



Heart Transplant

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Heart Disease and Transplant: General Information

A heart transplant is:

- surgery to remove a diseased heart and replace it with a healthy heart from a donor.
- for patients with heart failure that is not improving with medicine and other surgeries.
- a treatment for heart failure. It is not a cure.

In adults, heart failure is caused by:

- weakening heart muscle (cardiomyopathy)
- coronary artery disease
- heart valve disease
- congenital heart defect (something you were born with)
- recurring abnormal heart rhythms (ventricular arrhythmias) that are dangerous but don’t improve with other treatments
- failure of a previous heart transplant

Ask your transplant team about the benefits and risks of a heart transplant. Heart transplant has medical risks, like:

- higher risk of infection,
- organ rejection (when the body’s immune system attacks the new organ),
- medication side effects (hand tremors, diabetes, appetite changes, or mood swings),
- coronary artery disease,
- stroke, and
- death.

Heart transplant also has emotional and social risks, like:

- depression,
- anxiety,
- post-traumatic stress disorder,
- guilt,
- dependence on caregivers, and
- financial stress.

Heart Transplant Waitlist

If eligible for transplant, the patient is listed on the transplant waiting list, according to their medical need status.

- There are 6 medical need statuses.
- Status 1 is the most urgent and Status 6 is the least urgent.
- The transplant team reviews the patient's status while they wait for transplant.

Ask your transplant team about **increased-risk donors**.

- Patients who accept organs from increased-risk donors usually wait less time for an organ.
- An increased-risk donor is a deceased donor with higher risk of spreading one of the following undiagnosed diseases to a transplant patient (Abara et al., 2019):
 - human immunodeficiency virus (HIV),
 - hepatitis B, or
 - hepatitis C (HCV).
- Organs from increased-risk donors are not lower quality.

Before Heart Transplant: Caregiver Responsibilities

There are a lot of steps before a heart transplant. This is usually an overwhelming time for patients and caregivers.

To receive a heart transplant, the patient must complete an evaluation with the transplant team. This team can include:

- transplant cardiologist (heart doctor),
- transplant surgeon,
- nurse coordinator,
- social worker,
- psychologist,
- psychiatrist,
- pharmacist,
- dietician, and
- financial counselor.

Evaluation includes many appointments and tests to evaluate the patient's heart and general health. The treatment team reviews test results to decide if the patient is eligible for transplant. If the patient is eligible, they are placed on the transplant waitlist.

When they are on the transplant waitlist, the patient might:

- have frequent clinic visits to monitor weight and blood pressure.
- need frequent Echocardiogram (ECHO) tests. ECHO tests use sound waves (ultrasound) to create a picture of the heart that can show heart disease.

- need a Right Heart Catheterization (RHC). RHC is when a medical provider puts a catheter (small tube) in the patient's neck or groin to check pressure and blood flow in the right side of their heart.
- use a LifeVest (portable external defibrillator) to monitor heart rhythm and deliver a shock to the heart if it detects a dangerous rhythm. If worn correctly, it can save the patient's life.
- receive medication called inotropes through their veins (intravenously or IV).
- be evaluated for a Left Ventricular Assist Device (LVAD), a mechanical pump that pumps blood from the left ventricle of the heart through the rest of the body. A medical provider puts the pump into the patient's chest, and the pump is connected to a controller and battery pack outside of their body through a small cut in their stomach. LVAD is called a Bridge to Transplant because it helps patients stay alive until transplant.
- have fluid and sodium restrictions.
- be on extracorporeal membrane oxygenation (ECMO). ECMO is when a medical provider puts catheters in the patient's neck, groin, or chest to pump oxygen into their blood. Usually, patients are sedated and on a ventilator. Sometimes, they stay on a ventilator but not sedation, so they can continue physical therapy. If the patient is on ECMO, they will stay in the hospital while they wait for transplant.

