

The background features a large, light-colored triangle pointing downwards from the top left, containing a pattern of small grey dots. To the left of this triangle are overlapping geometric shapes in red, blue, and teal. On the right side, there is a vertical stack of three overlapping shapes in blue, red, and teal. The main title is centered in a large, dark blue serif font.

# Health Facts for You



**Your child's liver  
transplant evaluation**



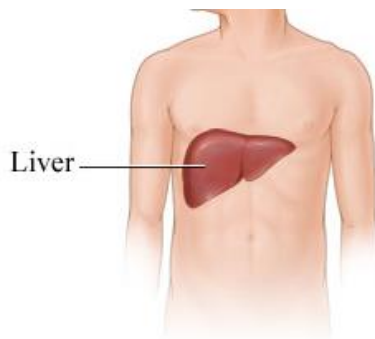
Welcome to the UW Health Liver Transplant Program. The team takes pride in building a care plan tailored to your child's needs. We are committed to their success. UW Health is a national and international leader in the field of transplantation. Our program provides care for both adults and children. 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 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
- Breaking down/processing medicines
- Blood clotting



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### **End-Stage Liver Disease**

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

- Biliary atresia
- Infection
- Inherited diseases
- Autoimmune diseases
- Cancer
- Fatty liver and metabolic diseases
- Medicine induced liver disease
- Alcohol abuse
- Poisons

### **After Your Child's Evaluation Testing**

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

1. Your child is approved to be added to the list. Or,
2. The team feels transplant is NOT the best option. Or,
3. The team needs more testing or information to make the decision.

You will be notified of the decision and next steps.

### **Where My Child's 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 months. Rarely, 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 child's new liver will come from. It is vital that you explore these options fully.

Deceased Donor Liver Donation		
<b>What?</b>	<b>Who?</b>	
Some patients may not have a living donor. They can go on the list to wait for a deceased donor transplant.	Deceased donor livers are offered to recipients according to the United Network for Organ Sharing (UNOS) guidelines. The Organ Procurement Organization (OPO) contacts the UW 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		
<p><b>Donation After Brain Death (Deceased Donor)</b></p> <p>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.</p>	<p><b>Donation After Circulatory Death (DCD)</b></p> <p>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, your child would need a second liver transplant.</p>	<p><b>Split Liver Transplant</b></p> <p>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, your child would need a second liver transplant. If you accept a split liver, you have a better chance of getting a transplant sooner.</p>
Live Donor Liver Donation		
<b>What?</b>	<b>Who?</b>	<b>Things to Know</b>
This is when a piece of a healthy person’s liver is transplanted into the recipient. 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. This is a more complex surgery, so 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.

### **Organs Meeting Risk Criteria for possible transmission of HIV, Hepatitis B and Hepatitis C**

Your child 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. Your child 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 transplant your child 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 your child receives a liver from a donor who has had hepatitis C, we will do tests to check for signs of this virus. Your child will need to take extra medicine after transplant if they 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, your child will not lose their 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, your child will not lose their place on the waiting list.

### **What will I be told about my donor?**

Privacy laws limit how much we can tell you about your child's 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 child's 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 your child.

### **The Transplant Waitlist**

Completing a transplant evaluation does not guarantee being put on the waitlist. If your child is approved for transplant after evaluation, your child 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 child's place on the list include your blood type and how sick your child is. This is based on your child's MELD score or PELD score or special status.

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

### **Multiple Listings and Transferring of Waiting Time**

Multiple listing is when your child is listed for transplant at two (2) or more transplant centers. Multiple listing can increase your

child's chances of getting an organ offer. It does not assure a shorter wait time.

UW Health allows multiple listing. Your child needs an evaluation at each transplant center. Each transplant center then decides whether to accept your child on their waiting list. You should check with your insurance to see if they cover more than one evaluation. Keep your child's health information and contact information updated at each transplant center where you are listed.

Many things affect wait times for transplant. You can transfer your child's primary waiting time to another transplant center, or switch time between transplant centers. Your child's transplant care will be done at the center where the transplant happens. To learn more about multiple listing or transferring waiting times, contact the transplant center where your child is 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 child's transplant may take many months or years.



Your child may go through many health changes during this time. It is vital to keep the transplant team informed of any changes in your child's 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 or going to the emergency room
- Having a significant change in health status
- Having a change in insurance coverage

- Having changes in contact information (such as phone number or address)
- Having changes in primary care provider information
- Having changes in support person or plan
- Planning to travel away from home
- Receiving a transplant at another center

The transplant team needs to be up to date on this information. This will help to ensure that your child is in the best condition for transplant. Some medicine changes or hospitalizations could change your child's status on the waitlist. It is vital that you contact the team with any health changes.

