



# Health Facts for You



Your liver transplant  
evaluation

**UW**Health



Welcome to the UW Health Liver 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. Our program provides care for both adult and pediatric patients. We offer both deceased and living donor transplantation.

### **The Liver**

It is good to have basic knowledge of how the liver works. The liver is part of the digestive system. It is the largest organ in the body. It has more than 500 functions, all of which are needed for life. Some of these functions include:

- Breaking down fats, storing nutrients, and making protein,
- Cleaning poisons and waste from the body,
- Fighting infections, and
- Blood clotting.

### **End-Stage Liver Disease**

This occurs when the liver has been permanently damaged. Causes may include:

- Infection (such as hepatitis),
- Inherited or autoimmune diseases,
- Cancer,
- Substance toxicity/abuse
  - Acetaminophen (Tylenol®) overdose
  - Chronic alcohol abuse
  - Poison

### **After Your Evaluation Testing**

When your evaluation testing is done, the transplant team will meet 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 notified of the decision and next steps.

## **Where My New Liver Will Come From**

### **The Organ Shortage**

There is a severe shortage of organs for transplant. This means that the wait for a liver transplant can take years. 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 liver 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 liver and other organs with blood and oxygen until a transplant team arrives. Once the liver is removed, it should be transplanted within 12 hours. Livers from these types of donors are called “standard donor” livers.

### **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 liver may have some damage due to lack of blood flow when organs are removed. This can cause problems for the patient who gets this liver. Most of the time these problems can be treated. A liver from a DCD donor has a higher rate of early failure compared to standard donor livers. If failure happens, you would need a second liver transplant.

You will be asked if you are willing to accept a DCD liver 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 liver, you will increase your chance of getting a transplant sooner.

### **Split Liver Transplant**

In a split liver transplant, a liver from a deceased donor is split into two parts and donated to two people on the waiting list. This can be done because the liver can regrow itself after the transplant. It will grow to normal size within weeks. The patients who get the parts must meet size criteria to be candidates for this option. This is a more complex surgery and there can be more problems. Most times these problems can be treated. A split liver transplant has a higher risk of failure compared to standard donor livers. If failure happens, you would need a second liver transplant. If you accept

a split liver, you have a better 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. We now have medicines to treat this virus, so we can use livers 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 you receive a liver from a donor who has had hepatitis C, we will do tests to check for signs of this virus. You will need to take extra medicine after transplant if you receive this type of liver.

Organs from donors with an active hepatitis C infection can be safely used. This is because we now have medicines to treat this virus. Patients who receive a liver from a donor with an active hepatitis C infection will 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 liver. If you agree, you will be required to sign a consent. If you choose not to accept this liver, you will not lose your place on the waiting list.

### **Hepatitis B Positive Donors**

Rarely (< 1% of all liver transplants done at UW) do we get livers from donors who had a possible past Hepatitis B infection. To make sure these livers are healthy to transplant, we do a biopsy of the liver. We feel these livers can be safely transplanted. If this option is chosen, the recipient needs to take an antiviral medicine after the transplant. This protects them from getting hepatitis B from the donor. The outcomes after getting a liver from a donor with hepatitis B are no different than getting a liver without hepatitis B. One advantage is that a liver may be available sooner. If you choose not to accept the liver, you will not lose your place on the waiting list.

### **Living Donation**

Donation is also possible from a living donor. In a living donor transplant, a piece of a healthy person's liver is transplanted into the recipient. This can be done because the liver grows back in both the donor and recipient after the transplant. Both the donated segment and the remaining section of the donor liver will grow to normal size within weeks. Living donors can be related or unrelated.

Benefits of living donation include being able to have a planned surgery and knowing the donor. This is a more complex surgery,

so this type of transplant can result in more problems. Most of the time these problems can be treated. Survival rates after a living donor liver transplant are close to those who have had a deceased donor transplant.

### **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 liver is found and who is first on the UNOS list to get the liver.

