Health Facts for You

Waiting for your heart transplant

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.

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

Status 1: Patients hospitalized with the following treatments:

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

Status 2: Patients hospitalized with the following 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 wait list, 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 a many months or years. You may go through 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 of your 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.

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 you to be brought to the hospital when you get the call. 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 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.

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 you 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 you are placed on the waiting list, the transplant team will discuss with you 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) informs the UW Transplant Program 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.

Tips to Prepare

Make sure your transplant team knows how to reach you.
When an organ becomes available, we need to be able to contact you within an hour. If we cannot reach you, we have to move on to the next patient.

- Keep your cell phone ringer on and next to your bed.
- Put ringers on the loudest setting.
- Keep your cell phone charged.
- Take your cell phone everywhere (church, grocery, doctor appointments, etc.).
- Give your transplant coordinator contact numbers of close family or friends. We will call someone you have listed to help us find you if we can't reach you at your main numbers.

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.
- Be clear with your support person about what you are asking them to do for you. Allow them to say "no" if they cannot make this commitment.
- A support person will need to be available for rides, coming to appointments, and helping you at home. You may need 24-hour care after transplant. Please make sure your support system can do this. Your transplant social worker will review your support expectations.
- When you are in the hospital, you must have someone with you who can learn about post-transplant care. Your primary support person is required to attend transplant classes.

- If your support person will not be driving from home, think about where your support persons will stay while you are in the hospital. UW Housing offers discounts at local hotels as well as the Restoring Hope Transplant House. Many area hotels have shuttles available. The housing number to assist to make arrangements is **(608) 263-0315**.
- Depending on the distance and time it takes to get to Madison, you may need to stay in the Madison area for a period of time after discharge from the hospital. Your support person will need to stay with you.
- You will need your support person(s) to help you after you return home from transplant. The amount of time needed is organ specific. The transplant social worker and your coordinator will discuss how long you will need this extra support.

Allow others to help you when you need it. Sometimes it is important to let go of pride and desire to be independent and allow others to help. 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 helpful for others to pick up a few things at the store, deliver a meal to your door, or help with raking and lawn mowing, or household chores. When you are back to full speed, you can offer to help them if you wish.

Organize personal affairs. This includes completing advance directives. The Transplant Social Work Team can answer questions you may have 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 will make it easier for someone to take over for you at any time.

Think about child and pet care arrangements for when you are in the hospital and while you are recovering. Know your options and have phone numbers and supplies ready to go.

Arrange for your transportation needs. When you get the call that an organ is available, you need a plan to get to UW Hospital.

- Have gas in the car.
- Have cash available at all times.
- Have a driver and a backup driver available.
- Have printed directions to UW Hospital ready for your driver and/or a GPS unit available to use.

After transplant, you will have many planned clinic visits, but some will be unplanned.

Pack your bags. You will need to be ready to go quickly after you get the call. Review the list in the “What to Bring to the Hospital” section.

Think about setting up a phone/email tree, blog or a key contact person. This will cut down on your phone calls in the hospital. Your hospital time is for rest and recovery, learning, procedures, etc. Sleep patterns change in the hospital. Getting as much rest as you can is very important.

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.
- Do this once a month while you wait for your call.
- Do internet research.
- 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. Sometimes, it is 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.

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.

Heart Failure Nurse Coordinator

This nurse will help to coordinate your care **before** transplant. If you have concerns about your heart failure symptoms, continue to contact your heart failure coordinator to address these concerns.

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 Surgery

What to Expect Before Surgery

When you get the call to come for transplant, you should not eat or drink anything from that point on.

You will be admitted to the Cardiac Surgery Unit (B4/5) to be prepared for surgery. This unit staff cares for people who are having heart surgery.

When you reach the unit, you will meet your nurse and be taken to your room. Depending on the situation, surgery may happen quickly after you arrive or you may wait several hours before having surgery. Several things need to be done before you go to surgery. These include:

- blood samples
- skin cleaning
- urine sample
- bowel prep
- physical exam
- medicines
- chest x-ray
- post-operative teaching
- special preparations for those with diabetes

Blood samples will be drawn as soon as you arrive.

A urine sample is needed to check for infection.

A chest x-ray is done to check for any changes since your last x-ray.

Your skin will be cleaned using a special soap. During surgery, hair may be removed from your abdomen. Both of these things help lower your risk for infection.

A physical exam and consent will be done by one of your doctors. They will explain the transplant to you and ask you to sign a consent form.

The anesthesia team will meet with you to review any concerns.

Admission questions will be asked by your nurse.

