Waiting for Your Heart Transplant

♥ Changes in status

- How long will I wait to get an organ?
- When should I call the transplant team?
- What do I need to do while waiting for an organ?

Waiting for your heart transplant may take a week or many months. You may go through many physical changes during this time. It is vital to keep the transplant team informed of any changes in your health status. Examples of things that you should call about include:

- Taking antibiotics or have an active infection
- Getting a blood transfusion
- Being hospitalized
- Increase or decrease in your weight (5 pounds or more)
- Have a significant change in your health status
- Have a change in insurance coverage
- Changes in contact information (ie: phone number or address)
- Changing your support person

The transplant team needs to be up to date on this information. This will help to ensure that you are in the best condition for your transplant. Keep in mind that some medicine changes or hospitalizations could change your status in UNOS. It is vital that you contact the team with any health changes.
Taking care of your health is very important while waiting for a heart. To do this take all of your medicine as told to by your doctor. You must also follow your plan for fluid and salt limits, diet, and exercise. Contact your heart failure nurse coordinator right away if you are worried about your health or have any of the following:

- Change in fatigue, tiredness, or energy level
- Shortness of breath
- Loss of appetite or “bloated” feeling
- Swollen ankles or legs
- Weight gain (more than 3 pounds over three days)
- Decreased urination
- Fever

If you cannot reach a coordinator and you think you need to go to the hospital, go to the nearest emergency room. Tell the doctor that sees you that you are waiting for a heart transplant. Have them call the transplant cardiologist on call at (608) 262-8915. Be sure to inform us of any drug changes that another doctor may make.

♥ Waiting on the list

- Where do I fall on the list?
- What happens while I wait?

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 patient who has the longest amount of time at the highest status. For example, a patient that has ever been listed as a status 1A will come up higher than a patient that has never had 1A regardless of overall time on the wait list. Your coordinator will be able to answer any questions you have about this.
The statuses are

1A  •  Patients on a Mechanical Circulatory Device that is having device-related problems. (And ANY patient who is on a device automatically gets 30 days of 1A time to use at the physicians discretion). Patients on high doses of intravenous (IV) medicines and are in the hospital

1B  •  Patients who are at home with either a Mechanical Circulatory Device or low doses of IV medicines.

2  •  Patients who are being managed at home with oral heart failure medicines

7  •  Patients who are not candidates for heart transplant at the present time, but will be a candidate soon.

While on the wait list, you will come to the cardiology clinic at least every 12 weeks and more often if needed. It is a good idea to bring a family member or friend with you to your appointments.

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.

♥Introduction to medicines and coping

•  What types of drugs will I need to take and why?
•  Will there be side effects to these drugs?
•  How will I finance these drugs?

After your transplant you will be on many medicines. You may take up to fifteen different drugs each day. These can be placed into one of three groups:

•  Drugs that prevent rejection (anti-rejection). You will be on these for the rest of your life.
•  Drugs that prevent infection (anti-infective). You will take these for about a year after your transplant.
•  Supplemental drugs. These may include vitamins and drugs for your blood pressure or cholesterol.

It is vital that you take all medicines as you are told to by your doctor.
There can be many side effects caused by the drugs you will be taking. These can include:

- Diabetes
- High cholesterol
- High blood pressure
- Weight gain
- Tremors
- Mood changes

Medicines can be given to help with some of the side effects. Others may just take time to fade away. It can be very hard to cope with the new drugs, side effects, and lifestyle changes. You should never stop a drug or change a dose without talking with your coordinator.

Be sure to talk with the financial counselor and social worker about drug coverage after transplant. These drugs are very costly. You will want to have a plan to cover your drug costs in case your insurance does not.

♥The Call

- How will I be reached?
- What do I need to have ready ahead of time?
- What will happen after I get the call?

Once you are listed you must be able to be reached at all times. You must inform your transplant coordinator if you are going to be out of the area or not available for any reason. If you need to travel more than an hour away from your house, you may need to be placed on temporary inactive status. You must always have a cell phone with you. Be sure your phone is always on and fully charged. If there is any concern that you are in an area where your cell phone may not have service, you should give your coordinator a different contact number to reach you.

The transplant coordinator will call you if an organ that may be a match for you becomes available. At this time you will be asked:

- To stop eating and drinking.
- About your current health status.
- To keep a phone line available, but to wait at home until you are called again OR to come to the UWHC.
You will need to bring your insurance information and a list of your medicines when you come to the hospital. You do not need to bring other items. It is a good idea to leave all jewelry (including rings) and other items of value at home.

You must be able to arrive at UW Hospital within 2-4 hours of being called. If you live nearby, you should have a friend or family member planning and ready to bring you in. You should not drive alone when you are coming for a transplant.

The transplant coordinator will tell you where to go once you arrive at the hospital. Please keep in mind that your surgery could be cancelled at any time.

It is vital that family and friends are involved in the planning process. Be sure that they are aware of the need for you to be reached at all times. They should also know the plans for you to be transported to the hospital when the call arrives. You will need to make plans for the care of your pets, children, work duties, and other responsibilities ahead of time. Being prepared will help you feel less stressed during your hospital stay.

