# Health Facts for You

Your liver transplant evaluation

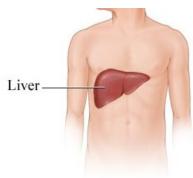
**LWHealth** 

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.



@ Healthwise, Incorporated

# **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<sup>®</sup>) overdose
  - Chronic alcohol abuse
  - Poison

# **After Your Evaluation Testing**

When your evaluation testing is done, the transplant team reviews and discusses your results. There are three possible decisions:

- 1. You are approved to be added to the list. Or,
- 2. The team feels transplant is NOT the best option for you. Or,
- 3. The team needs more testing or information to make the decision.

You will be notified of the decision and next steps.

## **Alcohol-Related Liver Disease**

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

You will meet with members of the transplant team. They will be collecting information to assess your risk of returning to alcohol use. 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**

You will be asked the questions below 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 counseling and/or group therapy. You will be asked to sign a release of information form that allows the team to communicate with your counselor. The team may call your counselor to discuss your progress.
- To attend peer support meetings 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 monitor for alcohol use.

Your insurance plan may also have a required period of sobriety. They may have rules for monitoring your sobriety.

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

- Continue to follow your plan for not drinking. This may include attending counseling and/or attending peer support meetings. The plan will be discussed at your evaluation.
- 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 and we are here to support you. We can connect you to available resources.
- It is our goal to build trust with you. If a return to drinking occurs, we want you to tell us directly. If you tell us, we treat that differently than

- if use is discovered through routine alcohol screening.
- If a return to drinking happens and you tell us, you and the transplant team will develop a plan for you to help you maintain sobriety. It often involves having more support for not drinking. Alcohol screening will continue. You may or may not be made inactive on the transplant waiting list.
- Being made inactive on the transplant waiting list means that you are not able to receive a transplant at that time.
- If you have a positive alcohol screen and have not come forward on your own, you will be made inactive on the transplant list. The transplant team will decide how long you are inactive and with your input will develop a plan to help you maintain sobriety.
- You must follow the 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. You will not be able to receive a liver transplant at UW Health.

# 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.

Deceased Donor Liver Donation				
What?	Who?			
Some patients may not have	Deceased donor livers are offered to recipients according to the			
a living donor. They can go	United Network for Organ Sharing (UNOS) guidelines. The			
on the list to wait for a	Organ Procurement Organization (OPO) contacts the UW			
deceased donor transplant.	Transplant Program when a liver is found and tells them who is			
	first on the UNOS list to get the liver. Below are the types of			
	deceased donor livers that patients may be offered.			

# **Types of Deceased Donor Livers**

# **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 the brain doesn't get enough oxygen and the brain stops working. This is often due to trauma or a stroke. Tests are done to tell when someone is brain dead. People who are brain dead are on a breathing machine. The breathing tube and medicines keep the heart beating and supply the 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 (DCD)**

Sometimes 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. Patients may or may not be able to donate. When the patient's heart stops beating, they are declared dead by the doctor. The transplant teams can remove the organs. This is called donation after circulatory death (DCD). The liver may have some damage due to lack of blood flow. This can cause problems for the recipient. These problems can be treated most of the time. 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.

# **Split Liver Transplant**

A liver from a deceased donor is split into two parts and donated to two people. 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. There is 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.

Live Donor Liver Donation						
What?	Who?	Things to Know				
This is when a piece of a healthy	Living	Benefits of living donation include being				
person's liver is transplanted into	donors can	able to have a planned surgery and				
the recipient. The liver grows back	be related or	knowing the donor. This is a more				
in both the donor and recipient	unrelated.	complex surgery, so this type of transplan				
after the transplant. Both the		can result in more problems. Most of the				
donated segment and the		time these problems can be treated.				
remaining section of the donor		Survival rates after a living donor liver				
liver will grow to normal size		transplant are close to those who have had				
within weeks.		a deceased donor transplant.				

# 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 liver are very small.

# **Hepatitis C Positive Donors**

Hepatitis C is a virus that can damage the liver. We now have medicines to treat this virus, so we can use livers 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 you receive a liver from a donor who has had hepatitis C, we will do tests to check for signs of this virus. You will need to take extra medicine after transplant if you receive this type of liver.

