- ✓ Use the incentive spirometer for at least 10 deep breaths every hour in the hospital and every 2 hours at home.
- ✓ Please take normal breaths in between turns.



Secretion Clearance Exercises

Flutter Valve/Acapella:

This device is used to help loosen mucus in your airways so you can cough it up more easily. The flutter valve consists of a mouthpiece, a protective cover, a steel ball, and a cone. When you exhale through the flutter valve, the ball moves, and vibrates to break up mucus.

- ✓ Sit up straight. Holding the flutter valve parallel to the floor, place the mouthpiece in your mouth. Inhale deeply and hold breath for 3 seconds. Then, keeping your cheeks firm, exhale normally through the flutter. Adjust the angle of the device to maximize the vibrations.
- ✓ Repeat 10 times per hour in the hospital and at least 3 times per day for 10 repetitions each time at home.



Controlled Coughing:

Coughing helps clear of excess mucus and foreign bodies. Coughing may be an automatic or an intentional action. Until your nerves recover, you may need to intentionally cough at least three times a day.

- ✓ Take a deep breath and hold it for 2 seconds. Now add to that breath by sniffing air through your nose to add to the volume already in your lungs. Using your abdominal muscles, force the air out and cough twice. Once to loosen the secretions, and once to move the secretions. Pause. If you are still having incisional pain, splint your chest and sides during a cough by hugging a pillow or folded blanket against the incision and abdomen while coughing. If your cough is dry or nonproductive, try one of the secretion clearance devices or techniques to help mobilize your secretions.

Huffing (Forced Expiratory Technique):

This technique is used to mobilize and clear secretions in your airway. It uses less energy than coughing.

- ✓ Through your nose, breathe in a medium sized breath. Open your mouth to form an “O”. Then squeeze air out using your chest and abdominal muscles to exhale. It should be like a forced sigh and sound like “Ho-Ho-Ho” – this action is similar to fogging a pair of eyeglasses before cleaning them. Do this all with one inspiration. Repeat several times.