



# Health Facts for You



Waiting for your liver  
transplant

**UW**Health



Welcome to the UW Health Liver 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. Our program provides care for both adult and pediatric patients. We offer both deceased and living donor transplantation.

### **The Liver**

It is good to have basic knowledge of how the liver works. The liver is part of the digestive system. It is the largest organ in the body. It has more than 500 functions, all of which are needed for life. Some of these functions include:

- Breaking down fats, storing nutrients, and making protein,
- Cleaning poisons and waste from the body,
- Fighting infections, and
- Blood clotting.

### **End-stage Liver Disease**

This occurs when the liver has been permanently damaged. Causes may include:

- Infection (such as hepatitis),
- Inherited or autoimmune diseases,
- Cancer,
- Substance toxicity/abuse
  - Acetaminophen (Tylenol®) overdose
  - Chronic alcohol abuse
  - Poison

## **Waiting for Your Transplant**

### **The Waitlist**

The United Network for Organ Sharing (UNOS) manages the waiting list. They match donor organs to recipients, 24 hours a day, 365 days a year. The factors that impact your place on the list include your blood type and how sick you are (your MELD score or PELD score for pediatrics).

For every donor, there is a list that is done by UNOS with possible recipients. It starts with the highest MELD or PELD score. The patient who has the highest MELD or PELD score for their specific blood type and is healthy enough for transplant will be called in to receive the liver. This is why it is hard to predict how long someone may wait for a liver.

### **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. You can transfer your primary waiting time to another transplant center, or switch time between transplant centers. You cannot split your total waiting time among multiple transplant centers. 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:

[https://unos.org/wp-content/uploads/unos/Multiple\\_Listing.pdf](https://unos.org/wp-content/uploads/unos/Multiple_Listing.pdf)

## 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 keep the transplant team informed of 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 will help to ensure 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

In order to remain 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 transplant coordinator will give you the proper orders. We expect that the tests will be done quickly. 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 discusses any new issues related to transplant.

Our goal is that when we have an organ 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.

## Alcoholic Liver Disease and Alcoholic Hepatitis

### Can I have a liver transplant if I have liver disease from alcohol use?

Alcohol use disorder is a disease that causes alcoholic liver disease and alcohol hepatitis. **A liver transplant will not fix your alcohol use disorder.** If you return to drinking, you may have recurrent alcoholic liver disease.

You will meet with members of the transplant team. They will decide if you are able to have a liver transplant. To have a liver transplant at UW Health, **you must agree to stop drinking alcohol. This is for the rest of your life.**

### Deciding Factors If You Can Have a Transplant

The questions below will be asked to help decide if you are eligible for transplant.

- Did you continue to drink after a medical provider told you to stop?
- How long has it been since you have stopped drinking?
- Do you understand the role alcohol has played in your liver disease?

- Have you completed alcohol treatment in the past and then returned to drinking?
- Do you use other illegal/street drugs?
- Do you work or have some other type of meaningful activity in your life?
- Do you have a sober support system?
- Do you continue to attend activities centered around alcohol?

#### **The Transplant Team May Need You:**

- To attend single counseling and/or group therapy. They may call your counselor to discuss your progress.
- To attend a public support group such as Smart Recovery, AA, etc.
- To bring a support person with you to your transplant clinic visits.
- To have random blood or urine tests to watch for alcohol use.

Your insurance plan may also have a required period of being off alcohol. They may have rules for watching avoidance of alcohol.

#### **What happens while I'm waiting for a liver transplant?**

- Continue to follow your plan for not drinking.
- Attend counseling and public support groups.
- You will be tested for alcohol use.

#### **What happens if I drink alcohol while I'm waiting for a liver transplant?**

- If you are struggling with cravings or return to drinking, let us know. We know recovery can be hard. There are many options for support and resources.
- If this happens, the team will discuss next steps.
- This may lead to being inactive on the waiting list. This will be for a

period of time while you receive treatment.