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 liver 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.

## **Alcoholic Liver Disease and Alcoholic Hepatitis**

### **Can I have a liver transplant if I have liver disease from alcohol use?**

Alcohol use disorder is a disease that causes alcoholic liver disease and alcohol hepatitis.

**A liver transplant will not fix your alcohol use disorder.** If you return to drinking, you may have recurrent alcoholic liver disease. You will meet with members of the transplant team. They will decide if you are able to have a liver transplant. To have a liver transplant at UW Health, **you must agree to stop drinking alcohol. This is for the rest of your life.**

### **Deciding Factors If You Can Have a Transplant**

The questions below will be asked to help decide if you are eligible for transplant.

- Did you continue to drink after a medical provider told you to stop?
- How long has it been since you have stopped drinking?
- Do you understand the role alcohol has played in your liver disease?
- Have you completed alcohol treatment in the past and then returned to drinking?
- Do you use other illegal/street drugs?
- Do you work or have some other type of meaningful activity in your life?
- Do you have a sober support system?
- Do you continue to attend activities centered around alcohol?

### **The Transplant Team May Need You:**

- To attend single counseling and/or group therapy. They may call your counselor to discuss your progress.
- To attend a public support group such as Smart Recovery, AA, etc.

- To bring a support person with you to your transplant clinic visits.
- To have random blood or urine tests to watch for alcohol use.

Your insurance plan may also have a required period of being off alcohol. They may have rules for watching avoidance of alcohol.

### **What happens while I'm waiting for a liver transplant?**

- Continue to follow your plan for not drinking.
- Attend counseling and public support groups.
- You will be tested for alcohol use.

### **What happens if I drink alcohol while I'm waiting for a liver transplant?**

- If you are struggling with cravings or return to drinking, let us know. We know recovery can be hard. There are many options for support and resources.
- If this happens, the team will discuss next steps.
- This may lead to being inactive on the waiting list. This will be for a period of time while you receive treatment.
- If you have a positive alcohol screen and have not come forward on your own, you will be made inactive on the list. The transplant team will decide how long.

### **What does being "inactive" mean?**

Being inactive means that you are not able to receive a transplant at that time. You and the transplant team will develop a plan for you to follow. It often involves having more support for not drinking. Alcohol screening will continue.

You must follow the treatment plan to return to an active status on the list. Any further

alcohol use while **inactive** will result in being removed from the waiting list. The transplant team will discuss your plan. It is likely you will **not** be able to receive a liver transplant at UW Health.

## Waiting for Your Transplant

### The Waitlist

The United Network for Organ Sharing (UNOS) manages the waiting list. They match donor organs to recipients, 24 hours a day, 365 days a year. The factors that impact your place on the list include your blood type and how sick you are. (This is based on your MELD score or PELD score for children.)

For every donor, there is a UNOS list with possible recipients. It starts with the highest MELD or PELD score. The patient with the highest MELD or PELD score for their specific blood type and is healthy enough for transplant will be called in to receive the liver. This is why it is hard to predict wait times.

### 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: [https://unos.org/wp-content/uploads/unos/Multiple\\_Listing.pdf](https://unos.org/wp-content/uploads/unos/Multiple_Listing.pdf)

### When to Call

Waiting for your transplant may take many months or years. You may go through many health changes during this time. It is vital to keep the transplant team informed of 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 be up to date on this information. This will help to ensure that you are in the best condition for your transplant. Some medicine changes 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, some of your medical tests will need to be updated on a regular basis. Most of these tests can be done by your local doctor and sent to us. Your coordinator will give you the proper orders. We expect that the tests will be done quickly. 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.

We require that all patients go through a formal re-evaluation every 1-2 years while on the waiting list. Patients come to UW Health for this re-evaluation visit. The doctor does a physical exam, reviews records, and discusses any new issues that might affect your ability to have the transplant.

Our goal is that when an organ becomes available, you will be ready. Knowing about changes in your health ahead of time 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.

