Health Facts for You

Your heart transplant evaluation

UW Health

Welcome to the UW Health Heart 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.

What is heart failure?

Heart failure means that your heart muscle is weakened. It is not pumping blood as it should. It does not mean that your heart has stopped or is about to stop. It just means that your heart doesn't pump as well as it once did.

The heart muscle can become weak and less able to pump blood out to the body. This is called "systolic" failure. In another type of heart failure, the heart cannot relax the right way to fill with blood. This is called "diastolic" failure. Some people have both problems. Both types have similar symptoms.

Heart failure also affects the kidneys. It makes it hard for the kidneys to get rid of sodium and water. The extra fluid can cause your feet, ankles, stomach, and legs to swell. "Congestive heart failure" means that your body is holding onto this extra fluid.

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 notified of the decision and next steps.

Where My New Heart Will Come From

The Organ Shortage

There is a severe shortage of organs for transplant. This means that the wait for a heart 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 heart 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 supplied with blood and oxygen until a transplant team arrives. Once the heart is removed, it should be transplanted within 4-6 hours. Hearts from these types of donors are called "standard donor" hearts.

"Increased Risk" Donors

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

Donors are deemed "increased risk" based on national guidelines. This may include risk factors such as prostitution, intravenous (IV) drug use, or those with same sex partners. The good must outweigh the would-be risk to accept donors of this type.

Potential donors have blood tests done to look for viruses such as HIV, Hepatitis B and Hepatitis C. No test is perfect, and false negative results can happen.

There is a small chance (1 in 60,000 to 1 in 2,000,000) that an infection could be passed on. We believe that the risks of getting this type of heart are very small. We tell you when the heart is offered if it is from an increased risk donor. You can then decide if you want to accept this type of heart or not. If you choose not to accept the heart, you will not lose your place on the waiting list.

Hepatitis C Positive Donors

Hepatitis C is a virus that can damage the liver. It does not affect the heart. We now have medicines to treat this virus. This means that we can often use hearts 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 heart. If you agree, you will be required to sign a consent. If you choose not to accept the heart, 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 heart is found and who is first on the UNOS list to get the heart.

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 heart 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, body weight, and how sick you are (or your health “status”). Your transplant coordinator will explain your status and let you know if it should change.

Priority is given to patients according to status on the list. Within each status, priority is given to the person who has the longest amount of time at the highest status. For example, a person who has ever been listed as a status 1 will come up higher than a person who has never had status 1. Your coordinator can answer any questions you have about this.

Heart Transplant Waitlist Statuses

Most patients fall into one of the statuses listed below. Status may change based on your current condition, treatment, and other clinical criteria. Your coordinator will review your status with you at the time of listing.

Status 1: Patients hospitalized with these treatments:

- VA ECMO
- Non-dischargeable biventricular support device
- Mechanical Circulatory Support Device (MCSD) with a life-threatening heart rhythm

Status 2: Patients hospitalized with these treatments:

- Non-dischargeable left ventricular support device
- Balloon pump (IABP) or percutaneous endovascular MCSD
- Life-threatening ventricular arrythmias without a transplanted device
- MCSD with a malfunction or mechanical failure
- Patients with mechanical support who only have one ventricle

Status 3: Patients hospitalized with:

- continuous monitoring and IV medicines supporting the heart; or
- discharged left ventricular assist device (LVAD) using discretionary 30 days; or
- MCSD device with one of following:
    - Device infection
    - Clotting
    - Right sided failure in addition to current left sided failure
    - Bleeding
    - Aortic valve failure

Status 4: Patient on supportive IV medicines without continuous monitoring; or retransplant; or diagnosis of one of these:

- Congenital heart disease
- Ischemic heart disease with unstable angina
- Hypertrophic cardiomyopathy
- Restrictive cardiomyopathy
- Amyloidosis

Status 5: Listed for more than one organ at the same hospital. (For example, listed for a heart and kidney transplant or listed for a heart and liver transplant.)

