



# Health Facts for You



Your lung transplant surgery  
and life after transplant

**UW**Health



## Table of Contents

<b>The Transplant Surgery</b> .....	1
<b>Home Care</b> .....	5
<b>Follow Up Clinic Visits</b> .....	8
<b>Blood (Lab) Tests</b> .....	10
<b>Respiratory Treatments</b> .....	14
<b>Organ Rejection</b> .....	25
<b>Infection</b> .....	26
<b>Nutrition</b> .....	30
<b>Staying Healthy</b> .....	34
<b>Other Things to Consider</b> .....	37
<b>Who to Call and When</b> .....	41

### The Transplant Surgery

When you are taken to the surgery area, one support person may stay with you until you are taken to the operating room (OR). Other family members may stay in the surgical waiting area. The OR nurses will provide your family with updates. After surgery, the surgeon will talk with your support person and/or family.

Once you are in the operating room (OR), you will meet your nurse who will answer questions, make sure you are comfortable, and explain what is happening.

There will be ECG (electrocardiogram) patches on your chest to check your heart rhythm, a blood pressure cuff on your arm, and a plastic clip on your finger to check your heart rate and oxygen levels. The anesthesiologist will ask you to breathe oxygen through a soft plastic mask. Medicines will be given through your IV.

After you are asleep, a breathing tube (endotracheal or ET tube) will be placed in your windpipe to breathe for you. Other lines and monitors will be added after you are asleep.

- Urine catheter: A small rubber tube (Foley catheter) will be in your

bladder. This allows us to measure your urine output.

- Intravenous catheter (IV): At least one IV will be placed in your hand, arm, or neck. This will be used to give you fluids and medicine until you are able to eat or drink. A few days after your transplant, the doctor will decide when the IV can be removed or replaced.
- A stomach tube will be passed through your mouth into your stomach when you have the breathing tube in. This is used to pull air out of your stomach.
- Chest tubes will be placed to remove fluid and air from your chest. Typically, 2 chest tubes are placed for each lung transplanted.
- You may also be placed on ECMO (extracorporeal membrane oxygenation). This is like an artificial lung and heart machine.

The surgery takes about 6-12 hours. After surgery, you will go back to your room.

### What to Expect After Surgery

After surgery you will be taken back to the unit for careful monitoring. Support persons will be able to make a short visit once you are settled. This could be an hour or more after you are back on the unit. Time to visit may be limited. Nursing staff may ask support persons to leave the room if needed for patient care.

You will have a breathing tube and will not be able to talk. You will have a heart monitor and multiple IV medicines. Chest tubes will be in place to remove extra fluid and air from the chest. You may hear a soft bubbling sound coming from the chest tube. This is normal. You may not remember much about the first hours after surgery. As you slowly wake up, you may hear beeps,

alarms, and voices. Your nurses check your blood pressure, temperature, and measure your urine output often during the first 24 hours. The breathing and stomach tube are removed once you are awake enough to breathe on your own. You will sit up in a chair shortly after the breathing tube is removed.

Because of the effects of anesthesia, the normal action of your bowels slows. Bowel function returns faster if you walk, so you will be encouraged to walk as soon as your doctors think it is safe.

### **Risk of Aspiration**

There is a high risk of food or liquid going down into your lungs after surgery. This is called aspiration. This can cause pneumonia. To keep you safe, a tube will be put in your nose and down into your stomach once the breathing tube is removed. This new tube will be used to give tube feedings and medicines.

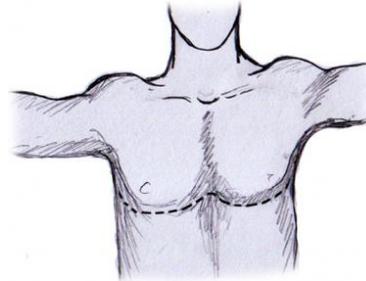
You will need a test called a swallow study before you will be allowed to drink fluids. This will show if fluid is going into your lungs. Once the doctor believes it is safe for you to eat and drink, you will slowly be allowed to start doing so.

### **Your Lungs**

You will have bronchoscopies in the hospital. During this test a camera goes down your nose or through your mouth to look at the inside of the new lungs, the internal attachment of the new lungs, and to remove secretions if needed. This usually happens before the breathing tube comes out and again before discharge.

### **Your Incision**

For a single-lung transplant, an incision (cut) is made from under your breast area. It will then extend across your rib cage to your back area on one side of the chest. For a double-lung transplant, an incision (cut) goes from arm pit to arm pit, across the sternum (breast bone). This is often called a “clam shell” incision.



The incision will have a dressing over it. The nurse will change the dressing after the first 48 hours and then every day. We will teach you how to clean and care for it. This helps you to be more aware of any signs of infection or problems. You may have staples or stitches, these are usually removed at your clinic visit with the doctor after transplant. Your incision may also have steri-strips for closure, keep these in place until they fall off on their own.

Your doctor will order pain medicine for you. When you are unable to eat or drink, you will get pain medicine through your IV. Later, you will take pain pills. Pain medicine should be taken to lessen incision pain and allow you to cough and deep breathe. Your walking, coughing, and deep breathing will be easier when your pain is managed.

You will be coughing, deep breathing and using the incentive spirometry device at least every 1-2 hours while awake. The staff will help you with this. Deep breathing helps air to reach your lower lungs. Coughing helps clear out secretions. Coughing and deep breathing are an important part of recovery and help to prevent pneumonia.

You will wear sequential compression devices (“SCDs” or leg pumps) during and after surgery when you are in bed. This improves blood flow and helps prevent blood clots. Walking helps the most. Once the breathing tube is removed, we will help you to the chair at least 3 times each day. The goal is for you to walk 5 times each day.

While in the hospital you will have blood tests daily or more often if needed. The results keep you and your health care team aware of how you are doing. You will learn about and track these tests too.

Many patients have their blood sugars checked during and after surgery. If you have diabetes or elevated glucose levels, you will likely get insulin through your IV. Your blood sugar levels will be checked often. You may continue to receive insulin over the next couple of days as you recover even if you have not needed insulin in the past. Well-managed blood sugars lower your risk of infection.

As your condition improves, the nurses will not be at your bedside as often. This is a good sign. You are on the road to recovery

### **Education After Transplant**

You must learn about the care of your new organ. Education after transplant will be scheduled with you. You will be given a booklet to review and other materials as needed. This may start as early as your first day after transplant based on how your recovery is going.

It is the expectation that your primary and secondary support person will be involved in your education. Your primary support person should plan on being at the hospital for 4-5 days (roughly 1-2 hours each session) at the minimum for education.

However, each learner is different, and some may require more sessions.

Your transplant coordinator will work with you and your support person to determine how you learn best. The sessions are scheduled in advance so your support person can participate. Some people find that they like to learn a lot of information at one time, while others find that shorter sessions may work best. As you recover from surgery, you may find that you get tired easily or lose focus. If this happens, please tell the staff.

Your education will cover the following:

- Home care after transplant
- When to call your transplant team
- Medicines
- Nutrition guidelines
- Infection and rejection
- Diabetes education (if needed)
- Bronchoscopies and biopsies
- Home records and vital signs
- Lab work
- Writing your donor family
- Lifestyle adjustments
- Activity/Pulmonary rehabilitation
- Follow up clinic visits and care

You and your support people will review all materials with your coordinator. You will also be given a transplant quiz to take before discharge. You will work together with your coordinator to ensure understanding of all the questions and answers.

## **Guidelines for Support Persons and Visitors**

Family and friends are welcome to visit often while their loved ones are in the hospital. Visiting hours in most units are from 8am-9pm, but those identified as primary support person may stay with the patient at any time. (Staying overnight may be difficult; a very limited supply of cots are available.) The primary support person is someone who has been identified before transplant and would normally provide a patient with significant physical, psychological or emotional support. Examples might be a close family member, partner or best friend. Visitors should check at the information desk or nursing unit before visiting.

## **What will happen after I am discharged?**

You will have to stay within 30 minutes of Madison for a minimum of 2 weeks after discharge from the hospital after surgery. Your support person will need to stay with you 24 hours a day. UW Housing offers discounts at local hotels as well as the Restoring Hope Transplant House. Many area hotels have shuttles available. The housing number to assist in making arrangements is **(608) 263-0315**.

You will have a transplant clinic visit and testing weekly or as needed following your surgery. If your doctor doesn't have any concerns at these visits, you will be cleared to leave the Madison area and return home.

## **Commitment to Follow-Up Care**

Your care after a transplant is for your entire lifetime. The follow-up schedule is intense for the first few months.

This long-term care includes:

- Bronchoscopies and biopsies
- Labs
- Medicines
- Transplant clinic visits

- Other tests (pulmonary function tests, chest x-rays, 6 minute walk tests, etc.)
- Hospital readmissions

## **Keeping the Commitment**

For a transplant to be a success, you need to commit to the following things:

- Follow the treatment plan.
- Twice daily documentation of blood pressure, heart rate, temperature, weight, and home spirometry.
- Call the transplant office about any new problems or symptoms related to your transplant or about any new medicines or tests you have.
- Take all prescription medicines as prescribed.
- Check with the transplant team when starting any new medicines to make sure there are no interactions.
- Follow the diet and exercise plan advised by your doctor.
- Go to your appointments, clinic visits, lab draws, and biopsies as requested by your transplant team.
- Do not abuse your body by smoking, drinking alcohol, or using non-prescribed medicines and herbals.
- Plan transportation for at least 6 weeks after surgery when you are unable to drive (or until you are off narcotics).

After your transplant, you will be on many medicines. You will be on some of them for the rest of your life. This includes medicines which:

- Prevent rejection
- Prevent infections
- Control blood pressure
- Control cholesterol
- Prevent bone loss
- Provide you with extra vitamins and minerals

- Manage blood sugars

The team will help you learn about the medicines you need, why you need them, and the dose prescribed for you. Not taking your medicines correctly can lead to rejection and other health problems.

## Home Care

### Keeping Records at Home

When you go home, you need to keep a record of your weight, temperature, blood pressure, heart rate, and spirometry. These vital signs are key in keeping an eye on your health and your new organ. We will give you an automatic blood pressure cuff, thermometer, and spirometer before you go home. Bring your vital signs record books to each clinic visits. We will look for trends in your numbers. We may make changes to your medicines based on your numbers.

### Daily Temperatures

- Take twice a day at the same time each day. Do not eat or drink anything 30 minutes before you take your temperature.
- Normal oral temperature is 98.6°F
- If you have a temperature higher than 100°F, call the transplant coordinator.
  - Drink fluids, if dehydrated.
  - Be sure to tell your coordinator if you took acetaminophen (Tylenol®) between readings.



### Blood Pressure and Heart Rate Checks

Do these checks 2 times a day-in the morning and evening.

- Normal blood pressure is 120/80.
- Normal heart rate is 60 – 100.
- If high (160/90 or higher), repeat in 15 minutes.
- Notify coordinator if:
  - Blood pressure is higher than 160/90.
  - If you have blood pressures outside of your normal values or you feel weak, dizzy, lightheaded, or have fallen, or have headaches.

### Daily Weights

- Make sure to empty your bladder before weighing yourself.
- Weigh at the same time each day in the morning, before breakfast.
- Wear the same amount of clothing each time you weigh yourself.
- Call the Transplant Coordinator if you notice any water weight gain (2-3 pounds a day or 5 pounds in one week).



