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Marie

Heart Transplant 2016

The heart transplant process

Corewell Health™

Victoria
Heart Transplant 2019

Notes

Notes

The heart transplant process

Your physicians believe that heart transplant may be a good treatment option. In order to help make this decision, you will need to have an evaluation for transplant. The evaluation includes laboratory tests, imaging tests and meeting with other members of our health care team. Depending on your medical history, or if a condition is found during evaluation, we may refer you to different specialists.

All of this information is collected and brought to a selection committee meeting where the team will discuss if a heart transplant would be a benefit to you.

We would like to provide you some basic information to get started. Your transplant coordinator will help guide you and your family through the evaluation process.

Team members

- **You**—you are a key member of your transplant team. You will be taking care of your new heart. You will need to know your medications, go to your appointments, live a healthy life and know when to call your transplant coordinator.
- **Transplant coordinator**—provides education about evaluation and transplant and coordinates appointments and tests.
- **Transplant cardiologist**—the doctor who manages your heart disease, and who manages the transplanted heart after surgery.
- **Transplant surgeon**—the doctor who will perform your heart transplant surgery.
- **Transplant social worker**—works with you and your family regarding any psychosocial, housing, or support system concerns in order to assess readiness for transplant. The transplant social worker will help to develop plans to address any needs or concerns prior to transplant.
- **Financial coordinator**—discusses the costs of transplant and helps you understand insurance coverage.
- **Pharmacist**—educates you and your family on medications, side effects, complications and medication safety.
- **Dietitian**—educates you and your family on nutrition needs before and after transplant.
- **Psychiatrist**—evaluates your psychological needs before transplant, if needed.

Garrett
Heart Transplant 2020

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Evaluation

- **Blood and laboratory tests**—during evaluation you will need to have blood and urine tests to check routine lab tests, learn your blood type, and check to see if you have, or are immune, to certain diseases or viruses.
- **Imaging and tests**—you will need a recent chest X-ray, computerized tomography scans, and heart and lung tests such as an echocardiogram, pulmonary function test and heart catheterization. The physician may order other imaging based on your history.
- You may be asked to have other health screening tests such as:
  - A dental exam
  - A prostate exam for men
  - Pelvic exam and Pap smear for women
  - A mammogram for women over age 40
  - DEXA scan to measure the density of your bone

When your evaluation is complete, the team will meet and discuss if it is safe and fitting to place you on the waitlist for a new heart. This is called our "selection meeting." Your transplant coordinator will contact you directly with the results of this meeting and will also send you a letter when a decision is made.

Reasons you might need a transplant (Inclusion criteria)

If you have one or more of the conditions listed below, a heart transplant may be needed:

- Advanced heart failure.
- Irregular heart rhythms not fixed by other treatments.
- A temporary or permanent ventricular assist device (VAD).

Reasons you may not qualify for a transplant (Exclusion criteria)

- Cancer
- Advanced age
- Advanced disease of other organs (like the kidneys, lungs or liver).
- Disease or severe illness that would affect your ability to recover after surgery (e.g., stroke).
- Vascular disease
- History of infections resistant to treatment.
- Obesity or severe malnutrition.
- No medical insurance or inability to pay for treatment or medications.
- Lack of caregiver plan, unstable housing or inability to travel to frequent appointments.
- Not taking medicines as prescribed, not following restrictions or recommended follow-up care.
- Psychological or cognitive diseases that could affect your ability to follow the post transplant treatment plan.
- Nicotine or marijuana use, alcohol or substance abuse.

Waitlist

- If you are chosen for transplant, you will be placed on a waiting list (or “waitlisted”).
- The waitlist is managed by the United Network of Organ Sharing (UNOS). UNOS is a private, not-for-profit organization that coordinates the nation’s transplant system through a government contract. UNOS is also responsible for collecting, managing and reporting data to help the transplant community learn. If at any time you have questions or concerns regarding the transplant evaluation process, our center or UNOS itself, we encourage you to contact their organization.
- Your place on the waitlist is determined by:
    - How sick you are
    - Blood type
    - Body size
    - Antibody levels
    - Waiting list status
- While you are on the waitlist, there are certain standards that must be met. These include:
    - Attending all scheduled appointments
    - Adhering to the medical plan
    - Taking all prescribed medications
    - Contacting our office to update any changes in your condition
    - Providing your current contact numbers
- Notify us if:
    - Your insurance has changed or is no longer active
    - You are planning to travel
    - Your contact information changes; we need to be able to reach you if a heart becomes available