Organs from donors with an active hepatitis C infection can be safely used. Patients who receive a liver from a donor with an active hepatitis C infection will take medicine to

treat the virus. When placed on the waiting list, the transplant team asks 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 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 is that a liver may be available sooner. If you choose not to accept the liver, 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) tells the UW Transplant team 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.

# The Transplant Waitlist

Completing a transplant evaluation does not guarantee being put on the waitlist. If you are approved for transplant after your evaluation, you will then be put on the waitlist.

### 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. This is based on your MELD or special status.

For every donor, there is a UNOS list with possible recipients. It starts with the highest MELD score. The patient with the highest MELD 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 wait times.

# 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. 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: <a href="https://unos.org/wp-content/uploads/unos/Multiple\_Listing.pdf">https://unos.org/wp-content/uploads/unos/Multiple\_Listing.pdf</a>

#### When to Call

Waiting for your transplant may take 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.
- Being started on a new medicine
- 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 any 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 be up to date on this information. 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.

# **Staying Healthy Before Transplant**

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.

### Nutrition

Nutrition plays a key role in the transplant process. Eating well and exercising before transplant may help you recover faster after surgery. After surgery, your body needs enough nutrition to promote healing, fight and prevent infection, and gain back weight you may have lost. In the long-term, good nutrition plays a key role in keeping you healthy.

### Frailty

You may be frail if you have lost weight without trying, feel weak or tire easily, walk more slowly, or need help for daily activities. This could include bathing, dressing, eating, getting out of bed and moving around on your own.

Causes of frailty include aging, being less active, chronic diseases, not eating well and malnutrition. People who get a transplant when they are frail stay longer in the hospital and get more infections. They are less likely to go home from the hospital and more likely to need rehabilitation.

### **Improve Your Strength with Exercises**

You can improve your strength if you add 30 minutes of exercise daily. This could be walking, weightlifting or sitting chair exercises. If you cannot exercise on your

own, you may need physical therapy (PT). Let your nurse or doctor know if you think you need PT.

It is important to exercise even if you have physical limitations. You can do these exercises at home, sitting down with either resistance bands or light weights. You can use common household items that have some weight to them. Examples could be filled water bottles, canned goods, or rocks. To gain strength, do these exercises daily. For each exercise, complete 3 sets of 10-15 repetitions. Do not rush. Go slowly.

# **Overhead Press**

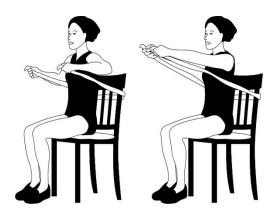
Sit on edge of a chair with your feet planted flatly on floor. Grab light dumbbells or a resistance band. Take a deep breath and tighten your core. Push the weights or band evenly over your head. Keep your neck and back in a neutral position. Bring the weights or band back down to the level of your ears and repeat. You can also do this activity standing with your feet evenly spaced apart. Keep your feet firmly on the ground.





# **Seated Press**

Wrap your band around the back of your chair and make sure it is secure. Sit with your weight evenly distributed. Take a deep breath. With a flat back and even posture, push your arms straight out in front of you. Make sure you are using your chest to push out your arms. Try not to move the position of your back. Bring your hands back to your chest and repeat.



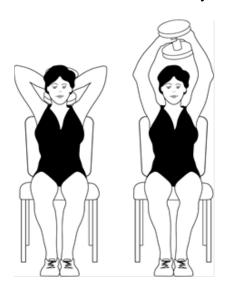
### **Horizontal Row**

Sit on the floor with your back straight. Place your band around your feet at the halfway point on the band, so the sides are even. Pull the band towards your chest. Squeeze your shoulder blades together. Slowly release the band back to the start. Repeat.



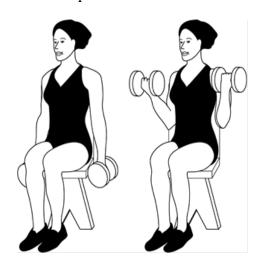
# **Triceps Extension**

This movement can be done with a band or light weights. Squeeze your arms up so they line up with your ears and bring them back down to the start. If you are using a band, make sure it is secure before you begin.



# **Biceps Curl**

Take a deep breath and exhale. Without changing your posture, curl the weights or band up to your shoulders and push back down. Repeat.



