Health Facts for You

Your heart transplant surgery

UW Health

The Transplant Surgery

When you are taken to the surgery area, your support persons may stay in the surgical waiting area or go back to the inpatient unit (B45). The OR nurses will provide your family with updates. After surgery, the surgeon will talk with your support persons

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 to watch your heart rhythm, a blood pressure cuff on your arm, and a plastic clip on your finger to check your heart rate 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.

- Urine catheter: A small rubber tube (Foley catheter) will be in your bladder. This allows us to track your urine output. It stays in place a few days but will be removed as soon as possible.
- Intravenous catheter (IV): At least one IV will be placed in your hand, arm, or neck. This will be used to give you fluids and medicine until you are able to eat or drink. A few days after your transplant, the doctor will decide when the IVs can be removed or replaced.
- A stomach tube will be passed through your mouth into your stomach when you have the breathing tube in. This is used to pull air out of your stomach.
- Chest tubes will be placed to remove fluid and air from your chest. These will be removed a few days after surgery.

The surgery takes about 6-12 hours. You will go to back to your room on the transplant unit for recovery. The nurses on the unit will let your support persons know when they can come to the room to see you

What to Expect After Surgery

You will arrive on the transplant unit with a breathing tube in place. The unit staff will start to wake you at an appropriate time to work on removing the breathing tube. 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.

You will have an **incision** down the center of the chest at your sternum. This may be closed with sutures, glue, staples, or a combination of closure methods. You may have a wound vacuum over the incision, or it may be covered with a dressing.

The incision will be covered with a dressing. We will teach you how to clean and care for the incision. This will help you be more aware of any signs of infection or problems. The staples or stitches will be removed at your clinic visit with your surgery team.

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. Coughing and deep breathing are an important part of recovery and help to prevent pneumonia.

You will wear Sequential Compression Devices ("SCDs" or leg pumps) during 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.

Your blood sugars will be checked during and after surgery. If you have diabetes or elevated glucose levels, 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. Well-managed blood sugars lower your risk of infection.

You may need to take insulin when you go home. If so, the diabetes education team will teach you and your family.

How will I know my transplant is working?

The transplant team will talk with you daily to review your heart function. You will have biopsies, echocardiograms, EKG's and your vital signs will be monitored closely to assess your heart function

Education After Transplant

You must learn about the care of your new organ. Education sessions will be scheduled with you. This may start as early as your first day after transplant based on how your recovery is going.

Your primary support person must be involved in your education. in order to help you once you return home. Your primary support person should plan on being at the hospital for 2-3 days at the minimum for education. However, each learner is different, and some may require additional sessions.

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

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

Guidelines for Primary Supports and Visitors

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 due to a limited supply of cots available for guests. 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.

What will happen after I am discharged from the hospital?

You will have to stay within 45 minutes of the hospital for a minimum of 1 week after discharge from the hospital following your transplant surgery. Your support person will need to stay with you 24 hours a day during this time.

UW Health Guest Services offers discounts at local hotels as well as the Restoring Hope Transplant House. Many area hotels have shuttles available. The phone number to call Guest Services to make housing arrangements is **(608) 263-0315**. If you live within 45 minutes of the hospital, you may return home after transplant.

When you return home, your support person should plan to stay with you 24 hours a day for 1-2 weeks. This time allows you to settle into a routine at home, arrange your home in a way that is convenient to you and have access to someone to help with cares and transportation.

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 heart 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.
- Monitoring your vital signs including daily weight and temperature and twice daily blood pressure and heart rate.
- Call the transplant office about any new problems or symptoms related to your transplant or about any new medicines or tests you have.
- Take all prescription medicines as prescribed.
- Follow the diet and exercise plan advised by your doctor.
- Go to your appointments, clinic visits, lab draws, and biopsies.
- Do not abuse your body by smoking, drinking alcohol, or using non-prescribed medicines and herbals.

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

It is recommended that you wait a few weeks or months after transplant to get vaccines. Please review timing of vaccines with your transplant coordinator after transplant. After transplant you should not get any live vaccines.

