Health Facts for You

Your heart transplant evaluation



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.

How do I know if I need a transplant?

Causes of heart diseases vary, but heart transplant is the most advanced therapy for the most severe heart disease. Your transplant evaluation will evaluate if there are other treatment options and if you are well enough to undergo transplant surgery.

After Your Evaluation Testing

When your evaluation testing is done, the transplant team reviews and discusses your results. There are three possible decisions:

- 1. You are approved to be added to the waitlist. 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 the brain doesn't get enough oxygen and the brain stops working. This is often due to trauma or a stroke. Tests are done to tell when someone is brain dead.

People who are brain dead are on a breathing machine. The breathing tube and medicines keep the heart beating and supply the organs 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.

Donation After Circulatory Death (DCD 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. When the heart stops beating, the person is declared dead by the doctor. The transplant teams can remove the organs. This is called donation after circulatory death (DCD).

The transplant team will use a machine to start pumping blood again to the organs in the body. Once the heart starts pumping blood again, doctors check to see how the heart is working. If the heart works as expected, success rates for patients who get a DCD heart are the same as with a brain dead donor heart.

DCD heart transplant is an option to improve access to quality donors in the United States. DCD heart transplants have been done in England and Australia. Results are as good as, or better than brain dead donors. As with any heart transplant there are risks during the time that the heart is not getting blood flow. This may lead to graft dysfunction at a rate similar to hearts from donors with brain death.

If you decide to accept a heart from a DCD donor, you will have access to an organ that might not be available to many other recipients. Some transplant centers have not yet started to use hearts from DCD donors. This increases your chances of getting a transplant sooner. This lowers your chances of dying while waiting for a heart form a brain dead donor.

You will be asked if you are willing to accept a DCD heart 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.

Other risks that apply to all heart transplants are described in the heart transplant consent form. This will be reviewed with you, and you will be asked to sign.

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 heart are very small.

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 Health 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.

The Transplant Waitlist

Completing a transplant evaluation does not guarantee being put on the waitlist. If you are approved for transplant after your evaluation, you will then be put on the waitlist.

The Waitlist

The United Network for Organ Sharing (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 based on 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

Patients on the waitlist are assigned a status based on how sick they are. Patients active on the waitlist are in one of 6 different statuses. Statues 4-6 patients are waiting at home for their transplant. Statuses 1-3 are patients who are admitted in the hospital. These patients are sicker and are prioritized on the wait list.

Your status may change based on your condition and the treatments needed. Your coordinator will review your status with you at the time of listing and if it changes.

While on the waitlist, you will come to the cardiology clinic. Bring a support person with you to your clinic visits.

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. 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: <u>https://unos.org/wp-</u> <u>content/uploads/unos/Multiple_Listing.pdf</u>

Re-evaluation While Waiting for Transplant

To stay active on the UNOS waiting list, your medical information needs to be updated on a regular basis. Most of these tests can be done by your local doctor and sent to us. We expect that the tests will be done as recommended. If these tests are not done, you may be made inactive on the waitlist until they are done.

All patients must have a formal reevaluation 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.

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
- Being started on a new medicine
- 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 any change in insurance coverage

- Changes in contact information (such as phone number or address)
- Changes in your support people 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.

Staying Healthy Before Transplant

Taking care of your health is very important while waiting. It is expected that you will take all medicines and vaccines 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.

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

Nutrition



Nutrition plays a key role in the transplant process. Eating well and exercising before transplant 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. 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, not eating well, 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 30 minutes of exercises daily. This could be walking, weightlifting, or sitting chair 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.

It is important to exercise even if you have physical limitations. You can do these exercises at home, 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 are unsure if you can or should do any of these exercises, please contact your care team to discuss.

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 up to 30 minutes from the first phone call attempt, the team will move on to the next potential recipient. You may not recognize the number calling as UW Health.

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.?
- Where will your support people stay while they are in Madison?

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. You will be directed when you should come to the hospital. It is important to arrive when instructed. Your safety when traveling is important, so be careful on your way here. The transplant is often done within 12-24 hours of the call.