# **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 are not available to return the call up to 30 minutes from the first phone call attempt, the team will move on to 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.?
- Where will your support stay while they are in Madison?

# 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. You will be directed when you should come to the hospital. It is important to arrive when instructed. 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 may be asked:

- To stop eating and drinking.
- To stop taking one or more of your medicines
- About your current health status.
- About your recent immunizations, illnesses, infections and medicines
- To come to UW Health **or** to keep a phone available, but to wait at home until you are called again.

It is very important 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.

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

You need to be prepared when you get the call. This call can come anytime, day or night. Be sure your cell phone is on and ready to call in case of delay or questions (608-263-6400 or 1-800-323-8942).

Plan to bring these items:

Copy of Advanced Directives/Health
Care Power of Attorney if it has
changed
All medicine bottles and list of
medicines
Form of payment for medicines at
discharge
Name of local pharmacy
Loose clothing (sweatpants or
something with elastic or drawstring
waist bands), T-shirts, socks and
supportive shoes for walking and
therapy.
If you use them, bring your glasses,
hearing aids, dentures, CPAP
machines/mask, blood pressure cuff,
diabetes supplies
Personal comfort items (electronic
devices, phone, chargers, and blanket
or pillow)

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

# **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, including biopsies and hospital stays.
- Follow recommendations for mental health or alcohol/substance use disorder.
- 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 medicines as directed.
- Follow the diet and exercise plan advised by your doctor.
- Go to your clinic visits.
- Get your labs drawn.
- See primary care provider for routine health maintenance.

# **Appointments**

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. 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.

# **Primary Care Visits**

You must have a primary care provider to address routine health issues. This might include diabetes, minor infections and

illnesses, and regular health care needs. Plan to see them shortly after your transplant.

We want you to live a healthy life after transplant. We will work closely with your primary care provider to give you the best care. We work together to advise you about your diet, exercise, and other health needs. The Transplant Team will manage your transplant medicines and address any transplant issues.

# **Types of Medicine After Transplant**

After your transplant, you will be on many medicines. You will be on most of them for the rest of your life. These medicines are important in the success of your transplant. You will need to know what medicines you are taking, why you are taking them, and the dose prescribed. Some of your medicines may need to be taken at the same time every day. Never stop or adjust medicines on your own. Not taking your medicines correctly can lead to rejection and other health problems.

# Immunosuppressive Medicines (Antirejection Drugs)

Immunosuppressants, also called "antirejection medicines," block or suppress your immune system. They are used to prevent rejection of new organs. All transplant patients take these medicines for the **rest of their lives**. Often, you will be on more than one kind. Your doctor will decide which ones you will need. You will need to take these multiple times a day.

## These may include:

- Prednisone (corticosteroids)
- Tacrolimus (Prograf<sup>®</sup>, Astagraf XL<sup>®</sup>, Envarsus XR<sup>®</sup>)
- Cyclosporine (Neoral®, Gengraf®, or other generic brand)
- Mycophenolate (Myfortic<sup>®</sup> or Cellcept<sup>®</sup>)

#### **Anti-infection Medicines**

Anti-infection medicines prevent common infections after transplant. You may need other medicines too. You may need medicines to prevent:

- Bacterial infections of the bladder and lung.
- Viral infections such as Cytomegalovirus (CMV) or herpes (cold sores).
- Fungal infections.

Most patients take other medicines to prevent stomach ulcers, control blood pressure and cholesterol, and supplements to support your bones and general health. You may also develop diabetes from the transplant medicines and need insulin or other medicines to manage blood sugar levels.

Some of these medicines are temporary but many are life-long. You may need opioid pain medicines right after surgery. You will not be able to take NSAID medicine after transplant.

#### **Vaccines**

Timing of when you receive a vaccine can impact when you can receive a transplant. You must be screened for conditions or medicines that might make the vaccines unsafe for you because of your immune system. No one who has had a transplant should be given a live vaccine.

The list below includes general guidelines. Your situation may be different. Other vaccines may be required. Your providers will discuss these with you on an individual basis. Always talk with your coordinator before getting any vaccines.

