# Health Facts for You

Your lung transplant evaluation

**LWHealth** 

Welcome to the UW Health Lung Transplant Program. The team takes pride in building a care plan tailored to your needs. We are committed to your success. UW Health is a national and international leader in the field of transplantation.

#### The Lung

To understand the transplant process, it is good to have basic knowledge of how the lungs work.

When you breathe in air, it goes to tiny air sacs called alveoli. Oxygen moves from the air into the blood. This blood leaves the lungs and goes to the heart. The heart pumps the blood to the rest of the body. This is how all your tissues and organs get oxygen. The lungs also remove gases, such as carbon dioxide.

When lungs are damaged, oxygen cannot get into the blood as well. The lungs also may not expand properly. These lung problems get worse despite medical treatment. This is when someone may consider a lung transplant. Some of the diseases that can be treated with a lung transplant include:

- Emphysema/COPD
- Cystic fibrosis
- High blood pressure that affects your lungs (pulmonary hypertension)
- Alpha-1-antitrypsin deficiency
- Bronchiectasis
- Congenital disease
- Sarcoidosis

#### **After Your Evaluation Testing**

When your evaluation testing is done, the transplant team meets to review results. There are three possible decisions:

- 1. You are approved to be added to the list. Or,
- 2. The team feels transplant is NOT the best option for you. Or,

3. The team needs additional testing or information to make the decision.

You will be told of the decision and next steps.

### Where My New Lung Will Come From

#### The Organ Shortage

There is a severe shortage of organs for transplant. This means that the wait for a lung transplant can be unpredictable. You will be given our recent waiting times to help you better understand your wait. Patients may die while they wait. The UW Transplant Program is a leader in finding new ways to increase the number of good organs for transplant. You have options about where your new lung will come from. It is vital that you explore these options fully.

### **Donation After Brain Death (Deceased Donor)**

The most common type of organ donor is a person who has suffered a head injury causing brain death. "Brain death" occurs when someone does not get enough oxygen to the brain and the brain then stops working. This is often due to trauma or a stroke. Doctors can do tests to tell when someone is brain dead.

The brain controls breathing. People in a hospital who are brain dead are on a breathing machine. The breathing tube and medicines keep the heart beating and supply the lungs and other organs with blood and oxygen until a transplant team arrives. Once the lung is removed, it should be transplanted within 12 hours. Lungs from these types of donors are called "standard donor" lungs.

### **Donation After Circulatory Death** (Deceased Donor)

There may be times that a patient's trauma is so bad that doctors can't save their life; but, they are not "brain dead." The doctor meets with the family to decide if life support should be stopped. If the family chooses to remove life support, the machines are turned off. These patients may or may not be able to donate.

Transplant teams are on site when the life support is turned off. When the heart stops beating, the person is declared dead by the doctor. The transplant teams can then remove the organs. This is called donation after circulatory death (DCD).

The lungs may have some damage due to lack of blood flow when the organs are removed. The increased risks with DCD lungs include:

- Primary graft failure
- Ischemia/reperfusion injury
- Shorter long-term graft survival

Long-term graft survival means how long a lung works. A standard lung has a graft survival of about 50% at 5 years. The graft survival of a DCD lung is similar to standard donor lungs.

A DCD lung can help you get a transplant sooner. This increases your chance of staying alive longer. This could be most helpful for patients who have many health concerns and those with worsening health.

You will be asked if you are willing to accept a DCD lung at your evaluation visit. If you are, you will sign a consent form for this. You can change your mind at any time. If you choose not to accept this type of organ, you will not lose your place on the list. If you accept a DCD lung, you will increase your chance of getting a transplant

sooner.

## Organs Meeting Risk Criteria for possible transmission of HIV, Hepatitis B and Hepatitis C

You may be offered an organ from a deceased donor thought to be at more risk for spreading certain infections.

Donors are deemed to meet risk criteria for possible transmission of HIV, Hepatitis B and Hepatitis C based on national guidelines. This may include risk factors such as prostitution, intravenous (IV) drug use, or those with same sex partners. Potential donors have blood tests done to look for viruses such as HIV, Hepatitis B and Hepatitis C. You will also be tested for HIV, Hepatitis B and Hepatitis C before your transplant. No test is perfect, and false negative results can happen.

