



# Health Facts for You



Your kidney transplant  
surgery

**UW**Health



## **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 or go back to the inpatient unit (B46). The OR nurses will provide your family with updates. After surgery, the surgeon will talk with your support person and/or family.

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. At least one intravenous catheter (IV) will be placed in your hand or arm before you go to surgery. This will be used to give you fluids until you are able to eat or drink.

The surgery takes about 3-5 hours. You will go to the Recovery Room for about 1 hour before going back to your room on the transplant unit.

## **Your Incision**

Your new kidney will be in a different place than your own kidneys. The incision will be 9-12 inches long on either the right or left lower side of the abdomen. Your muscle and skin will be closed with staples or stitches and glue.

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 called a cystogram.

You will have a **small rubber tube (Foley catheter)** placed in your bladder during surgery. The Foley will usually be in place for 2 days. The Foley helps us to closely watch your urine output and allows the stitches in your bladder to heal. After the Foley is taken out, we will still measure your urine each time you go to the bathroom. You will use a plastic collection "hat" in the toilet or a urinal while in the hospital so amounts can be measured easily.

## **What to Expect After Surgery**

You can expect to wake up shortly after getting to the unit. Though you will likely feel drowsy, 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. You will be encouraged to walk as soon as your nurses 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 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 including scheduled acetaminophen (Tylenol). Other methods are available like ice or heat. 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 is 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 out of bed to the chair and/or walking at least 3 times each day.

Many patients have their blood sugars checked. If you have diabetes, you can expect to receive insulin through your IV. Some patients who have not needed insulin in the past will be given insulin if their blood sugars are high.

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

Blood is drawn daily to measure your creatinine, a measure of kidney function. This shows us how well your new kidney is working. The nurse also checks your urine

output. The transplant team will talk with you daily to review your kidney function. You will start tracking and learning about these tests.

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.

### **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 8am-9pm, but those identified as primary support persons may stay with the patient at any time. (Staying overnight may be difficult; a very limited supply of cots is available.) Primary support persons are those who normally provide a patient with significant physical, psychological or emotional support. Examples might be a close family member, partner or best friend. Visitors should check at the information desk or nursing unit before visiting.

## **Delayed Graft Function**

### **What is delayed graft function (DGF)?**

Your transplanted kidney is called a graft. Delayed graft function (DGF) can occur right after surgery. It means your new kidney is not working as it should and you still need dialysis. You may hear your transplant team say that the kidney is “sleepy”. This means you have delayed graft function. It takes some time for the kidney to heal from the transplant surgery. Some people may require dialysis for a short time after their transplant. Up to 30% of deceased-donor kidneys and 5% of living donor kidneys may have some degree of DGF.

### **How do I know I have DGF?**

With DGF, your new kidney may make little or no urine. Kidney labs (creatinine) remain high in your blood tests. During this time, if you were on dialysis before the transplant, you will continue to need dialysis. Usually 3 times per week. If you were not on dialysis before your transplant, your old kidneys will still make urine. The transplanted kidney will not be able to clear the wastes from your blood. You may have to be placed on dialysis for a short time. This is to clear the wastes from the blood until the new kidney starts to work properly.

### **How is DGF treated?**

The function of your new kidney is checked by creatinine levels. Your urine output is also checked. You may need dialysis or diuretics (water pills) and close watch of your kidney function. Your doctor may biopsy the kidney to check for rejection. You will have to follow salt, potassium, phosphorous, and water restrictions. It is like the plan you were following before the transplant. The transplant team will decide when this diet plan is no longer needed. Your blood pressure, anti-rejection, and

other medicines will be changed as needed. Also, changes in your diet, fluid intake, and diuretics may be needed.

### **Will my kidney recover from DGF?**

Yes. Most of the transplanted kidneys with DGF recover. At UW Health, 95% of kidney transplants are working one year after transplant. Only 1 to 2% of all kidney transplants fail to work. After the kidney starts working, it will work like any other transplanted kidneys.

### **How long will DGF last?**

There is no exact timeline for how long DGF will last. It will vary from patient to patient. DGF recovery is most often seen in about 7-10 days but can take up to 3-4 weeks for full DGF recovery.

### **What will happen after I am discharged?**

You will be followed in the DGF Clinic at the UW Transplant Clinic. You will have to limit your fluid intake just like when you were on dialysis before your transplant. You should also limit salt, phosphorous and potassium in your diet. This is called a renal diet. You must check your weight daily and blood pressure twice each day. You will be given a urine collection device. You will measure and record how much urine you are making each day. Bring the record with you to each clinic visit. This is an important sign of your kidney starting to work. If you are being discharged with a new dialysis line, your nurse will tell you how to take care of that line. Most often, it will be cared for by nurses in the Transplant Clinic.

### **Delayed Graft Function (DGF) Clinic**

The DGF Clinic is set up so that we can follow you closely. You do not have to stay in the hospital until your DGF improves. If you live close to UW Health (less than about 50 miles) you can be discharged from the hospital and go home. If you live far away

from UW Health (greater than about 50 miles), you will likely stay in a hotel close to the hospital. You will need to have a support person staying with you (either at home or in the hotel). You will need to have someone transport you to and from the clinic for your visits. If you stay in a hotel the cost will be covered by UW Health.

You will return to the Delayed Graft Function (DGF) Clinic three times a week for labs, dialysis and clinic appointments with transplant nephrology. This is to closely follow your kidney function and fluid status.

Sometimes you may have to return for an extra visit. You will have labs drawn here in the outpatient lab before each clinic visit. After your clinic visit, it will be decided if you need dialysis on that day. If you need dialysis, this can be done in our dialysis unit at the hospital. We will also decide if your anti-rejection, blood pressure, and anemia medicines need to be changed. You will also have a clinic visit with your transplant surgeon about 2 weeks after discharge. When you no longer need dialysis, you will be discharged from the DGF Clinic. You will return to the UW Transplant Clinic for routine follow-up visits.