Supporting the Patient

As a caregiver, you can help the patient navigate this overwhelming process. You can:

- learn about the patient's diagnosis (there are many reasons they may need a transplant).
- go to the evaluation and follow-up appointments with the patient.
- take notes and ask questions during the evaluation and follow-up appointments.
- pack lunches and snacks to get through the full day of evaluation appointments.
- help the patient follow recommendations from the transplant team.
- work with the transplant team's financial counselor and social worker to make sure the patient has insurance for treatment and access to medication.
- help the patient follow good health habits.
- listen to the patient.
- offer comfort and encouragement to the patient.
- make plans if you and the patient must move closer to the transplant center while on the waiting list. (Ask your center about their requirements.)
- make sure the patient takes their medication correctly, including IV inotropes.
- help the patient with medical devices, like LifeVest and LVAD.
- monitor the patient's fluid and sodium intake.
- visit the patient in the hospital. If they are very sick or on ECMO, they might stay in the hospital to wait for transplant.

The waiting period before transplant can be stressful. Ask the transplant social worker for support.

While waiting for transplant, many patients experience:

- worsening health,
- anxiety,
- depression,
- panic, and
- lower quality of life.

As a caregiver, [you must take care of yourself during this time¹](#). You might feel:

- fatigue,
- anxiety, and
- depression.

¹ <https://power2save.org/caregiver-toolkit-chapter-3/>

During Heart Transplant: Caregiver Responsibilities

When the transplant team accepts a heart for the patient, they will:

- tell the patient (if they are already at the hospital).
- call the patient and tell them to come to the hospital (if they are at home). This can happen any time during the day or night. The team will call you if they need help contacting the patient.
- **not** give information about the donor to the patient, caregivers, or family (due to federal law).

When the patient is admitted to the hospital they will:

- have blood tests. Most heart surgeries require blood transfusions.
- not be able to eat or drink before surgery (NPO, or nothing by mouth).
- meet with the intake nurse.
- sign consents before starting surgical preparation.
- have an X-Ray.
- go to different places in the hospital for testing and surgery preparation. Staff will update you as they can.
- receive anesthesia 1-1.5 hours before surgery. They will not be awake during the surgery or feel any pain.
- receive a breathing tube. Intubation is a normal part of surgery.

Important! Sometimes, transplant surgery is canceled because the organ might not be a good match for the patient. This is disappointing, but it means the patient is at the top of the waitlist. They might get another call soon.

Heart transplant surgery can take many hours.

- The surgeon might tell you how long surgery could take. This is an estimate and can change.
- Surgery can take longer for patients who have had an LVAD or other chest surgeries.
- The surgeon will remove devices (pacemaker, LVAD) before transplant surgery.
- The medical team will update you as often as they can.
- After surgery, the patient will go to a recovery room then the Intensive Care Unit (ICU).
- As the patient recovers, they will move from the ICU to a different hospital unit. Patients spend different amounts of time in ICU.

When you see the patient, they will have:

- tubes in their chest to remove extra fluid from their body. Tubes are removed before discharge.
- stitches (sutures) in their chest, around the chest tube. Sutures are removed at the 1st follow-up visit.
- machines monitoring them, so the transplant team can see how well they are recovering.
- a breathing tube. Breathing tubes are usually removed 6-24 hours after surgery).

During the Transplant Hospitalization

The patient will probably stay in the hospital for 2 or more weeks after surgery. The patient will be monitored closely by:

- the cardiac transplant team,

- the critical care team, and
- other specialty teams, for “consults” to make sure other organs are adjusting well.
 - nephrology (kidney)
 - pulmonology (lungs/breathing)
 - hepatology (liver)
 - psychology or psychiatry (mental health)

Many different providers will go in the patient’s room throughout the day. You should spend most of the day at the hospital, so you can:

- meet the providers,
- learn about the different teams,
- know the patient’s daily schedule,
- hear all the updates, and
- ask questions.
- attend educational sessions to learn about post-transplant care:
 - signs of rejection,
 - potential activity limitations,
 - environment exposure risks to be aware of,
 - nutritional needs,
 - hygiene,
 - signs of infections,
 - and lifestyle changes.
- You will learn how to care for the patient at home (wound care, wound vac, medication management, etc.).