- If you have a positive alcohol screen and have not come forward on your own, you will be made inactive on the list. The transplant team will decide how long.

#### **What does being "inactive" mean?**

Being inactive means that you are not able to receive a transplant at that time. You and the transplant team will develop a plan for you to follow. It often involves having more support for not drinking. Alcohol screening will continue.

You must follow the treatment plan to return to an active status on the list. Any further alcohol use while **INACTIVE** will result in being removed from the waiting list. The transplant team will discuss your plan. It is likely you will **not** be able to receive a liver transplant at UW Health.

#### **Caring for Yourself While Waiting**

Taking care of your health is very important while waiting for a transplant. 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.

#### **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 that may be a match for you 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 you feel less stressed during your hospital stay.

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**

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

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

## **Where My New Liver Will Come From**

### **The Organ Shortage**

There is a severe shortage of organs for transplant. This means that the wait for a liver 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 liver 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 supply the liver and other organs with blood and oxygen until a transplant team arrives. Once the liver is removed, it should be transplanted within 12 hours. Livers from these types of donors are called “standard donor” livers.

### **Donation After Circulatory Death (Deceased 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.

Transplant teams are on site when the life support is turned off. When the heart stops beating, the person is declared dead by the doctor. The transplant teams can then remove the organs. This is called donation after circulatory death (DCD).

The liver may have some damage due to lack of blood flow when organs are removed. This can cause problems for the patient who gets this liver. Most of the time these problems can be treated. A liver from a DCD donor has a higher rate of early failure compared to standard donor livers. If failure happens, you would need a second liver transplant.

You will be asked if you are willing to accept a DCD liver 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. If you accept a DCD liver, you will increase your chance of getting a transplant sooner.

### **Split Liver Transplant**

In a split liver transplant, a liver from a deceased donor is split into two parts and donated to two people on the waiting list. This can be done because the liver can regrow itself after the transplant. It will grow to normal size within weeks. The patients who get the parts must meet size criteria to be candidates for this option. This is a more complex surgery and there can be more problems. Most times these problems can be treated. A split liver transplant has a higher risk of failure compared to standard donor livers. If failure happens, you would need a second liver transplant. If you accept a split liver, you have a better chance of getting a transplant sooner.

### **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 kidney are very small.

### **Hepatitis C Positive Donors**

Hepatitis C is a virus that can damage the liver. We now have effective medicines to treat this virus so we can use livers from donors who have had or have hepatitis C.

Donors that have had hepatitis C and do not have an active infection are very low risk. If you receive a liver from a donor that has had hepatitis C, we will do tests to check you for signs of this virus. You will need to take extra medicine after transplant if you receive this type of liver.

Donors that have an active hepatitis C infection can be safely used because we now have good medicines to treat this virus.

Patients who receive a liver from a donor with an active hepatitis C infection will 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 liver. If you agree you will be required to sign a consent. If you choose not to accept this liver, you will not lose your place on the waiting list.

### **Hepatitis B Positive Donors**

Rarely (< 1% of all liver transplants done at UW) do we get livers from donors who had a possible past Hepatitis B infection. To make sure these livers are healthy to transplant, we do a biopsy of the liver. We feel these livers can be safely transplanted. If this option is chosen, the recipient needs to take an antiviral medicine for a short time after the transplant. This protects them from getting hepatitis B from the donor. The outcomes after getting a liver from a donor with hepatitis B are no different than getting a liver without hepatitis B. One advantage for patients is that they may get an offer for a liver sooner. If you choose not to accept the liver, you will not lose your place on the waiting list.

### **Living Donation**

Besides deceased donor transplants, patients may get a liver from a living donor. In a living donor transplant, a piece of a healthy person's liver is transplanted into the recipient. This can be done because the liver grows back in both the donor and recipient after the transplant. Both the donated segment and the remaining section of the donor liver will grow to normal size within weeks. Living donors can be related or unrelated.

