Health Facts for You

Preparing for your heart transplant evaluation

UWHealth

HE-579725-20

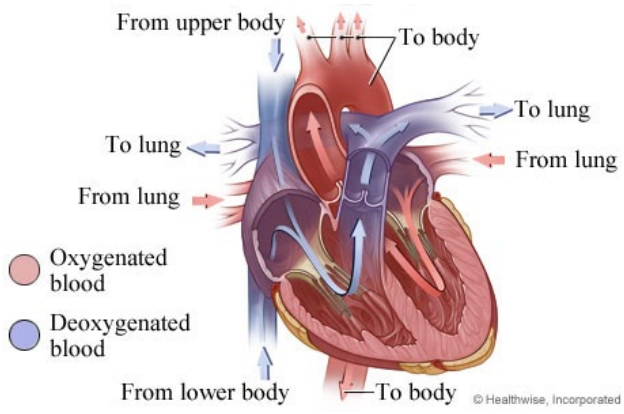
Welcome to the UW Health Heart Transplant Program. The team takes pride in building a care plan tailored to your needs. We are committed to your success. UW Health is a national and international leader in the field of transplantation.

The Heart
It is good to have basic knowledge of heart failure. Heart failure can be caused by many things. These include:

- Blockage of blood vessels to the heart (coronary artery disease)
- Heart attack
- High blood pressure
- Chronic heart valve problems (due to past rheumatic fever or infection)
- Less pumping ability of the heart muscle for an unknown reason
- An infection of the heart
- Heart defects present at birth
- Genetic reasons

Heart failure means that your heart muscle is weak. It does not pump blood as it should. This does not mean that your heart has stopped or is about to stop. It means your heart does not pump like it should.

The picture below shows how the heart works normally. If it gets too weak, medicines and other treatments may not be enough.



Transplant Evaluation Visit
On average, the evaluation takes 3-4 days. This depends on testing that you have had in the past. It is meant to provide the team with a complete overview of your heart disease and needs. The evaluation is truly a "whole body scan." It is not unusual to find something that requires more testing. This may mean more visits at UW Health or somewhere closer to where you live.

The evaluation will include many tests. These include:

- Cardiac (heart) tests: echocardiogram, right heart catheterization, exercise stress test, EKG
- Chest x-rays
- Abdominal ultrasound
- Ultrasound of the arteries
- Bone density scan
- Chest CT with contrast
- Blood and urine tests
- Dental exam
- Eye exam
- Pap/Pelvic/HPV testing
- Mammogram
- Colonoscopy

Since transplant is so complex and a strong support system is important in helping you have a successful experience, you are **required** to identify 1 to 2 people in your life who are willing and able to provide in-person support as you prepare for and recover from transplant. Support people can be family, friends, or guardians who are 18 years of age or older. A support person **must** be with you for your visits with the team during the evaluation.

To prepare for your evaluation, we have enclosed:

- **Advance Directives**
  These are legal forms that clearly state what actions to take if you can

no longer make decisions for yourself. We strongly advise you to complete advance directives. If you have one, please **bring a copy** with you. We will add it to your medical record. We can help you complete these forms if you haven't already.

- **Patient and Support Expectations** These are documents that explain how we want patients and their support people to partner with us in their transplant care. Please read these documents with your family, friends, and other support people. These documents will also be discussed with you and your support person and signed at your evaluation visit.

What to Bring to Your Evaluation

☐ Transplant evaluation folder
☐ **At least** one person you have identified as a support person
☐ Copy of Advanced Directives/Health Care Power of Attorney if you have them filled out
☐ Completed Vaccine History form
☐ A list of your current medicines and supplements or pill bottles. This list should include doses and why you take them. Also bring medicines you may need to take during your appointment.
☐ A list of questions you or your support person have for the transplant team.
☐ Your insurance cards
☐ Phone charger
☐ Light jacket or sweater
☐ Snacks/sack lunch
☐ Something to do (tablet, book, etc.) between appointments
☐ Social security number (for future transplant listing if approved for transplant)

The Transplant Process

Evaluation

- In order to make sure transplant is the best option, over weeks or months, you will:
  - Meet with the transplant team.
  - Complete tests and labs.
- After your evaluation, we will follow up with you about next steps.

Waiting Period

- If a transplant is considered by the team to be the best option, and you wish to proceed with surgery, you will be added to the national waitlist.
- This is done through the United Network for Organ Sharing (UNOS). UNOS is in charge of placing the donated organ with the right recipient, per UNOS policies.
- This phase can last days or years.
- You will have appointments and testing every 3-6 months.

Surgery

- You receive the organ transplant and heal in the hospital.
- While healing, you and your family learn about new medicines, self-care, follow-up tests and clinic visits.

Follow-up

- This phase begins when you leave the hospital.
- Medicines, labs, clinic visits and follow-up care are needed in order to lead a normal, active, and healthy life**.**

Team Members

Transplant Surgeons
Transplant surgeons meet with you during the evaluation. They review your record and test results and explain the surgery. They review the risks and benefits of transplant. The surgeon does the surgery and works with other doctors to manage your care after the transplant.

Transplant Medicine Doctors
These doctors help to decide if a transplant is the best option for you. They stay involved while you are on the waiting list and after the transplant.