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

Your care after a transplant is for your entire lifetime. The follow-up schedule is intense for the first few months.

This long-term care includes:

- Biopsies: A procedure where a small piece of tissue is taken from your kidney to look for damage.
- Labs (blood and urine tests)
- Medicines
- Transplant clinic visits
- Other tests and visits with providers

### **Keeping the Commitment**

For a transplant to be a success, you need to commit to the following things:

- Follow the treatment plan.
- Daily blood pressure, heart rate, temperature and weight.
- Call the transplant office about any new problems or symptoms related to your transplant or about any new medicines or tests you have.
- If you have any non-transplant related questions or issues call your primary care provider.
- Take all prescription medicines as prescribed.
- Check with the transplant team when starting any new medicines to make sure there are no interactions.
- 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.

### **Medicines After Transplant**

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

The team will help you learn about the medicines you need, why you need them, and the dose prescribed for you. Not taking your medicines correctly can lead to rejection and other health problems.

## 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. **Always talk with your coordinator before getting any vaccines.**

### Vaccines Recommended Before and After Transplant

- Inactivated influenza, injected
- 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®)

### Vaccines NOT Recommended After Transplant

- Varicella (Varivax®)
- Influenza, intranasal live vaccine
- Measles, Mumps, Rubella
- Rotavirus

### Other Vaccines to Discuss With Your Provider

- Quadrivalent meningococcal conjugate or polysaccharide
- Haemophilus influenzae type b

## Home Care

### Keeping Records at Home

When you go home, you need to keep a record of your weight, temperature, blood pressure and heart rate. These vital signs are key in keeping an eye on your health and your new organ. If needed, we will give you an automatic blood pressure cuff and a thermometer before you go home. Bring your vital signs record books to each clinic visits. We will look for trends in your numbers. We may make changes to your medicines based on your numbers.

### Daily Temperatures

- Take once a day at the same time each day. Do not eat or drink anything 30 minutes before you take your temperature.
- Normal oral temperature is 98.6°F or 37.0°C.
- If you have a temperature higher than 100.5°F or 38.3°C, call the transplant coordinator.
  - Drink fluids, if dehydrated.
  - Do not take acetaminophen (Tylenol®), aspirin, or prednisone between readings.



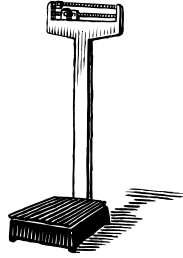
### Blood Pressure and Heart Rate Checks

Do these checks 2 times a day-in the morning and evening.

- Normal blood pressure is less than 120/80.
- Normal heart rate is 60 – 100.
- If high, repeat and record in 2 hours.
- Call your transplant coordinator if:
  - Blood pressure is higher than 180/90.
  - If you have symptoms of low blood pressure such as weakness, dizziness, lightheaded.

### Daily Weights

- Make sure to empty your bladder before weighing yourself.
- Weigh at the same time each day before breakfast.
- Wear the same amount of clothing each time you weigh yourself.
- Call the Transplant Coordinator if you notice any water weight gain (2-3 pounds a day or 5 pound in one week).
- If you cannot see the scale number, you may want to get a talking scale.



### Blood Glucose Checks

If you have diabetes or high blood glucoses in the hospital, you may need to check your blood glucose levels at home. Talk with your nurse or doctor about the plan for these glucose checks.

### Incision Care

Your anti-rejection medicines can make your incision take longer to heal. Your incision may take over a month to fully heal.

You will have either staples or stiches and glue on your incision. If you have staples they will likely be removed at your first clinic visit. They will be replaced with steri-strips (paper-like strips). These will curl up, loosen, and fall off over time. Do not pull these off. Doing so may cause your incision to open. If you have glue on your incision, this will heal up on its own.

You may shower. Wash gently as the rest of the abdomen is washed. Use a washcloth with mild soap and water to gently clean the incision. Do not rub over the area. Do not take any tub baths until your incisions are healed and there are no scabs. Do not put

any creams, ointments, or powders on the site.

When you go home, your dressing should be changed at least once a day until it is healed (about 2-4 weeks after surgery). A nurse will give you a three-day supply of dressings to place over the incision and an abdominal binder to keep the dressings in place. If you need more supplies you can buy them at a local drug store. Wear the abdominal binder when you are up moving around.

Your incision may burn easily in sunlight. Avoid direct sunlight to the area.

If you have a drain, it may be removed before you go home or you may go home with it in place. You will need to wash the drain site just like you wash your incision. If you go home with the drain, you will need to measure and record the amount of drainage. Your nurse will teach you about how to do this.

### Activity Guidelines

Because the new organ is closer to the outside of your body, it could be injured if you get hit. You can do non-contact sports such as bowling, golf, swimming, etc. You can exercise with moderation and slowly increase your activity level. **Walking and climbing stairs are good for you.** Increase what you do each day.

You will need to restrict your activity for the first **6 to 8 weeks** after your transplant. After that you can return to your normal routine.



- Do not drive for 4 weeks or as long as you are on pain pills.



### **NO DRIVING**

- Always wear a seatbelt.
- Do not lift, push, or pull more than 10 pounds for 8 weeks.
- Talk with your transplant team before you travel or take a long trip.

### **Sexual Activity**

You can resume sex when you feel able. There is no restriction on any position you may use during sex. Once your organ works, you and your partner have a much better chance of getting pregnant. You should talk to your doctor about birth control. Some of the medicines you take after transplant may be harmful to the fetus so changes may be needed before pregnancy.