### Blood Glucose Checks

If you have diabetes or take steroids, you may need to check your blood glucose levels at home. Talk with your diabetes team about the plan for these glucose checks. If you have any signs/symptoms of high or low blood sugar levels, call your coordinator.



- Hyperglycemia (high): extreme thirst, blurred vision, frequent urination, fatigue, confusion
- Hypoglycemia (low): sweating, shaking, dizziness, confusion, blurred vision, hunger

### My Home Vital Sign Records

Day	Sunday		Monday		Tuesday		Wednesday		Thursday		Friday		Saturday	
<b>Date</b>														
<b>Time</b>	AM	PM	AM	PM	AM	PM	AM	PM	AM	PM	AM	PM	AM	PM
<b>Weight</b>														
<b>B/P</b>														
<b>Temperature</b> <small>Call if &gt; than 100°F</small>														
<b>Pulse/Heart Rate</b>														
<b>Notes</b>														
Day	Sunday		Monday		Tuesday		Wednesday		Thursday		Friday		Saturday	
<b>Date</b>														
<b>Time</b>	AM	PM	AM	PM	AM	PM	AM	PM	AM	PM	AM	PM	AM	PM
<b>Weight</b>														
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<b>Weight</b>														
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<b>Temperature</b> <small>Call if &gt; than 100°F</small>														
<b>Pulse/Heart Rate</b>														
<b>Notes</b>														

## Incision Care

Your anti-rejection medicines can make your incision take longer to heal. Your incision may take over a month to fully heal.

You will have either staples, stitches, steri-strips (paper-like strips) and/or glue on your incision. If you have staples or stitches they will be removed at a follow up clinic visit. Steri-strips will curl up, loosen, and fall off over time. Do not pull these off. Doing so may cause your incision to open. If you have glue on your incision, this will heal up on its own.

You may shower. Use a washcloth with mild anti-bacterial soap and water to gently clean the incision. Do not rub over the area. Do not take any tub baths until your incisions are healed and there are no scabs. Do not put any creams, ointments, or powders on the site.

When you go home, your dressing should be changed at least once a day until it is healed (about 2-4 weeks after surgery). A nurse will give you a 3-day supply of dressings to place over the incision. If you need more supplies you can buy them at a local drug store.

As your wound heals, you may notice some redness, soreness, numbness and itching. This is normal. Call your coordinator for any increase in swelling, tenderness, redness or drainage (especially with an odor or green/yellow in color). These may be signs of infection.

## Pulmonary Rehabilitation

The goal of pulmonary rehabilitation after your lung transplant is to make sure that you stay on the road to recovery by working on your strength and endurance. A quick start is vital! You will begin exercises very soon after transplant. This will:

- Increase your strength
- Reduce your risk of pneumonia
- Reduce your risk of developing blood clots in your legs
- Shorten your length of stay in the hospital

A member of the rehab team will visit with you shortly after your transplant. Our goal is to have you perform upwards of 30 minutes of activity each day before you go home. Keep in mind, each person will recover at a different rate. Your plan will be made to suit you and your specific needs.



## Activity Guidelines

You can exercise with moderation and slowly increase your activity level. Walking and climbing stairs are good for you. Increase what you do each day.

You will need to restrict your activity for the first 10 weeks after your transplant. After that you can return to your normal routine.

- Do not drive for 6 weeks or as long as you are on narcotics
- Always wear a seatbelt
- Do not lift, push, or pull more than 10 pounds for 10 weeks
- Do not reach above shoulder level
- Avoid heavy weight bearing that causes pain (ex. using your arms to push up from a chair)
- Do not play sports like tennis, golf, softball, bowling, or do any other sport that could cause injury to your chest area for 3 months



## Sexual Activity

You can resume sex when you feel able. There is no restriction on any position you may use during sex. You should talk to your doctor about birth control. Some of the

medicines you take after transplant may be harmful to a fetus so changes may be needed before pregnancy.

### **Going Back to Work**

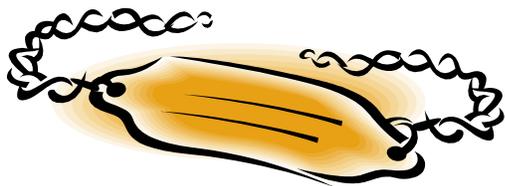
We encourage patients to return to work after having a transplant. You may not be able to do the same duties as before your transplant. It depends on the type of work you do, but that doesn't mean you can't work at any job. The social worker will meet with you after your transplant and talk about returning to work. The social work team will help you with paperwork or questions you may have.

### **Insurance**

Always notify your transplant team of any current or future insurance changes or updates.

### **Medical Alert Bracelet**

We suggest all patients wear medical alert bracelets after transplant. The National Kidney Foundation will provide one free bracelet or necklace to all new transplant patients. Your transplant coordinator will give you this form. Suggested wording to be engraved on your bracelet is "Lung Transplant, (608)263-6400".



### **Primary Care Provider**

You must have a local doctor to follow your care. Plan to see your local doctor shortly after discharge. We rely on the local doctor to address routine health issues such as diabetes and minor infections. We will work closely with your doctor to give you the best care.

### **Follow Up Clinic Visits**

Your follow up appointments may be in person, telephone, or video, depending on your health. Your first clinic visit is about 1 week after you leave the hospital. This will be scheduled before you go home. Future appointments will be made by the clinic. Plan on spending 3 to 4 hours at UW Health for your clinic visits if they are scheduled to be done in person. Please be prepared to be admitted to the hospital with little notice.

### **Labs Before Clinic Visits**

Complete labs as instructed by your transplant coordinator. If you do not plan on completing labs at UW the day of your clinic visit, you should have your labs done at least one week before your clinic visit. This allows the team to have test results when they see you in clinic. Your coordinator will let you know if you need to stop eating or drinking before your lab draw.

**Do not take any of your medicines needing a drug level to be drawn until after your lab draw.**

### **What to Bring to Clinic Visits**

- Your medicines
- A list of your current medicines
- Your patient education materials
- Home records of your weight, blood pressure, heart rate, temperature, spirometry, and blood sugars (as indicated)
- Spirometer
- A snack
- Duck-billed mask and hand sanitizer
- A list of questions

### **Arrive Early for Clinic Visits**

Plan to arrive at the Transplant Clinic at least 15 minutes before your scheduled appointment time. You need to register and check in. Staff will weigh you, take your blood pressure, and review your medicines.

If you need any prescription refills, please tell the staff at this time.

### **Bronchoscopies and Biopsies**

Bronchoscopies are done to inspect your new lung(s), to check for infection, get tissue biopsies, and to diagnose abnormal findings. Biopsies are done to check for rejection. This can happen when your body's immune system attacks your new organ.

During a biopsy, pieces of tissue are taken from the inside of your lung. If a biopsy is done because your lung(s) is not showing normal function, it may be somewhat urgent. You may need to make plans to come to UW Health without much warning. You must have an adult to drive you home from the procedure or your exam will be cancelled.

Bronchoscopies and biopsies are done regularly (at least):

- Once before you are discharged.
- 5 more scheduled procedures during the first year.
- More often if you have concerning signs or symptoms.
- After your first anniversary, only as needed.

If you are on a blood thinning medicine (such as Coumadin<sup>®</sup>, Plavix<sup>®</sup> or Eliquis<sup>®</sup>), you will need to get detailed instructions from your doctor or coordinator on when to stop taking this medicine before a procedure.

### **Day of the Bronchoscopy**

- Do not eat or drink anything after midnight. However, if your bronchoscopy is after 12pm you may have **clear liquids** before 8am.
- With as little water as possible, please take only your immunosuppressive medicines and your beta-blocker blood pressure medicine before your procedure.

After the bronchoscopy:

- When it is safe to do so, you can take the rest of your medicines.
- You may have a sore throat. You may wish to gargle with lightly salted water or suck on hard candy.
- Do not drive.
- Do not drink alcohol.
- If you had a biopsy, you may cough up tiny spots of blood. This should last no longer than one day. If it does, let your coordinator know.
- You may feel like you have the flu for about 24 hours after the procedure, including a low grade fever and chills. If this lasts longer than 24 hours, notify your coordinator.

### **Other Tests**

You may have additional testing on the day of your clinic visit. These may include, but are not limited to:

- Chest X-ray
- Pulmonary Function Test (PFT): a series of breathing tests to give your doctor details about how well your lungs work
- Six Minute Walk Test (6MWT): gives your doctor an idea on your ability to perform daily activities



## Visits With Your UW Provider

You will see the provider for your clinic appointment. If you would like to meet with a pharmacist, dietitian or social worker please let your coordinator know before your appointment and we can try to arrange this.

## Before You Leave the Clinic

- Obtain an After-Visit Summary. This will have an updated medicine list, your lab results, and any follow up instructions.
- Obtain an updated standing lab order if needed.
- Schedule your next visit.

## Blood (Lab) Tests



### Why do I need to have labs test done?

It is very important that your health care team knows how well your new lung(s) is working, and if there are problems with your medicines. To check for these issues, you must have blood tests drawn on a regular basis after transplant. Blood tests are often the only way we are able to tell there is a problem with the new lung(s). Blood tests can often show us if there is a problem even before you have any symptoms.

### Where can I have my lab tests done?

Blood tests are done daily in the hospital after transplant. When you go home, you can have blood tests done near home. Check your insurance plan to see if there is a certain lab you must use. Often, blood tests can be drawn at any local clinic or hospital.

If your labs will be drawn near your home, your transplant coordinator will give you a 'lab letter' (paper order) to give to your local lab. Your coordinator will also send a fax to your local lab. This letter tells your lab to fax the results to the UW Transplant Office

at **608-263-0597**. You can help by reminding your lab to fax these results as well.

Each standing lab order is typically good for one year from the original order date. Please help remind your coordinator when your lab orders need to be renewed.

### How often do I need to have my lab tests done?

You will have at least weekly lab work after you are discharged from the hospital. The frequency of the blood tests decreases over time. The transplant team lets you know how often to do blood tests. **All** transplant patients have blood tests done at least once every 3 months for the rest of their lives.

### What should I do with my lab tests results?

Your local lab will send your results to UW. Your transplant coordinator will contact you with results.

### Drug Levels

We also draw blood to make sure you are getting the right amount of your anti-rejection and anti-infective drug. Right after transplant, these are often done once a week. The blood test needs to be drawn about 12 hours from the time you took your last dose of the medicine. You should **not** take your morning dose of these medicines until **after** the lab draw. Take your other medicines at the normal time.

If requested to have these tests processed at UW, you will be provided with a mailer for the lab tests to be sent back to UW. Take the mailer with you to the lab and get the blood tube filled along with your other lab tubes. Then, have the lab tech write on the label with the time and date the blood was drawn and place the label on the tube. Please also ensure that the anti-rejection or anti-

infective medicine name (example: tacrolimus) is on the tube. If you do not have a label, you can ask the lab to provide one.

You can mail it on your way home or ask the lab to put it in the mail for you. The mailer is already addressed and stamped. If you have an upcoming visit at UW within a few days of your lab draw, you may bring the mailer with you and drop it off at the lab in the hospital.

The mailer and blood tube are good for 7 days. If it arrives to UW Health after that time frame, we will not be able to process the specimen and will have to ask you to repeat the test.

Mailers will be sent in the mail to you. Please contact your coordinator to get more mailers sent. Please allow up to 2 weeks to receive these mailers.