Nurses are a great resource. They know a lot about the patient’s condition and treatment, so ask them questions and learn from them. Their first priority is caring for the patient, so remember to ask if it’s a good time to talk. Make a list of your questions, so you are ready.

While recovering in the hospital, the patient:

- will start immunosuppressant medications to help their body accept the new heart. They will take these medications at the same time every day.
- will have heart biopsies to check for signs of rejection (when the body attacks a new organ).
- might hear a heartbeat in their ears for the first time. They might need to adjust to the sound.
- might be confused, delirious, forgetful, or even hallucinate. New medications, stress, and recent anesthesia cause these symptoms. Tell the transplant team if you see a big change in the patient.
- might move to an acute rehabilitation unit (acute rehab) to build strength through physical therapy, before going home. Acute rehab might be in the same hospital or a different facility.

Preparing for Discharge from the Hospital

Some patients discharge, or leave, the hospital and go to a rehab hospital for intensive physical therapy before they can go home.

The inpatient case managers will help you arrange supplies and services the patient needs when they leave the hospital, like:

- a walker,
- tube feeding supplies (if they need liquid nutrients through their veins, because they cannot take food or liquids by mouth),

- Wound Vac (helps a wound heal by decreasing the air pressure around it, also called negative pressure wound therapy),
- home health services,
- scale to weigh the patient,
- thermometer,
- blood pressure cuff,
- pill box, and
- pill cutter.

When you are not at the hospital with the patient, use the time to:

- disinfect and clean the home.
- go grocery shopping so there is enough food and drink when the patient arrives,
- learn about transplant food safety with the transplant team and the nutrition providers, and
- ask the pharmacist about food-drug interactions.

Caregiving for a heart transplant patient is a big job. You must also take care of yourself.

- Go home and rest. Do not sleep at the hospital.
- Trust the hospital staff to care for your patient and call you with any needs.
- Talk to the transplant social worker if you are feeling overwhelmed.
- Talk about how you are feeling.
- Ask for help. [Don't try to do everything alone²](#).

After Heart Transplant: Caregiver Responsibilities

Taking care of a new heart is a big job.

After discharge from the hospital, the patient will need a lot of help. Ask your transplant center how close you and the patient must stay to the center. If the patient lives far from the center, you might have to make plans to stay close.

You will take care of the patient at home until they improve enough to take care of themselves. You will:

- learn about the new medication the patient must take (use, dosage, and side effects),
 - help the patient take their medications **exactly** as prescribed,
 - use a pill box to help the patient organize their medication,
 - look for side effects (hand tremors, shakiness, etc.),
- track blood pressure, temperature, and weight,
- take the patient to right heart catheterization (RHC), follow-up, and lab appointments (several a week to start),
 - During RHC, providers will take and test tissue from the heart (biopsy).
 - If they see signs of rejection, they will increase medication or readmit the patient to the hospital.
- prepare meals,
- change wound dressings,
- complete (or ask for help with) household chores,
- help the patient with daily living and hygiene activities, and
- help the patient report concerns or symptoms,
- monitor the patient's mental health.

² <https://power2save.org/caregiver-toolkit-chapter-3/>

- Heart transplant patients have more risk for depression, anxiety, PTSD, guilt, and caregiver dependence.
- They hear and feel a strong heartbeat which can be a reminder of the donor's sacrifice.
- support the patient during cardiac rehabilitation (cardiac rehab), a medical program that helps patients improve heart (cardiovascular) health after, and sometimes before, heart surgery, heart transplant, or LVAD implant. Patients will go several times a week, starting 6 weeks after transplant. Cardiac rehab has 3 equally important parts:
 1. Exercise counseling and training.
 2. Education for heart-healthy living.
 3. Counseling to reduce everyday stress, because stress is unhealthy for the heart.