Status 6: All remaining active candidates.

Status 7: Patients who are not candidates for heart transplant now but will be a candidate soon.

While on the waitlist, you will come to the cardiology clinic. Bring a family member or friend with you to your clinic visits.

When to Call

Waiting for your transplant may take many months or years. You may have many health changes during this time. 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 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 medical tests 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 as recommended. 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.

All patients must have 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 talks about any new issues related to transplant.

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 heart failure team. Contact them with symptoms.

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.

This list 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
- Influenza, intranasal live vaccine
- 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®)
- Measles, Mumps, Rubella
- Rotavirus

Other Vaccines to Discuss with Your Provider

- Quadrivalent meningococcal conjugate or polysaccharide
- Haemophilus influenzae type b

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.

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)**

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 45 minutes of UW Health for a minimum of 1 week after transplant with your support person.
- Plan transportation for 4-6 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.

Biopsies are done:

- Weekly for 4 weeks.
- Every 2 weeks for 8 weeks.
- Monthly for 3 months.
- Every 6 weeks until your 1st anniversary.
- Every 3 to 12 months based on if you have had rejection during your first year.
- More often if you have a rejection.

With each biopsy you will also have labs, a chest x-ray, and sometimes an echocardiogram.

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

Types of Medicine After Transplant

Immunosuppressive Medicines (Anti-rejection 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 life-long. 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.

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.

Your primary support person must be involved in your education. They should plan on being at the hospital for 3-4 days at minimum for education. However, each learner is different; some may require more time to learn.

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 people to return to work after having a transplant. You may not be able to do the same duties as before your transplant. It doesn't mean you can't work at any job. It just depends on the type of work you do. The social worker will meet with you after your transplant. You can talk about going back to work and get help to fill out any paperwork you may have.

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.

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 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 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:

Questions and Notes About My Insurance

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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) and 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.

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 is 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.**

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

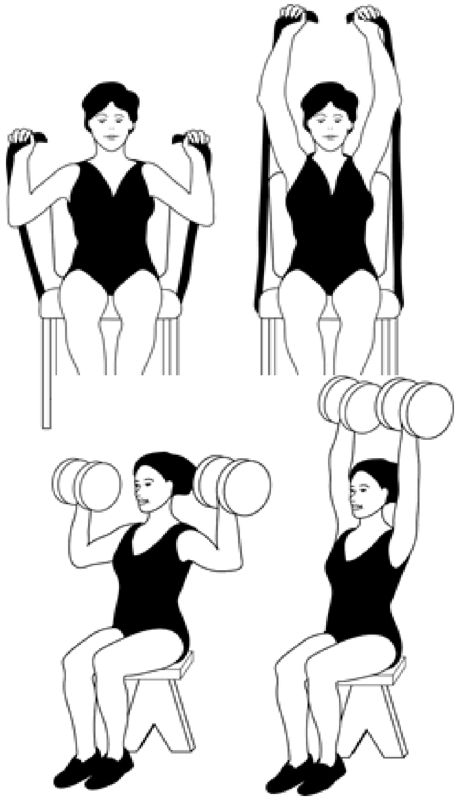
You can improve your strength if you add daily exercises. If you cannot exercise on your own, you may need physical therapy (PT). Let your nurse or doctor know if you think you need PT. They can help set it up.

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.

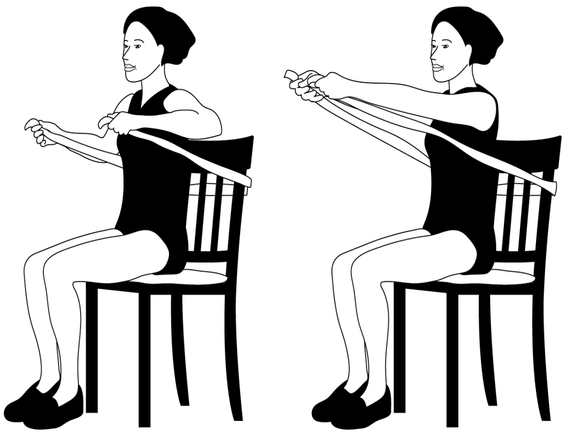
Based on your current treatment, you may have been given physical restrictions by your care team. **Please do not do any of the exercises below that may go against those restrictions**. If you unsure if you can or should do any of these exercises, please contact your care team to discuss.

