

## Waiting on the Waitlist

### What to Expect While You Wait

During the waiting period, you will visit with the transplant team every three months or more often as needed. In addition to routine doctor appointments, you will need to have routine labs and testing based on your condition and doctor recommendations. It is important to have the testing done as scheduled at a Nebraska Medicine location as the results can affect your listing status.

#### Routine lab, testing and consults

- **Labs:** CBC, CMP, Immuknow, cytotoxic antibodies, PSA, TSH/T4, A1c, pregnancy test, 24 hour urine. Some of these labs will be done at least every three months with your appointments while others are done once a year. It is important to get labs done one hour before your appointment with the doctor unless told otherwise
- **Substance screening:** You may periodically be screened to make sure that you are not abusing drugs, alcohol or nicotine. Failing one of these screens could result in being made inactive on the heart transplant list or removed all together
- **EKG:** Records the electrical signals in your heart
- **Echocardiogram:** Ultrasound of your heart
- **Right heart catheterization:** Measures the pressures in your heart and lungs
- **Cardiopulmonary stress test:** Measures how well your heart and lungs are working during exercise
- **Pulmonary function test:** Checks how well your lungs are working
- **Chest X-ray:** Produces images of the heart, lungs, airways, blood vessels and bones
- **Dental clearance:** There is a direct link between your dental care and heart health. It is important to have good dental care and hygiene. If you do not already have dental insurance you will need to work towards getting this. You will be required to get dental clearance yearly
- **Mammogram, cervical screening and/or colonoscopy:** To screen for cancer. If you have active cancer, you would not be a candidate for heart transplant
- **Eye exam annually (if diagnosed with diabetes):** To rule out any eye problems related to diabetes
- **Infectious disease appointment at Nebraska Medicine location:** To ensure you are up-to-date with your vaccinations and to review your risk of infection. Due to the medications you will take after transplant, you will be at increased risk of infection. You will be required to stay current on your vaccines both before and after transplant which includes:
  - » Flu shot every year
  - » Pneumonia vaccine – frequency varies before and after transplant
  - » Tetanus every 10 years
  - » Shingrix
  - » Hepatitis series
- **Electrophysiology appointment at Nebraska Medicine location (if you have a pacemaker and/or defibrillator):** It is important our electrophysiology team see you at least once so they are familiar with you and your device should you ever be admitted to the hospital. This does not mean you have to switch providers and use the EP team here if you are already established with your own

## Patient Expectations while on the Waitlist

While on the waitlist for transplant, your team expects you to comply with all of the below expectations. The goal of these expectations is to improve your chance of getting a heart and set you up for success after receiving a heart. Failure to follow these expectations could result in you being made inactive for transplant or removed from the list.

**Communicate:** The number one thing you can do to improve your chance of success is to communicate with your heart transplant team. It is especially important for you to communicate the following:

1. Changes to phone numbers or address: We need to know how to get ahold of you when we have a heart offer for you.
2. Changes to insurance: Before being listed for transplant, we made sure that your insurance will cover the surgery, hospital stay and medications you will need after transplant. If your insurance changes, and we are not aware, it could result in these things not being covered. If you know your insurance is going to change or has changed at any time, please call the financial counselors right away.
3. Changes in how you are feeling: It is important to let us know if you are feeling worse, are hospitalized anywhere or seen in an Emergency Department, or receive blood products.
4. Changes in care partner: Our goal is to set you up for success after transplant and having a defined care partner that is available for education, rides and help at home is very important for that. If you lose your care partner please discuss with the transplant team so that we can work with you to find someone else to be your support system.

**Primary care needs:** You are expected to have a local primary care physician while listed and after transplant. The transplant team will manage problems associated with your heart. However, if you develop problems not related to your heart, we rely on your primary care physician to manage these. If you do not have a primary care doctor, please get one right away. Once you have one, let your coordinator know the name and phone number of your doctor.

**Travel:** if you are traveling more than four hours away, let your transplant team know. If you already live four hours from the transplant center, let your team know if you are traveling an additional hour away (for example, if you live four hours away and you are traveling to a town that is five hours from the transplant center).

**Compliance:** We expect that you will come to all appointments, complete all labs and testing, and take medications as prescribed. If you are not able to make it to an appointment, you should call as soon as you know to reschedule, but at least 24 hours before the appointment time. If you are unable to tolerate or take a medication that your provider has prescribed, talk with your provider before stopping the medication or changing the dose yourself.