There is a small chance (at most, 1 organ in 10,000) that an infection could be passed on. After your transplant you will be tested for HIV, Hepatitis B and Hepatitis C. These infections all have good treatment options. We believe that the risks of getting this type of kidney are very small.

#### **Hepatitis C Positive Donors**

Hepatitis C is a virus that can damage the liver. It does not affect the lungs. We now have medicines to treat this virus. This means that we can often use lungs from donors who have had or have hepatitis C.

Donors who have had hepatitis C and do not have an active infection are very low risk. If the donor has had hepatitis C, we will do tests to check for signs of this virus. You likely would not need other medicines.

If the donor had an active hepatitis C infection, you need to take medicine to treat the virus. When placed on the waiting list,

the transplant team asks if you are willing to accept a hepatitis C donor lung. If you agree, you will be required to sign a consent. If you choose not to accept lung, you will not lose your place on the waiting list.

#### What will I be told about my donor?

Privacy laws limit how much we can tell you about your donor. We can't tell you the donor's age, gender, or personal health history. The United Network for Organ Sharing (UNOS) distributes the organs. The Organ Procurement Organization (OPO) tells the UW Transplant team when a lung found and who is first on the UNOS list to get the lung.

The OPO carefully screens all would-be donors for any illness that could affect the transplant organ or the patient who gets it. This screening can be limited by time constraints between the time that the donor was injured and when the organ is obtained. The donor's evaluation and screening results may impact your care after transplant. This may include the need for other tests or medicines. We believe the risk of these treatments outweighs the risk of waiting for another organ. We use our best knowledge and judgment to make sure every organ we transplant will work and will not harm the person who gets it.

#### How do I choose?

There are risks and benefits of each type of lung transplant. Members of the transplant team can tell you more about this topic. They can help you choose the option that may be best for you.

#### Waiting for Your Transplant

#### The Waitlist

UNOS manages the waiting list, matching donor organs to recipients, 24 hours a day, 365 days a year. You will be listed by blood type, height, and lung allocation score (LAS) variables.

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

- Forced vital capacity This is a lung function test. It measures the amount of air you can breathe out after you breathe in as deeply as you can. This number may be lower in patients with lung disease.
- **Pulmonary artery pressure** This is the pressure the heart must produce to pump blood through the lungs. This may be high in some people with severe lung disease.
- Oxygen at rest This is the amount of oxygen needed at rest to maintain oxygen levels in the blood. People with severe lung disease may need more oxygen.
- **Age** This is the person's age at the time lungs are offered.
- **Body mass index** BMI is a ratio of a person's weight to height. When used with other test results, it helps to assess health status.
- Diabetes This may predict future problems in some people with lung disease.
- Functional status The New York Heart Association's ratings measure how a person's lung disease affects their ability to function in daily life.
- **6-minute walk distance** In the 6-minute walk test, patients are asked

to walk as far as they can in 6 minutes. The distance walked is a measure of how well you can manage your daily life.

- Assisted ventilation The use of a ventilator, BiPAP, or CPAP to assist breathing may be a measure of how severe the disease is and may affect success after a transplant.
- Pulmonary capillary wedge
   pressure (PCW or "Wedge
   Pressure") Blood that returns to the
   heart from the lungs must get by this
   pressure. This can become higher
   when the heart is not pumping as
   well as it could.
- **Serum creatinine** This measures how well your kidneys work. High creatinine levels reflect impaired kidney function.
- **Diagnosis** Research has shown that urgency among people needing a lung transplant and success after a lung transplant varies among people with different lung diseases.
- Other lab tests Bilirubin, blood gases, cardiac index, etc.

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

### Multiple Listings and Transferring of Waiting Time

Multiple listing is when you are listed for transplant at two (2) or more transplant centers. Multiple listing can increase your chances of getting an organ offer. It does not assure that you will have a shorter wait time.

UW Health allows multiple listing. You need an evaluation at each transplant center. Each transplant center then decides whether

to accept you on their waiting list. You should check with your insurance to see if they cover more than one evaluation. You will need to keep current health information and contact information at each transplant center where you are listed.