### Staying Healthy Before Transplant

Taking care of your child's health is very important while waiting. It is expected that your child will take all medicines as directed and attend all appointments. You must also follow your child's plan for diet and exercise.

### Nutrition

Nutrition plays a key role in the transplant process. Eating well and being at a healthy weight may help your child recover faster after surgery. After surgery, your child's body needs enough nutrition to promote healing, fight and prevent infection, and gain back weight they may have lost. Transplant medicines can lower your child's appetite or change their sense of taste. In the long-term, good nutrition plays a key role in keeping your child healthy.

### Getting the Call

When your child is on the waiting 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 may not recognize the number calling at UW Health.

You need to have a plan ready for when the call comes.

- How will you get to American Family Children's Hospital?
- Who will come with you and your child?
- Who will take care of things at home while you are in the hospital with your child, such as your other 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. You will be directed when you and your child 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 will be asked:



- To have your child stop eating and drinking.
- About your child's current health status.
- About your child's recent immunizations, illnesses, infections and medicines
- To come to American Family Children's Hospital **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 bring your child to the hospital when you get the call. You will need to make plans for the care of your pets, other children, work duties, and other responsibilities ahead of time. Being prepared will help to lower your stress.

**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:

<input type="checkbox"/> All medicine bottles and list of medicines
<input type="checkbox"/> Insurance/ Medicare/Medicaid cards
<input type="checkbox"/> Contact information for your child’s pediatrician or primary care physician (family doctor)
<input type="checkbox"/> Name/phone number of local pharmacy
<input type="checkbox"/> Form of payment for medicines at discharge
<input type="checkbox"/> Special toys, security/comfort items for your child
<input type="checkbox"/> Loose fitting clothing for your child, socks, shoes or slippers that cover the feet
<input type="checkbox"/> Personal toiletries or comfort items (hygiene or entertainment related)

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

**The Transplant Surgery**

**What to Expect Before Surgery**

You will be admitted to AFCH to be prepared for surgery. Based 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 labs and tests, meeting your transplant surgery team, consent for surgery, admission questions and physical exam, and teaching about the surgery and recovery.

**The Transplant Surgery**

When your child goes to the surgery area, one support person may stay with your child until your child go to the operating room (OR). Surgery will take about 8-12 hours.

Your child will have a large incision under the rib cage across their entire abdomen. The incision will be closed with sutures and glue and steri-strips (similar to small pieces of white tape). The incision will be covered with a dressing. Your child may also have drains (plastic tubes). These drains are often removed before leaving the hospital.

**What to Expect After Surgery**

Your child will go to the ICU after surgery. Your child will have a breathing tube until the doctors feel it is safe to have it removed. The ICU stay is usually 1-2 days, or until your doctors think your child is ready to go to the transplant unit.

You may hear beeps, alarms, and voices. Nurses check your child’s blood pressure, temperature, and urine output often during the first 24 hours.

Pain medicine will be given as needed. During the time your child is unable to eat or drink, it will be given through the IV. Later, your child can take pain pills. Pain



medicine should be taken to lessen incision pain. Walking, coughing, and deep breathing will be easier when pain is controlled.

Blood samples are drawn every day or more often if needed. The results of these tests keep you and your health care team aware of how your child is doing. You will start tracking these tests and taught what the results mean.

As your child's condition improves, the nurses will not be at your bedside as often. This is a good sign. Your child is on the road to recovery.

### **Education After Transplant**

You must learn about the care of your child's new organ. Education sessions will be scheduled with you and your child. You will be expected to attend an education class every day. This may start any time based on how your child's recovery is going. You may have education sessions with your child's transplant coordinator, transplant pharmacist, transplant dietitian, therapists, and diabetes nurse educators. Both primary support and secondary support persons must be involved in education.

### **Guidelines for Primary Supports and Visitors**

Visitors should check at the information desk or nursing unit before visiting. The main hospital phone number is 608-263-6400.