Major
Heart Transplant 2021

Your rights and alternatives

- You have the right to refuse transplant. If you do not want a transplant, talk with your doctor about other options.
- The alternative treatment to transplant is surgical or medical management. Discuss other options with your doctor if you feel a transplant is not right for you.
- If you are on the waiting list for a heart transplant, you have the right to transfer from one transplant hospital to another. You can be listed at multiple transplant hospitals.
- You have the right to file a grievance with UNOS. Call **888.894.6361**.

Transplant outcomes

- We will give you statistics about transplant outcomes from the Scientific Registry of Transplant Recipients (SRTR).
- This information is updated every 6 months, both at our hospital and nationwide.
- We are required to notify you if we do not meet required outcomes.
- More information can be found at **srtr.org**.
- Contact your transplant coordinator for assistance or with any questions.

Transplant at a center not approved by medicare

If the transplant occurs at a facility not approved for transplantation by Medicare, the immunosuppressive drugs prescribed may not be covered under Medicare Part B. Our center is Medicare approved for transplant.

Program coverage plan

A transplant doctor and surgeon are available 24 hours a day, seven days a week. They are available to address concerns and to facilitate the transplant process.

Privacy information

We follow the patient privacy guidelines required by HIPAA (the Health Insurance Portability and Accountability Act). To keep you safe during the organ transplant process, we must make sure that your blood type matches your donor’s blood type. To do this, we need to include your medical record number/UNOS ID number on an ABO and Vital Information Form. This form may be kept in the donor’s medical record. The donor’s medical record number/UNOS ID number may be kept on the same form in your medical record.

Benefits of a transplant

Heart transplant is a treatment option for serious heart disease. We cannot predict how your body will respond to a heart transplant. The potential benefits do not come from surgery alone, but also depend on you following the treatment plan prescribed by your transplant team.

A successful heart transplant may give you increased strength, stamina and energy. You should be able to return to a more normal lifestyle and have more control over your daily living.

Risks after transplant

- Rejection occurs when your immune system discovers your new organ and tries to attack it. Immune-suppressing drugs are used to prevent rejection by lowering your body's ability to fight your new organ as well as fight bacteria and viruses. The only way to diagnose rejection is with a biopsy. You could be hospitalized to treat a rejection.
- Infection after transplant can occur at any time because your body is not as able to fight bacteria and viruses as well as it did before your transplant. Infections last longer than before you received your transplant and are much more severe. You are more at risk for getting the flu than most people, and the flu will be worse for you after transplant. You are encouraged to get a flu shot after transplant, but you need to talk about the timing of a flu shot with your doctor.
    – Opportunistic infections come from viruses your body normally carries. Your immune system is able to keep these viruses in check. With the use of immune-suppressing drugs, your body is no longer able to keep these viruses in check.

Side effects from lifetime use of immune-suppressing drugs may include, but are not limited to:

- High blood pressure
- High cholesterol
- High blood sugar
- Poor wound healing
- Thinning of the skin
- Water weight gain
- Changes in texture or amount of hair
- Cancer including lymphoma and skin cancer
- Tremors
- Acne
- Seizures
- Ulcers
- Glaucoma
- Cataracts
- Damage to your transplanted heart or to other organs
- Loss of the strength of your bones

There are seven possible waitlist status types:

Status	In other words
1	**You are critically ill and need support from:** • A heart and lung bypass machine called extracorporeal membrane oxygenation • Temporary devices to support both sides of the heart that prevent you from leaving the hospital Or you have: • A heart pump called a VAD and you have a life-threatening heart rhythm (arrhythmia)
2	**You are critically ill and need support from:** • A temporary device to support one side of your heart that prevents you from leaving the hospital • An intra-arterial balloon pump that helps to support the work of your heart • An invasive (implanted) line that contains a pump to help support the work of your heart Or you have: • A VAD that is not working well • A severe, life-threatening heart rhythm • Any type of heart support and you only have one ventricle
3	**You are critically ill and need multiple intravenous medications and invasive monitoring** Or you have a VAD and are using your "30 days" Or you have a VAD complication like an infection, a clot in the pump, right heart failure, or severe, repeated bleeding
4	**You have one of the following things:** • A VAD • A need for IV medications, but you do not need to stay in the hospital • A need for another heart transplant • A diagnosis of: – Congenital heart disease – Ischemic heart disease with chest pain – Hypertrophic or restrictive cardiomyopathy, or amyloidosis
5	**You need a heart transplant with another organ transplant**
6	**You don't meet any of the above criteria**
7	**You are inactive on the waiting list**

Caregiver support

A caregiver is someone who helps you with your medicines, driving to clinic appointments and supports you as you recover from surgery. A caregiver is usually a family member and can be a close friend. It is expected that you will have a caregiver with you 24 hours a day, seven days a week, for at least the first four weeks at home.

If you live more than two hours away, it is expected that you stay in the local area for up to three months.

More information will be provided on how to take care of yourself after you have received your transplant.

Removal from waitlist

At any time, your team may determine that transplant is no longer an option for you. In this case, you will be removed from the waitlist.

Examples of reasons for removal include:

- Your health improves and you no longer need a transplant.
- The transplant selection team determines you no longer meet criteria for a transplant.
- Your health declines and you are no longer a transplant candidate.

Psychosocial:

- **Depression, anxiety or guilt.** It is common to feel sad or depressed after a surgery, procedure or recent hospitalization. These emotions may be from:
  - Not knowing what to expect
  - Not being able to do tasks without becoming overly tired
  - Feeling dependent on others
- Feelings of sadness are normal, and should slowly go away within a few weeks as you get back to your normal routine and activities. Sometimes a depressed mood can keep you from leading a normal life. When a depressed mood is severe and lasts every day for two or more weeks, evaluation for possible treatment is necessary to help you cope and recover. Your transplant social worker, psychologist or psychiatrist is available to help you work through these feelings.

Financial:

Transplant is a lifelong financial commitment. It is possible there will be costs to you that are not covered by insurance. These costs may include:

- Insurance deductibles and medication co-pays
- Out-of-pocket expenses such as:
  - Transportation
  - Housing and in-home support

Deb
Heart Transplant 2017

Transplant risks

There are risks in all surgeries, especially those done under general anesthesia. General anesthesia is a treatment that puts you into a deep sleep so you do not feel pain during surgery. Many complications are minor and get better on their own. In some cases, the complications are serious enough that you may need another surgery or procedure. You must be aware of the risks and complications explained in this document, including those that may result in serious injury and death.

Medical:

- **Bleeding during or after surgery** may mean that you need to receive blood transfusions or blood products. Blood and blood products could contain bacteria and viruses that can cause infection. Although rare, these infections include, but are not limited to, HIV, hepatitis B, and hepatitis C.
- **It may take some time for your transplant to work.** This delay may increase the length of your hospital stay and increase the risk of other complications.
- **After surgery, you will wear special air-filled boots** to help stop blood clots from forming in your legs. But, there is still a chance blood clots may develop and can break free. These clots can move through the heart to the lungs or brain, causing a stroke. They can cause serious problems with breathing or brain function, which can lead to death. Blood clots are treated with blood-thinning drugs that may need to be taken for an extended period of time.
- **Damage to nerves may occur.** This can happen from pressure or positioning of the arms, legs or back during the surgery. Nerve damage can cause numbness, weakness, loss of movement and/or pain. In most cases, these symptoms are short term, but in rare cases they can last for longer periods of time or even become permanent. Nerve damage may also affect how your diaphragm works.
- Other risks and possible complications associated with heart transplants include:
  - Pressure sores on the skin
  - Burns caused by the use of electrical equipment during surgery
  - Damage to arteries and veins
  - Pneumonia
  - Change in voice
  - Heart attack
  - Permanent scarring at the site of the incision
  - Irregular heart rate and rhythm
  - Multiple organ failure
  - Death
  - Clots
  - Difficulty swallowing
- With your transplant, we are replacing the diseased organ. **There is a risk of your disease returning after transplant**

The donor heart

Hearts for transplant come from people who have died (donors) who did not have major health problems. The donor's cause of death is usually an accident or sudden illness. Donors are expected to have good heart function. Organ function may depend on your donor's age, social history or medical history. Donors are screened and may not donate if they test positive for HIV or have heart abnormalities and/or damage.