There are many reasons that affect how long you wait for transplant. You can transfer your primary waiting time to another transplant center, or switch time between transplant centers. You cannot split your total waiting time among multiple transplant centers. Your transplant care will be done at the center where you have your transplant. To learn more about multiple listing or transferring waiting times, contact the transplant center where you are listed or want to be listed. For more information: <a href="https://unos.org/wp-content/uploads/unos/Multiple Listing.pdf">https://unos.org/wp-content/uploads/unos/Multiple Listing.pdf</a>

#### When to Call

While you are waiting, you may have many health changes. It is vital to tell the transplant team about any changes in your health status. Examples of things that you should call about include:

- Taking antibiotics or having an active infection.
- Getting a blood transfusion.
- Being hospitalized.
- An increase or decrease in your weight (5 pounds or more).
- Having a significant change in your health status.
- Having a change in insurance coverage.
- Changes in contact information (such as phone number or address).
- Changes in your support person or plan.
- Planning to travel away from home.

The transplant team needs to know about these changes. This ensures that you are in

the best condition for your transplant. Some new medicines or hospitalizations could change your status on the waitlist. It is vital that you contact the team with any health changes.

### Re-evaluation While Waiting for Transplant

To stay active on the UNOS waiting list, your LAS information needs to be updated before it expires. These should be updated anytime you have a significant change in your health or every 6 months. Candidates with a LAS score of 50 or more must be updated every 14 days. We want you to be ready if an organ becomes available. If these tests are not done, you may be made inactive on the waitlist until they are done.

While on the wait list, you will be seen in the Lung Transplant Clinic often. How often depends on how sick you are. This could be as often as weekly but no less frequent than every 6 months to update your LAS. At these visits testing and teaching will be done to help you prepare for transplant. It is helpful to bring your primary support person to your visits.

Our goal is that when an organ becomes available for you, you will be ready. Knowing about changes in your health helps to assure us that it is safe for you to have surgery when the time comes.

Waiting on the transplant list can be stressful for you, your family and friends. Be sure that you talk with your support people about your appointments, your health status, and your plans.

#### **Caring for Yourself While Waiting**

Taking care of your health is very important while waiting. It is expected that you will take all medicines as directed by your doctor and attend all appointments. You must also follow your plan for diet and exercise. Continue to follow the instructions from your lung transplant team. Contact them with any new or worsening symptoms.

#### **Getting the Call**

When on the list, the transplant team should be able to reach you at any time of the day, any day of the week. If the transplant team contacts you and you cannot return the call within one hour, the team will call the next potential recipient.

You need to have a plan ready for when the call comes.

- How will you get to UW Health?
- Who will come with you?
- Who will take care of things at home while you are in the hospital, such as your children, pets, etc.?

#### **Getting to the Hospital Quickly**

When you get the call, you have a short amount of time to gather your things and make final arrangements. As a rule, the sooner you can get to the hospital, the better. Your safety when traveling is important, so be careful on your way here. The transplant is often done within 24 hours of the call.

The Organ Allocation Specialist will call you if an organ becomes available. You will be asked:

- To stop eating and drinking.
- About your current health status.
- To come to UW Health **OR** keep a phone available, but to wait at home until you are called again.

It is vital that family and friends are involved in the planning process. Be sure

they know that you need to be reachable at all times. They should also know the plan for getting you to the hospital when you get the call. Make plans for the care of your pets, children, work duties, and other responsibilities ahead of time. Being prepared will help to lower your stress.

There may be times when the donor organ becomes unsuitable for transplant. In an event of one of these "dry runs" you will be discharged home to wait until another donor becomes available.

#### What to Bring to the Hospital

Be prepared when you get the call. This call can come anytime, day or night.