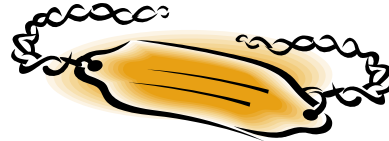
### **Going Back to Work**

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 about returning to work. She will help you with paperwork or questions you may have.

**Always notify your transplant team of any current or future insurance changes or updates.**

### **Medical Alert Bracelet**

We suggest all patients wear medical alert bracelets after transplant. The National Kidney Foundation will provide one free bracelet or necklace to all new transplant patients. Your transplant coordinator will give you this form upon discharge.



### **Local Doctor Visits**

You must have a local doctor to follow your care. Plan to see your local doctor within a month after discharge. We rely on the local doctor to address routine health issues such as diabetes and minor infections. We will work closely with your doctor to give you the best care.

The transplant team will manage your transplant medicines. The transplant team will also address any issues about your new organ. You will need to follow the advice of your local doctor and the transplant team about diet, exercise, and other health needs. We want you to live a normal, healthy life after transplant.

### **Transplant Clinic Visits**

Your follow up appointments may be in person, telephone, or video, depending on your health. Your in-person follow-up visits will be at the Transplant Clinic. Your first clinic visit is about 2-3 weeks after you leave the hospital. This will be scheduled before you go home. Future appointments will be made by the clinic. Plan on spending 3-4 hours at UW Health for your clinic visits if they are in person.

### **What to Bring to Clinic Visits**

- Your medicines
- A list of your current medicines
- Your patient education materials
- Records of your weight, blood pressure, heart rate, and temperature at home
- Records of your local blood test (lab) results
- Records of your blood sugar readings if you have diabetes
- A snack
- A list of questions

### **Labs Before Clinic Visits**

You will have your blood drawn about 90 minutes before your clinic visit. This allows the team to have test results when they see you in clinic. Go to the outpatient lab on the 2<sup>nd</sup> floor. The orders for your tests will be ready for you when you arrive at the lab.

Your coordinator will let you know if you need to stop eating or drinking before these labs. **If you have a clinic visit in the morning**, do not take your tacrolimus or cyclosporine until after the lab draw. It is okay to take your other medicines. **If you have a clinic visit in the afternoon**, talk with your coordinator.

If your insurance company does not allow you to have lab tests drawn at UW Health, make a plan with your coordinator to have the lab tests done before your clinic visit. If you are being seen by phone, video or at an outreach clinic, a lab order will be faxed to your local lab to have your labs drawn at your there before the visit.

### **Arrive Early for Clinic Visits**

Plan to arrive at the Transplant Clinic at least 15 minutes before your scheduled appointment time. You need to register and check in. Staff will weigh you, take your blood pressure, and review your medicines. If you need any supplies or prescriptions, please tell the staff at this time.

### **What to Expect During Clinic Visits**

You will see the provider for your clinic appointment. If you would like to meet with a pharmacist, dietitian or social worker please let your coordinator know before your appointment.

### **Before Leaving the Transplant Clinic**

- Obtain an After-Visit Summary. This will have an updated medicine list, your lab results, and any follow up instructions.
- Obtain an updated standing lab order if needed.
- Schedule your next visit.

### **Outreach Clinics**

We have transplant outreach clinics throughout Wisconsin and Illinois. UW Transplant providers see patients at these clinics. These clinics are for stable patients only. If you need further care, like a biopsy, you will need to come to UW Health Transplant Clinic in Madison. Talk with your coordinator if you would like to move your visit to an outreach clinic.

## **Blood (Lab) Tests**

### **Why do I need to have labs test done?**

It is very important that your health care team knows how well your new organ is working, and if there are problems with your medicines. To check these issues you must have blood tests drawn on a regular basis after transplant. Blood tests are often the only way we are able to tell there is a problem with the new organ. Blood tests can often show us if there is a problem even before you have any symptoms.

### **Where can I have my lab tests done?**

Blood tests are done daily in the hospital after transplant. When you go home, you can have blood tests done near home. Check your insurance plan to see if there is a certain lab you must use. Often, blood tests are drawn at any local clinic or hospital.

If your labs will be near home your transplant coordinator will give you a 'lab letter' (paper order) to give to your local lab. This letter tells your lab to fax the results to the UW Transplant Office at 608-262-5624.

### **How often do I need to have my lab tests done?**

Most often, in the first weeks after the transplant, you have blood tests drawn two times a week on Monday and Thursday. It is best to have your labs drawn early in the morning so you can get your results by mid-afternoon. The frequency of the blood tests decreases over time. The transplant team lets you know how often to do blood tests. **ALL** transplant patients have blood tests done at least once per month for the rest of their lives.

### **What should I do with my lab tests results?**

Your local lab should also get the results to you as soon as they are ready. You should then record the lab values in the record book. If you have questions, or the values are outside of the expected ranges you have been taught, call the transplant coordinator or the transplant office. There will be times when you will know the results before your coordinator.