Benefits of living donation include being able to have a planned surgery and knowing the donor. However, because this is a more



complex surgery, this type of transplant can result in more problems. Most of the time these problems can be treated. Survival rates after a living donor liver transplant are close to those who have had a deceased donor transplant.

### **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 liver is found and who is first on the UNOS list to get the liver.

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 liver 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.

### **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 Transplant Surgery Unit (B4/6) to be prepared for surgery. This unit staff cares for people who have received or are receiving a kidney, pancreas, or liver transplant.

When you reach the Transplant Surgery 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 (if you make urine)
- bowel prep
- physical exam
- medicines
- chest x-ray
- post-operative teaching
- electrocardiogram (ECG)

- special preparations for those with diabetes
- dialysis (if needed)
- pre-surgical medicine

**Blood samples** will be drawn as soon as you arrive.

**A urine sample** will be done (if you are making urine) to check for infection.

**A chest x-ray and electrocardiogram (ECG)** are done to assure your health before the transplant.

You may have a **bowel prep** to clean out your bowels. If your transplant is from a living donor, you will be on a liquid diet the day before surgery and will not be able to eat or drink anything after midnight.

**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. At this time, they will explain the transplant to you and ask you to sign a consent form.

**Hospital 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

- Prednisone or dexamethasone (corticosteroids)
- Tacrolimus (Prograf<sup>®</sup>, Astagraf XL<sup>®</sup>, Envarsus XR<sup>®</sup>)

- Mycophenolate (Myfortic<sup>®</sup> or Cellcept<sup>®</sup>)

## The Transplant Surgery

When you are taken to the surgery area, one support person may stay with you until you are taken to the operating room (OR). Other family members may stay in the surgical waiting area. The OR nurses will provide your family with updates. After surgery, family members will be contacted by the surgeon to discuss your transplant. They will be able to make a short visit to see you once you are settled in the Intensive Care Unit (ICU). Our ICU is called the TLC.

Once you are in the operating room (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. 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.

- Arterial line: A catheter in your wrist to monitor your blood pressure closely.
- Central line: A catheter inserted in blood vessels your neck or chest to administer IV fluids and other medicines during and after surgery.
- Urine catheter: A small rubber tube (Foley catheter) will be placed in your bladder. This allows us to track your urine output. It stays in place until the day after surgery.

## **Your Incision**

You will have a large incision made to your upper abdomen under your rib cage. The incision will run across your entire abdomen. Using this incision, your surgical team will take out your old liver and replace it with your new liver transplant. At the end of your surgery, the incision will be closed with staples, glue and steri-strips (similar to small pieces of white tape). Your surgeons will also likely place temporary drains (plastic tubes) that exit through the skin. These drains are often removed before you are discharged from the hospital.

## **What to Expect with a Liver and Kidney Transplant**

If you are receiving a kidney transplant with your liver, your new kidney will be placed in a different area than your own kidneys. If you have a kidney transplant during the surgery, a small tube called a **stent** is placed in the area where the new kidney's ureter is stitched to the bladder. The stent is inside the ureter and extends into the bladder. This tube helps keep this new connection straight while it heals and allows the urine to flow into the bladder. The stent must be removed later. This is most often done at your first or second clinic visit. This procedure is called a cystogram.

## **What to Expect After Surgery**

After surgery you will be taken back to the ICU (TLC) for observation and careful monitoring. You will have a breathing tube until your doctors feel it is safe to have it removed. You can expect to be in the ICU for 1-2 days, or until your doctors think you are ready to go to the transplant unit.

During your hospital stay you may hear beeps, alarms, and voices. Your nurses will check your blood pressure, temperature, and measure your urine output often during the first 24 hours.

Because of the effects of anesthesia, the normal action of your bowels slows. Bowel function can return 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.

The **incision** will have a dressing over it at first which will stay on for 48 hours after surgery. We will teach you how to clean and care for it. This will help you be more aware of any signs of infection or problems. The staples or stitches will likely be removed at your first clinic visit.