## Lab Test Details

Lab Test	Normal Values	What It Is	Reasons for High or Rising Values	Reasons for Low or Decreasing Values	When to Call Your Transplant Coordinator
<b>Hematocrit (HCT)</b>	<b>35 – 50</b>	The amount of red blood cells (RBCs) in the blood. RBCs carry oxygen in the body. When the hematocrit (HCT) is low you may feel tired or weak.	<ul style="list-style-type: none"> <li>• Thicker blood</li> <li>• Smoking</li> <li>• Dehydration</li> </ul>	<ul style="list-style-type: none"> <li>• Anemia</li> <li>• Bleeding</li> <li>• Side effects of medicines</li> <li>• The kidneys not working well</li> </ul>	<ul style="list-style-type: none"> <li>• If the HCT drops by 5 or more points between readings, or slowly trends down.</li> <li>• If the HCT is less than 30.</li> <li>• If the HCT is more than 50.</li> </ul>
<b>White Blood Cell count (WBC)</b>	<b>3,000 - 10,000 (3 – 10)</b>	The cells in the body that fight off infection.	<ul style="list-style-type: none"> <li>• Infection</li> <li>• High doses of prednisone</li> <li>• If your spleen has been removed.</li> </ul>	<ul style="list-style-type: none"> <li>• Infection (CMV)</li> <li>• Side effects of medicines</li> </ul>	<ul style="list-style-type: none"> <li>• If your WBC is less than 3.</li> <li>• If your WBC is more than 10.</li> </ul>
<b>Creatinine</b>	<b>0.5 – 1.5</b>	A protein waste product made by the muscles and removed from the body by the kidneys. Creatinine measures how well the kidney transplant is working.	<ul style="list-style-type: none"> <li>• Rejection</li> <li>• Infection</li> <li>• Dehydration</li> <li>• Side effects of medicines</li> </ul>	<ul style="list-style-type: none"> <li>• Improving kidney function</li> </ul>	<ul style="list-style-type: none"> <li>• An increase of 0.3 or more from your baseline value.</li> <li>• A slow increase over time.</li> </ul>
<b>Glucose (Blood Sugar)</b>	<b>70 – 99</b>	The amount of sugar in the blood stream. Glucose is the main source of energy for the body. Insulin is a hormone that helps the body use glucose and keeps the glucose levels in the blood within normal ranges.	<ul style="list-style-type: none"> <li>• Side effects of medicines</li> <li>• Diabetes</li> <li>• Infection</li> <li>• Not taking enough insulin</li> </ul>	<ul style="list-style-type: none"> <li>• Taking too much insulin</li> <li>• Not eating</li> <li>• Nausea, vomiting, diarrhea</li> <li>• Exercise</li> </ul>	<ul style="list-style-type: none"> <li>• If you do not have diabetes, call if the fasting glucose level is over 100.</li> <li>• If you have diabetes, call your diabetes team to adjust your medicines if blood sugars are higher or lower than goal range (about 70 to 150).</li> </ul>

Lab Test	Normal Values	What It Is	Reasons for High or Rising Values	Reasons for Low or Decreasing Values	When to Call Your Transplant Coordinator
<b>Potassium (K+)</b>	<b>3.5 – 5.5</b>	An electrolyte the body uses that helps muscles function, especially the heart.	<ul style="list-style-type: none"> <li>• The kidneys not working well</li> <li>• Eating foods that contain a lot of potassium</li> <li>• Dehydration</li> <li>• Side effects of medicines</li> </ul>	<ul style="list-style-type: none"> <li>• Nausea, vomiting, or diarrhea</li> <li>• Side effects of medicines</li> <li>• Not getting enough potassium in the diet</li> </ul>	<ul style="list-style-type: none"> <li>• If the potassium is less than 3.5.</li> <li>• If the potassium is 5.8 or higher.</li> </ul>
<b>Magnesium</b>	<b>1.6-2.6</b>	Supports a healthy immune system, keeps the heartbeat steady, healthy brain development and bones to remain strong.	<ul style="list-style-type: none"> <li>• The kidneys not working well</li> <li>• Side effects of medicines</li> </ul>	<ul style="list-style-type: none"> <li>• Nausea, vomiting, or diarrhea</li> <li>• Not getting enough magnesium in the diet</li> </ul>	<ul style="list-style-type: none"> <li>• If the magnesium is less than 1.6</li> <li>• If the magnesium is 2.6 or higher.</li> </ul>
<b>Drug levels (Tacrolimus, Cyclosporine, Everolimus or Sirolimus)</b>	Your transplant team will tell you your target range.	Measures the amount of medicine in your blood to know if you are getting enough medicine but not too much.	<ul style="list-style-type: none"> <li>• Taking the medicine <b>before</b> your blood draw</li> <li>• Other medicines</li> <li>• Changes in diet</li> <li>• Diarrhea</li> </ul>	<ul style="list-style-type: none"> <li>• Missing doses of medicines</li> <li>• Other medicines</li> <li>• Changes in diet</li> </ul>	<ul style="list-style-type: none"> <li>• Your transplant coordinator will call you if you need any changes in your dose of medicines.</li> </ul>

## Respiratory Treatments

You will be on various respiratory (lung) therapies following transplant. Below you will find a general recommendation on the order of completing:

1. Bronchodilator (Albuterol<sup>®</sup>, Xopenex<sup>®</sup>, Duoneb<sup>®</sup>) as applicable
2. Hypertonic saline as applicable
3. Airway clearance therapy
4. Inhaled antibiotics (amphotericin, Tobin<sup>®</sup>, Colistin<sup>®</sup>) as applicable
5. Other medicines (Flovent<sup>®</sup>, Pulmicort<sup>®</sup>, Advair<sup>®</sup>)
6. Incentive spirometry: 10 times hourly during the first 6 weeks after transplant
7. Home spirometry: Perform when breathing is at baseline, 1-2 hours after completing airway treatments

If you have questions or need more supplies of any of your respiratory equipment (other than your pocket spirometer), contact your home health equipment (DME) provider.

### Airway Clearance

There are many possible treatments that your doctor might recommend to help you to remove mucus from the lungs. This can also prevent lung collapse or open up areas that have collapsed. A member of the team will teach you how to use these.

- Positive Expiratory Pressure (PEP)
- Aerobika
- Acapella
- Coughing and deep breathing.
  1. It is best if you are in an upright position. Place your hand on your stomach. Breathe in deeply and slowly through your nose. Focus on pushing your stomach out as you breathe in. Hold your breath for a second or two.
  2. Breathe out slowly and fully through your mouth.
  3. Repeat twice more.

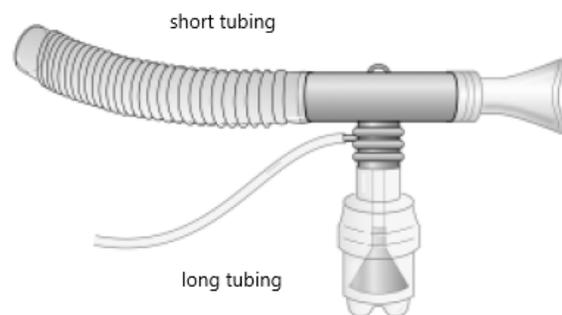
4. Breathe in again and hold your breath. Then cough (if told to do so) from deep in the lungs (not a shallow throat cough) or repeat step 2. Support (splint) your incision to decrease pain while coughing.
5. Repeat exercise.

### Nebulizer

A nebulizer is a small cup that holds liquid medicine. The medicine is turned into a fine mist by a small air compressor. Taking slow, deep breaths of mist takes the medicine right to the lungs where it works quickly and has fewer side effects compared with medicines taken by mouth.

### What equipment do I need to use the small volume nebulizer?

- Air compressor
- Small volume nebulizer kit:
  - Medicine cup
  - Insert and cap
  - “T” connector
  - Short “according” tubing
  - Mouthpiece
  - Long smooth tubing
- Plastic medicine vials



### How do I prepare the nebulizer?

1. Wash your hands well with soap and warm water and dry.
2. Plug in the air compressor and set it on a hard surface, such as a table. Twist and push the long, smooth tubing on the compressor outlet to make a snug fit.
3. Check filter per manufacturer instruction or monthly with use. Replace if dirty, clogged or wet.
4. Add the medicine into the cup. Unit dose plastic vials. Twist off the end of the vial and squeeze the liquid into the cup.
5. Place the mouthpiece and short tubing on the T-piece. Connect the T-piece onto the medicine cup. Attach the smooth tubing from the compressor to the nebulizer.
6. Turn the compressor on. You should see a fine mist. If not, disconnect the smooth tubing and feel for air coming from the compressor. Then check all connections. If the nebulizer is still not misting, consult the instruction manual for proper setup.

### How do I do the nebulizer treatment?

1. Place the mouthpiece in your mouth. Some small children use a mask over the mouth and nose rather than a mouthpiece.
2. Take slow, deep, even breaths through the mouth. Hold your breath briefly on each inhale. Breathe out slowly.
3. Make sure the medicine cup is kept upright.
4. Stop the treatment if you notice any side effects or reactions to the medicine.
5. Do the treatment until the medicine is finished (no mist comes out). If the medicine sticks to the sides of the cup, gently tap the sides of the cup.

6. After the treatment, take the medicine cup apart. Rinse it with hot tap water. Allow it to air dry on a clean towel.



### How do I clean and disinfect the nebulizer?

All of your nebulizer parts must be cleaned and disinfected twice a week. There are 3 ways to clean and disinfect a nebulizer: by hand; or by heat methods: dishwasher or microwave.

### How do I clean and disinfect by hand?

To clean and disinfect by hand, you can use either vinegar and water method or rubbing alcohol method. If you have cystic fibrosis (CF) do not use the vinegar and water method.

### Vinegar and Water Method

1. Take the nebulizer apart. Wash the pieces in warm soapy water.
2. Rinse with hot tap water.
3. Place the nebulizer pieces in a bowl and add enough vinegar and water mixture to completely cover the pieces. Make the mixture of 1 part white vinegar (5% solution from your grocery store) to 3 parts water (1 cup vinegar to 3 cups water).
4. Soak the pieces for 30 minutes to 2 hours.
5. Rinse all of the pieces with **sterile water**. Do not use water from the faucet, bottled, or distilled water. You can make water sterile by

boiling it for 5 minutes. Use this water once, and then throw it out.

6. Place the pieces on a paper towel to dry.

### **Rubbing Alcohol Method**

1. Take the nebulizer apart. Wash the pieces in warm soapy water.
2. Rinse with hot tap water.
3. Place the pieces in a bowl and add enough rubbing alcohol (isopropyl alcohol) to completely cover the pieces.
4. Soak the pieces for 5 minutes.
5. Rinse the pieces with **sterile water**. Do not use water from the faucet, bottled, or distilled water. You can make water sterile by boiling it for 5 minutes. Use this water once, and then throw it out.
6. Place the nebulizer

### **How to Clean and Disinfect by Heat?**

Use heat methods below only for sturdy, hard plastic nebulizer cups. Heat cleaning may melt lighter, clear plastic nebulizers.

### **Dishwasher**

1. Take the nebulizer apart.
2. Place the pieces in a dishwasher basket on the top rack of the dishwasher.
3. After the dishwasher cycle is done, remove the pieces and shake out the extra water.
4. Air-dry the pieces on a paper towel.

### **Microwave**

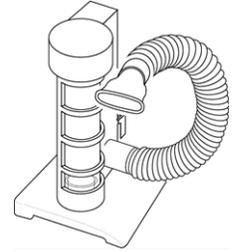
1. Take the nebulizer apart. Wash the pieces in warm soapy water.
2. Rinse with hot water.
3. Place the pieces in a bowl. Add enough water to completely cover the pieces.
4. Microwave for 3-5 minutes. Use shorter time in high power

microwaves to keep the pieces from melting.