### **Anti-Rejection Drug Levels**

We also draw blood to make sure you are getting the right amount of your anti-rejection drug. Right after transplant, these are often done once a week on Mondays. The blood test needs to be drawn about 12 or 24 hours from the time you took your last dose of the medicine depending on the instructions you have been given. You should **not** take your morning dose of this medicine until **after** the lab draw. Take your other medicines at the normal time

<b>Lab Test</b>	<b>Normal Values</b>	<b>What It Is</b>	<b>Reasons for High or Rising Values</b>	<b>Reasons for Low or Decreasing Values</b>	<b>When to Call Your Transplant Coordinator</b>
<b>Hematocrit (HCT)</b>	<b>35 – 50</b>	The amount of red blood cells (RBCs) in the blood. RBCs carry oxygen in the body. When the hematocrit (HCT) is low you may feel tired or weak.	<ul style="list-style-type: none"> <li>• Thicker blood</li> <li>• Smoking</li> <li>• Dehydration</li> </ul>	<ul style="list-style-type: none"> <li>• Anemia</li> <li>• Bleeding</li> <li>• Side effects of medicines</li> <li>• The kidneys not working well</li> </ul>	<ul style="list-style-type: none"> <li>• If the HCT drops by 5 or more points between readings, or slowly trends down.</li> <li>• If the HCT is less than 30.</li> <li>• If the HCT is more than 50.</li> </ul>
<b>White Blood Cell count (WBC)</b>	<b>3,000 - 10,000 (3 – 10)</b>	The cells in the body that fight off infection.	<ul style="list-style-type: none"> <li>• Infection</li> <li>• High doses of prednisone</li> <li>• If your spleen has been removed.</li> </ul>	<ul style="list-style-type: none"> <li>• Infection (CMV)</li> <li>• Side effects of medicines</li> </ul>	<ul style="list-style-type: none"> <li>• If your WBC is less than 3.</li> <li>• If your WBC is more than 10.</li> </ul>
<b>Creatinine</b>	<b>0.5 – 1.5</b>	A protein waste product made by the muscles and removed from the body by the kidneys. Creatinine measures how well the kidney is working.	<ul style="list-style-type: none"> <li>• Rejection</li> <li>• Infection</li> <li>• Dehydration</li> <li>• Side effects of medicines</li> </ul>	<ul style="list-style-type: none"> <li>• Improving kidney function</li> </ul>	<ul style="list-style-type: none"> <li>• An increase of 0.3 or more from your baseline value.</li> <li>• A slow increase over time.</li> </ul>
<b>Glucose (Blood Sugar)</b>	<b>Fasting: 70 – 99</b>	The amount of sugar in the blood stream. Glucose is the main source of energy for the body. Insulin is a hormone that helps the body use glucose and keeps the glucose levels in the blood within normal ranges.	<ul style="list-style-type: none"> <li>• Side effects of medicines</li> <li>• Diabetes</li> <li>• Infection</li> <li>• Not taking enough insulin</li> </ul>	<ul style="list-style-type: none"> <li>• Taking too much insulin</li> <li>• Not eating</li> <li>• Nausea, vomiting, diarrhea</li> <li>• Exercise</li> </ul>	<ul style="list-style-type: none"> <li>• If you do not have diabetes, call if the fasting glucose level is over 100.</li> <li>• If you have diabetes, call your diabetes team to adjust your medicines if blood sugars are higher or</li> </ul>

Lab Test	Normal Values	What It Is	Reasons for High or Rising Values	Reasons for Low or Decreasing Values	When to Call Your Transplant Coordinator
					lower than goal range (about 70 to 150).
<b>Potassium (K+)</b>	<b>3.5 – 5.5</b>	An electrolyte the body uses that helps muscles function, especially the heart.	<ul style="list-style-type: none"> <li>• The kidneys not working well</li> <li>• Eating foods that contain a lot of potassium</li> <li>• Dehydration</li> <li>• Side effects of medicines</li> </ul>	<ul style="list-style-type: none"> <li>• Nausea, vomiting, or diarrhea</li> <li>• Side effects of medicines</li> <li>• Not getting enough potassium in the diet</li> </ul>	<ul style="list-style-type: none"> <li>• If the potassium is less than 3.5.</li> <li>• If the potassium is 5.8 or higher.</li> </ul>
<b>Drug levels (tacrolimus, cyclosporine, or sirolimus)</b>	<b>Your transplant team will tell you your target range.</b>	Measures the amount of medicine in your blood to know if you are getting enough medicine but not too much.	<ul style="list-style-type: none"> <li>• Taking the medicine <b>before</b> your blood draw</li> <li>• Other medicines</li> <li>• Changes in diet</li> <li>• Diarrhea</li> </ul>	<ul style="list-style-type: none"> <li>• Missing doses of medicines</li> <li>• Other medicines</li> <li>• Changes in diet</li> </ul>	<ul style="list-style-type: none"> <li>• Your transplant coordinator will call you if you need any changes in your dose of medicines.</li> </ul>

## Nutrition

Nutrition plays a key role in the transplant process. Before transplant, eating well and being at a healthy weight may help you recover faster from surgery. After transplant, good nutrition plays a key role in the healing process, maintaining transplant function and your overall health.

### Nutrition After Transplant

After surgery, your body needs enough nutrition to promote healing, fight and prevent infection, and gain back weight you may have lost. You may have a lower appetite or change in your sense of taste due to medicines you will be taking. Even though you may not feel hungry, you will need to eat.

### Tips

- Eat small, frequent meals or 3 meals with 2-3 snacks in between.
- Include high calorie, high protein foods like yogurt, pudding, cottage cheese, nuts, peanut butter, shakes, lean meats and eggs.
- Use nutritional supplement drinks such as Boost<sup>®</sup>, Ensure<sup>®</sup>, or Carnation Breakfast Essentials<sup>®</sup>.

Sometimes right after kidney transplant, your new kidney may not be working as it should. This is called **delayed graft function (DGF)** or “sleepy” kidney. You may need dialysis. While you have DGF, follow a renal diet which is low in sodium, potassium, and phosphorus. Once your kidney wakes up and you no longer have DGF, you can stop the renal diet and instead follow the healthy eating guidelines in this handout.

### Food Safety After Transplant

Patients are at higher risk of foodborne illnesses. To prevent these illnesses, practice

food safety. The booklet “Food Safety for Transplant Recipients” provides ways you can lower your risk of foodborne illness.