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

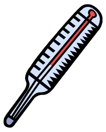
- Quadrivalent meningococcal conjugate or polysaccharide
- Haemophilus influenzae type b

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. We will give you an automatic blood pressure cuff and a thermometer before you go home. Bring your vital signs record to each clinic visit. We will look for trends in your numbers. We may make changes to your medicines based on your numbers.

Daily Temperatures



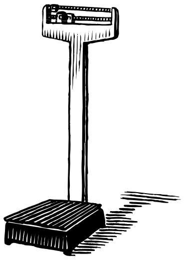
- Take once a day at the same time each day. Do not eat or drink anything 30 minutes before you take your temperature.
- Normal oral temperature is 98.6°F or 37.0°C.
- If you have a temperature higher than 100.5°F or 38.3°C or 3 degrees higher than your normal, call the transplant coordinator.
  - Drink fluids, if dehydrated.
  - Do not take acetaminophen (Tylenol®) or other fever-reducing medicines until talking with your transplant coordinator if you have a fever.

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.
- Take your blood pressure with your feet on the ground and uncrossed.
- Call your transplant coordinator if:
  - Blood pressure is higher than 140/100 more than two readings in a row.
  - If you have blood pressure lower than 90/50 or you have symptoms of low blood pressure such as weakness, dizziness, lightheadedness.
- Normal heart rate is 60 – 100.
- Call your transplant coordinator if your heart rate is less than 60 or more than 120 or if your heart rate is irregular.

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 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 sugars in the hospital, you will 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 or stitches, they will likely be removed at your first surgery clinic visit. You may also have steri-strips (paper-like strips) over incisions. 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. 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, you may leave the incision uncovered or may be told to continue to apply a dressing. If you wear a dressing it should be changed at least once a day until it is healed (about 2-4 weeks after surgery). A nurse will give you a 3-day supply of dressings to place over the incision. If you need more supplies, you can buy them at a local drug store.

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

As your wound heals, you may notice some soreness, numbness, and itching. This is normal and should improve over time. Call your transplant coordinator for any increase in swelling, tenderness, redness, drainage, or if the wound opens.

Activity Guidelines
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.

Some people need physical and/or occupational therapy when going home. This is to help build strength.

We will help you arrange cardiac rehabilitation when you go home. The goal of cardiac rehab is to build endurance. A member of the rehab team will visit with you after your transplant. They will start exercises with you as soon as possible. Even if you are exercising at home, we still recommend that you participate in cardiac rehabilitation.

Keep in mind, each person recovers differently. Your plan will be made to meet your needs.

You will have some activity restrictions in the first **8 to 12 weeks** after your transplant. After that you can return to your normal routine.

- Do not drive until cleared by the surgical team. This typically occurs with your surgery clinic visit about 4 weeks after transplant. Sit in the backseat of a car to lower your risk of an air bag injury.

- Always wear a seatbelt.
- Do not lift, push, or pull more than 8 pounds for 4 weeks. At your surgery clinic visit, you may be cleared to lift more.
- Do not reach above shoulder level.
- Talk with your transplant team before you travel or take a long trip. Avoid air travel for at least one year after transplant.

Sexual Activity
Once home, you may engage in sexual activity as you feel able and have the desire. Care should be taken to avoid positions that strain your healing sternum (breastbone). The peak effort with sex is equal to climbing stairs at a moderate pace. That would likely be "somewhat hard" on the exertion scale.

Some heart medicines can affect your sexual drive and ability. If you have questions or concerns about this, please talk with your doctor or heart care team.

You should talk to your doctor about birth control. Some of the medicines you take after transplant may be harmful to the fetus. If you are planning to get pregnant, please discuss this with your transplant team.

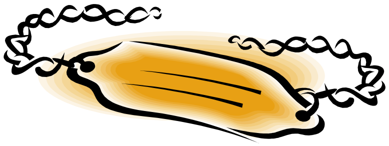
Going Back to Work

We encourage patients to return to work after having a transplant. You may not be able to do the same duties as before your transplant. It depends on the type of work you do, but that doesn't mean you can't work at any job. Your transplant team will talk with you about returning to work. They will help you with paperwork or questions you may have.

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 work with you to complete this form.



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.