Plan to bring these items:

- Advance Directive (Durable Power of Attorney for Health Care or Living Will)
- ALL medicine bottles and list of medicines, one day supply of medicines, and your insurance/ Medicare/Medicaid cards.
- Local doctor/specialist contact information
- Local pharmacy phone number
- Loose clothing (sweat pants or something with elastic or drawstring waist bands), T-shirts, socks and supportive shoes for walking and therapy
- Hygiene items, glasses, pajamas, slippers, robes etc.
- Personal comfort items (electronic devices, phone, chargers, and blanket or pillow)
- Not a lot of money, but enough to pay for 1 month's supply of medicines after hospital discharge (or credit card/check book)
- Blood pressure cuff (if applicable)
- If you have diabetes, glucose meter with supplies

- Cell phone on and ready to call in case of delay or questions (608-263-6400 or 1-800-323-8942)
- Your nebulizer, if you already have one
- Enough oxygen to get to the hospital and home in case of a dry run

Please do not bring large amounts of cash, credit cards, jewelry or valuable items.

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

Your care after a transplant is for your entire lifetime. This long-term care includes:

- Biopsies.
- Labs and other tests.
- Medicines.
- Transplant clinic visits.

#### **Keeping the Commitment**

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

- Follow the treatment plan.
- 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 directed.
- Follow the diet and exercise plan advised by your doctor.
- Go to your clinic visits.
- Get your lab draws and biopsies.
- Do not abuse your body by smoking, drinking alcohol, or using non-prescribed medicines and herbals.
- Stay within 30 minutes of UW Health for a minimum of 2 weeks after discharge with your support person.
- Plan transportation for at least 6 weeks after surgery when you are unable to drive.

#### **Appointments and Medicines**

The follow-up schedule is intense for the first few months. Labs and 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 organ. If a biopsy is done because your organ is not showing normal function, it may be somewhat urgent. You may need to make plans to come to UW Health without much warning.

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
- Control blood sugars

You will need to know what medicines you are taking, why you are taking them, and the dose prescribed for you. Not taking your medicines correctly can lead to rejection and other health problems.

You must have a local doctor to follow your care. Plan to see your local doctor shortly after your transplant. We rely on the local doctor to address routine health issues. This might include diabetes, minor infections and illnesses, and regular health maintenance. We will work closely with your doctor to give you the best care. The Transplant Team will manage your transplant medicines and address any transplant issues. Follow the advice of your local doctor and the transplant team for diet, exercise, and other health needs. We want you to live a healthy life after transplant.

#### **Health Concerns After Surgery**

After transplant, people can live a healthy life. The main issues are the **increased risks of infection and rejection**. To prevent infections, wash your hands often and wear a mask at times. Sometimes, it is best to avoid crowded places, areas with poor ventilation, or people who may be contagious.

The risk of rejection is greatest the first 6 – 12 months after transplant. It is common to have a rejection. This is the body's normal immune response to "foreign" tissue. When rejection occurs, we need to adjust your medicines to further block your immune system. These medicines have side effects that can cause new health concerns. This can include high blood pressure, high cholesterol, diabetes, and osteoporosis. Most of these side effects can be managed with medicines, diet, exercise, and how well you follow your treatment plan.

#### **Activity Levels**

Over time, most patients can go back to their normal activity with minor changes. It will take some time to gain strength and endurance. Keeping up with an exercise routine is the best way to manage your weight and improve your well-being.

#### 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. Your transplant team will talk with you about returning to work. They will help you with paperwork or questions you may have.

#### **Coping**

During the transplant process, it is common to feel anxious, depressed, or frustrated. Stress can cause these feelings and so can your medicines. Talk with someone about your feelings. The transplant team, your nurse, or social worker can help you cope with these emotions. The transplant team can help to find a mental health provider close to home to help you during this stressful time. Sharing your feelings with your loved ones and others may also be helpful. Most areas have support groups for transplant recipients and loved ones.

#### **Family Support**

The transplant process can be very tough for family members. Many family members have anxiety during the process. Your social worker can help you find resources in your area. There are many things that can be done during this time to ease concerns. This includes:

- Talking about hopes and fears.
- Discussing your wishes about advance directives.
- Attending transplant support groups.
- Visiting a counselor.
- Being paired up with a mentor.

#### **Keeping Family Members Updated**

It is a good idea to choose one family member as the primary contact. This person can update other family members and friends about your status. Make sure the transplant team has that person's contact information.