You can find it online at:

<http://www.fda.gov/food/foodborneillnesscontaminants/peopleatrisk/ucm312570.htm>.

You can also find it by searching the booklet title.

### Long Term Nutrition Guidelines

After transplant, you will need to develop and maintain a healthy lifestyle. This helps prevent problems like diabetes, osteoporosis, and heart disease. Weight gain can happen after transplant due to an increased appetite from steroids, unhealthy eating habits, lack of exercise, and family history of obesity. Making healthy food choices can help prevent these problems.

### Ways to Achieve a Healthy Weight and Lower Your Risk for Heart Disease

- Eat regular meals: 3 meals per day or small, frequent meals.
- Control portion sizes at meals.
- When dining out, control portion sizes by splitting a meal with someone or ordering the kids portion size.
- Choose healthy snacks.
- Limit intake of high calorie, high fat sweets such as cakes, cookies, ice cream, and candy.
- Make physical activity part of your daily routine at least 4-5 days a week.
- Choose lean meats. Choose fish and skinless poultry more often than red meat. Consume 6-8 ounces per day. Trim the fat off the meat and remove the skin from poultry before cooking.
- Lower your use of butter and lard. Choose margarine that is trans-fat free.
- Use olive oil, canola oil, or other vegetable oil with cooking.

- Avoid high fat, processed meats such as brats and sausage.
- Choose low fat dairy products such as skim or 1% milk, low fat yogurt, and low-fat cottage cheese. Limit intake of high fat dairy products such as whole milk, ice cream, and custards.
- Choose low fat versions of salad dressings, mayo, sour cream, and cream cheese.
- Choose baked or low-fat versions of crackers and chips.
- Eat more fiber foods such as whole grain breads and cereals, whole grain pastas, brown rice, dry beans and peas, fruits and vegetables.

### **Choose Low Sodium Foods**

A diet low in sodium can help control blood pressure and prevent fluid retention. To lower your sodium intake:

- Avoid adding salt to your foods. Use herbs, spices, or blends such as Mrs. Dash<sup>®</sup> instead of salt.
- Avoid foods with large amounts of sodium such as processed foods like ham, bacon, sausage, cheese, canned vegetables and soups, and boxed meals.
- Avoid salt substitutes with potassium.
- Read food labels to find out if foods are high in salt.

### **Carbohydrates**

If you have diabetes or high blood sugars, you may need to eat a diet that has a consistent amount of carbohydrate at each meal. Guidelines for this kind of diet include:

- Choose a variety of foods at each meal that includes fruits, vegetables, proteins, and carbohydrates.
- Do not skip meals. Eat about the same amount of carbohydrate at each

meal. Foods that contain carbohydrate are: breads, cereals, pasta, rice, starchy vegetables such as potatoes, corn, and peas, fruits, milk and yogurt, and sweets.

- Limit your intake of concentrated sweets such as regular soda, candy, or jams.

### **Dietary Supplements**

- Avoid herbal or dietary supplements unless approved by the transplant team first.
- Avoid potassium supplements or salt substitutes that contain potassium.

### **Fluid Volume**

It is important to know how much fluids you should drink at home. You may need to drink more fluids or restrict your fluids depending on your health.

### **Dehydration (Dry)**

Dehydration is when your body loses fluid. This happens when you don't drink enough fluids. It can happen if you lose fluid through diarrhea or vomiting. High blood sugars or fevers can also cause dehydration.

Signs of dehydration:

- Decrease in weight
- Decrease in blood pressure when standing
- Increase in pulse when standing
- Lightheaded or dizzy when standing
- Thirst
- Decrease in urine output
- Muscle cramps

### **What to Do If You Are Dehydrated**

Drink plenty of fluids. Avoid caffeine and alcohol. If you exercise, increase your fluids so you do not get dehydrated. If you have a lot of vomiting or diarrhea, you may need IV fluids. Your blood pressure and pulse should be close to the same when you are lying down and when you are standing.

### **Overhydration (Wet)**

Overhydration is when your body has too much fluid. This may be because of side effects of medicines or something could be wrong with your kidney.

Signs of overhydration:

- Increase in weight
- Swelling

### **What to Do If You Are Overhydrated**

Limit your fluid intake. Call your transplant coordinator.

### **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, 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.

### **Organ Rejection**

Rejection is when your body's immune system attacks your new organ. Your body is trying to destroy it. There are two kinds of rejection. Treatment varies for each. The signs and effects also vary for each type of organ.

All types of rejection are diagnosed by a biopsy. "Biopsy" means taking a small sample of tissue from an organ. It will be looked at under a microscope. A biopsy is often done when you have abnormal blood test results.

### **Acute Cellular Rejection**

This type of rejection is a **direct** response to your new organ. The T cells (or "killer cells") of your immune system see your organ as foreign. A biopsy is done to diagnose this. The first treatment is high dose steroids. Starting treatment sooner improves the outcomes. If the steroids do not help, you may need to come to the hospital for IV medicine. Your doctor may also increase your anti-rejection medicines.

### **Acute Antibody-Mediated Rejection (AMR)**

AMR is an **indirect** response to your new organ. The B cells (or "memory cells") of your immune system notice the cells from the new organ. An immune response begins. The body starts to make new antibodies to fight off the new organ. Treatment includes different medicines. If needed, antibodies can be removed from your blood. This process is called plasmapheresis. It is like dialysis. The goal is to remove harmful antibodies that are fighting your new organ.

### **Chronic Rejection**

Chronic AMR may be diagnosed if the rejection has been ongoing or the biopsy shows tissue scarring. Your doctor will review the risks and benefits of ongoing treatment based on these results. You may need other medicines and treatments.