The nurse from the transplant program will call you if an organ becomes available. You may be asked:

- To stop eating and drinking
- To stop taking one or more of your medicines
- About your current health status
- About your recent immunizations, illnesses, infections, and medicines
- To come to UW Health **or** keep a phone available, but to wait at home until you are called again

It is vital that your support people 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. You will also need a plan to get home from the hospital since you will not be able to drive. 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

You need to be prepared when you get the call. This call can come anytime, day or night. Be sure your cell phone is on and ready to call in case of delay or questions (608-263-6400 or 1-800-323-8942).

Plan to bring these items:

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

Surgery

Day of Surgery

When you are taken to surgery, your support people may stay in the surgical waiting area. The nurses will provide them 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.

The surgery takes about 8-12 hours.



After Surgery

You will go to back to your room on the transplant unit for recovery. The nurses on the unit will let your support people know when they can come to the room to see you. Time to visit may be limited. Nursing staff may ask them to leave the room if needed for patient care.

Equipment and Other Changes to Expect

You may need tubes, lines, and monitors after surgery. Tubes remove fluid from your body. Lines give you fluid and medicine. Monitors tell us how your heart and lungs are doing. Removal of tubes and lines is based on your progress. This is a list of common tubes, lines, and monitors:

- Intravenous catheter (IV)
- Chest tube
- Breathing tube
- Stomach tube
- Foley catheter
- Pulse oximeter (pulse ox)
- Safety equipment and restraints
- Sequential stockings
- Telemetry

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. You will be



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encouraged to walk as soon as your nurses think it is safe.

You will have an incision down the center of the chest at your sternum. This may be closed with sutures, glue, staples, or a combination of closure methods. The incision will have a dressing over it.

Your doctor will order pain medicine for you. Your walking, coughing, and deep breathing will be easier when your pain is controlled. Coughing and deep breathing are an important part of recovery and help to prevent pneumonia.

Your blood sugars will be checked during and after surgery. You may need insulin as you recover even if you have not needed insulin in the past. Well-managed blood sugars lower your risk of infection. You may need to take insulin when you go home. If so, the diabetes education team will teach you and your support people.

The average hospital stay is about 3 weeks. It may be longer or shorter depending on how you are healing.

Education After Transplant

You must learn about the care of your new organ. Education sessions are **required** with **you and your support person** in order



to be discharged. This may start any time based on how your recovery is going. You may have education sessions with your transplant coordinator, transplant pharmacist, transplant dietitian, physical and occupational therapists (PT and OT), and diabetes care and education specialists.

Guidelines for Visitors

Visitors should check at the information desk or nursing unit before visiting. The main hospital phone number is **608-263-6400**.

What will happen after I am discharged from the hospital?

You will have to stay within 45 minutes of the hospital for a minimum of 1 week after discharge from the hospital. Your support person will need to stay with you 24 hours a day during the first 2-3 weeks. This time allows you to settle into a routine at home, arrange your home in a way that is convenient to you, and have access to someone to help with cares and transportation.

Finding Area Lodging

UW Health Guest Services may offer discounts at local hotels. Many area hotels have shuttles available. The phone number to call Guest Services to make lodging arrangements is (608) 263-0315. If you live within 45 minutes of the hospital, you may return home after surgery.

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, including biopsies and hospital stays.
- 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 and inform the transplant team of any over-the-counter medications and supplements.
- Follow the diet and exercise plan advised by your doctor.
- Go to your clinic visits and bring your medication list.
- Get your labs drawn.
- Follow recommendations for mental health or alcohol/substance use treatment.
- Follow up primary care doctor for routine health maintenance.
- Plan transportation for at least 6 weeks after surgery or until you are approved to return to driving.

Appointments

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. Clinic visits and biopsies are done weekly for a period of time. Your team will decide when you can be seen less often.

You will be given a schedule for the first few months after transplant. This is subject to change based on your condition or doctor availability. We will call you with changes.

Primary Care Visits

You must have a primary care provider to address routine health issues. This might include diabetes, minor infections and illnesses, and regular health care needs. Plan to see your local doctor shortly after your transplant.

We want you to live a healthy life after transplant. We will work closely with your primary care provider to give you the best care. We work together to advise you about your diet, exercise, and other health needs. The transplant team will manage your transplant medicines and address any transplant issues.