### **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 are not available to return the call within one hour, the team will move on to 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 you to be brought to the hospital when you get the call. You will need to 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.



## **What to Bring to the Hospital**

You need to be prepared when you get the call. This call can come anytime, day or night.

You should plan to bring these items:

- Cell phone on and ready to call in case of delay or questions (**608-263-6400** or **1-800-323-8942**); bring phone charger
- Advance Directive (Durable Power of Attorney for Health Care or Living Will)
- **ALL** medicine bottles **and** list of medicines
- Insurance/Medicare/Medicaid cards
- Local doctor/specialist contact information
- Local pharmacy phone number
- **NOT** a lot of money/credit cards (just enough to pay for 1 month's supply of medicines after discharge)
- Loose fitting clothing, socks, shoes or slippers that cover the foot
- Personal toiletries or comfort items (hygiene or entertainment related)
- Blood pressure cuff (if applicable)
- If you have diabetes, glucose meter with supplies

**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.

## **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 decrease your immune system further. These medicines have side effects that can cause new health concerns. High

blood pressure, high cholesterol, diabetes, and osteoporosis can occur. Most of these side effects can be treated. Diet, exercise, and how well you follow your treatment plan all affect how you will be able to manage the side effects.

### **Activity Levels**

Over time, most patients can go back to their normal activity with minor adjustments. It will take some time to gain strength and endurance. Keeping up with an exercise routine once you have recovered from surgery 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 After Transplant**

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 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.

## Common Financial Questions

Below are some common questions which other transplant patients have found helpful.

- My lifetime insurance maximum is:  
\$ \_\_\_\_\_
- What would be my monthly total co-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: \$ \_\_\_\_\_
- How would this expense fit into my budget?
- How will I get coverage if I reach my lifetime maximum?
- What would I do if my insurance was changed? (Notify your coordinator right away!)
- My health plan referral guidelines:  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_



“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](http://www.medicare.gov).

### Questions to Ask

Medicare is complex. Your transplant social worker and transplant financial counselors can help answer your questions. Here are some examples:

1. What is my co-pay for anti-rejection medicines? (covered under Part B, not under Part D)
2. Is my benefit affected by in-network 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?
3. 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?
4. When will my eligibility start?
5. What if I have an employer group health plan?
6. What if I have COBRA?
7. 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

### Immunosuppressive Medicines (Anti-rejection Drugs)

Immunosuppressants, also called “anti-rejection 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 may include:

- Prednisone (corticosteroids)
- Tacrolimus (Prograf<sup>®</sup>, Astagraf XL<sup>®</sup>, Envarsus XR<sup>®</sup>)
- Cyclosporine (Neoral<sup>®</sup>, Gengraf<sup>®</sup>, or other generic brand)
- Mycophenolate (Myfortic<sup>®</sup> or Cellcept<sup>®</sup>)
- Sirolimus (Rapamune<sup>®</sup>)
- Everolimus (Zortress<sup>®</sup>)
- Belatacept (Nulojix<sup>®</sup>)
- Azathioprine (Imuran<sup>®</sup>)

### 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.

### Medicines to Reduce Stomach Acid

Most patients take medicines to reduce stomach acid. They also prevent stomach ulcers and reflux disease.

### Supplements

These provide your body with needed vitamins and minerals. Patients may take:

- Multivitamins
- Calcium
- Vitamin D

### Aspirin

This prevents blood clots and decreases the risk of heart problems.

### Docusate With Senna

This prevents constipation and helps your bowels move. You do not need this when your bowels are moving well.

### Other Medicines

Many patients have high blood pressure after their transplant. You may need medicine to treat this. You may also develop diabetes and need insulin or other medicines to manage blood sugar levels. You may need narcotic pain medicines right after the 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 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<sup>®</sup>)

## **Vaccines NOT Recommended After Transplant**

- Varicella (Varivax<sup>®</sup>)
- Influenza, intranasal live vaccine
- Measles, Mumps, Rubella (MMR)
- 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.