Clinic Visits and Heart Biopsies

Your follow-up appointments will be scheduled prior to discharge from the hospital. The follow-up schedule is intense for the first few months. You will have frequent biopsies with your clinic visit. During a biopsy, pieces of tissue are taken from the inside of your organ and studied under a microscope.

Biopsies are done:

- Weekly for 4 weeks
- Every 2 weeks for 8 weeks
- Monthly for 3 months
- Every 6 weeks until your first anniversary
- In the second year you may need to continue to have biopsies depending on rejection and clinical history.
- You will be given a schedule for the first few months after transplant. This is subject to change based on your condition or doctor availability. We will call you with changes.

Before Your Heart Biopsy

The doctor or nurse will go over the test with you. They will:

- Explain why you are having the test.
- Tell you about the risks involved.
- Answer any questions that you may have.

You will be asked to sign a consent form. Signing this form allows the doctor to do the biopsy.

During the Heart Biopsy

The test is done in the cardiac catheterization lab. It lasts about 30 minutes. You will be asked to take off some of your clothes and to lie on an x-ray table. The x-ray equipment is used to help the doctor place the tools in the proper place in the body. The side of your neck will be cleaned. Drapes will be placed around the area to keep it clean. The doctor doing the biopsy will be wearing a gown, gloves, and a mask. The doctor will numb the skin with a local anesthetic. When this is done, you may feel pressure at the site, but no pain. The doctor will then put an IV in your neck vein. If you feel the need to move your arms or legs or to sneeze or cough during the test, please tell the staff.

To perform the biopsy, a flexible tool (bioptome) is placed into the right ventricle of the heart. This tool is used to take tiny pieces of tissue from the lining of the heart. During the procedure you may feel a few irregular heartbeats.

After the test, the large IV line is taken out. A bandage will be placed over the site. You will have a chest x-ray after each biopsy. You may have an echocardiogram the same day as your biopsy. After your biopsy, you will be able to go home or return to your hospital room.

After your doctor reviews the results and recommends changes, your coordinator will call you. This will usually be the day after your biopsy. Your results will be one of the following:

- Grade 0: No rejection
- Grade 1R: Mild
- Grade 2R: Moderate
- Grade 3R: Severe

What to Bring to Clinic Visits and Biopsies

- Your medicines including diabetes supplies if taking insulin
- A list of your current medicines
- Records of your weight, blood pressure, heart rate, and temperature at home
- Records of your blood sugar readings if you are checking your blood sugar at home
- A snack or something to drink
- A list of questions

Preparing for a Biopsy

- Do not eat or drink after midnight. You may take sips or bites of pudding or applesauce needed to take your medicines. If you are having labs drawn with your procedure, do not take your tacrolimus, sirolimus or cyclosporine. Bring your medicines with you to take after the procedure or lab draw.
- Wear comfortable clothes that have an easily removeable upper layer.
- If you are taking insulin, please follow the instructions you have been given for your insulin dosing when not eating.
- If you are on blood thinning medicine (such as Eliquis or warfarin), you will be told when to stop taking this medicine before a procedure.

Arrive Early for Clinic Visits and Biopsies

Plan to arrive at the clinic at least 15 minutes before your scheduled appointment time. You need to register and check in.

When You Leave the Transplant Visit or Biopsy

- Obtain an After Visit Summary (AVS). This includes an updated medicine list, your lab results, and any follow up instructions.
- After every biopsy, complete a chest x-ray before leaving the hospital.

Labs Draws with Visits

Most patients will have labs drawn with your biopsy, however, due to timing of your appointment, you may be told to arrive early for your lab draw. Please complete your lab draw as instructed by your transplant coordinator. Your coordinator will let you know if you need to stop eating or drinking before these labs. **Do not take your tacrolimus, sirolimus, or cyclosporine until after the lab draw.**

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.

Anti-Rejection Drug Levels

Whether you have your labs drawn with your appointments at UW or at your local lab it is important to have your labs drawn at the correct time to make sure you are getting the right amount of your anti-rejection drug. The blood test needs to be drawn about 12 hours from the time you took your last dose of the immunosuppressant medicine. You should **not** take your morning dose of this medicine until **after** the lab draw.