#### Financial Planning

#### **Understanding Your Insurance Plan**

You will need to learn more about your insurance plan. A person who gets a transplant needs life-long follow-up care and medicines. Learn about your co-pays and deductibles for clinic visits and tests. This will help you budget for this expense. Many plans have a yearly maximum for co-pays or deductibles. When you have reached the limit, your insurance may pay 100%. Refer to your insurance booklet and keep track of your healthcare expenses.

Contact your insurance company. Ask about your lifetime and transplant maximums. You may need secondary coverage or other ways to pay for expenses. Once you reach the limit, insurance will not cover more. Transplant patients often reach their limit.

Know the referral guidelines of your health plan. UW Health is a hospital-based clinic. You will get bills from the hospital and the doctors. If insurance guidelines aren't followed, you may need to pay for the bill.

You may need to stay in Madison for some time after your transplant. Most insurance plans require prescriptions to be filled at certain pharmacies. Know your preferred pharmacy in your hometown and in Madison.

#### **Other Coverage Options**

Your social worker will talk with you about eligibility for government programs. Always notify your transplant team of any current or future insurance changes or updates.

Common Financial Questions Below are some common questions which	Questions and Notes About My Insurance		
other transplant patients have found helpful.			
• My lifetime insurance maximum is:			
\$			
<ul> <li>What would be my monthly total co-</li> </ul>			
pay be if prescribed 15 medicines?			
15 x \$ (the co-pay			
amount per prescription) =			
\$			
• What are the co-pays and deductibles			
for clinic visits and procedures?			
What do I need to pay out-of-pocket?			
Monthly clinic and procedure co-			
pays: \$			
TT 1141' C'.'.			
<ul> <li>How would this expense fit into my budget?</li> </ul>	-		
<ul><li>How will I get coverage if I reach</li></ul>			
my lifetime maximum?			
What would I do if my insurance			
was changed? (Notify your			
coordinator right away!)			
<ul> <li>My health plan referral guidelines:</li> </ul>			

#### **About Medicare**

Medicare is health insurance for the following people:

- People age 65 and older
- People under 65 with disabilities

There are 4 parts to Medicare.

**Part A** covers inpatient hospital care after the deductible is met. This includes the transplant surgery. Most people do not pay a monthly premium for Part A.

Part B covers 80% of doctor's services (both inpatient and outpatient) & 80% of outpatient care. If you have Medicare A at the time of transplant, Part B will also pay for 80% of the cost of your anti-rejection medications when Medicare is your primary payer. If you have a secondary policy or supplement, the remaining 20% is billed under your medical plan, NOT under your prescription drug plan.

There is a monthly premium for Part B which changes each year. You can check www.medicare.gov for the current rate.

**Part C** is a Medicare Advantage Plan. In most cases, you cannot join a Medicare Advantage Plan if you have end stage renal disease (ESRD). This plan includes Part A and Part B and sometimes Part D. By law, Medicare Advantage Plans must provide all services covered by Part A and Part B of Original Medicare. While a Medicare Advantage Plan may provide more coverage, it cannot provide any less coverage than found in Original Medicare. To find out about your Medicare Advantage Plan go to your plan's website and search for the Summary of Benefits Information (https://www.medicare.gov/ and click on "Find health and drug plans") or call your plan.

**Part D** covers some medicines. If you did not have Medicare at the time of transplant, it may pay for your anti-rejection medicines. Premiums vary by plan. You can explore options at www.medicare.gov.

#### **Ouestions to Ask**

Insurance is complex. Your transplant social worker and transplant financial counselors can help answer your questions. Here are some example questions to ask your insurance:

- 1. How do I request a case manager?
- 2. What is my co-pay for anti-rejection medicines? (covered under Part B, not under Part D)
- 3. Is my benefit is affected by innetwork vs out-of-network pharmacies? Can I use a local retail pharmacy? Am I restricted to a mail order pharmacy? Does this impact the cost?
- 4. How much is my deductible? How much are my co-pays and yearly out of pocket maximums? How much will I have to pay for medicines during the year?
- 5. When will my eligibility start?
- 6. What if I have an employer group health plan?
- 7. What if I have COBRA?
- 8. Can I be denied Medicare coverage?

#### After Signing Up for Medicare

After sending in your application, you should get a card from the Social Security Administration within 8 weeks. If you have not received a card by that time, contact the Social Security Administration.