5. Place the pieces on a paper towel to dry.

### **Incentive Spirometer**

Deep breathing is vital to your well-being. Deep breathing expands the small air sacs of your lungs. Deep breathing also helps keep your lungs and airways clear. You take deep breaths each hour without being aware of it. These deep breaths are automatic and occur in the form of sighs and yawns. There are times when your normal breathing pattern changes. Your breathing becomes more shallow when:



- You are moving very little.
- You are on bedrest.
- You have pain after surgery.

You may try to avoid deep breathing after surgery to reduce pain. Taking full, deep breaths will help prevent lung problems after surgery. Pain medicine can be given to help you take deep breaths more easily. Your nurse will explain the deep breathing and coughing exercises you will need to do after surgery. These are done to improve lung expansion and to prevent infection and other lung problems. We will also show you how to use the incentive spirometer. This is a tool to help you breathe deeply. Also, you need to cough when you have secretions in your lungs.

### **How to Use Your Incentive Spirometer**

1. Hold the unit upright, breathe out like normal and place your lips tightly around the mouthpiece.
2. **Take a deep breath.** Inhale enough air to slowly raise the Flow Rate Guide between the arrows.
3. **Hold the deep breath.** Continue to inhale, keeping the guide as high as

you can for as long as you can, or as directed by your nurse or respiratory therapist.

4. **Breathe out and relax.** Remove the mouthpiece and breathe out like normal. After each long, deep breath, take a moment to rest, relax, and breathe normally. Repeat these steps 10 times an hour while you are awake, every day you are in the hospital or as directed by your nurse.
5. Cough after using your breathing tool ten times.

### Pocket Spirometer

After having a lung transplant, you will need to check your lung function every day. Many patients who have rejection do not feel any different. Patients are often not aware they are rejecting their new lungs. Rejection causes swelling in the airways of your lungs. A decrease in your lung function is a sign of rejection.

We gave you a Smart One spirometer to look at your lung function. Using this tool, you will look at:

- **Forced expiratory volume in one second (FEV1):** This measures the volume of air that you exhale during the first second that you are forcing air out of your lungs.
- **Peak expiratory flow (PEF):** This measure how fast the air comes out of your lungs.



### Setup

You must use the Smart One spirometer with the Smart One app. To begin, download the Smart One app on your smart phone or tablet. You can download this for free from Apple Store (for iPhone and iPad).

The first time you open the app, you will need to allow Smart One to access your device's location. This will allow your phone/tablet's Bluetooth to find your spirometer. You will also need to enter your details: birthdate, origin, weight, height, and sex. This will help the app figure out values for your lung measurements. You will only need to do this the first time. Your smartphone will then connect to your spirometer each time you open the app.

### Using the Spirometer

You will need your spirometer and your phone/tablet. It is best to do the test standing or sitting upright.

1. Open the app. The display screen will say "Connected device."
2. When you are ready to perform your test, press the "start test" button on your phone.
3. The screen will read, "Blow to start first test." Take the deepest breath you can, filling your lungs with air.
4. Press your lips tightly around the mouthpiece, then blow the air out as fast and hard as you can. Do this until you cannot blow any more air out. The device will display a message such as "Good job" or "Blow faster" when the test is complete.
5. Repeat the test two more times for a total of three attempts

The Smart One app will save the best results from your three attempts. Document this number on your home records sheet (see next page)

## How to Check Your Results

You can view your results, by choosing “Results” from the menu at the bottom of your screen. You will be looking for a 10% decline in your results.

Swelling in the lungs may be caused by things other than rejection. A cold or infection can also cause swelling. With a 10% or more decrease in your spirometry numbers, you need to call your transplant coordinator. The transplant coordinator will figure out what is causing the drop. With rejection, quick treatment prevents further lung damage.

## How do you know you have a 10% change?

Remember, you will be recording your spirometer values (with an emphasis on your FEV1) twice daily, in the morning and at night time. Your spirometer will automatically give you your highest reading of your three blows each time you use it. Over time, you will be able to figure out what your “best overall FEV1” is. We suggest highlighting this number on your home records or circling it so you know what number to use for comparison.

Call your coordinator if your daily spirometry falls 10% or more from your best FEV1 (the one you highlighted/circled) on two readings in a row.

## Here are some examples to help you out:

1. If your best FEV1 for today is higher than the “best overall FEV1”, good for you! That means your lung function is improving and you may even have a new “best overall FEV1”.
2. If your best FEV1 for today is lower than the “best overall FEV1” then we need to figure out if your value has

dropped more than 10%. There are two ways to do this:

- Take your “best overall FEV1” and multiply it by 0.9. This will give you a value that represents a full 10% drop. If your daily FEV1 for today is lower than this value, then there may be reason for concern.
- Utilize the FEV1 chart on the following pages to automatically calculate the 10% drop value.

If you have a 10% drop, it’s ok, just make a note of it. If on your next attempt you have a similar value that represents a 10% drop from your “best overall FEV1”, this means you have two consecutive values that are concerning and you will need to call your coordinator to discuss.

The key point to remember is that you aren’t calculating a 10% drop from day to day or from morning to night. Rather, you **MUST** calculate your 10% drop from your “best overall FEV1”.

## Cleaning

Dust or foreign bodies (such as hair or mucus) could slow or block the moving parts of the turbine. This could make the result less accurate or damage the spirometer.

- **Turbine**-Clean the turbine weekly. To clean the turbine, pull it out of the socket by turning it counterclockwise and simply pulling it out. See the Smart One user manual to find out how to remove and replace the turbine. Wash the turbine in warm soapy water and move it around for 2-3 minutes. Rinse in clean water. Never clean under a direct stream of

water. Shake gently and allow to air dry on a towel.

- **Mouthpiece**-Clean the mouthpiece daily. Pull it apart from the turbine and wash in warm soapy water. Rinse with clean water and allow to air dry on a towel.

### **Clinic Visits**

Your results will be reviewed at your clinic visits. Bring your home records and/or phone/tablet with you to transplant clinic.

### **Batteries**

The device runs on 2 AAA batteries. A message will display on your phone/tablet when the battery is low.

## Spirometry Record

My current best overall FEV1 is \_\_\_\_\_

Date:			Date:			Date:		
	AM	PM		AM	PM		AM	PM
<b>FEV1</b>								

Date:			Date:			Date:		
	AM	PM		AM	PM		AM	PM
<b>FEV1</b>								

Date:			Date:			Date:		
	AM	PM		AM	PM		AM	PM
<b>FEV1</b>								

Date:			Date:			Date:		
	AM	PM		AM	PM		AM	PM
<b>FEV1</b>								

Date:			Date:			Date:		
	AM	PM		AM	PM		AM	PM
<b>FEV1</b>								

Date:			Date:			Date:		
	AM	PM		AM	PM		AM	PM
<b>FEV1</b>								

Date:			Date:			Date:		
	AM	PM		AM	PM		AM	PM
<b>FEV1</b>								

Date:			Date:			Date:		
	AM	PM		AM	PM		AM	PM
<b>FEV1</b>								

\*\*Call your coordinator if your daily spirometer reading drops by 10% or more from your best overall FEV1 on two readings in a row\*\*

## UW Health Transplant Center

\*\*Call your coordinator if your daily spirometer reading drops by 10% or more from your best overall FEV1 on two readings in a row\*\*

<b>FEV1 Chart</b>									
<b>My best overall FEV1</b>	<b>10% drop</b>								
0.50	0.45	0.81	0.73	1.12	1.01	1.43	1.29	1.74	1.57
0.51	0.46	0.82	0.74	1.13	1.02	1.44	1.30	1.75	1.58
0.52	0.47	0.83	0.75	1.14	1.03	1.45	1.31	1.76	1.58
0.53	0.48	0.84	0.76	1.15	1.04	1.46	1.31	1.77	1.59
0.54	0.49	0.85	0.77	1.16	1.04	1.47	1.32	1.78	1.60
0.55	0.50	0.86	0.77	1.17	1.05	1.48	1.33	1.79	1.61
0.56	0.50	0.87	0.78	1.18	1.06	1.49	1.34	1.80	1.62
0.57	0.51	0.88	0.79	1.19	1.07	1.50	1.35	1.81	1.63
0.58	0.52	0.89	0.80	1.20	1.08	1.51	1.36	1.82	1.64
0.59	0.53	0.90	0.81	1.21	1.09	1.52	1.37	1.83	1.65
0.60	0.54	0.91	0.82	1.22	1.10	1.53	1.38	1.84	1.66
0.61	0.55	0.92	0.83	1.23	1.11	1.54	1.39	1.85	1.67
0.62	0.56	0.93	0.84	1.24	1.12	1.55	1.40	1.86	1.67
0.63	0.57	0.94	0.85	1.25	1.13	1.56	1.40	1.87	1.68
0.64	0.58	0.95	0.85	1.26	1.13	1.57	1.41	1.88	1.69
0.65	0.59	0.96	0.86	1.27	1.14	1.58	1.42	1.89	1.70
0.66	0.59	0.97	0.87	1.28	1.15	1.59	1.43	1.90	1.71
0.67	0.60	0.98	0.88	1.29	1.16	1.60	1.44	1.91	1.72
0.68	0.61	0.99	0.89	1.30	1.17	1.61	1.45	1.92	1.73
0.69	0.62	1.00	0.90	1.31	1.18	1.62	1.46	1.93	1.74
0.70	0.63	1.01	0.91	1.32	1.19	1.63	1.47	1.94	1.75
0.71	0.64	1.02	0.92	1.33	1.20	1.64	1.48	1.95	1.76
0.72	0.65	1.03	0.93	1.34	1.21	1.65	1.49	1.96	1.76
0.73	0.66	1.04	0.94	1.35	1.22	1.66	1.49	1.97	1.77
0.74	0.67	1.05	0.95	1.36	1.22	1.67	1.50	1.98	1.78
0.75	0.68	1.06	0.95	1.37	1.23	1.68	1.51	1.99	1.79
0.76	0.68	1.07	0.96	1.38	1.24	1.69	1.52	2.00	1.80
0.77	0.69	1.08	0.97	1.39	1.25	1.70	1.53	2.01	1.81
0.78	0.70	1.09	0.98	1.40	1.26	1.71	1.54	2.02	1.82
0.79	0.71	1.10	0.99	1.41	1.27	1.72	1.55	2.03	1.83
0.80	0.72	1.11	1.00	1.42	1.28	1.73	1.56	2.04	1.84