### **How do you test for rejection?**

The sooner we find and treat rejection, the better the outcomes. Lab tests are often the fastest way to catch a problem. Make sure you have your labs done as scheduled by your transplant team. You will also need a



biopsy. Other tests might include an ultrasound or scan.

### **What are the signs of rejection?**

You may have signs of rejection. The first symptom you will often see is changes in your lab results. Other signs you might notice on your own. **Call your coordinator** for any of these signs.

### **Signs of Kidney Rejection**

- Increased creatinine
- Increased temperature
- Increased weight
- Decreased urine output
- Ankle swelling
- Swelling or tenderness over kidney
- Body aches

### **Kidney Obstruction**

A kidney obstruction is when the tube that connects your kidney and your bladder (ureter) is narrowed. You will have a stent placed in the ureter during surgery to prevent blockage. A stent is a small, soft, hollow tube. This stent is usually removed in the clinic within 6 weeks after surgery. A urine sample is required before removal.

### **Signs of Obstruction**

A blockage or obstruction that develops that prevents urine from draining out of the kidney into the bladder. This causes pressure in the kidney. Signs of this pressure include:

- Swelling of leg on same side as affected kidney
- Increased creatinine
- Increased blood pressure
- Increased weight
- Decreased urine output

If you have any of these signs, call your transplant coordinator.

### **Testing and Treatment for Obstruction**

To check for an obstruction, an ultrasound of your new kidney will be done. You may need a percutaneous nephrostomy tube. This is a small, soft plastic tube. It enters the skin in your lower abdomen to drain urine from the kidney. The purpose of this tube is to relieve pressure in the kidney.

### **Infection Risk**

#### **Reasons for Infection Risk**

When you have an organ transplant, a new organ is placed in your body to take over the function of your failed organ. As with anything foreign to your body, such as virus, your immune system will recognize the new organ as being foreign and try to get rid of it. This is called rejection.

After transplant you take medicines to prevent this rejection process. These medicines weaken your immune system to allow your transplant to be accepted by your body.

As a result of your weakened immune system, you are more at risk to get infections. This includes typical, everyday infections such as colds and flu, and also some unusual infections that are unique to transplant patients. When you get an infection, you will not be able to fight it as well because of your weakened immune system. Some symptoms of infection may be more severe, and they may not go away as quickly as before. Also, you may need medicine to help you get better. Sometimes you will need to be admitted to the hospital to give stronger medicines to treat the infections.

Your transplant team tries to adjust your medicines, so you get enough to prevent rejection, but not weaken the immune system too much.

## How to Prevent Infections

It is important to protect yourself from infections. There are ways you can protect yourself.

- Frequent hand washing/hand sanitizer use
- Avoid direct contact with people known to be ill
- Avoid raw or undercooked meats
- Avoid changing cat litter boxes or cleaning birdcages
- Wear gloves when doing gardening, farm work, or outdoor work
- Practice good routine dental care
- Keep up to date on vaccinations
- Keep all pet immunizations up to date
- Avoid smoking and exposure to secondhand smoke
- Practice safe sex
- Wear protective clothing and insect repellent when outdoors
- If you have well water, contact the Department of Natural Resources or your county health department to have your well tested yearly.

## Treatment

Many of these infections can be treated by your local doctor. However, you should tell the transplant team whenever you have any of the below symptoms of infection. You may need medicine to treat infections. Most of these medicines are safe to take. Some medicines used to treat infections can affect some transplant medicines. Be sure to contact the transplant team with any new medicine you are taking.

## Types and Symptoms of Infections

### Viral Infections

Many common upper respiratory and gastrointestinal infections are caused by viruses. There is no cure for these common viruses; they simply have to run their course. Try to get plenty of rest and drink plenty of fluids to help your body fight the virus. You should see your local doctor if your symptoms last longer than expected or if you seem to be getting worse instead of better as time goes on.

Respiratory infection symptoms:

- Fever (oral temperature over 100.5°F)
- Cough
- Yellow or green tinged phlegm
- Sore throat
- Fatigue

Gastrointestinal infection symptoms:

- Fever (oral temperature over 100.5°F)
- Chills
- Diarrhea
- Nausea
- Vomiting
- Fatigue

As well as common, general viruses, transplant patients need to be aware of other specific viruses that can cause problems following organ transplant

### Cytomegalovirus (CMV)

Cytomegalovirus or CMV is a virus that most people have been exposed to. It lives in the body for years and often goes unnoticed until a person has a suppressed immune system. You will take valganciclovir (Valcyte<sup>®</sup>) or acyclovir (Zovirax<sup>®</sup>) for three to six months after transplant to help prevent CMV. These first three months are the time when you are

most at risk for getting CMV, but you can develop CMV at any time.

Symptoms of CMV can include:

- Nausea
- Vomiting
- Diarrhea
- Feeling tired
- Decreased white blood cell count (often less than 2)
- Fever (oral temperature over 100.5°F)

There is a blood test for CMV. Your transplant doctor will decide if testing is needed. CMV can be a very serious infection, but there is medicine to treat it.

### **BK Virus**

BK virus is a virus that may affect people who have had a kidney transplant. It usually stays hidden in the transplanted kidney but can become active and cause damage to the new kidney. Most people do not have any symptoms, so blood tests are done to check for it.

### **Herpes Infections**

Herpes simplex is a virus most people have been exposed to sometime in their lives. It can remain hidden in our bodies for years and become active at any time. It most commonly causes **cold sores** on the lips and in the mouth. This can be treated with antiviral medicines. Another type of herpes simplex causes genital sores. You may have these viruses with no symptoms. After transplant when the immune system is weakened, symptoms may appear. These can be controlled with medicines.