You will not know the identity of your donor. A lot of tests are done on the donor heart to make sure it is the best one for you.

Transmissible diseases and cancers

- All donors are tested for transmissible diseases and it is not possible to screen for every transmissible disease. There may be a small risk of getting HIV, hepatitis B, hepatitis C, cancer, malaria, or other infectious disease that was not detected at the time of donation.
- Some donor test results may require additional testing or treatment after your transplant. This will be discussed with you as needed.
- Even though there is a detailed screening process for donors, there is a risk of undetected HIV, hepatitis B, hepatitis C. Any risk factors associated with a higher chance of contracting HIV, hepatitis B, or hepatitis C will be discussed with you if you are a potential recipient for that donor.

Rahn
Heart Transplant 2010

I’ve made it to “the list”

You have made it through the evaluation and now you are taking a new step in the transplant process. It is common for patients to feel excited and hopeful about being that much closer to receiving a transplant. It can be rewarding. However, it can also be difficult. No matter how long you wait for a donor heart to become available, the waiting can feel like a long time. Many patients and their support persons have moments where they feel stressed, frustrated, depressed or guilty. These feelings are normal, and you can call your heart transplant social worker at any time for support, information and resources specific to transplant.

The call

The transplant coordinator will call you to come to the hospital when donor heart is available. You will always have the option to say you do not want the organ transplant. If the surgeon later finds out the organ is not usable or the donor does not match your blood type, the transplant will be canceled. If you are well enough, you may be sent home to wait for another donor heart.

Before surgery

- You will:
  - Not be able to eat or drink anything
  - Be asked to sign a consent form
  - Ne examined and asked questions by your doctors and nurses
  - Have a chest X-ray, electrocardiogram and blood tests
  - Remove all jewelry, dentures, contact lenses, glasses, and make-up
  - Bathe with special soap from your nurse
  - Have an IV started
- You may:
  - Have your body hair clipped

Once everything is done and your new heart is ready, you will be moved to the operating room. Your family will be taken to the waiting room. The transplant coordinator will check on you and your family.

Transplant surgery

Surgery may take six to 12 hours.

There will be many doctors and nurses in the operating room with you. The room will be cold, so ask for a warm blanket if you need one. You will see a lot of medical equipment that will be used to monitor you during surgery. The anesthesiologist is the doctor who will help you relax and sleep for the surgery. The surgeon will make an incision (cut) in your chest just large enough to safely remove your diseased organ and transplant the new organ.

The following will be placed in surgery:

- A breathing tube (endotracheal tube) is placed down your throat to help you breathe
- A stomach tube (gastric tube) is placed into your nose or mouth to your stomach to empty it
- A bladder tube (Foley catheter) is placed into your bladder to empty it
- Chest tubes are placed in your chest to drain excess blood and fluid
- IVs are placed in your veins to give fluids, medications and blood and to monitor pressures

After transplant surgery

Right after the surgery is done, you will go to a critical care area in the Corewell Health Fred and Lena Meijer Heart Center. Your family will be allowed to visit you as soon as the transplant team determines you are ready. The transplant nurses will explain everything to your family and significant others

- Family members or friends who are sick are NOT allowed to visit you
- Washing your hands is the best way to decrease the spread of infection
- Everyone will need to wash their hands before entering your room

Recovery

After surgery, you will be cared for by a specialized transplant team. How long you are in the hospital depends on the rate of your recovery. You will remain in the hospital as long as your doctor feels it is needed. In general, your hospital stay will be three to four weeks.

Life after transplant

After you leave the hospital, you will still be recovering. For the first four to six weeks, you will have some restrictions on daily activities. The transplant team will follow your progress and monitor you on a long-term basis. You must come to follow-up appointments and have lab tests and studies done on a frequent and regular basis to see how well the transplant is working. Biopsies will be done on a regular schedule to check for rejection.