Recovery can take time. Talk often with the transplant team to monitor the patient's recovery. Make a list of all appointments, procedures, and medication changes to help you, the patient, and the transplant team.

Post-Transplant Medications

After surgery, the transplant team will prescribe many medications. Some will have very specific instructions. For example:

- Some immunosuppressant medication must be taken 12 hours apart.
- Other medication cannot be taken before laboratory blood draws.

If the patient does not take their medication correctly, their body can reject the new organ. This means that their immune system will attack the new organ because their body doesn't recognize it. Rejection is most common for transplant patients who miss medications.

As a caregiver, you must:

- help the patient take medication **exactly** when and how it is prescribed.
- order refills.
- make sure the patient takes the correct dose (doses change often).
- help the patient organize their medications.

Ask the transplant pharmacist or nurse to help you organize medications before the patient is discharged from the hospital. They might recommend you use a pill box.

Lab and Clinic Appointments

You will help the patient go to all lab and clinic appointments to monitor:

- the patient's general health.
- how the new organ is working.
- early signs of rejection.
- signs of infection.
- how the patient's body is handling anti-rejection medication.
- talk about any changes the patient should make.
- pain. Tell the transplant team immediately if the patient has pain. Pain over the incision area can be a sign of rejection.

Other caregiver responsibilities

For the first 4-6 weeks (at least), you will need to:

- drive the patient to their clinic appointments,
- prepare meals,
- lift anything 10 pounds or more,
- and help the patient with other lifestyle changes needed to take care of their new organ.

Call the transplant center immediately if the patient has a fever or acts out of character.

Being a heart transplant caregiver is rewarding and challenging. [You must take care of yourself³](#).

- Remember to ask for help, to avoid caregiver burnout.
- Attend support groups for caregivers.
- Remember to take care of your own health.
- Go to your scheduled medical appointments.
- Don't stop taking your prescription medicine.

Questions to Ask Your Heart Transplant Center

When choosing a transplant center (especially if you and the patient can move), look for a center that has shorter wait times and higher success rates.

Consider asking centers the following questions:

- What are the risks and benefits of receiving a heart transplant?
- How far away from the transplant center can the patient live when they are on the waiting list?
- Does the patient need a caregiver while they wait for transplant?
- How far away from the transplant center can the patient and caregiver live after transplant?
- How long will the patient need a caregiver?
- Can the caregiver work while caring for the patient?
- How does the center decide listing status?
- What is the patient's listing status?
- What are the risks and benefits of accepting an organ from an increased risk donor?
- Can the patient be listed at more than one transplant center?
- Do you have a partner facility the patient can be listed with as well?
- Will the patient need an LVAD while waiting for transplant?
- How can I protect my job while being a caregiver? (Insert link to General Content sections on employment)

Heart Transplant Caregiver Resources

- American Heart Association: <https://www.heart.org/>
- International Society of Heart and Lung Transplantation (ISHLT): <https://www.isHLT.org/about/patient-resources>
- Dilated Cardiomyopathy Foundation: <https://dcmfoundation.org/>

³ <https://power2save.org/caregiver-toolkit-chapter-3/>

LVAD (Left Ventricular Assistive Device)

General Information about LVAD Implant

A left ventricular assist device (LVAD) is:

- for patients who have a weak heart or have end stage heart failure.
- also called a battery-operated pump.
- a mechanical pump that pumps blood from the left ventricle of the heart through the body.
- put into the patient's chest and connected by a tube (driveline) to a controller and battery pack through an opening in the patient's stomach.
- called a Bridge to Transplant, because it keeps very sick patients alive while they wait for a heart transplant.
- called Destination Therapy when used for patients who are not eligible for transplant (because of age, weight, lifestyle, and medical risk).

Before, During, and After LVAD Implant: Caregiver Responsibilities

Before LVAD Implant

LVAD is a planned surgery, so you will have time to plan to prepare. Learn as much as you can about LVAD by:

- meeting with other patients and caregivers at support groups.
- signing up for educational opportunities.
- reading about LVAD.
- talking with members of the LVAD team.

