

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.

Receiving the Call

1. Don't panic.
2. Call your care partner to drive you to the hospital. You **MUST** have someone drive you to the hospital.
3. Be ready to leave and travel to the hospital after taking the call. Do not race to the hospital. Obey speed limits and get here as soon as you are able.
4. Don't eat or drink anything (unless otherwise directed by your coordinator).
5. Don't take any blood thinners.
6. Grab your "go bag."
7. Bring all of your VAD equipment with you if applicable.
8. Bring your medication list.
9. Go to the Clarkson Tower main entrance located off 42nd and Dewey streets, and check in at the Access desk on the main level.

Heart Transplant Surgery

Waiting for Surgery

After you get to the hospital and check in, you will be taken to your hospital room where you will wait until surgery. A team of people will be getting you prepared and ready for surgery. If you are on Warfarin (blood thinner), nurses will give you medications to reverse the effects of those medications so you do not bleed too much during surgery. Your family may wait with you before you are taken to the operating room.

Remember this is a long process and you may have to wait based on many factors:

- Travel distance for the organ
- Time spent recovering the organ
- Testing to make sure the organ is suitable

Ideas for your "Go Bag"

- List of your medications
- Eyeglasses, hearing aids, dentures
- Pillow
- Phone charger
- Toiletries:
 - » Toothpaste
 - » Toothbrush
 - » Floss
 - » Lip balm
- Gum and/or mints
- Entertainment ideas:
 - » Books or magazines
 - » iPad or tablet (Disclaimer: The hospital is not responsible for your valuables. Please be mindful of all personal items in your room and have a family member watch over them while you are in the intensive care unit and/or away from the floor at procedures.)
 - » Notepad and pen (can be helpful to write down any questions)
- Comfy pants to wear under your hospital gown
- Comfortable shoes or slippers for walking the halls after your procedure
- Women – supportive bra. A bra with a front clasp is most convenient
- If you have an LVAD, bring all of your equipment
- Your CPAP machine, mask and tubing, if you have one
- A copy of your advanced directive or living will if not already on file