When you get your card, call UW Health Registration (608) 261-1600 to update your information. You should also call your Transplant social worker. Always notify your transplant team of any current or future insurance changes or updates.

#### **Types of Medicine After Transplant**

After your transplant, you will be on many medicines. You will be on some of them for the rest of your life. Never stop or adjust medicines on your own. These medicines are important in the success of your transplant.

#### Immunosuppressive Medicines (Antirejection Drugs)

These medicines block or suppress your immune system. They are used to prevent rejection of new organs. All transplant patients take these medicines for the **rest of their lives**. There are different kinds. Often, you will be on more than one kind. Your doctor will decide which ones you will need. You will need to take these multiple times a day. These will include:

- Prednisone
- Tacrolimus or cyclosporine or sirolimus
- Mycophenolate

#### **Anti-infection Medicines**

Anti-infection medicines prevent common infections after transplant. You may need other medicines too based on the type of donor. You may need medicines to prevent:

- Bacterial infections of the bladder and lung.
- Viral infections such as CMV or herpes (cold sores).
- Fungal infections.

#### **Other Medicines**

Most patients take other medicines to reduce stomach acid, control blood pressure and cholesterol and supplements to support your bones and general health. Some of these medicines are temporary but many are lifelong. You may also develop diabetes and need insulin or other medicines to manage blood sugar levels. You may need narcotic pain medicines right after surgery.

You will need to know your medicines. This includes what you are taking and why. Not taking your medicines correctly can lead to rejection and other health problems.

You must have a local doctor to follow your care. Plan to see your local doctor shortly after your transplant. We rely on the local doctor to address routine health issues. This might include diabetes, minor infections and illnesses, and regular health care needs. We will work closely with your doctor to give you the best care. The transplant team manages your transplant issues and medicines. Follow the advice of your local doctor and the transplant team for diet, exercise, and other health needs. We want you to live a healthy life after transplant.

#### **Vaccines**

Timing of when you receive a vaccine can impact when you can receive a transplant. You must be screened for conditions or medicines that might make the vaccines unsafe for you because of your immune system. No one who is waiting for or 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 Before and After Transplant

- Inactivated influenza, injected
- Hepatitis B
- Hepatitis A
- Diphtheria/Tetanus/ Pertussis (Tdap, DTaP, Td or DT)
- Polio, Inactivated
- Pneumococcal polysaccharide or conjugate
- Human papillomavirus (HPV) (for ages 9-26)
- Varicella zoster (Shingrix®)

### Vaccines NOT Recommended After Transplant

- Varicella (Varivax<sup>®</sup>)
- Measles, Mumps, Rubella
- Rotavirus

### Other Vaccines to Discuss With Your Provider

- Quadrivalent meningococcal conjugate or polysaccharide
- Haemophilus influenzae type b

#### **Staying Healthy Before Transplant**

#### Nutrition

Nutrition plays a key role in the transplant process. Eating well and being at a healthy weight may help you recover faster after surgery. After surgery, your body needs enough nutrition to promote healing, fight and prevent infection, and gain back weight you may have lost. Transplant medicines can lower your appetite or change your sense of taste. In the long-term, good nutrition plays a key role in keeping you healthy.

#### **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.

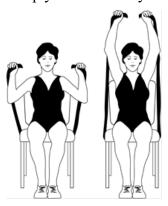
#### **Improve Your Strength With Exercises**

You can improve your strength if you add daily exercises. If you cannot exercise on your own, you may need physical therapy (PT). Let your nurse or doctor know if you think you need PT. They can help set it up.

There are exercises you can do at home even if you have physical limitations. You can do these sitting down with either resistance bands or light weights. You can use common household items that have some weight to them. Examples could be filled water bottles, canned goods, or rocks. To gain strength, do these exercises daily. For each exercise, complete 3 sets of 10-15 repetitions. Do not rush. Go slowly.

#### **Overhead Press**

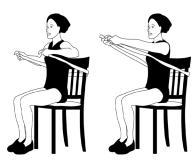
Sit on edge of a chair with your feet planted flatly on floor. Grab light dumbbells or a resistance band. Take a deep breath and tighten your core. Push the weights or band evenly over your head. Keep your neck and back in a neutral position. Bring the weights or band back down to the level of your ears and repeat. You can also do this activity standing with your feet evenly spaced apart. Keep your feet firmly on the ground.





