



# Health Facts for You



Preparing for 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.

## The Heart

To understand the transplant process, 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 itself,
- Heart defects present at birth,
- Genetic reasons.

Heart failure means that your heart muscle is weakened. 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 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 can’t relax enough to fill with blood. This is called “diastolic” failure. Some people can have both problems. Both types have similar symptoms.

## 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 tests
- Chest x-rays
- Abdominal ultrasound
- Ultrasound of the arteries
- Bone density scan
- Chest CT with contrast
- Blood tests
- Urine test
- General Health Testing
  - Dental exam
  - Eye exam
  - Vaccines
  - Mammogram
  - Colonoscopy

## What to Bring to Your Transplant Evaluation

<input type="checkbox"/> This packet	<input type="checkbox"/> Completed Vaccine History form
<input type="checkbox"/> <b>At least</b> one person you have identified for support	<input type="checkbox"/> Copy of Advanced Directives if you have them filled out
<input type="checkbox"/> Your insurance cards	<input type="checkbox"/> Snacks/sack lunch
<input type="checkbox"/> Completed <b>Transplant Evaluation Checklist</b> (found in this packet)	<input type="checkbox"/> Something to do (tablet, book, etc.)
<input type="checkbox"/> An overnight bag with essential items. Some patients are admitted for conditions found during the evaluation.	<input type="checkbox"/> A list of your current medicines and pill bottles. This list should include doses and why you take them.
<input type="checkbox"/> A list of questions you or your support person have for the transplant team.	<input type="checkbox"/> Other:

## **Transplant Team Members**

### **Transplant Surgeons**

Transplant surgeons meet with you and your family 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.

### **Medical Specialists**

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.

### **Clinical Social Workers**

Social workers talk with you about your emotional health and social situation. They will discuss community resources and help with financial matters. They help support you during the transplant process. Social workers can answer your questions about

advance directives. They can help you complete them if needed. They can also help to find support groups.

### **Clinical Dietitians**

Clinical dietitians assess your nutritional status. They help you to make a plan for good nutrition.

### **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.

**Case Managers**

Case managers focus on the plan for leaving the hospital. Some patients need skilled nursing care or other services. The case managers can help arrange this care.

**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, cardiology, hepatology, 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.

## The Transplant Process

### Evaluation

- In order to make sure transplant is the best option, you will:
  - Meet with the transplant team.
  - Have tests and labs done.
- This phase can take days, weeks or months.
- When your evaluation is done, you will get written notice of our decision.
- You may also start to seek out potential living donors (for kidney and liver transplant) during this phase.

### Waiting Period

- If you and the UW Health transplant team believes transplant is your best option, you will be added to the national waitlist. This is done through the [United Network for Organ Sharing](#) (UNOS). UNOS is in charge of all organ allocation.
- This phase can last days or years.
- Find potential living donors (for kidney and liver transplant).
- If a living donor is approved, you will be scheduled for surgery after the donor work-up is done.

### 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 starts when you leave the hospital. It lasts the rest of your life.
- Medicines, labs tests, clinic visits and follow-up care are needed.
- The transplant team will support you long-term, so you can lead a normal, active, and healthy life.

## Social Work Support

A transplant social worker will meet with you at your evaluation. They will ask you questions about:

- you and your family,
- how you cope,
- your drug/alcohol use,
- your support systems,
- how well you will be able to follow important instructions.

These questions help them learn more about your needs before the transplant.

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**  
Please read these documents with your family, friends, and other support persons. The transplant process can be long. You will need extra help and support to have a successful experience. **An adult must be with you at this visit.** This could be a family member, friend or guardian. This person must be willing and able to provide in-person support as you prepare for and recover from transplant.

## 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.

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:  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

## 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.** 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.

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 © 9/2019. University of Wisconsin Hospitals and Clinics Authority. All rights reserved. Produced by the Department of Nursing. HF#8109.