## FEV1 Chart

<b>My best overall FEV1</b>	<b>10% drop</b>								
2.05	1.85	2.36	2.12	2.67	2.40	2.98	2.68	3.29	2.96
2.06	1.85	2.37	2.13	2.68	2.41	2.99	2.69	3.30	2.97
2.07	1.86	2.38	2.14	2.69	2.42	3.00	2.70	3.31	2.98
2.08	1.87	2.39	2.15	2.70	2.43	3.01	2.71	3.32	2.99
2.09	1.88	2.40	2.16	2.71	2.44	3.02	2.72	3.33	3.00
2.10	1.89	2.41	2.17	2.72	2.45	3.03	2.73	3.34	3.01
2.11	1.90	2.42	2.18	2.73	2.46	3.04	2.74	3.35	3.02
2.12	1.91	2.43	2.19	2.74	2.47	3.05	2.75	3.36	3.02
2.13	1.92	2.44	2.20	2.75	2.48	3.06	2.75	3.37	3.03
2.14	1.93	2.45	2.21	2.76	2.48	3.07	2.76	3.38	3.04
2.15	1.94	2.46	2.21	2.77	2.49	3.08	2.77	3.39	3.05
2.16	1.94	2.47	2.22	2.78	2.50	3.09	2.78	3.40	3.06
2.17	1.95	2.48	2.23	2.79	2.51	3.10	2.79	3.41	3.07
2.18	1.96	2.49	2.24	2.80	2.52	3.11	2.80	3.42	3.08
2.19	1.97	2.50	2.25	2.81	2.53	3.12	2.81	3.43	3.09
2.20	1.98	2.51	2.26	2.82	2.54	3.13	2.82	3.44	3.10
2.21	1.99	2.52	2.27	2.83	2.55	3.14	2.83	3.45	3.11
2.22	2.00	2.53	2.28	2.84	2.56	3.15	2.84	3.46	3.11
2.23	2.01	2.54	2.29	2.85	2.57	3.16	2.84	3.47	3.12
2.24	2.02	2.55	2.30	2.86	2.57	3.17	2.85	3.48	3.13
2.25	2.03	2.56	2.30	2.87	2.58	3.18	2.86	3.49	3.14
2.26	2.03	2.57	2.31	2.88	2.59	3.19	2.87	3.50	3.15
2.27	2.04	2.58	2.32	2.89	2.60	3.20	2.88	3.51	3.16
2.28	2.05	2.59	2.33	2.90	2.61	3.21	2.89	3.52	3.17
2.29	2.06	2.60	2.34	2.91	2.62	3.22	2.90	3.53	3.18
2.30	2.07	2.61	2.35	2.92	2.63	3.23	2.91	3.54	3.19
2.31	2.08	2.62	2.36	2.93	2.64	3.24	2.92	3.55	3.19
2.32	2.09	2.63	2.37	2.94	2.65	3.25	2.93	3.56	3.20
2.33	2.10	2.64	2.38	2.95	2.66	3.26	2.93	3.57	3.21
2.34	2.11	2.65	2.39	2.96	2.66	3.27	2.94	3.58	3.22
2.35	2.12	2.66	2.39	2.97	2.67	3.28	2.95	3.59	3.23

## FEV1 Chart

<b>My best overall FEV1</b>	<b>10% drop</b>								
3.60	3.24	3.91	3.52	4.22	3.80	4.53	4.08	4.84	4.36
3.61	3.25	3.92	3.53	4.23	3.81	4.54	4.09	4.85	4.37
3.62	3.26	3.93	3.54	4.24	3.82	4.55	4.10	4.86	4.37
3.63	3.27	3.94	3.55	4.25	3.83	4.56	4.10	4.87	4.38
3.64	3.28	3.95	3.56	4.26	3.83	4.57	4.11	4.88	4.39
3.65	3.29	3.96	3.56	4.27	3.84	4.58	4.12	4.89	4.40
3.66	3.29	3.97	3.57	4.28	3.85	4.59	4.13	4.90	4.41
3.67	3.30	3.98	3.58	4.29	3.86	4.60	4.14	4.91	4.42
3.68	3.31	3.99	3.59	4.30	3.87	4.61	4.15	4.92	4.43
3.69	3.32	4.00	3.60	4.31	3.88	4.62	4.16	4.93	4.44
3.70	3.33	4.01	3.61	4.32	3.89	4.63	4.17	4.94	4.45
3.71	3.34	4.02	3.62	4.33	3.90	4.64	4.18	4.95	4.46
3.72	3.35	4.03	3.63	4.34	3.91	4.65	4.19	4.96	4.46
3.73	3.36	4.04	3.64	4.35	3.92	4.66	4.19	4.97	4.47
3.74	3.37	4.05	3.65	4.36	3.92	4.67	4.20	4.98	4.48
3.75	3.38	4.06	3.65	4.37	3.93	4.68	4.21	4.99	4.49
3.76	3.38	4.07	3.66	4.38	3.94	4.69	4.22	5.00	4.50
3.77	3.39	4.08	3.67	4.39	3.95	4.70	4.23	5.01	4.51
3.78	3.40	4.09	3.68	4.40	3.96	4.71	4.24	5.02	4.52
3.79	3.41	4.10	3.69	4.41	3.97	4.72	4.25	5.03	4.53
3.80	3.42	4.11	3.70	4.42	3.98	4.73	4.26	5.04	4.54
3.81	3.43	4.12	3.71	4.43	3.99	4.74	4.27	5.05	4.55
3.82	3.44	4.13	3.72	4.44	4.00	4.75	4.28	5.06	4.55
3.83	3.45	4.14	3.73	4.45	4.01	4.76	4.28	5.07	4.56
3.84	3.46	4.15	3.74	4.46	4.01	4.77	4.29	5.08	4.57
3.85	3.47	4.16	3.74	4.47	4.02	4.78	4.30	5.09	4.58
3.86	3.47	4.17	3.75	4.48	4.03	4.79	4.31	5.10	4.59
3.87	3.48	4.18	3.76	4.49	4.04	4.80	4.32	5.11	4.60
3.88	3.49	4.19	3.77	4.50	4.05	4.81	4.33	5.12	4.61
3.89	3.50	4.20	3.78	4.51	4.06	4.82	4.34	5.13	4.62
3.90	3.51	4.21	3.79	4.52	4.07	4.83	4.35	5.14	4.63

## FEV1 Chart

<b>My best overall FEV1</b>	<b>10% drop</b>								
5.15	4.64	5.46	4.91	5.77	5.19	6.08	5.47	6.39	5.75
5.16	4.64	5.47	4.92	5.78	5.20	6.09	5.48	6.40	5.76
5.17	4.65	5.48	4.93	5.79	5.21	6.10	5.49	6.41	5.77
5.18	4.66	5.49	4.94	5.80	5.22	6.11	5.50	6.42	5.78
5.19	4.67	5.50	4.95	5.81	5.23	6.12	5.51	6.43	5.79
5.20	4.68	5.51	4.96	5.82	5.24	6.13	5.52	6.44	5.80
5.21	4.69	5.52	4.97	5.83	5.25	6.14	5.53	6.45	5.81
5.22	4.70	5.53	4.98	5.84	5.26	6.15	5.54	6.46	5.81
5.23	4.71	5.54	4.99	5.85	5.27	6.16	5.54	6.47	5.82
5.24	4.72	5.55	5.00	5.86	5.27	6.17	5.55	6.48	5.83
5.25	4.73	5.56	5.00	5.87	5.28	6.18	5.56	6.49	5.84
5.26	4.73	5.57	5.01	5.88	5.29	6.19	5.57	6.50	5.85
5.27	4.74	5.58	5.02	5.89	5.30	6.20	5.58	6.51	5.86
5.28	4.75	5.59	5.03	5.90	5.31	6.21	5.59	6.52	5.87
5.29	4.76	5.60	5.04	5.91	5.32	6.22	5.60	6.53	5.88
5.30	4.77	5.61	5.05	5.92	5.33	6.23	5.61	6.54	5.89
5.31	4.78	5.62	5.06	5.93	5.34	6.24	5.62	6.55	5.90
5.32	4.79	5.63	5.07	5.94	5.35	6.25	5.63	6.56	5.90
5.33	4.80	5.64	5.08	5.95	5.36	6.26	5.63	6.57	5.91
5.34	4.81	5.65	5.09	5.96	5.36	6.27	5.64	6.58	5.92
5.35	4.82	5.66	5.09	5.97	5.37	6.28	5.65	6.59	5.93
5.36	4.82	5.67	5.10	5.98	5.38	6.29	5.66	6.60	5.94
5.37	4.83	5.68	5.11	5.99	5.39	6.30	5.67	6.61	5.95
5.38	4.84	5.69	5.12	6.00	5.40	6.31	5.68	6.62	5.96
5.39	4.85	5.70	5.13	6.01	5.41	6.32	5.69	6.63	5.97
5.40	4.86	5.71	5.14	6.02	5.42	6.33	5.70	6.64	5.98
5.41	4.87	5.72	5.15	6.03	5.43	6.34	5.71	6.65	5.99
5.42	4.88	5.73	5.16	6.04	5.44	6.35	5.71	6.66	5.99
5.43	4.89	5.74	5.17	6.05	5.45	6.36	5.72	6.67	6.00
5.44	4.90	5.75	5.17	6.06	5.45	6.37	5.73	6.68	6.01
5.45	4.90	5.76	5.18	6.07	5.46	6.38	5.74	6.69	6.02

## **Organ Rejection**

Rejection is normal immune response to a foreign organ in the body and is a common problem after transplant. Your body is trying to destroy it. Treatment varies for each kind of rejection. The signs and effects also vary for each type of organ.

Rejection can be diagnosed through blood work or a biopsy. “Biopsy” means taking a small sample of tissue from an organ. It will be looked at under a microscope. A biopsy is done during a bronchoscopy when you have a change in your breathing, a change in your lung function, or have recently been treated for rejection.

### **Acute Cellular Rejection**

This type of rejection is a **direct** response to your new organ. The T cells (or “killer cells”) of your immune system see your organ as foreign. A biopsy is done to diagnose this.

This type of rejection tends to happen in the first 12 months after transplant but can also occur at any other time.

A biopsy with proven rejection often requires treatment. Treatment may require hospitalization for more monitoring and medicines. Your doctor may also increase your anti-rejection medicines. With prompt medical treatment, acute cellular rejection can usually be stopped.

A repeat biopsy will be done 4-6 weeks later to see if the treatment worked.

### **Acute Antibody-Mediated Rejection (AMR)**

AMR is an *indirect* response to your new organ. It is diagnosed through blood work. The B cells (or “memory cells”) of your immune system notice the cells from the new organ. An immune response begins.

The body starts to make new antibodies to fight off the new organ. Treatment includes different medicines. If needed, antibodies can be removed from your blood. This process is called plasma exchange. The goal is to remove harmful antibodies that are fighting your new organ.

### **Chronic Rejection**

Chronic rejection typically occurs at some point after the first year. Usually it is suspected with a slow decline in lung function. Changes of chronic rejection may be seen on CT Chest. Rarely, chronic rejection may be seen on transbronchial biopsies. Chronic rejection has several names including bronchiolitis obliterans syndrome “BOS” or chronic lung allograft dysfunction “CLAD”. Your doctor will review the risks and benefits of ongoing treatment based on these results. You may need other medicines and treatments.

## **Testing for Rejection/Signs**

### **How do you test for rejection?**

Most people with lung transplants have rejection. The sooner we find and treat rejection, the better the outcomes. Acute cellular rejection is tested through a biopsy. Acute antibody-mediated rejection is tested through blood work. Chronic rejection is done through comprehensive testing like chest CTs, your ability to perform activities of daily living, pulmonary function tests, etc.

### **What are the signs of rejection?**

Rejection may cause your lung(s) to work less efficiently. This can produce symptoms. These are often the same symptoms of advanced lung disease that you had before the transplant. *Call your coordinator* for any of these signs.

## Signs of Lung Rejection

- Shortness of breath
- Feeling more tired than usual
- 10% decrease or more from your best overall FEV1 on two consecutive occasions
- Increase coughing (usually dry)
- Change in sputum color
- Low-grade fever

## Infection

### Reasons for Infection Risk

As a result of your weakened immune system, you are more at risk to get infections. This includes typical, everyday infections such as colds and flu, and also some unusual infections that are unique to transplant patients. When you get an infection, you will not be able to fight it as well because of your weakened immune system. Some symptoms of infection may be more severe, and they may not go away as quickly as before. Also, you may need medicine to help you get better. Sometimes you will need to be admitted to the hospital to give stronger medicines to treat the infections.