Varicella zoster virus, also known as shingles, is another type of herpes virus. Shingles appear as a rash or series of small blisters. They may be painful and most often form on one side of the chest, back,

hip or head. Shingles occur more often in older people. Transplant patients may get shingles because of the weakened immune system. Early treatment will help shorten the length of the illness and may ease symptoms.

**There is a shingles vaccine that is safe** for patients to get after transplant. This vaccine is called Shingrix. It is **not** a live vaccine. If your local medical team recommends this vaccine, please check with your transplant coordinator to see if the time is right for you. The other shingles vaccine (Zostavax) is a live vaccine and is **not safe** to get after transplant.

If you have never had **Varicella zoster** or the **chicken pox**, or received the vaccine with proven immunity, you will need to be very careful being around those who have chicken pox. The virus is highly contagious as early as 5 days before the person breaks out in the red, open sores, called vesicles. These fluid-filled sores are highly contagious; avoid contact with them even if you have had chicken pox in the past. You may be at-risk to develop the disease if your immunity is low. Contact your transplant coordinator if you have had close contact with someone who you think may be contagious.

### **Influenza (Flu)**

Influenza is a viral infection of the nose and throat. It is more severe than the common cold and comes on suddenly. The flu is caused by germs found in the air and on surfaces.

Influenza can be mild to severe. You should get a flu shot (vaccination) every year to help prevent you from getting sick. There are many strains of influenza, so you may get influenza even if you got your flu

shot. Symptoms include fever, head and muscle aches, extreme tiredness, and sometimes cold symptoms.

### **Epstein - Barr virus (EBV)**

EBV can cause infectious mononucleosis (mono). It can also put you at risk for lymphoma, or a cancer of the lymphatic system. There is a blood test for EBV. Symptoms include enlarged lymph nodes, tiredness, sore throat, and fever.

### **Papillomaviruses**

Papillomaviruses are a family of viruses that can cause warts on the hands, fingers, face, and genitals. Decrease your risk for these viruses by limiting close contacts and use safe sex practices.

### **Hepatitis B**

Hepatitis B is a viral infection of the liver that is spread through blood and sexual contact. It can lead to liver failure. Patients should be vaccinated against Hepatitis B before transplant.

Hepatitis B can be treated with anti-viral medicines. After transplant, Hepatitis B can re-activate and cause liver damage, so patients with Hepatitis B need life-long anti-viral therapy after transplant.

### **Hepatitis C**

Hepatitis C is another viral infection of the liver that can lead to liver damage. It is spread through blood or sexual contact. After transplant, Hepatitis C can re-activate and damage the liver. There are medicines to treat Hepatitis C and prevent liver damage after transplant.

\*If you have agreed, there is the possibility you may receive an organ with Hepatitis C or Hepatitis B, even if you do not have the virus before transplant. You have to sign a special consent form to receive these organs. After your transplant, the doctors

will prescribe anti-viral therapy to treat these viruses. Hepatitis B anti-viral is taken life-long. Hepatitis C antiviral therapy is generally completed over the course of a few months. Your doctors will decide when you should start therapy for either virus.

### **West Nile Virus (WNV)**

WNV is a virus that can affect the central nervous system. It is most often spread through the bite from an infected mosquito. In patients with weakened immune systems it can be very severe. It can cause encephalitis, meningitis, and even death. Transplant recipients should wear long-sleeved shirts and pants and use insect repellents to prevent mosquito bites. Symptoms can include fever, neck stiffness, tremors, muscle weakness, vision loss, confusion, or numbness.

### **Lyme Disease**

Lyme disease is a tick-borne illness. It is spread through a tick bite and can start as a rash near the site of the bite. Symptoms of Lyme disease can include tiredness, loss of appetite, headache, neck stiffness, localized swelling and fever. If you had a recent tick bite along with these symptoms, notify your provider.

### **Toxoplasmosis**

Toxoplasmosis is a parasite spread by consuming undercooked meat, contaminated water, or infected cat feces. Donors may not know they are infected, so all donors are screened for this infection. If your donor is positive for toxoplasmosis, you will need treatment to prevent active disease.

### **Bacterial Infections**

Bacterial infections can and should be treated with antibiotics.

### **Pneumonia**

Pneumonia is a lung infection. There are different types of pneumonia caused by bacteria, viruses, or fungus. Symptoms include cough with green, yellow, or brown mucous, fever, chills, shortness of breath, chest pain, and weakness.

One type of bacterial pneumonia is **Pneumocystis carinii** or **PCP**. You are at higher risk for this type after transplant. This is an infection in your lungs. After your transplant, you will take TMP/Sulfa (Bactrim), atovaquone or an inhaled medicine called pentamidine to help protect you from this infection. Symptoms include cough, fever and problems breathing.

### **Urinary Tract Infections**

Urinary tract infections (UTI) occur when germs get into the urinary tract. Symptoms include burning or pain with urination, increased pressure, or feeling the need to urinate right away, urinating small amounts more often, bloody urine and fever or chills.

### **Clostridium difficile**

*Clostridium difficile* (*C. diff*) is a germ that lives in the digestive tract (stomach and intestines or bowel). *C. diff* can make toxins that cause watery diarrhea, belly pain/tenderness, fever, loss of appetite, and nausea. People who are taking antibiotics can get sick with *C. diff*. There are medicines that can be used to treat *C. diff*.

### **Wound Infections**

If you develop an infection in your **incision, drain, or catheter site**, contact your transplant coordinator right away. You may need antibiotics to treat the infection. Symptoms of wound infections include:

- Increased redness or warm to the touch.
- Pus-like or green drainage.
- Temperature by mouth is greater than 100.5°F or 38.3°C.
- Excessive swelling or bleeding or bruising.
- Increased pain you cannot control with your pain medicine.