## **Commitment to Follow-Up Care**

Your child's care after a transplant is for their 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 your child's treatment plan, including biopsies and hospital stays.
- Ensure your child follows recommendations for mental health or alcohol/substance use disorder.
- Call the transplant office about any new problems or symptoms related to your child's transplant or about any new medicines or tests they have.
- Have your child take all prescription medicines as directed. Monitor that your child is taking their medicines.
- Follow the diet and exercise plan advised by your transplant doctor.
- Go with your child to their clinic visits.
- Get your child's lab drawn.
- Continue to help your child to live a healthy lifestyle by avoiding alcohol, smoking, and non-prescription drugs.
- Follow up your child's primary care doctor for routine health maintenance, including vaccines.

## 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 child's immune system attacks their new liver. During a biopsy, pieces of tissue are taken from the inside of your child's liver. If a biopsy is done because your child's liver is not showing normal function, it may be somewhat urgent. You may need to make plans to come to American Family Children's Hospital without much warning.

## Primary Care Visits

Your child must have a primary care provider to address routine health issues. This might include well child visits, vaccinations, minor infections and illnesses, and regular health maintenance. Plan to see them shortly after transplant.

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

## Types of Medicine After Transplant

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



## Immunosuppressive Medicines (Anti-rejection Drugs)



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

### These may include:

- Prednisone or prednisolone (corticosteroids)
- Tacrolimus (Prograf<sup>®</sup>, Astagraf XL<sup>®</sup>, Envarsus XR<sup>®</sup>)
- 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 based on the type of donor. You may need medicines to prevent:

- **Bacterial** infections of the bladder and lung.
- **Viral** infections such as 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.

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 your child receives a vaccine can impact when they can receive a transplant. Your child must be screened for conditions or medicines that might make the vaccines unsafe because of their immune system. **No one who has had a transplant should be given a live vaccine** (Varicella (Varivax<sup>®</sup>), Influenza, intranasal live vaccine, Measles, Mumps, Rubella (MMR), Rotavirus). Because of your child's potential transplant their vaccine schedule may be different than other children.

The list below includes general guidelines. Your situation may be different. Other vaccines may be required. Your child's 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, children can live a long, healthy, and productive life. The main issues are the **increased risks of infection and rejection**. To prevent infections, wash your hands and your child's 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. We will talk about when they can return to school.

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 child's medicines to weaken their 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 child's treatment plan all affect how your child will be able to manage the side effects.

## Activity Levels

Most children can go back to their normal activities with minor adjustments. It will take some time to gain strength and endurance. Keeping up with an age-appropriate exercise routine after recovering from surgery is the best way to manage your child's weight and improve your child's well-being.

## Going Back to School

We encourage children to return to school after having a transplant. Your child's transplant team will talk with you about any activity restrictions and when to plan on return to school or daycare. Support people may be off of work for up to a few months after transplant. The team will help you with return to school paperwork as needed and help to fill out any paperwork you may have.

## 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 child's medicines. Talk with someone about how you or your child is feeling. The transplant team, your child's nurse, child life staff, or social worker can help your child cope with these emotions. Sharing feelings with loved ones and others may also be helpful. Most areas have support groups for transplant recipients and loved ones.

About Depression:

<http://www.helpstartshere.org/mind-and-spirit/depression>

About Anxiety:

<http://www.helpstartshere.org/mind-and-spirit/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 support person as the primary contact. This person can update other family members and friends about your child's status. Make sure the transplant team has that person's contact information.

## Staying Prepared

**Make sure your child's transplant team knows how to reach you.** Contact your child's transplant coordinator if contact numbers change for you or your support persons.



**Have your child's support persons in place.** A child's primary support persons are typically their parent(s)/guardian(s) but may also include a family member or close friend. Choose 1 to 2 adults you feel close with who have the time, health, and flexibility to help you and your child through this process.



**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 transplant materials you are given including resources on the next page.
- Join a transplant support group in person or online.
- If you have questions, contact your transplant coordinator.

## 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 center-specific 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

<https://www.uwhealth.org/transplant/transplant/10355> or scan the QR code below. Meet your transplant team, read patient stories, watch educational videos, and more.

Information about mentor programs



### Transplant Families

<https://www.transplantfamilies.org/>

Provides inspiration, support, and education to families who have children with solid organ or bone marrow transplants.

### Starzl Network

<https://starzlnetwork.org/>

Serves to support and unite the global pediatric transplant community. and offers educational resources for patients and families.

## Who and When to Call

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### Transplant Nurse Coordinator

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Call:

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

Contact:

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

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### Social Worker

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Call for:

- **Change in support person plan**

Contact:

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

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### Financial Counselor

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Call for:

- Change in insurance

Contact:

- Monday-Friday, 8:00a.m.-4:30p.m.
  - 608-263-8770
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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#8247.