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.

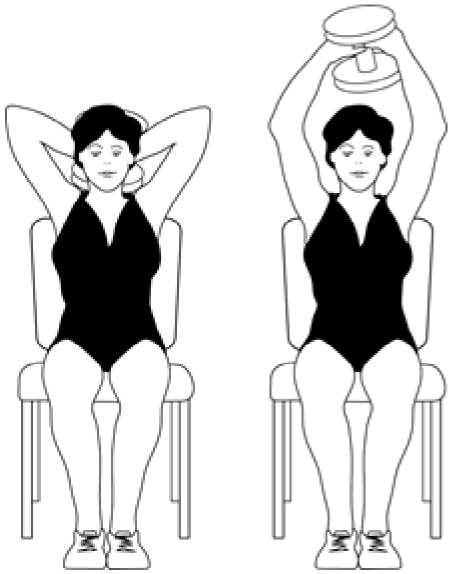


Seated Press
Wrap your band around the back of your chair and make sure it is secure. Sit with your weight evenly distributed. Take a deep breath. With a flat back and even posture, push your arms straight out in front of you. Make sure you are using your chest to push out your arms. Try not to move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

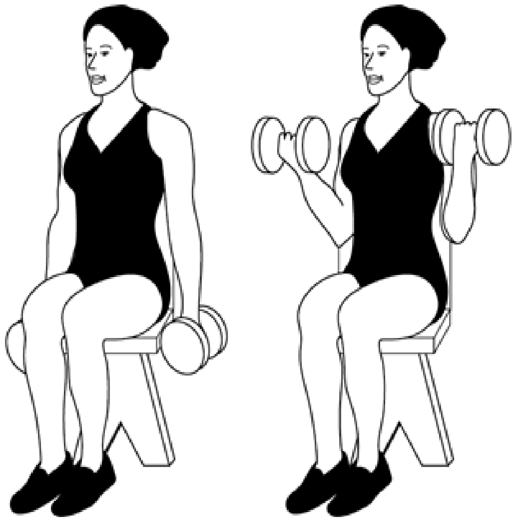


Horizontal Row
Sit on the floor with your back straight. Place your band around your feet at the halfway point on the band, so the sides are even. Pull the band towards your chest. Squeeze your shoulder blades together. Slowly release the band back to the start. Repeat.

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.



The Transplant Surgery

When you go to the surgery area, one support person may stay with you until you go to the operating room (OR). Other family members may stay in the surgical waiting area. Your support persons should bring something to do since the time may seem to pass slowly. The nurses will provide your family with updates.

Once you are in the operating room (OR), you will meet nurses and other staff. They answer questions, make sure you are comfortable, and explain what is happening. There will be ECG (electrocardiogram) patches on your chest, a blood pressure cuff on your arm, and a plastic clip on your finger to check your heartbeat 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. Other lines and monitors are added after you are asleep.

- Urine catheter: A small rubber tube (Foley catheter) will be in your bladder. This allows us to track your urine output. It stays in place until the day after surgery.
- Intravenous catheter (IV): At least one IV will be placed in your hand, arm, or neck. This will be used to give you fluids 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.

The transplant surgery will take about 6-8 or more hours.

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. 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 tube is 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. Once we hear bowel sounds or you pass gas, you will be able to start drinking liquids and will slowly advance to a regular diet.

Your Incision

The incision will have a dressing over it. The nurse will change the dressing to start. 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. The staples or stitches are usually removed at your clinic visit with the surgeon after transplant.

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. 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. 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.

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

Caring Bridge
www.caringbridge.org
Free on-line resource to update your family and friends.