# **Vaccines to Get Before Transplant**

- Inactivated influenza, injected
- COVID-19 boosters
- Hepatitis B
- Hepatitis A
- Diphtheria/Tetanus/ Pertussis (Tdap, DTaP, Td or DT)
- Polio, inactivated
- Pneumococcal polysaccharide or conjugate
- Human papillomavirus (HPV) (for ages 9-26)
- Varicella zoster (Shingrix<sup>®</sup>)

# Other Vaccines to Discuss With Your Provider

- Quadrivalent meningococcal conjugate or polysaccharide
- Haemophilus influenzae type b
- Measles, Mumps, Rubella (MMR)
- Travel vaccines

# **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, osteoporosis or cancer 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. 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. When you are ready to return to work depends on the type of work you do. Talk with your transplant team about returning to work. We will complete medical leave paperwork for your job if needed.

# **Coping After Transplant**

During the transplant process, it is common to feel anxious, depressed, or frustrated. Stress can cause these feelings and so can your medicines. Talk with someone about your feelings. The transplant team is here to support you. If you want to see a mental health provider, you can contact your primary care provider or insurance company. Sharing your feelings with your loved ones and others may also be helpful. Most areas have support groups for transplant recipients and loved ones. You can ask your social worker for resources. The resources below may also be helpful.

#### Depression

http://www.helpstartshere.org/mind-andspirit/depression

### Anxiety

http://www.helpstartshere.org/mind-andspirit/anxiety/about-anxiety-disorders.html Coping Emotionally after an Organ Transplant

http://www.webmd.com/a-to-z-guides/life-after-transplant-coping-emotionally

**Guided Imagery** 

https://www.healthjourneys.com/

Mindfulness Meditation

https://www.mindfulnesscds.com/ Mindful meditation may reduce reactions to stress.

# Support People

The transplant process can be very tough for support people. Many support people have anxiety during the process. It is important for support persons to take care of themselves during this time.

# **Keeping Support People Updated**

It is a good idea to choose one person as the primary contact. This person can update other family members and friends about your status. Make sure the transplant team has that person's contact information.

# **Staying Prepared**

Make sure your transplant team knows how to reach you. Contact your transplant coordinator if contact numbers change for you or your support persons. Have your cell phone on you at all times.

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. Contact your transplant coordinator with any changes in your support plan.

Allow others to help you. Letting go of pride and your desire to be independent can be difficult. It is important though during the transplant process. 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 picking up a few things at the store, bringing a meal, or helping with outdoor or household chores. When you are back to full speed, you can do small favors in return if you choose.

Life Preparations for Surgery. This means completing advance directive forms. Transplant social workers can answer questions 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 in advance will make it easier for someone to take over for you at any time.

Arrange for your transportation needs to and from appointments and testing.



**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.
- Review resources on the next page.
- 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. It can be 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.

# **Helpful Resources**

The resources below may be helpful for transplant patients and their families.

# **Know Your Rights**

https://autisticadvocacy.org/policy/toolkits/organs/

Information to end discrimination in organ transplant.

# Scientific Registry of Transplant Recipients

http://www.srtr.org

Data on national, regional and centerspecific success rates.

# **Transplant Living**

http://www.transplantliving.org

A patient education site developed by UNOS. Information on support groups and the costs of transplant can be found here.

#### **UNOS**

# http://www.unos.org

United Network for Organ Sharing (UNOS) is the private, non-profit organization that manages the nation's organ transplant system.

# **UW Health Transplant**

 $\frac{https://www.uwhealth.org/transplant/transpl}{ant/10355}$ 

Meet your transplant team, read patient stories, watch educational videos, and more. Information about mentor programs

# Caring Bridge

https://www.caringbridge.org

Free on-line resource to update your family and friends.

# Who and When to Call

# **Transplant Nurse Coordinator**

#### Call:

- If you are hospitalized or receive a blood transfusion
- When complete required evaluation testing

#### Contact:

- Monday-Friday, 8:00a.m.-4:30p.m.
- 608-263-1384

#### **Social Worker**

#### Call for:

# • Change in support person plan

#### Contact:

- Monday-Friday, 8:00a.m.-4:30p.m.
- 608-263-1384

#### **Financial Counselor**

### Call for:

• Change in insurance

#### Contact:

- Monday-Friday, 8:00a.m.-4:30p.m.
- 608-263-8770

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 © 4/2024 University of Wisconsin Hospitals and Clinics Authority. All rights reserved. Produced by the Department of Nursing HF#8137