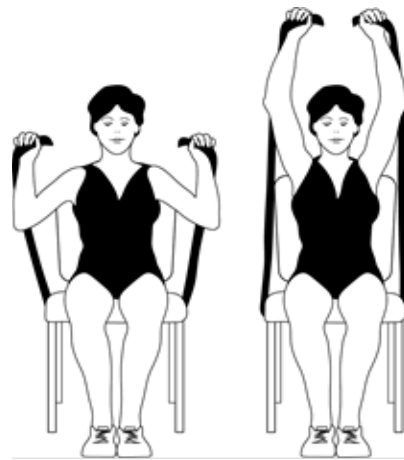
### Improve Your Strength with Exercises

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

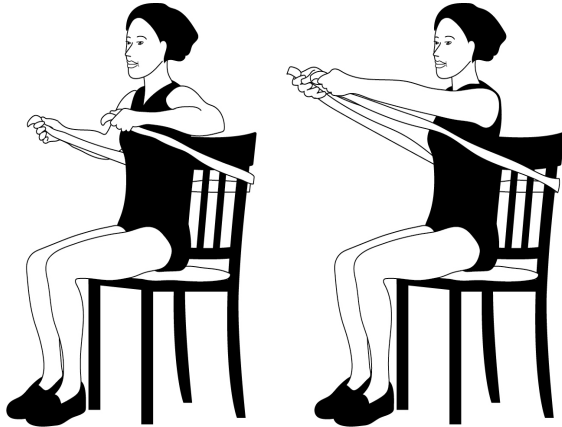
Sit on edge of a chair with your feet planted flatly on floor. Grab light dumbbells or a resistance band. Take a deep breath and tighten your core. Push the weights or band evenly over your head. Keep your neck and back in a neutral position. Bring the weights or band back down to the level of your ears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





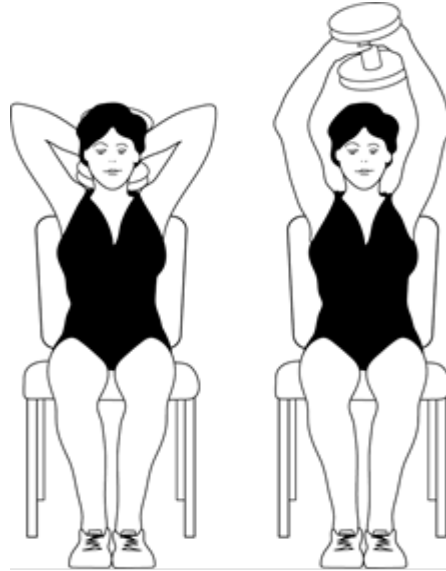
### Seated Press

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.



### 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.



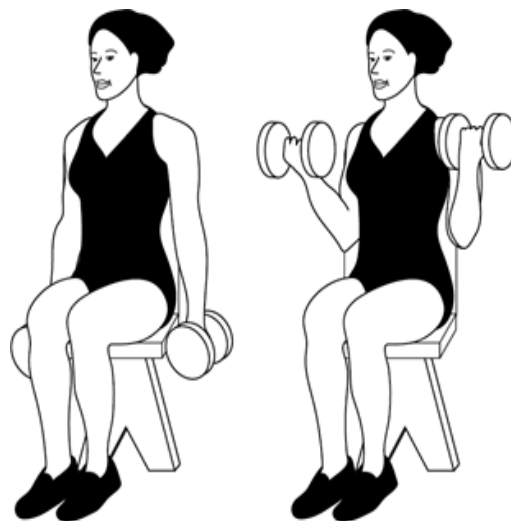
### Horizontal Row

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.



### 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 1 to 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 center-specific 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**

<https://www.uwhealth.org/transplant/transplant/10355>

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

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

<https://www.uwhealth.org/transplant/transplant-mentor-program/10615>

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#8137.