Types of Medicine After Transplant

After your transplant, you will be on many medicines. You will be on most of them for the rest of your life. These medicines are important in the success of your transplant. You will need to know what medicines you are taking, why you are taking them, and the dose prescribed. Some of your medicines may need to be taken at the same time every day. Never stop or adjust medicines on your own. Not taking your medicines correctly can lead to rejection and other health problems.

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 could include:

- Prednisone
- Tacrolimus or cyclosporine
- 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:

- TMP/Sulfa (Bactrim) for bacterial infections of the bladder and lung
- Acyclovir, Valacyclovir, or other medicine for viral infections such as cytomegalovirus (CMV) or herpesvirus (cold sores).
- Posaconazole for fungal infections.

Other Medicines

Most patients take other medicines to prevent stomach ulcers, control blood pressure and cholesterol, and supplements to support your bones and general health. You may also develop diabetes from the transplant medicines and need insulin or other medicines to manage blood sugar levels.

Some of these medicines are temporary but many are life-long. You may need opioid pain medicines right after surgery for a short time. You will not be able to take NSAID medicine 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 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 to Get Before and After Transplant

- Inactivated influenza, injected
- COVID-19 boosters
- 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[®])
- RSV (for patients age 60 or over)

Vaccines NOT Recommended After Transplant

- Varicella (Varivax[®])
- Measles, Mumps, Rubella (MMR)
- Rotavirus

Other Vaccines to Discuss With Your Provider

- Quadrivalent meningococcal conjugate or polysaccharide
- Haemophilus influenzae type b
- Travel vaccines

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. You may not be able to travel or use public transportation for the year after transplant to decrease your risk of infection. You may need to modify some things about your lifestyle after transplant to decrease the risk of infection.

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 (problems with your bones). 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. When you are ready to return to work depends on the type of work you do. Talk with your transplant team about returning to work. We will complete medical leave paperwork for your job if needed.

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 is here to support you. If you want to see a mental health provider, you can contact your primary care provider or insurance company. Sharing your feelings with your loved ones and others may also be helpful. There may be support groups for transplant recipients and support people available. Below are some websites which may be helpful in coping after transplant.

Support People

The transplant process can be very tough for support people. Many support people have anxiety during the process. It is important that they take care of their physical and mental health during this time.

Keeping Support People Updated

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

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 people. Have your cell phone on and with you at all you at all times.

Have your support people in place.

Support people can be family, friends, or guardians who are 18 years of age or older. Choose 1 to 2 people you feel close with who have the time, health, and flexibility to provide inperson support as you prepare and recover from transplant. Contact your transplant social worker with any changes in your support plan.

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. Life preparations for surgery This means completing advance directive forms. Transplant social workers can answer questions about these forms. Consider a plan for the care of your pets, 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.

Know Your Rights

https://autisticadvocacy.org/policy/toolkits/o rgans/

Information to end discrimination in organ transplant.

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/transpl ant/10355

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

Caring Bridge

https://www.caringbridge.org

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

UW Health Transplant Peer Mentor Program Program that connects transplant recipients for peer support. Contact<u>your transplant</u> <u>social worker for more information.</u>

Learn More

For more resources about transplant at UW Health, scan the QR code below.



Who and When to Call

Transplant Nurse Coordinator

Call:

- If you are hospitalized or receive a blood transfusion
- When evaluation testing done
- Your contact information changes Contact:
 - Monday-Friday, 8:00a.m.-4:30p.m.
 - 608-263-1384

Social Worker

Call for:

• Change in support plan

Contact:

- Monday-Friday, 8:00a.m.-4:30p.m.
- 608-263-1384

Financial Counselor

Call for:

• Change in insurance

Contact:

- Monday-Friday, 8:00a.m.-4:30p.m.
- 608-263-8770

Your health care team may have given you this information as part of your care. If so, please use it and call if you have any questions. If this information was not given to you as part of your care, please check with your doctor. This is not medical advice. This is not to be used for diagnosis or treatment of any medical condition. Because each person's health needs are different, you should talk with your doctor or others on your health care team when using this information. If you have an emergency, please call 911. Copyright © 6/2024 University of Wisconsin Hospitals and Clinics Authority. All rights reserved. Produced by the Department of Nursing HF#8163.