Your transplant team tries to adjust your medicines, so you get enough to prevent rejection, but not weaken the immune system too much.

### How to Prevent Infections

It is important to protect yourself from infections. There are ways you can protect yourself.

- Frequent hand washing/hand sanitizer use
- Wear a spore filter (duckbill) mask:
  - When in the hospital, clinic, or lab areas
  - In crowded areas where you are unable to control the distance between you and others.

- When working in dusty places (attics or construction areas) or working with soil or mulch. This includes any yard work, gardening, or farming
- When flying
- Avoid direct contact with people known to be ill.
- Avoid raw or undercooked meats
- Avoid changing cat litter boxes or cleaning birdcages.
- Do not keep fresh cut flowers in the home, the flowers form mold in the standing water.
- Wear gloves when doing gardening, farm work, or outdoor work.
- Practice good routine dental care.
- Keep up to date on vaccinations.
- Keep all pet immunizations up to date.
- Avoid smoking and exposure to secondhand smoke (including campfires).
- Practice safe sex.
- Wear protective clothing and insect repellent when outdoors.
- If you have well water, you will need to drink bottled water.

### Treatment

You should tell the transplant team whenever you have any of the below symptoms of infection. You may need medicine to treat infections. Most of these medicines are safe to take. Some medicines used to treat infections can affect some transplant medicines.

## Types and Symptoms of Infections

### Viral Infections

Many common upper respiratory and gastrointestinal infections are caused by viruses. There is no cure for these common viruses; they simply have to run their course. Try to get plenty of rest and drink plenty of fluids to help your body fight the virus. You should see your local doctor if your symptoms last longer than expected or if you seem to be getting worse instead of better as time goes on.

Respiratory (lung) infection symptoms:

- Fever (oral temperature over 100°F)
- Cough
- Yellow or green tinged phlegm
- Sore throat
- Fatigue

Gastrointestinal (stomach/intestine) infection symptoms:

- Fever (oral temperature over 100°F)
- Chills
- Diarrhea
- Nausea
- Vomiting
- Fatigue

As well as common, general viruses, transplant patients need to be aware of other specific viruses that can cause problems following organ transplant

### Cytomegalovirus (CMV)

Cytomegalovirus or CMV is a virus that most people have been exposed to. It lives in the body for years and often goes unnoticed until a person has a suppressed immune system. You will take valganciclovir (Valcyte®) after transplant to help prevent CMV. Some people will only need these medicines for a short time (roughly 3-12 months). Others take them lifelong.

Symptoms of CMV can include:

- Nausea
- Vomiting
- Diarrhea
- Feeling tired
- Decreased white blood cell count (often less than 2)
- Fever (oral temperature over 100°F)

There is a blood test for CMV. Your transplant doctor will decide if testing is needed. CMV can be a very serious infection, but there is medicine to treat it.

### Herpes Infections

Herpes simplex is a virus most people have been exposed to sometime in their lives. It can remain hidden in our bodies for years and become active at any time. It most commonly causes *cold sores* on the lips and in the mouth. This can be treated with antiviral medicines such as acyclovir. Another type of herpes simplex causes genital sores. You may have these viruses with no symptoms. After transplant when the immune system is weakened, symptoms may appear. These can be controlled with medicines.

Varicella zoster virus, also known as shingles, is another type of herpes virus. Shingles appear as a rash or series of small blisters. They may be painful and most often form on one side of the chest, back, hip or head. Shingles occur more often in older people. Transplant patients may get shingles because of the weakened immune system. Early treatment will help shorten the length of the illness and may ease symptoms.

### Influenza (Flu)

Influenza is a viral infection of the nose and throat. It is more severe than the common cold and comes on suddenly. The flu is caused by germs found in the air and

on surfaces.

Influenza can be mild to severe. You should get a flu shot (vaccination) every year to help prevent you from getting sick. You cannot get the nasal spray as it is a live vaccine. There are many strains of influenza, so you may get influenza even if you got your flu shot. Symptoms include fever, head and muscle aches, extreme tiredness, and sometimes, cold symptoms.

### **Epstein - Barr virus (EBV)**

EBV can cause infectious mononucleosis (mono). It can also put you at risk for lymphoma, or a cancer of the lymphatic system. There is a blood test for EBV. Symptoms include enlarged lymph nodes, tiredness, sore throat, and fever.

### **Papillomaviruses**

Papillomaviruses are a family of viruses that can cause warts on the hands, fingers, face, and genitals. Decrease your risk for these viruses by limiting close contacts and use safe sex practices.

### **Hepatitis B**

Hepatitis B is a viral infection of the liver that is spread through blood and sexual contact. It can lead to liver failure. Patients should be vaccinated against Hepatitis B before transplant.

Hepatitis B can be treated with anti-viral medicines. After transplant, Hepatitis B can re-activate and cause liver damage, so patients with Hepatitis B need life-long anti-viral therapy after transplant.

### **Hepatitis C**

Hepatitis C is another viral infection of the liver that can lead to liver damage. It is spread through blood or sexual contact. After transplant, Hepatitis C can re-activate and damage the liver. There are

medicines to treat Hepatitis C and prevent liver damage after transplant.

\*If you have agreed, there is the possibility you may receive an organ with Hepatitis C or Hepatitis B, even if you do not have the virus before transplant. You have to sign a special consent form to receive these organs. After your transplant, the doctors will prescribe anti-viral therapy to treat these viruses. Hepatitis B anti-viral is taken life-long. Hepatitis C antiviral therapy is generally done over the course of a few months. Your doctors will decide when you should start therapy for either virus.

### **West Nile Virus (WNV)**

WNV is a virus that can affect the central nervous system. It is most often spread through the bite from an infected mosquito. In patients with weakened immune systems it can be very severe. It can cause encephalitis, meningitis, and even death. Transplant recipients should wear long-sleeved shirts and pants and use insect repellents to prevent mosquito bites. Symptoms can include fever, neck stiffness, tremors, muscle weakness, vision loss, confusion, or numbness.

### **Lyme Disease**

Lyme disease is a tick-borne illness. It is spread through a tick bite and can start as a rash near the site of the bite. Symptoms of Lyme disease can include tiredness, loss of appetite, headache, neck stiffness, localized swelling and fever. If you had a recent tick bite along with these symptoms, notify your provider.

### **Toxoplasmosis**

Toxoplasmosis is a parasite spread by consuming undercooked meat, contaminated water, or infected cat feces. Donors may not know they are infected, so all donors are screened for this infection. If

your donor is positive for toxoplasmosis, you will need treatment to prevent active disease.

### **Bacterial Infections**

Bacterial infections can and should be treated with antibiotics.

### **Pneumonia**

Pneumonia is a lung infection. There are different types of pneumonia caused by bacteria, viruses, or fungus. Symptoms include cough with green, yellow, or brown mucous, fever, chills, shortness of breath, chest pain, and weakness.

One type of bacterial pneumonia is **Pneumocystis jiroveci** or **PJP**. You are at higher risk for this type after transplant. This is an infection in your lungs. After your transplant, you will take TMP/Sulfa (Bactrim), atovaquone or an inhaled medicine called pentamidine to help protect you from this infection. Symptoms include cough, fever and problems breathing.

### **Urinary Tract Infections**

Urinary tract infections (UTI) occur when germs get into the urinary tract. Symptoms include burning or pain with urination, increased pressure, or feeling the need to urinate right away, urinating small amounts more often, bloody urine and fever or chills.

### **Clostridium difficile**

*Clostridium difficile* (C.diff) is a germ that lives in the digestive tract (stomach and intestines or bowel). C.diff can make toxins that cause watery diarrhea, belly pain/tenderness, fever, loss of appetite, and nausea. People who are taking antibiotics can get sick with C.diff. There are medicines that can be used to treat C.diff.

### **Wound Infections**

If you develop an infection in your **incision, drain, or catheter site**, contact your transplant coordinator right away. You may need antibiotics to treat the infection. Symptoms of wound infections include:

- Increased redness or warm to the touch.
- Pus-like or green drainage.
- Temperature by mouth is greater than 100°F or 38.3°C.
- Excessive swelling or bleeding or bruising.
- Increased pain you cannot control with your pain medicine.

### **Fungal Infections**

There are different types of fungal infections. They can be difficult to treat in transplant patients and most often will require the use of anti-fungal medicines.

- **Thrush:** The most common fungal infection after transplant is a yeast infection in your mouth called thrush. Right after transplant, you may be on a medicine called Nystatin or another antifungal medicine to help prevent thrush. Symptoms include small, white bumps or patches in your mouth or throat. They may be painful or cause problems swallowing.
- **Athlete's foot** is another common fungal infection. You may use over-the-counter remedies to relieve the symptoms of athlete's foot. Contact your transplant coordinator or local doctor if symptoms persist.
- **Aspergillus:** Aspergillus is a common fungus found indoors and outdoors. Most people breathe in aspergillus spores without being affected. When your immune system is weakened, exposure to this fungus can cause illness. The

most common place for this infection is the lung but can be found in other parts of your body. In addition to lifestyle changes to lower your risk of exposure, you may need antifungal medicines to prevent this infection. Type and length of treatment are based on your risk.

- **Other common fungal infections:** Other common sites for fungal infections after transplant are fingernails or toenails. Avoid sharing manicure and pedicure tools with others. It is very hard to get rid of a fungal infection in the nail beds.

You may develop symptoms of a yeast infection in your surgical incision, in skin folds, in the vagina, urinary tract, lungs, or eyes. Symptoms of a fungal infection may include white or yellow discharge or film, itching and pain. If you develop any of these symptoms, contact your transplant coordinator or local doctor.

## Nutrition

Nutrition plays a key role in the transplant process. Before transplant, eating well and being at a healthy weight may help you recover faster from surgery. After transplant, good nutrition plays a key role in maintaining transplant function and your overall health.



### Nutrition After Transplant

After surgery, your body needs enough nutrition to promote healing, fight and prevent infection, and gain back weight you may have lost. You may have a lower appetite or change in your sense of taste due to medicines you will be taking. Even though you may not feel hungry, you will need to eat.

## Tips

- Eat small, frequent meals or 3 meals with 2-3 snacks in between.
- Include high calorie, high protein foods like pudding, cottage cheese, nuts, peanut butter, shakes, lean meats and eggs.
- Use nutritional supplement drinks such as Boost<sup>®</sup>, Ensure<sup>®</sup>, or Carnation Breakfast Essentials<sup>®</sup>.

## Long Term Nutrition Guidelines

After transplant, you will need to develop and maintain a healthy lifestyle. This helps prevent problems like diabetes, osteoporosis, and heart disease. Weight gain can happen after transplant due to an increased appetite from steroids, unhealthy eating habits, lack of exercise, and family history of obesity. Making healthy food choices can help prevent these problems.

## Ways to Achieve a Healthy Weight and Lower Your Risk for Heart Disease

- Eat regular meals: 3 meals per day or small, frequent meals.
- Control portion sizes at meals.
- When dining out, control portion sizes by splitting a meal with someone or ordering the kids portion size.
- Choose healthy snacks.
- Limit intake of high calorie, high fat sweets such as cakes, cookies, ice cream, and candy.
- Make physical activity part of your daily routine at least 4-5 days a week.
- Choose lean meats. Choose fish and skinless poultry more often than red meat. Consume 6-8 ounces per day. Trim the fat off the meat and remove the skin from poultry before cooking.