Your doctor will order **pain medicine** for you. During the time you are unable to eat or drink, you will receive it in your IV. Later, you will receive pain pills. Pain medicine should be taken to lessen incision pain. Your walking, coughing, and deep breathing will be easier when this is done.

You will be coughing, deep breathing and using the incentive spirometry device at least every 1-2 hours while awake. Your nurse will help you with this. Deep breathing helps air to reach your lower lungs. Coughing helps clear out secretions, so pneumonia is less likely to occur. Coughing and deep breathing are an important part of recovery.

You will wear Sequential Compression Devices ("SCDs" or leg pumps) during surgery and for the first few days after surgery when you are in bed. This will aid in blood flow and help prevent blood clots. You will be expected to be up walking within the first 8-12 hours. You will then need to be up out of bed to the chair and/or walking at least 3 times each day.

While in the hospital you will have blood samples drawn every day or more often if

needed. The results of these tests keep you and your health care team aware of how you are doing. You will become involved in tracking these tests and understanding their meaning.

Many patients will have their blood sugars checked during their hospital stay. If you have diabetes, you can expect to receive insulin through your IV. Your blood sugar levels will be checked often. 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 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.

### **Education After Transplant**

It is very important that you learn about the care of your new organ after your transplant. During your hospital stay, there are daily classes. You will be expected to attend class every day. This may start as early as your first day after transplant depending on how your recovery is going. It is the expectation that your primary support person will be involved in your education as well in order to assist you once you return home. The classes are daily at 10:00am.

- **Monday:** Medications & Honoring Your Donor
- **Tuesday:** Laboratory Tests
- **Wednesday:** Home Cares
- **Thursday:** Complications & Nutrition
- **Friday:** Medications
- **Saturday:** Home Cares 1
- **Sunday:** Home Cares 2

### **How will I know my transplant is working?**

Blood will be drawn daily to measure your liver function tests and creatinine (kidney function). These show us how well your new liver and your kidneys are working. The transplant team will talk with you daily to review your liver function. They will 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 are 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 appointments, clinic visits, lab draws, and biopsies.
- Do not abuse your body by smoking, drinking alcohol, or using non-prescribed medicines and herbals.

### **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.

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
- Control 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, you will need to take extra care, 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 adjustments. Please note that it will take some time to gain strength and endurance. Keeping up with an exercise routine once you have recovered from surgery 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 depends on the type of work you do, but that doesn't mean you can't work at any job. Your transplant team will talk with you about returning to work. They will help you with paperwork or questions you may have.

## Things to Remember After Your Transplant

### Take medicines as directed.

- Anti-rejection medicines include: Myfortic<sup>®</sup>, Prednisone, Tacrolimus, Envarsus, Cyclosporine, Belatacept, Sirolimus, and Azathioprine.
- 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.

### 1. 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.

## 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. The level should be drawn 24 hours after your last dose of Envarsus or Sirolimus.
- After you have your labs drawn, you should take your anti-rejection medicines right away.

## Home Care

- Every day: Check your weight, blood pressure, pulse, and temperature as instructed by the transplant team. Please call your coordinator if you have:
  - Oral temperature higher than 100.5°F or 38.3°C
  - Blood pressure is higher than 180/90.
  - Weight gain of 3 pounds in one day or 5 pounds in one week.
- Activity: Do not lift, push, or pull more than 10 pounds for 8 weeks. It is good to walk and use stairs while healing.

## Transplant Clinic Visits

- Complete labs as directed by staff with your appointments. **Please bring your record book (including vital signs and blood sugars if checking) and medication list to all your clinic visits.**
- You will be instructed 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.

### 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 (ex: 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 can't wait, call **(608) 263-6400** and ask for the Transplant nurse on call.

Emergencies, call **911**.

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 © 2/2021 University of Wisconsin Hospitals and Clinics Authority. All rights reserved. Produced by the Department of Nursing HF#8138.