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 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®, Ensure®, or Carnation Breakfast Essentials®.

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® 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.

Food Safety

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: https://www.fda.gov/food/people-risk-foodborne-illness/food-safety-older-adults-and-people-cancer-diabetes-hivaids-organ-transplants-and-autoimmune

Food Safety When Dining Out

- Avoid entrée items that have uncooked or undercooked ingredients like eggs, poultry, meat, or fish. Don't hesitate to ask your server about the menu items.
- Avoid buffets. It is hard to control portion sizes at buffets. Foods may also be undercooked or have been at an unsafe temperature for too long.
- It is safe to dine at the hospital cafeteria. The food is prepared fresh and does not sit out for long periods of time.

Specific Foods to Avoid

- Hotdogs, deli meat, luncheon meat, smoked fish or meats, and precooked seafood should be reheated to steaming hot or ≥165°F
- Unpasteurized pâtés or meat spreads
- Unpasteurized/raw milk
- Cheeses made from unpasteurized milk. (Check the food label to be sure.) Common cheeses made with raw milk: feta, brie, camembert, blue, and queso-fresco.
- Unwashed fruits and vegetables
- Raw sprouts (alfalfa, bean, or other sprouts)

- Unpasteurized juices, ciders, or kombucha
- Raw or undercooked meat, poultry, or fish (raw sushi)

Internal Cooking Temperatures

It is important to heat up some foods to certain temperatures. The list below gives recommended internal cooking temperatures.

- Beef, pork, veal, and lamb (≥145°F); ground meat (≥160°F)
- Poultry (ground, parts, whole and stuffing; ≥165°F)
- Eggs (cook until yolk and white are firm); egg dishes (≥160°F)
- Fin fish (≥145°F or flesh is opaque)
- Shrimp, lobster, and crabs (flesh is pearly and opaque)
- Clams, oysters, and mussels (shells open)
- Scallops (flesh is milky white, opaque, and firm)
- Leftovers (cook or reheat to ≥165°F)

Other Food Safety Tips

Clean: Wash hands and surfaces often.

- Wash your hands with warm water and soap before eating, handling food, after using the bathroom, changing diapers, and handling pets.
- Wash cutting boards and dishes, used to prepare raw meats, in hot soapy water.
- Rinse and scrub fresh fruits and vegetables under running tap water. Do this even for foods with skins and rinds that are not eaten

Separate: Separate raw meats from other foods.

- Use one cutting board for fresh produce. Use a separate board for raw meats.
- Never place cooked food on a plate that had raw meats on it unless the plate has been washed with hot, soapy water.
- Separate raw meats from other foods in your grocery bags.
- Store raw meats separately in fridge (for example, on a bottom shelf).

Cook: Cook to the right temperature.

- Cooking to recommended internal temperatures kills harmful bacteria.
- Use a food thermometer to ensure proper cooking temperature.
- Bring sauces, soups, marinades, and gravy to a boil when reheating.

Chill: Refrigerate foods promptly.

- Use an appliance thermometer to be sure the temperature stays below 40ºF for refrigerator and below 0ºF for freezer.
- Divide large amounts of leftovers into shallow containers for quicker cooling. Refrigerate within 2 hours (1 hour if air temperature is > 90°F).
- Never thaw food at room temperature. Defrost in the fridge, in cold water, or in the microwave.
- Check the dates on foods and throw away if expired.
- Discard or freeze leftovers after 3 days.

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 3 kinds of rejection. Treatment varies for each. The signs and effects of rejection also vary for each type of organ.

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. Your doctor may also increase your anti-rejection medicines. Depending on the timing after transplant and the degree of rejection noted, you may have to be hospitalized for treatment.

Most people with a heart transplant have 1 or 2 acute rejection episodes. You are most at risk for this in the first few months after transplant. However, you can have acute cellular rejection at any time after transplant. The best thing that you can do to prevent rejection is to take your medicines as ordered by your doctor.

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. You may need to be admitted to hospital.

Chronic Rejection or Coronary Allograft Vasculopathy (CAV)

CAV is a form of chronic rejection that narrows the blood vessels of your transplanted heart. CAV is not caused by plaque. The vessel wall grows in thickness, leaving less room for blood to pass through.