#### **Seated Press**

Wrap your band around the back of your chair and make sure it is secure. Sit with your weight evenly distributed. Take a deep breath. With a flat back and even posture, push your arms straight out in front of you. Make sure you are using your chest to push out your arms. Try not to move the position of your back. Bring your hands back to your chest and repeat.



#### **Horizontal Row**

Sit on the floor with your back straight. Place your band around your feet at the halfway point on the band, so the sides are even. Pull the band towards your chest. Squeeze your shoulder blades together. Slowly release the band back to the start. Repeat.



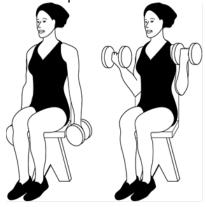
#### **Triceps Extension**

This movement can be done with a band or light weights. Squeeze your arms up so they line up with your ears and bring them back down to the start. If you are using a band, make sure it is secure before you begin.



#### **Biceps Curl**

Take a deep breath and exhale. Without changing your posture, curl the weights or band up to your shoulders and push back down. Repeat.



#### Staying Prepared

Make sure your transplant team knows how to reach you. Contact your transplant coordinator if contact numbers change for you or your support persons.

Have your support persons in place. This is often a family member or close friend. Choose 2 people you feel close with who have the time, health and flexibility to be your caregiver. Your support person must be an adult.

Allow others to help you. Letting go of pride and your desire to be independent can be difficult. It is important though during the transplant process. Think about how you have felt when someone has had an illness, a death or even a new baby in the family. People are usually quite happy to help out but need to know best ways to help you. It could be picking up a few things at the store, bringing a meal, or helping with outdoor or household chores. When you are back to full speed, you can do small favors in return if you choose.

Organize personal affairs. This means completing advance directive forms. Transplant social workers can answer questions about these forms. Consider a plan for your bill payments, mail and email while you are not able to do these things. Having a plan in advance will make it easier for someone to take over for you at any time.

**Arrange for your transportation needs** to and from appointments and testing.

Learn about transplant and what to expect. As you learn about what to expect you will feel more comfortable with the process.

- Review your transplant materials.
- Review resources on the next page.
- Join a transplant support group in person or online.
- If you have questions, contact your transplant coordinator.

Take time each day to get exercise. Find an activity that you enjoy doing. Fresh air is good for the mind, body and soul. It can be hard to make yourself walk or be active when you do not feel good. But the more you use your muscles before transplant, the quicker you will recover.

#### **Helpful Resources**

The resources below may be helpful for transplant patients and their families.

#### **Guided Imagery**

https://www.healthjourneys.com/

The use of relaxation and meditation to improve mood and physical well-being.

#### **Know Your Rights**

https://autisticadvocacy.org/policy/toolkits/organs/

Information to end discrimination in organ transplant.

#### **Mindfulness Meditation**

https://www.mindfulnesscds.com/

Mindful meditation may reduce reactions to stress.

### Scientific Registry of Transplant Recipients

http://www.srtr.org

Data on national, regional and centerspecific success rates.

#### **Transplant Living**

http://www.transplantliving.org

A patient education site developed by UNOS. Information on support groups and the costs of transplant can be found here.

#### **UNOS**

http://www.unos.org

United Network for Organ Sharing (UNOS) is the private, non-profit organization that manages the nation's organ transplant system.

#### **UW Health Transplant**

 $\frac{https://www.uwhealth.org/transplant/transpl}{ant/10355}$ 

Meet your transplant team, read patient stories, watch educational videos, and more. Information about mentor programs

#### **UW Health Transplant Mentor Programs**

 $\frac{https://www.uwhealth.org/transplant/transpl}{ant-mentor-program/10615}$ 

#### Caring Bridge

www.caringbridge.org

Free on-line resource to update your family and friends.

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 © 2/2021 University of Wisconsin Hospitals and Clinics Authority. All rights reserved. Produced by the Department of Nursing HF#8173.