- Lower your use of butter and lard. Choose margarine that is trans-fat free.
- Use olive oil, canola oil, or other vegetable oil with cooking.
- Avoid high fat, processed meats such as brats and sausage.
- Choose low fat dairy products such as skim or 1% milk, low fat yogurt, and low-fat cottage cheese. Limit intake of high fat dairy products such as whole milk, ice cream, and custards.
- Choose low fat versions of salad dressings, mayo, sour cream, and cream cheese.
- Choose baked or low-fat versions of crackers and chips.
- Eat more fiber foods such as whole grain breads and cereals, whole grain pastas, brown rice, dry beans and peas, fruits and vegetables.

### **Choose Low Sodium Foods**

A diet low in sodium can help control blood pressure and prevent fluid retention. To lower your sodium intake:

- Avoid adding salt to your foods. Use herbs, spices, or blends such as Mrs. Dash<sup>®</sup> instead of salt.
- Avoid foods with large amounts of sodium such as processed foods like ham, bacon, sausage, cheese, canned vegetables and soups, and boxed meals.
- Avoid salt substitutes with potassium.
- Read food labels to find out if foods are high in salt.

### **Carbohydrates**

If you have diabetes or high blood sugars, you may need to eat a diet that has a consistent amount of carbohydrate at each meal. Guidelines for this kind of diet include:

- Choose a variety of foods at each meal that includes fruits, vegetables, proteins, and carbohydrates.
- Do not skip meals. Eat about the same amount of carbohydrate at each meal. Foods that contain carbohydrate are: breads, cereals, pasta, rice, starchy vegetables such as potatoes, corn, and peas, fruits, milk and yogurt, and sweets.
- Limit your intake of concentrated sweets such as regular soda, candy, or jams.

### **Dietary Supplements**

- Avoid herbal or dietary supplements unless approved by the transplant team first.
- Avoid potassium supplements or salt substitutes that contain potassium.

## Food Safety

Transplant patients are at higher risk of foodborne illnesses. To prevent these illnesses, practice food safety. The booklet “Food Safety for Transplant Recipients” provides ways you can lower your risk of foodborne illness. You can find it online at: <https://www.fda.gov/food/people-risk-foodborne-illness/food-safety-older-adults-and-people-cancer-diabetes-hiv-aids-organ-transplants-and-autoimmune>

### Food Safety When Dining Out

- Avoid entrée items that have uncooked or undercooked ingredients like eggs, poultry, meat, or fish. Don’t hesitate to ask your server about the menu items.
- Avoid buffets. It is hard to control portion sizes at buffets. Foods may also be undercooked or have been at an unsafe temperature for too long.
- It is safe to dine at the hospital cafeteria. The food is prepared fresh and does not sit out for long periods of time.

### Specific Foods to Avoid

- Hotdogs, deli meat, luncheon meat, smoked fish or meats, and precooked seafood should be reheated to steaming hot or  $\geq 165^{\circ}\text{F}$
- Unpasteurized pâtés or meat spreads
- Unpasteurized/raw milk
- Cheeses made from unpasteurized milk. (Check the food label to be sure.) Common cheeses made with raw milk: feta, brie, camembert, blue, and queso-fresco.
- Unwashed fruits and vegetables
- Raw sprouts (alfalfa, bean, or other sprouts)

- Unpasteurized juices, ciders, or kombucha
- Raw or undercooked meat, poultry, or fish (raw sushi)

### Internal Cooking Temperatures

It is important to heat up some foods to certain temperatures. The list below gives recommended internal cooking temperatures.

- Beef, pork, veal, and lamb ( $\geq 145^{\circ}\text{F}$ ); ground meat ( $\geq 160^{\circ}\text{F}$ )
- Poultry (ground, parts, whole and stuffing;  $\geq 165^{\circ}\text{F}$ )
- Eggs (cook until yolk and white are firm); egg dishes ( $\geq 160^{\circ}\text{F}$ )
- Fin fish ( $\geq 145^{\circ}\text{F}$  or flesh is opaque)
- Shrimp, lobster, and crabs (flesh is pearly and opaque)
- Clams, oysters, and mussels (shells open)
- Scallops (flesh is milky white, opaque, and firm)
- Leftovers (cook or reheat to  $\geq 165^{\circ}\text{F}$ )

### Other Food Safety Tips

**Clean:** Wash hands and surfaces often.

- Wash your hands with warm water and soap before eating, handling food, after using the bathroom, changing diapers, and handling pets.
- Wash cutting boards and dishes, used to prepare raw meats, in hot soapy water.
- Rinse and scrub fresh fruits and vegetables under running tap water. Do this even for foods with skins and rinds that are not eaten

**Separate:** Separate raw meats from other foods.

- Use one cutting board for fresh produce. Use a separate board for raw meats.
- Never place cooked food on a plate that had raw meats on it unless the plate has been washed with hot, soapy water.
- Separate raw meats from other foods in your grocery bags.
- Store raw meats separately in fridge (for example, on a bottom shelf).

**Cook:** Cook to the right temperature.

- Cooking to recommended internal temperatures kills harmful bacteria.
- Use a food thermometer to ensure proper cooking temperature.
- Bring sauces, soups, marinades, and gravy to a boil when reheating.

**Chill:** Refrigerate foods promptly.

- Use an appliance thermometer to be sure the temperature stays below 40°F for refrigerator and below 0°F for freezer.
- Divide large amounts of leftovers into shallow containers for quicker cooling. Refrigerate within 2 hours (1 hour if air temperature is > 90°F).
- Never thaw food at room temperature. Defrost in the fridge, in cold water, or in the microwave.
- Check the dates on foods and throw away if expired.
- Discard or freeze leftovers after 3 days.

## **Fluid Volume**

It is important to know how much fluids you should drink at home. You may need to drink more fluids or restrict your fluids depending on your health.

### **Dehydration (Dry)**

Dehydration is when your body loses fluid. This happens when you don't drink enough fluids. It can happen if you lose fluid through diarrhea or vomiting. High blood sugars or fevers can also cause dehydration.

Signs of dehydration:

- Decrease in weight
- Decrease in blood pressure when standing
- Increase in pulse when standing
- Lightheaded or dizzy when standing
- Thirst
- Decrease in urine output
- Muscle cramps

### **What to Do If You Are Dehydrated**

Drink plenty of fluids. Avoid caffeine and alcohol. If you exercise, increase your fluids so you do not get dehydrated. If you have a lot of vomiting or diarrhea, you may need IV fluids. Your blood pressure and pulse should be close to the same when you are lying down and when you are standing. Call your transplant coordinator.

### **Overhydration (Wet)**

Overhydration is when your body has too much fluid. This may be because of side effects of medicines or something else.

Signs of overhydration:

- Increase in weight
- Swelling/puffiness (especially in your lower extremities)

### **What to Do If You Are Overhydrated**

Limit your fluid intake. Call your transplant coordinator.

## **Frailty**

You may be frail if you have lost weight without trying, feel weak or tire easily, walk more slowly, or need help for daily activities. This could include bathing, dressing, eating, getting out of bed and moving around on your own.

Causes of frailty include aging, being less active, chronic diseases, and malnutrition. People who get a transplant when they are frail stay longer in the hospital and get more infections. They are less likely to go home from the hospital and more likely to need rehabilitation.

## **Staying Healthy**

After transplant, there are ways you can help to stay healthy. First, keep a good relationship with your primary care provider (PCP). Your PCP will be able to help you with routine visits for check-ups and do health screenings to catch problems early.

## **Bone Health**

Long-term use of steroids (like prednisone) may weaken your bones. To prevent bone weakness and fractures you may need to increase your calcium and Vitamin D intake. Steroids increase bone loss, decrease your body's ability to make bones, and decrease the amount of calcium your body can absorb. Exercise helps keep your bones strong. Get out and walk to help keep your bones and muscles in good shape.



After transplant, you will have a bone mineral density test (also called a DEXA scan) to evaluate your bone density. This may be done as early as 6 months after your transplant and then again every 1-3 years depending on your risk factors. The lower the density of a bone, the higher the risk that it will break. A bone scan is painless. It

takes about 40 minutes. The radiation dose is very small.

The results of your bone density test will help decide on any necessary treatment options that you may need.

## **Colonoscopy**

Due to the increased risk of cancer after transplant, you will need to have a screening colonoscopy at least every 5 years or as clinically indicated. Most commonly, this will be completed by your local provider. However, if you need assistance in getting this done after transplant, let your coordinator know and it may be able to get completed at UW Health.

## **Diabetes**

People with diabetes should have yearly screenings with their local providers for watch for and prevent complications. Screening should include eye exams, foot exams, and signs of peripheral vascular disease (PVD).

## Vaccines

You must be screened for conditions or medicines that might make a vaccine unsafe for you because of your weakened immune system. No one who has had a transplant should be given a live vaccine.

The list below includes general guidelines. Your situation may be different. **Always talk with your coordinator before getting any vaccines.**

Vaccines recommended after transplant:

- Annual inactivated influenza, injected - yearly
- Diphtheria/Tetanus/ Pertussis (Tdap) – every 10 years or with an injury
- Pneumococcal polysaccharide or conjugate: Two different vaccines are needed. The transplant staff will help with the schedule.

Vaccines that should NOT be given after transplant:

- Varicella (Varivax®)
- Measles, Mumps, Rubella
- Influenza nasal spray

Vaccines that may be given after transplant:

- Hepatitis B: Complete the series if not finished prior to transplant
- Hepatitis A: Complete the series if not finished prior to transplant

Other vaccines to discuss with your provider:

- Quadrivalent meningococcal conjugate and MenB vaccines
- Shingles vaccine series (Shingrix®)
- Human papillomavirus vaccine series (ages 9 through 45 years)
- COVID-19 vaccine

People living with you or with whom you have frequent contact should get the

influenza vaccine. They can receive the live nasal spray.

## Heart Disease

There are things that you can do on  your own after transplant to lower your risk of heart disease:

- **Avoid smoking and secondhand smoke:** Smoking causes damage to the blood vessels and makes your blood more likely to clot.
- **Eating healthy:** A healthy diet can reduce the risk of stroke and improve your health.
- **Manage stress:** Stress negatively affects other risk factors such as high blood pressure, smoking and weight gain.
- **Physical activity:** Being active every day helps to lower your risk of heart disease and stroke. It improves blood pressure, weight loss, and even improves mood and energy levels.
- **Maintain a healthy weight:** Extra weight makes your heart work harder and can lead to high blood pressure, diabetes, and stroke.

## Cancer

Transplant patients take medicines life-long to prevent rejection of their new organ. These medicines suppress the body's normal immune system response of attacking foreign objects and abnormal cells, like cancer. Being immune-suppressed can also make your body vulnerable to viruses. Some viruses are known to stimulate certain types of cancer. Also, many patients have a family history of cancer, a history of cancer before transplant, or ongoing disease that may put them at a higher risk for certain cancers.

## **Most Common Types of Cancer After Transplant**

Transplant patients have 5 times the risk or greater for these types of cancer:

- skin cancer,
- lymphoma,
- Kaposi Sarcoma,
- liver cancer, and
- cancer of the anus, vulva and lip.

Other common cancers that are more common after transplant include:

- lung,
- kidney,
- colon,
- pancreas,
- Hodgkin lymphoma, and
- melanoma.