### **Fungal Infections**

There are different types of fungal infections. They can be difficult to treat in transplant patients and most often will require the use of anti-fungal medicines.

- **Thrush:** The most common fungal infection after transplant is a yeast infection in your mouth called thrush. Right after transplant, you may be on a medicine called Nystatin or another antifungal medicine to help prevent thrush. Symptoms include small, white bumps or patches in your mouth or throat. They may be painful or cause problems swallowing.
- **Athlete's foot** is another common fungal infection. You may use over-the-counter remedies to relieve the symptoms of athlete's foot. Contact your transplant coordinator or local doctor if symptoms persist.

- **Aspergillus:** Aspergillus is a common fungus found indoors and outdoors. Most people breathe in aspergillus spores without being affected. When your immune system is weakened, exposure to this fungus can cause illness. The most common place for this infection is the lung but can be found in other parts of your body. In addition to lifestyle changes to lower your risk of exposure, you may need antifungal medicines to prevent this infection. Type and length of treatment are based on your risk.
- **Other common fungal infections:** Other common sites for fungal infections after transplant are fingernails or toenails. Avoid sharing manicure and pedicure tools with others. It is very hard to get rid of a fungal infection in the nail beds.

You may develop symptoms of a yeast infection in your surgical incision, in skin folds, in the vagina, urinary tract, lungs, or eyes. Symptoms of a fungal infection may include white or yellow discharge or film, itching and pain. If you develop any of these symptoms, contact your transplant coordinator or local doctor.

## Things to Remember After Your Transplant

### Take medicines as directed.

- 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.

### Labs

- Take a copy of your lab order with you when you go to lab.
- Complete labs as instructed
- 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 medicine level is done with your lab draws. It may be done 1-2 times per week.
- 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<sup>®</sup> 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:
  - Fever >100.5°F.
  - Systolic blood pressure (top number) above 180 or diastolic blood pressure (bottom number) above 90.
  - Weight gain of 3 pounds in one day or 5 pounds in one week.
- Activity: Don't lift more than 10 pounds until your transplant doctors

say it's ok. It is good to walk and use stairs while healing.

### Sign Up for MyChart

MyChart is an internet-based service that lets you access your medical and health plan information.



**MyChart is not for urgent needs.** Call your coordinator for urgent needs or call 911 for emergencies.

### Reasons to Sign Up

- Get test results quickly.
- View lab orders in the letters section.
- View your instructions (“After Visit Summaries”).
- Send secure messages to your coordinator and providers.
- Access paperless billing.

The MyChart app is available for both Apple and Android mobile devices. The mobile app provides access to many MyChart features, but it does not replace the web-based application. Certain features are only available on the web site.



### Transplant Clinic Visits

- Complete labs as directed by staff with your appointments. **Please bring to all of your clinic visits:**
  - your record book (including vital signs and blood sugars if checking), and
  - medicine list.
- You will be told when to follow-up after discharge from the hospital.
- Please arrange a ride. You **WILL** have driving restrictions after transplant until cleared by the doctor.

### 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.

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 © 12/2020 University of Wisconsin Hospitals and Clinics Authority. All rights reserved. Produced by the Department of Nursing HF#8176.

## Who and When to Call

Who	Why	When/ Phone Number
<b>Transplant Coordinator/ Transplant Office</b>  <b>Your Coordinator:</b> <hr style="width: 20%; margin-left: 0;"/>	<ul style="list-style-type: none"> <li>• Medicine refills</li> <li>• Lab results</li> <li>• Questions about transplant medicines, symptoms or other transplant-related questions</li> </ul>	Monday-Friday 8:30a.m.-4:30p.m. <b>608-263-1384</b>
<b>Transplant Clinic</b>	To schedule, change or cancel a transplant clinic appointment	Monday-Friday 8:30a.m.-4:30p.m. <b>608-262-5420</b>
<b>Social Worker</b>	<ul style="list-style-type: none"> <li>• Worries about your emotional health</li> <li>• Problems paying for your medicines</li> <li>• Questions about your insurance or Social Security Disability</li> </ul>	Monday-Friday 8:30a.m.-4:30p.m. <b>608-262-5420</b> <b>608-263-1384</b>
<b>Financial Counselor</b>	<ul style="list-style-type: none"> <li>• Questions about new Medicare applications</li> </ul>	Monday-Friday 8:30a.m.-4:30p.m. <b>608-263-8770</b>
<b>Organ Allocation Specialist (On-Call)</b>	<ul style="list-style-type: none"> <li>• Fever over 100.5°F or chills</li> <li>• Nausea, vomiting or diarrhea for more than 24 hours</li> <li>• Blood in urine or problems urinating</li> <li>• Problems with drains</li> <li>• Other urgent symptoms</li> </ul>	Monday-Friday 8:30a.m.-4:30p.m. <b>608-263-6400</b>
<b>Local doctor/ health care provider</b>	<ul style="list-style-type: none"> <li>• Problems not related to your transplant</li> <li>• Refills of non-transplant medicines</li> </ul>	
<b>Call 911 or go to the nearest emergency room</b>	<ul style="list-style-type: none"> <li>• Trouble breathing</li> <li>• Heavy bleeding or bleeding you can't stop</li> <li>• Chest pain</li> <li>• Fainting or passing out</li> <li>• High blood pressure with headache or vomiting</li> <li>• Unable to take medicines for 24 hours</li> <li>• Seizure or stroke</li> <li>• Severe pain</li> <li>• Anything else you think might be an emergency</li> </ul>	If you are in a local emergency room or hospital, call your Coordinator.