Make sure you learn:

- what to expect during the surgery and recovery process.
- how you will support the patient.
- what type of device the patient will receive (model, equipment).
- the survival rates and what the patient's life might be like after surgery.
- the medical and psychological risks:
 - blood clots,
 - bleeding,
 - infection,
 - right heart failure (an LVAD is on the left side of the heart),
 - anxiety,
 - depression,
 - loss of sleep,
 - dependence on caregivers,
 - body image issues, and
 - not being able to continue activities the patient enjoys.
- how to prepare the patient's home:
 - make sure there are 3-prong outlets by the patient's bed.
 - remove throw rugs.

LVAD Surgery

The day before surgery the patient will prepare in the hospital or clinic.

- This could include a right heart catheterization (RHC).
- RHC is when a catheter in the patient's neck or groin checks pressure and blood flow in the right side of the heart.

The surgeon might tell you how long the LVAD surgery could take.

- This is an estimate and can change.
- Surgery can take longer for patients who have had other chest surgeries.

After surgery, the patient:

- will be closely monitored in the Intensive Care Unit (ICU).
- might stay on oxygen, but the breathing tube will be removed 6-24 hours after surgery.
- will have tubes in their chest to remove extra fluid. (Tubes are removed before discharge.)
- will move from the ICU to a different hospital unit as they recover.
- might be discharged to an acute rehab unit, to build strength before going home.

You should spend most of the day at the hospital. You will:

- learn from staff during the patient's hospitalization.
- complete required educational hours, so the patient can be discharged.
- watch videos and do hands-on training to learn how to:
 - change bandages.
 - care for the LVAD device (change batteries, etc).
 - understand different alarm sounds.

After LVAD Surgery

You must care for the patient 24/7 after LVAD surgery. Usually, patients need constant care for 6-12 weeks. Some patients need constant care for as long as they have the LVAD.

You will:

- change dressing (bandages).
- help manage medications, including blood thinner injections.
- track the patient's weight, temperature, and PT (prothrombin time)/INR (international normalized ratio).
 - A PT (or pro time test) tests a sample of blood to see how quickly the blood clots.
 - It monitors how well blood-thinning medicine like warfarin (Coumadin) is working.
 - You might have a home PT/INR machine.
- help the patient follow LVAD nutrition instructions, like:
 - limiting salt,
 - drinking enough fluid, and
 - monitoring Vitamin K (important with medication to prevent blood clots).
- record all LVAD alarms.
- meet frequently with the LVAD team to check the alarm history and change settings.
- check LVAD batteries to make sure they are charged overnight and before leaving the home.
- help with household chores.
 - The patient will have lifting restrictions after surgery.
 - Restrictions change as they get stronger, but they can never lift more than 50 pounds.
- remind the patient to do safety checks of LVAD equipment and follow equipment directions.

- help the patient shower, making sure the driveline area (where the tube enters the skin) does not get wet.
- [create an emergency plan](#)⁴ in case you lose power.
 - Ask your transplant center if they tell the electric company the patient has an LVAD.
 - Most companies prioritize LVAD patients when they restore power.
 - LVAD patients **always** need access to electricity.

Additional Considerations for LVAD Caregivers

LVAD patients can travel.

- Make travel plans with an LVAD center close to where you are traveling.
- Ask your center to help connect you with the center.
- Ask how you can keep the patient safe when you travel.

In a health emergency, Emergency Medical Services (EMS) must know the patient has an LVAD. Ask your LVAD center if they tell local EMS about the patient's LVAD or if you should.

Understand the benefits and risks of LVAD.