Teaching will be started so you will know what to expect after surgery.

Medicines used to prevent rejection will be given to you during surgery. Your doctor will decide which medicines you will receive before and after your transplant. This may include:

- Methylprednisolone
- Tacrolimus or cyclosporine
- Mycophenolate

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 along 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 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 the 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 even if you have not needed insulin in the past. Well-managed blood sugars lowers 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.

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.

The staff will work with you and your support person to understand how you learn best. Some people find that they like to learn a lot of information at one time, while others find that shorter sessions may work best. As you recover from surgery, you may find that you get tired easily or lose focus. If this happens, please tell the staff. Your education will cover the following:

- Home care after transplant
- When to call
- Medicines
- Nutrition
- Signs of infection and rejection
- Diabetes education (if needed)

You and your support person will review all materials with your coordinator before going home.

How will I know my transplant is working?

Your vital signs and labs will be monitored closely. The transplant team will talk with you daily and answer any questions you have about your progress.

Guidelines for Primary Supports and Visitors

Family and friends are welcome to visit often while their loved ones are in the hospital. Visiting hours in most units are from 8 am-9 pm, but those identified as primary support persons may stay with the patient at any time. (Staying overnight may be difficult; a very limited supply of cots is available.) Primary support persons are those who normally provide a patient with significant physical, psychological or emotional support. Examples might be a close family member, partner or best friend. Visitors should check at the information desk or nursing unit before visiting.

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 prescribed.
- 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 at least 1 week after transplant with your support person.

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 and studied under a microscope. 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. This includes medicines which:

- Prevent rejection
- Prevent infections
- Control blood pressure
- Control cholesterol
- Prevent bone loss
- Provide you with extra vitamins and minerals
- Manage blood sugars

You will need to know what medicines you are taking, why you are taking them, and the dose prescribed for you. 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 such as diabetes, minor infections and illnesses, and regular health maintenance. We will work closely with your doctor to give you the best care. The Transplant team will manage your transplant medicines and address any issues about your transplant. You will need to 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.

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 decrease your immune system further. These medicines have side effects that can cause new health concerns. High blood pressure, high cholesterol, diabetes, and osteoporosis can occur. Most of these side effects can be treated. Diet, exercise, and how well you follow your treatment plan all affect how you will be able to manage the side effects.

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. 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.

Top 6 Things to Remember After Your Transplant

1. **Take medicines as directed.**
    - Anti-rejection medicines include: Mycophenolate, prednisone, tacrolimus or cyclosporine.
    - Your anti-rejection medicines and doses will be specific to you. The transplant doctors will order the medicines they feel will best fit your needs.
    - It is important you do **NOT** miss doses of these medicines.
    - Do not change your medicine doses or stopping taking any medicine without talking with the transplant team.
    - Please call the transplant team before starting any new medicines including over -the-counter medicines or supplements.
2. **Labs**
    - Take a copy of your lab order with you when you go to lab.
    - Complete labs as instructed by your transplant coordinator.
    - If you are scheduled to have labs completed on a holiday, it is OK to have them completed the next day instead.
3. **Anti-Rejection Medicine Levels**
    - Your anti-rejection medication level is done with your lab draws. It may be done 1-2 times per week but is patient specific.
    - This level should be drawn 12 hours after you last took a dose tacrolimus or cyclosporine.
    - After you have your labs drawn, you should take your anti-rejection medicines right away.
4. **Home Care**
    - Every day: You will need to check your weight, blood pressure, pulse, and temperature.
    - Activity: You will have lifting and driving restrictions.
5. **Transplant Clinic Visits**
    - Complete labs as directed by staff with your appointments. **Please bring to all your clinic visits:**
        - Record book (including vital signs and blood sugars if checking), and
        - Medicine list.
    - You will be told when to follow up after discharge from the hospital.
    - Please arrange a ride. You WILL have driving restrictions after transplant until cleared by the doctor.
    - Your coordinator will address other follow up needs during discharge teaching.

6. Primary Care Visits

- See your primary care provider within 1 month of discharge. You will need to call to schedule this visit.
- This visit is to review your medicine list and new health concerns (such as diabetes after transplant). Your primary care team will continue to be responsible for your general health care and health maintenance visits.
- The transplant team and your primary care doctor will work as a team in your care.

Contact Information

Your coordinator___________________
Phone___________________________
General office number is:**(608) 263-1384**

After hours: For transplant questions that cannot wait, call **(608) 263-6400** and ask for the Transplant nurse on call.

Emergencies, call **911.**