In order to watch for chronic rejection, you will have a regular cardiac catheterization or other stress cardiac testing. If CAV is found, you may need other medicines and treatments.

What are the signs of rejection?

You may have signs of rejection. **Call your coordinator** for any of these signs. Do not ignore these symptoms. Timely diagnosis and treatment of rejection is crucial in protecting your new heart.

Signs of Heart Rejection

- Short of breath
- More tired than usual
- Sudden weight gain
- Irregular heart rhythm or palpitations
- Sudden rise or drop in blood pressure
- Lightheaded or dizzy
- Low-grade fever (99°F to 100°F) for 2 days
- Nagging cough that lasts more than 2 days
- Swelling or puffiness in the ankles or feet

The sooner we find and treat rejection, the better the outcomes. Do not wait until your next clinic visit to report concerns.

Infection Risk

Reasons for Infection Risk

After transplant, you will take medicines to prevent rejection. 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 a mask when in a hospital or clinic
- Wear gloves and mask when doing gardening, farm work, outdoor work, or any work that increases airborne dust
- 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.

Bacterial Infections

Bacterial infections can and should be treated with antibiotics after being seen by a provider.

- **Pneumonia** is a lung infection that can be caused by bacteria. Symptoms include cough with green, yellow, or brown mucous, fever, chills, shortness of breath, chest pain, and weakness.
- **Urinary tract infections** 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.
- **Wound Infections:** If you develop an infection in your **incision or drain sites,** 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 will take an antifungal medicine 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 stop 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 or confirm that a lab order was sent to your local 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 most of your lab draws.
- This level should be drawn 12 hours after you last took a dose tacrolimus or cyclosporine. The level should be drawn 24 hours after your last dose of Envarsus® or sirolimus.
- After you have your labs drawn, you should take your anti-rejection medicines right away.

Home Care

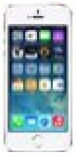
- **Every day**: Check your temperature and weight . Call your coordinator if you have:
    - Fever >100.5°F or 3 degrees above your normal.
    - Weight gain of 3 pounds in one day of 5 pounds in one week.
- **Twice a day**: Check your blood pressure and pulse. Call your coordinator if you have:
    - Blood pressure is higher than 140/100 more than two readings in a row.
    - If you have blood pressure lower than 90/50 or you have symptoms of low blood pressure such as weakness, dizziness, lightheadedness.
    - Heart rate less than 60 or more than 120 or if the rate is irregular.
- **Activity**: Don't lift more than 8 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 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, and diabetes management if needed
- The transplant team and your primary care doctor will work as a team in your care.

Who and When to Call

Who	Why	When/ Phone Number
Transplant Coordinator/ Transplant Office **Your Coordinator:** ____________________	• Medicine refills • Lab results • Questions about transplant medicines, symptoms or other questions related to your transplant *If call goes to voicemail please leave a detailed message as to why you are calling. Staff may be on the phone or away from our desk. We return calls based on priority.	Monday-Friday 8:00a.m.-4:30p.m. **608-262-8915** Your Coordinator's phone number: _________________
Organ Allocation Specialist (On-Call)	• Fever over 100.5°F or chills • Nausea, vomiting or diarrhea for more than 24 hours • Blood in urine or problems urinating • Problems with drains • Other urgent symptoms	Evenings, weekends, and holidays **608-263-6400** Ask for the heart transplant coordinator on call
Outpatient Transplant Social Worker	• Questions regarding insurance • Returning to work • Payment assistance • Options for community services if needed	Monday-Friday 8:00a.m.-4:30p.m. **608-821-1537**
Local doctor/ health care provider	• Problems not related to your transplant • Refills of non-transplant medicines	
Call 911 or go to the nearest emergency room	• Trouble breathing • Heavy bleeding or bleeding you can't stop • Chest pain • Fainting or passing out • High blood pressure with headache or vomiting • Unable to take medicines for 24 hours • Seizure or stroke • Severe pain • Anything else you think might be an emergency	If you are in a local emergency room or hospital, call your Transplant Coordinator or coordinator on call depending on time of day.