**Substance free:** It is expected that you will not use drugs or nicotine while listed for transplant and after you receive your heart, this includes marijuana in any form (smoking, edible, etc.). It is also important to not abuse alcohol. You may have random substance screenings, and failing one may make you not eligible to receive a heart transplant. Use of prescribed narcotics should be discussed with your advanced heart failure cardiologist.

**Be available:** A heart may become available at any time day or night. When we call you with an offer, we usually are not calling from a hospital phone line so it's important that you answer your phone whenever possible and do not screen your calls. If we can't reach you, we can't transplant you. Always have your cell phone charged and with you. When the transplant team receives notification of a donor organ, we have a short time to offer you the heart and get your acceptance. We will do our best to get ahold of you, but if we are unable to reach you after multiple tries, we may have to move on to the next patient on the list. This does not affect your status on the list for any future donors.

**Stay healthy:** To get better after transplant, it is important to stay in the best health you can while on the waitlist. Below are ways you can do this.

1. Decrease your risk for infections. Stay away from sick people, do not get tattoos and wash your hands. Get all immunizations as directed by your heart transplant team.
2. Stay mentally well. Your mood during this time is important. Maintain a routine and surround yourself with a good support system. Your transplant team is here to listen and talk at any time.
3. Maintain physical strength. Exercise is a very important part of your health, both before and after transplant. Stay as active as you can while you wait for your heart. Follow a heart healthy, low salt diet. It is important that you have adequate nutrition while you wait to maintain your strength. If you are having troubles with nutrition, reach out to your transplant team who can schedule an appointment with the dietician.

**OneChart sign up:** All patients are required to sign up for OneChart Patient access if able. This site allows you to communicate with your provider from the comfort of your own home, request prescription refills, access test results and manage your appointments. If you have not already signed up, please ask your team at your next appointment for help or visit: [www.onechartpatient.com/mychart/](http://www.onechartpatient.com/mychart/).

## What is one thing you can change right now that will help you after transplantation?

**Hand washing!** Hand washing is a very effective way to decrease the chance of getting an infection. You and your family should wash your hands well and often. Hand washing is especially important after coming into the house from outside, after using the bathroom, before preparing food or eating, and after being around crowds of people.



You probably think that you know how to wash your hands, after all you have been doing it all your life. Studies done in hospitals have shown that people frequently do not do a good job of washing their hands. Now is a good time to break old hand washing habits.

1. Turn on the tap and wet your hands. Once wet, remove them from the flow of water.
2. Put soap into wet hands. Rub hands together washing between and around fingers while you sing the "ABC" song or your favorite song to yourself. (You will be surprised at how long this takes) Your hands should not be under the flowing water during this time.
3. Once you have finished the song, rinse your hands well, and then dry them on a clean cloth or paper towel. Turn off the tap using the towel.
4. If possible, use the towel to open the bathroom door to leave and then throw the towel away.

## Caregiver Expectations

Social support is a big part of long term transplant success. All patients must have a care partner (or team of people) for assistance both before and after transplant. A care partner should be over the age of 21 years old, have average reading skills, good judgement, and be reliable. Patients will need a care partner available for at least the first 12 weeks but up to a year after discharge from the hospital.

Care partner(s) responsibilities include:

1. Read the transplant binders after patient is listed for and receives a transplant.
2. Be routinely available in the hospital after transplant from 8 a.m. to 4 p.m. If the care partner has questions for the physician, they should be available when the doctor is rounding to ask these questions. **They will also need to be present for all education which is done during these hours.**
3. Provide rides for the patient to medical appointments, rehab and to get lab work done.
4. Help the patient with their activities of daily living. The care partner must be able to lift at least 10 pounds and perform household duties as required. The patient will not be able to lift 10 pounds for eight weeks after surgery.
5. Assist in making medication changes, know when to refill prescriptions, and know how to fill patient's pill box.

If your identified care partner changes during your transplant listing time, please notify your transplant coordinator.

## The Call

Receiving the call that there is a heart for you can be an exciting and nerve racking time. This section will cover some ideas of how you can prepare for that time so it is less stressful.

### Preparing for the Call

1. Choose a support person who can drive you to the hospital. You must get to the transplant center without delay.
2. Check on lodging for family members before the transplant. There are many options close to the hospital and your social worker or transplant scheduler can help provide you a list of places that have discounted rates.
3. Make a list of people whom you want contacted when the call comes that a heart is available. Give this list to a family member to make those calls once you are at the transplant center.
4. Pack a "go bag" for you and your support person. You will not need much the first few days but your support person will. Your support person can bring in more things after you are moved out of the intensive care unit.