Pre-Transplant Nurse Coordinators
These nurses coordinate your care before transplant. They are involved from the time of the first referral until a transplant is received. They arrange any tests needed to get you placed on the waitlist. This nurse helps you through the evaluation process. These nurses contact your local doctors and other healthcare facilities as needed.

Post-Transplant Nurse Coordinators
These nurses coordinate your care after transplant. They are involved from the time of transplant through long-term, post-transplant care. They serve as your link to the rest of the transplant team after surgery. They work with the doctors to coordinate your medical needs. They teach you and your family and advocate for you. These nurses contact your local doctors and other healthcare facilities as needed.

Transplant Social Workers
A transplant social worker will meet with you at your evaluation. They will talk with you about your support system, your drug/alcohol use, how you cope, and how well you will be able to follow important instructions. These questions help them learn more about your needs before the transplant. They can help with connecting you with community resources such as counseling, support groups, and financial support. They can also help you complete advance directives if needed. Social workers are also available for support after your transplant.

Transplant Dietitians
Clinical dietitians assess your nutritional status, mobility, and strength. They help you to make a plan for good nutrition and exercise.

Physician Assistants and Nurse Practitioners
These advanced practice providers care for you before and after your transplant. They check on you as you recover and help to manage your medicines. They also help to plan for your discharge needs. You will see them in transplant clinic before and after your surgery.

Surgical Residents and Transplant Fellows
These doctors mainly assist with hospital care. This includes getting you ready for and assisting with surgery. They help to manage issues after surgery and prepare you for discharge. You may also see transplant fellows at transplant clinic visits.

Financial Counselors
These staff work with you and your insurance company before and after transplant. They help to work through matters such as billing, deductibles, and drug coverage. They teach you about the financial aspects of transplant. They are the best resource for any questions about insurance.

Transplant Pharmacists
Pharmacists work with the team to make sure the medicines are used correctly. They watch for side effects and try to minimize them. They also help to manage the timing of the medicines.

Inpatient Transplant Nurses
These nurses care for you in the hospital. You will have a primary nurse. This nurse works with the rest of the team to get you ready for discharge.

Inpatient Nurse Case Managers and Social Workers
Nurse case managers and social workers are available to help develop your plan for leaving the hospital. Some patients need skilled nursing care or other services. They help arrange this care or connect you to other community resources.

Transplant Clinic Nurses
These nurses care for you during clinic visits. They provide care and support for you after procedures. They arrange follow-up care and provide education.

Office Support Staff
Support staff answer your phone calls and work with the coordinators and other staff. They help coordinators to manage lab results and patient issues and concerns.

Spiritual Care
Chaplains help people find comfort and meaning from their faith during illness recovery. Our chaplains provide spiritual and emotional support. They also perform sacraments. Faith and medicine offerings are provided in the hospital chapel. Catholic and Protestant services are held on Sundays.

Other Expert Doctors
Other doctors may be involved either during the evaluation or after transplant. UW Health has many specialized doctors who work with the rest of your team. Infectious disease, dental, endocrine, and urology are just a few of the teams that can assist in your care if needed.

Other Services
Other services are available to help you and your family. For example, Interpreter Services help those who need translation. Housing assistance can help if you need short-term housing.

Financial Planning

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.

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. Contact your insurance company to ask about travel, lodging, and meal reimbursement benefits related ot transplant. This may affect how you financially plan for transplant and recovery.

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.

- 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?
- What would I do if my insurance was changed? (Notify your coordinator right away!)
- My health plan referral guidelines:

  _____

  _____

  _____

Tips for Talking with Your Health Care Provider

You and your health care team are working toward the same goal - good health for you. Talk together about your health and any problems you may have. Here are a few tips to make the most of your time together.

Use clinic and hospital visits to learn how to best care for yourself. Ask questions. Practice new skills. Get advice about what might work best for you.

Be a partner in making decisions. Ask about your options. Find out about pros and cons of any decision. Plan your care with the health care team and others who support you.

When you make an appointment, ask if you need any tests before you come in. You may need to wait to eat or drink until after a test is done. Ask if you can do the test before your appointment. You may be able to get the results during your clinic visit.

Prepare for your visit. Think about the reason for your clinic visit. Write down what you want to tell your provider. Write down any questions you have. Ask the person who comes with you to help keep track of questions and answers.

Be clear about your health problem and how you feel. Before your clinic visit, you may want to write down:

- How long you have had your health problem
- What you have done about it
- How your health problem changed or stayed the same
- What makes it better or worse

Share what you have been doing about your health problem. If you have been treating yourself or changed the treatment, tell your provider. To best help you, your team needs to know how you are caring for yourself.

Listen carefully and ask questions. If you don't understand, ask questions. Ask for more information if you need it. Take notes or ask for a written sheet if this would help you. Ask your health care provider:

- What your health problem is
- What caused it
- What you should do about your health problem
- When it will improve
- If you need a follow-up visit

Make sure you know and agree with the plan.

- Repeat what you have heard to make sure you understand what was said.
- Make sure the instructions are right for you. If they aren't, tell your provider. The plan can be changed to better meet your needs.
- Understand side effects and what to expect from any new medicines.
- Find out who to call for questions after you go home.
- Take your after-visit summary sheet at the end of a clinic visit. You can also find it in MyChart.

Learn More

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

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.
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