- During recovery from LVAD surgery, the patient might be removed from the active transplant waitlist.
- The patient's quality of life will be different. They might:
 - have more energy and stamina.
 - worry less about major heart failure.
 - feel less stress.
- The patient will be connected to a controller and battery pack 24 hours a day.
 - Help them choose accessory options to carry the controller and batteries.
 - Save receipt and submit them when the patient does yearly taxes.
- With the LVAD device, the patient:
 - will have limited movement.
 - might have to change sleeping positions.
 - cannot put their body fully into water (pool, hot tub, bath, lake, etc.).
 - cannot jump or do contact sports.

LVAD Caregiver Resources

- My LVAD: <https://www.mylvad.com/>
- I Decide LVAD: <https://patientdecisionaid.org/lvad/>
- LVAD Gear: <https://lvadgear.com/>
- HeartMate LVAD: <https://www.heartmate.com/patient>
- MedTronic (HeartWAre LVAD): <https://www.medtronic.com/us-en/patients.html>

⁴ <https://power2save.org/caregiver-toolkit-chapter-4/>

A Heart Transplant/LVAD Caregiver's Perspective: Don R.

Every Heart Transplant Caregiver should know: “Every patient is different and every situation is unique. Be prepared for anything to happen, and be aware that there isn't a typical timeline for a return to good health or if that will even happen. Allow your family, friends and medical staff into your inner circle so you never feel that you are alone in being the caregiver. Pray for the best, prepare for the worst, and believe that every day is a new day. “

As a caregiver I wish I would have known: “The weight of being the caregiver to a sick patient can be overwhelming. The medical and personal care of your patient might be only half of your responsibilities as caregiver. Maintaining a strong spirit of positivity is critical and can be contagious to the patient and family. It's okay to have weak moments and loss of emotions at times, but being a caregiver with strong determination and devotion will always shine hope on what might otherwise be situations with unknown outcomes.”

The most difficult aspect of being a caregiver: “For me, it was giving up "control" and leaving the patient's room even if it was for short durations. I always wanted to be available when a medical provider was in the room and at times there was a lineup of doctors and nurses waiting to do their jobs. I thought that I would miss something even though the nursing staff was always proactive in giving me updates on something I missed. A feeling of complacency also was in my mind as the patient started to recover but still had episodes of setback. Because she had had two significant setbacks, the feeling that another might occur always was there and maybe caused my anxiety of leaving the floor at times.”

The most rewarding aspect of being a caregiver was: “Looking back at the diaries and social media posts I made to update friends and family across the US on the patient's progress and then realizing the unbelievable journey she took and survived. Living it day to day was certainly memorable, but to see it again from a perspective that most people saw as big changes and improvements made me realize the inspiration she gave to many in her toughness and survival.”

I was most surprised as a caregiver by: “Even though the science of medical procedures is unbelievably technical and a patient must put themselves in the best place to receive the best care, the human body and the person's will to fight to live are equally as important. With all of the best laid plans and courses of care set for the patient, the strength, determination, faith, and recognizing that there's an army of people praying and cheering for a patient to survive and get on with life helps to make miracles happen. To work for the best outcome, the caregiver should be prepared to place your life on hold and focus on the patient's health, survival and recovery. With the difficulties they face every minute of every day, being there and committed 100% to their well-being will help the patient prosper.”

How I would recommend other caregivers prepare for this experience: “Place your trust, confidence and love in the medical care team. Be INVOLVED in the care plan and daily activities surrounding your patient. Strive to learn as much as possible and ask questions of everybody to ensure full understanding or remove doubt in your mind. Don't be afraid to leave your comfort zone, and just make up your mind that you'll do every task expected of you even though you don't believe you can do it (change medical dressings, clean wounds, observe a patient with tubes and machines attached to every inch of a body).”

How I would recommend other caregivers to take care of themselves during this process: “Keep a daily diary or use social media posts to your private group to share daily activities, emotions and events. It's a great stress reliever, promoter of understanding to a civilian in a medical world, and is an invaluable record of the incredible journey that you and your patient have undergone. The bonus is that your patient will really appreciate seeing exactly what they experienced and catch them up on the days, months, or years that they missed.”

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