Once at the hospital, you will be very busy getting ready for surgery. This will include:

- Talking with the doctors.
- Signing consent forms.
- Having blood drawn.
- Washing your chest and abdomen.
- Getting a chest x-ray.
- Having an IV line placed.

You may be given medicine to help you relax during this time.
In the Operating Room

Family may stay with you until you are taken to the OR. Once you are in the OR, you will meet your nurse who will 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 and medicines will be given through your IV. After you are asleep, a breathing tube (endotracheal or ET tube) will be placed in your windpipe to breathe for you. Other lines and monitors will be added after you are asleep.

A Note to Families

For most surgeries, patients are away from you for 7 or more hours. During this time, you will be directed to a waiting area. Feel free to bring along a book or something to do since the time may seem to pass slowly. If you wish to leave the waiting area, sign in/out at the nurses’ station. The nurses will keep you informed during surgery. After surgery, the surgeon will talk with you.

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Financial planning

- What costs do I need to plan for?
- What does my insurance plan cover?
- How will this impact my budget?

When planning for a transplant it is vital to be aware of how added costs will impact your budget. You must be aware of:

- Insurance benefits and drug co-pays or deductibles. Transplant patients need medicines for the rest of their lives. You may take 8-15 different drugs after your transplant.
- Where you can get your prescriptions filled at home and in Madison. You may need to stay in Madison for some time after your surgery. Most insurances request that patients get their drugs from certain pharmacies.
- Yearly out-of-pocket limit for co-pays or deductibles. Once you reach this limit your insurance may pay 100%. It is vital to know your plan and keep track of your healthcare costs.
- Travel expenses including gas, food and lodging.

Contact your insurance company to find out if your insurance policy has a lifetime maximum. This will help you to plan for extra coverage or other options to cover any further costs. For most people, lifetime maximums were eliminated in January, 2014. If your policy has a lifetime maximum, transplant patients often reach this. Then, once you reach that maximum benefit limit, insurance will not cover any further expenses after that time.

Know your co-pays and deductibles for clinic visits and procedures. Transplant patients receive life long follow-up care. This will include clinic visits and procedures. Knowing your co-pays and deductibles will ensure that you are prepared to budget for this expense.

Know the referral rules of your health plan. UWHC is a hospital-based clinic and you will get separate bills from the hospital and the doctors for their care. If you fail to follow the rules, you many need to pay for the cost of a service, which would have otherwise been covered by insurance.
Monthly co-pay per prescription _________________________________

Total co-pay if you were on 15 drugs:
    15 X (co-pay amount per drug) ______________ = _____________

Plan to fit this cost into your budget.
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Lifetime maximum insurance coverage _________________________________

Coverage options once my maximum is reached
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Plan for change of insurance/loss of insurance
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Heart attack: Cause and effect

Heart disease is usually caused by a problem with the coronary arteries, which supply blood and oxygen to the heart. In some cases, the heart muscle can become damaged and disordered as a result of heart disease. This can lead to heart attack.

- The heart muscle needs a constant supply of oxygen and blood supply. If the coronary arteries become blocked, the heart muscle will not get enough oxygen and blood. The heart muscle may begin to die or become scarred. This is called a heart attack.

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Your transplant social worker can help you find resources in your area.

At the time of transplant, family members will be taken to a waiting area. The nursing staff will provide updates about how the patient is doing during the surgery. Family members will be able to make a short visit to the ICU after surgery once the patient is settled.

It is a good idea to choose one family member as the primary contact. This person can leave a cell phone number with the nursing staff so they can be contacted if needed. This person can update other family members and friends about the patient’s status.

There may be family and friends who wish to send flowers to the hospital. Fresh flowers and live plants are not allowed in the rooms of transplant patients.

♥The Cardiothoracic Surgery and Transplant Unit (B4/5)

When you come back from the operating room, you will have a breathing tube, IV lines, drains and monitors. You can expect to wake up shortly after getting to the unit. Though you will likely feel drowsy, you may hear beeps, alarms, bubbling noises and voices.

Many patients who have had heart surgery tell us that they recall little of the first hours after surgery. When you first wake up, the breathing tube may startle you and make you feel anxious. The nurses will help you relax and be more comfortable while the tube is in place. The important thing is to let the breathing machine (ventilator) work for you. It will give you puffs of air until you are able to breathe on your own. Since it is put through the mouth and windpipe, you are not able to talk, but you can nod, squeeze hands, or use a notepad to communicate. Nurses are nearby to help you and reassure you. In 4-6 hours, the tube is often removed and you are able to talk and begin taking ice chips and fluids.

All patients will have their blood sugars checked during their hospital stay. If you have diabetes, you can expect to receive insulin through your IV. You may continue to receive insulin over the next couple of days as you recover. Some patients who have not needed insulin in the past will be given insulin if their blood sugars are high.
As you become more stable, many of the IV lines and monitors will be removed. This is a sign that you are doing well. As your condition improves, the nurses will watch you closely but they will not be at your bedside as often. This is a good sign. You are on the road to recovery.

**A note to family and friends**

Visitors are asked to access and enter the nursing unit from the D elevators. The B elevator entrance to the unit is for staff only.

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The next picture shows the ICU as it will appear right after surgery. This picture is only a model. Your surgery may be more complex. If you or your family has any questions, please feel free to ask the staff.