Skin cancer is the most common type of cancer after transplant. Skin cancer is the uncontrolled growth of abnormal skin cells. Transplant patients have a 20-60 times higher risk of skin cancer than the general population. Risk factors include life-long sun exposure, fair skin, history of burns, and family history. The level of anti-rejection medicines and amount of time taking them also increase risk.

Lymphoma or Post Transplant Lymphoproliferative Disease (PTLD) has the highest incidence within the first year of transplant. This is when anti-rejection medicines are at their highest, although it can occur any time after transplant. PTLN is often related to Epstein Barr Virus.

Signs and symptoms of lymphoma can include:

- unexplained fevers,
- night sweats,
- unintended weight loss, and
- enlarged lymph nodes (in the absence of other infection).

Treatment varies based on extent of disease, time frame after transplant, age of recipient, and amount of current anti-rejection medicine. The transplant team works closely with the cancer and infectious disease teams if lymphoma occurs.

## **How to Prevent Skin Cancer**

There are many things you can do to prevent skin cancer.

- Reduce your exposure to sun as much as you can.
- Use sunscreen daily. Apply sunscreen with SPF 30 or higher. Apply a thick coat of sunscreen to all exposed skin 30 minutes before going out in the sun. Reapply every 2 hours that you remain in the sun. Reapply after swimming or sweating. Even if the sunscreen is water-resistant, some will wash off.
- Wear clothing that covers the skin. Wear wide brim hats and UV (ultraviolet) blocking sunglasses.
- Avoid mid-day sun (10:00 AM-4:00 PM). This is when the sun's rays are most intense
- Remember that sunburns can occur on cloudy days or from water or snow glare.
- Find shade under a tree, umbrella or other ways when you can.
- Use lip balm or cream that has SPF to protect your lips.
- Never go to UV tanning booths.
- Know which medicines can make your skin more likely to sunburn.
- Check your skin head-to-toe every month. Skin cancer usually appears as a growth that changes in color, shape or size.
- See your skin doctor (dermatologist) yearly for a full skin exam.

## How to Prevent Other Cancers

- If you smoke, quit now.
- Avoid second-hand smoke.
- Eat a diet rich in fruits and vegetables and low in saturated fats.
- Exercise regularly.
- Attend yearly physical exams with your local health care team.
- Let your doctors know of any new symptoms or complaints. See your doctor if you notice a suspicious lesion. This includes a non-healing sore, red scaly patch, shiny bump, wart-like growth or irregular shaped mole.

Early detection and treatment save lives. Cancer screenings (pap tests, mammograms, colonoscopies, prostate tests) should be guided by your primary care provider.

## For More Information

[www.transplantliving.org](http://www.transplantliving.org)

[www.cancer.org](http://www.cancer.org)

[www.skincancer.org](http://www.skincancer.org)

[www.lymphoma.org](http://www.lymphoma.org)

[www.healthytransplant.com](http://www.healthytransplant.com)

## Other Things to Consider

### Swimming

After 3-6 months of your transplant, you are allowed to swim in chlorinated pools. After the first year, you may choose to swim in the ocean as well, with the understanding that swimming of any kind has an infection risk. Each person should be aware of the risks and make the decision that is best for him/her.

Swimming in fresh water (like ponds, lakes, rivers) carries the greatest risk of infections and should be avoided or done so with extreme caution. Hot tubs should also be avoided.

If you chose to swim, avoid swallowing any water and rinse off as soon as possible after swimming.

If you have an open wound or abrasion of any kind, it is not safe to swim at all.

### Yard Work

It is highly recommended that you avoid gardening, mulching, mowing, farming, raking and any other activities that include direct contact with soil and plants. Similarly, avoid wood burning fireplaces or campfires. These types of activities can expose you to serious infections, specifically fungus. If possible, stay indoors with the windows closed during these activities. If you must do these activities, wear a duck-billed mask and gloves.

## Traveling/Vacation

When you travel, always be sure to let your transplant coordinator know when and where you plan to go. Avoid air travel during the first year after transplant.

### Traveling tips:

- Take at least a few extra days' worth of medicines, **more** than what you think you will need in case of an emergency.
- If you are traveling by plane, be sure to carry-on your medicines. **Do not** put medicines in your checked luggage. The medicines must be in their original bottles. Your coordinator can provide you with a letter from UW Health Transplant to verify this need. You will need to wear your duck-billed mask while on the plane.
- If you will need lab (blood) work done while you are gone, it is your responsibility to find a lab or transplant center nearby that will be able to do this. Tell your coordinator where you will be getting your lab work done to ensure orders are placed.
- Based on where you travel, it may be best to drink only bottled water and avoid ice cubes.
- Be cautious of the food you eat. (Refer to Food Safety section.)
- Based on your lung function or oxygen needs, you may need special altitude testing at UW before you travel.

## Animals

Pets can sometimes pass infections to humans. Talk to your coordinator about pet safety. In general:

- No birds should be in your home after transplant.

- You should not handle animal waste, specifically cat litter.
- Do not clean fish tanks or animal cages.
- Talk to your transplant team about any exotic pets.
- Wash your hands after handling pets.

## Writing to Your Donor Family

UW Organ and Tissue Donation (UW OTD) facilitates the exchange of correspondence between transplant recipient and donor families. We encourage all transplant recipients to write to their donor family.

Many donor families are comforted by the messages they receive from the recipients of their loved one's donation.

### When Writing Your Letter or Card

- Only include your first name.
- Acknowledge the donor family's loss. Thank them for their gift and let them know their loved one will not be forgotten.
- Include details about yourself such as your occupation, hobbies or interests.
- Share information about your family and friends and include their first names and ages, if you wish.
- Briefly describe how long you waited for a transplant and what the wait was like for you and your family.
- Explain how the transplant has improved your health or changed your life:
  - Have you returned to work, school or a favorite activity?
  - Describe activities that you can now do.
  - Share life events that you've enjoyed (graduations, marriages, births).

You may choose to send a card or letter. You can include a photo. You may include the state where you live. Do not include any identifying personal information such as last name, address, city, telephone number, email, Facebook account or place of employment.

### **Sample Letter**

Dear Donor Family,  
I have been thinking about you and your family since I received the gift of life through your loved one's gift of organ donation. I want you to know that I continue to give thanks each day for this gift. I'm so sorry for the loss of your loved one. I hope you can find some comfort knowing my life has completely changed because of this generous act. Words cannot express how thankful I am for your compassion. You have my deepest sympathy for the loss of your loved one and my greatest thanks for this second chance at life.

Sincerely,  
(Sign your first name only)

### **Sample Message for a Card**

Please accept my gratitude for the gift of life that I received through your family's unselfish gift of organ donation. Words cannot express how thankful I am for your generosity and compassion. You have my deepest sympathy for the loss of your loved one and my greatest thanks for this second chance at life. Thank you.  
(Sign your first name only)

### **Sending Your Letter or Card**

Please print the following information on a separate piece of paper and include it with your letter or card. This information is necessary for identification purposes. **It will not be shared with your donor family.**

- The date you're mailing the letter or card to UW OTD
- Recipient's first and last name
- Date of transplant
- Organ(s) transplanted
- Send the letter or card, including the separate piece of paper, to UW Organ and Tissue Donation via U.S. mail to:

**UW Organ and Tissue Donation  
Attn: Donor Family Services  
448 Science Drive, Suite 250  
Madison, WI 53711-1175**

Or email, including the information requested above on the separate piece of paper, to Donor Family Services at [dfs@uwhealth.org](mailto:dfs@uwhealth.org).

You may also give your card or letter to your post-lung transplant coordinator and he/she can facilitate delivering it to the UW OTD.

Your donor family may not respond to your correspondence. Don't let that stop you from writing again. Any letters UW OTD receives from the donor family will be forwarded to you. If you and your donor family agree to communicate directly this will be arranged through Donor Family Services at UW OTD. Questions can be directed to [dfs@uwhealth.org](mailto:dfs@uwhealth.org).

## MyChart



### Sign Up for MyChart

MyChart is an internet-based service that lets you access your medical and health plan information.

**MyChart is not for urgent needs.** Call the clinic for urgent needs or call 911 for emergencies.

### Reasons to Sign Up

- Get test results quickly.
- View lab orders in the letters section.
- View your instructions (“After Visit Summaries”).
- Send secure messages to your coordinator and providers.
- Access paperless billing.

The MyChart app is available for both Apple and Android mobile devices. The mobile app provides access to many MyChart features, but it does not replace the web-based application. Certain features are only available on the web site.

If you need assistance with MyChart, you can call #877-768-0732.

## Housing in Madison

### Hotel Reservations

UW Health patients and families may be eligible to stay at a local hotel for a reduced rate. To arrange accommodations, please contact Guest Services at **(608) 263-0315**.

**Guest Services hours:** 7:30am-9pm daily

### Restoring Hope Transplant House

The Restoring Hope Transplant House is a “home away from home” for patients and families who are in the Madison area for transplant related care. This is not a medical facility. It is a caring environment that offers high quality, affordable accommodations for patients and their adult family members and caregivers. You can contact the Restoring Hope Transplant House by phone at **(608)-831-1726**. You can learn more at [www.restoringhope.org](http://www.restoringhope.org).

Your health care team may have given you this information as part of your care. If so, please use it and call if you have any questions. If this information was not given to you as part of your care, please check with your doctor. This is not medical advice. This is not to be used for diagnosis or treatment of any medical condition. Because each person’s health needs are different, you should talk with your doctor or others on your health care team when using this information. If you have an emergency, please call 911. Copyright © 6/2021 University of Wisconsin Hospitals and Clinics Authority. All rights reserved. Produced by the Department of Nursing HF#6686.

## Who and When to Call

Who	Why	When/ Phone Number
<b>Transplant Coordinator/ Transplant Office</b>  <b>Your Coordinator:</b> <hr style="width: 20%; margin-left: 0;"/>	<ul style="list-style-type: none"> <li>• Medicine refills</li> <li>• Lab results</li> <li>• Questions about transplant medicines, symptoms or other questions related to your transplant</li> </ul>	Monday-Friday 8:00a.m.-4:30p.m. <b>608-265-5658</b>
<b>Transplant Clinic</b>	To schedule, change or cancel a transplant clinic appointment	Monday-Friday 8:30 am-4:30 pm <b>608-262-5420</b>
<b>Organ Allocation Specialist (On-Call)</b>	<ul style="list-style-type: none"> <li>• Fever over 100°F or chills</li> <li>• Nausea, vomiting or diarrhea for more than 24 hours</li> <li>• Blood in urine or problems urinating</li> <li>• Problems with drains</li> <li>• Other urgent symptoms</li> </ul>	Evenings, weekends, and holidays <b>608-263-6400</b>
<b>Local doctor/ health care provider</b>	<ul style="list-style-type: none"> <li>• Problems not related to your transplant</li> <li>• Refills of non-transplant medicines</li> </ul>	
<b>Call 911 or go to the nearest emergency room</b>	<ul style="list-style-type: none"> <li>• Trouble breathing</li> <li>• Heavy bleeding or bleeding you can't stop</li> <li>• Chest pain</li> <li>• Fainting or passing out</li> <li>• High blood pressure with headache or vomiting</li> <li>• Unable to take medicines for 24 hours</li> <li>• Seizure or stroke</li> <li>• Severe pain</li> <li>• Anything else you think might be an emergency</li> </ul>	If you are in a local emergency room or hospital, call your Transplant Coordinator.