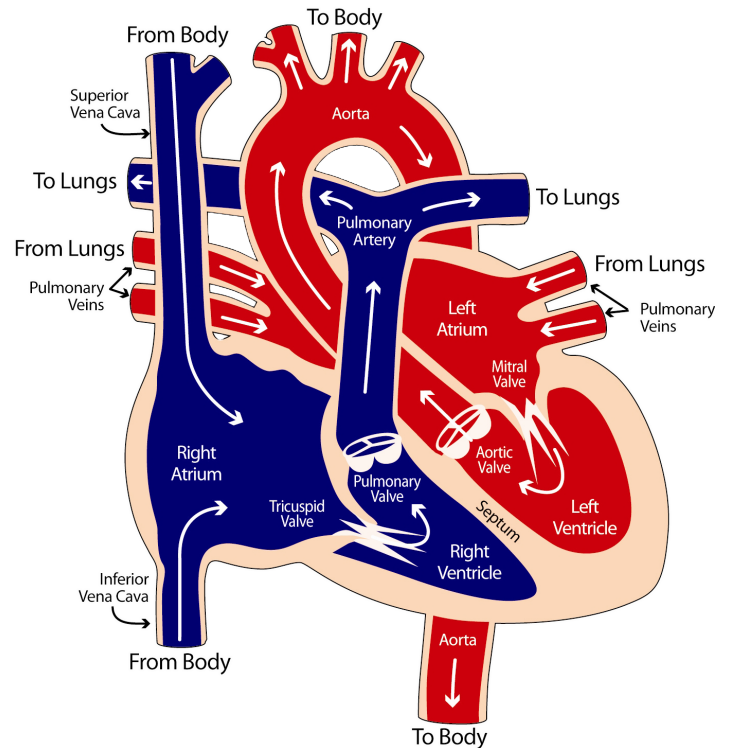


EVALUATION

When is a Heart Transplanted?

The heart is a pump. Its only job is to move blood into the lungs and throughout the body. This movement of blood is essential to supply the body tissue with nutrients and oxygen and to remove waste products from cells. The heart is made up of a special type of muscle called myocardium. The natural pacemaker of the heart stimulates the muscle to contract. When the heart muscle contracts, the blood is pushed out of the heart chambers to the body. When the muscle relaxes, the chambers fill with blood.



If the heart becomes diseased so that the pump no longer moves the blood effectively, a heart transplant may be necessary. A heart transplant is when the patient's sick heart is removed and replaced with a new heart from a deceased donor.

Most patients who receive a heart transplant suffer from failure of the muscle pump, either from coronary artery disease, cardiomyopathy, or heart defects present at birth. Coronary artery disease is caused by narrowing of the coronary arteries due to an accumulation of fatty deposits which line the inside of the vessels. This leads to decreased blood flow and therefore a severe lack of oxygen to the cells of the heart. Cardiomyopathy is a condition wherein the heart muscle is too weak to pump blood. There are several reasons why this occurs. Sometimes a bacterial or viral illness causes inflammation of the heart muscle. Sometimes cardiomyopathy is hereditary. Candidates who are born with heart defects, which are unable to be surgically repaired, may require heart transplantation. Some candidates undergo heart surgery but over time the heart muscle becomes weak, requiring transplant.

Sometimes patients' hearts are too weak before transplant. They may need a ventricular assist device (VAD) which helps the heart pump while they are waiting for a heart transplant.

Patients are placed on the heart transplant waiting list when their chances of living a longer, healthier life are better with a new heart than with their own heart.

The Purpose of the Heart Transplant Evaluation is to:

- Introduce you to the members of the University of Michigan Pediatric Heart Transplant Team and confirm the diagnosis. In most cases, the referring doctor already has made the diagnosis. However, all the information will need to be reviewed to make sure that the Pediatric Heart Transplant Team understands each child's medical condition as completely as possible and is in a position to make the best possible recommendation for each child.
- Determine how severe the heart disease is in order to select the options for management, which may include heart transplant. If heart transplant is an option, this evaluation will help the Pediatric Heart Transplant Team determine the urgency of the need for transplant.
- Inform you and your family about the heart disease, the transplant operation, risks and benefits of both a heart transplant and the medicines used following transplant, and other possible ways to treat the heart disease.
- The evaluation process is also a time for the family to decide if transplant is something they would like to move forward with if a heart transplant is an option.

Medical Evaluation

The patient evaluation requires several tests to gather information the team needs to make a decision about heart transplant. It may be necessary for your child to undergo testing on additional days as determined after the evaluation.

Heart Catheterization: A test that measures the blood pressure in both the heart and lungs. If the pressures are high, the doctor will try to reduce them with different medicines. This process tells the doctors whether the heart transplant will help, or if the candidate would be better suited with another type of treatment. The right heart catheterization is performed in the Cardiac Catheterization Laboratory. Although the catheterization takes about 15 minutes, the entire procedure may take up to one hour.

For the test, the neck or groin is numbed with a local anesthetic, and a needle is placed in the vessel. A thin tube is passed through the needle into the vessel and guided to the heart where the pressures are measured. The staff will want to observe the candidate for a short while after the procedure to ensure that there are no difficulties.

Echocardiogram (ECHO): A test that uses sound waves to create a moving picture of the heart. The picture is much more detailed than an x-ray image and involves no radiation exposure.

Electrocardiogram (ECG): A test that records the electrical activity of the heart.

Chest X-Ray: An x-ray of the chest, lungs, heart, large arteries, ribs and diaphragm.

Blood Test: Several blood tests may be ordered. Blood for all the tests can be drawn at the same time. The tissue-typing test reveals the specific genetic makeup and any antibodies (PRA) that may be in the blood. This information helps us match the candidate with a donor. Blood chemistries tell us about kidney and liver function. Hematology studies determine how well blood clots and carries oxygen to cells. Finally, viral titers show the medical team what viral infections, such as chicken pox, hepatitis or HIV the candidate has had in the past.

MRI, CT and Ultrasound

Your child may get an MRI, CT scan or an ultrasound as part of the evaluation.

- The **MRI (magnetic resonance imaging)** is a painless test that uses radio waves to take pictures of the heart. The MRI helps the transplant team examine the heart's size, shape, position and blood supply. Because your child needs to remain still for this study, it may be necessary for your child to be sedated by a doctor or nurse specialized in sedating children.
- A **CT (computed tomography)** scan uses x-rays to take pictures of your child's body. It can be used to take pictures of many different parts of the body. The machine takes pictures of very small sections of the body part being scanned. The child will lie on a table that moves through the middle of a "donut-hole" in the CT machine. Nothing will hurt or touch your child during the scan. Because your child needs to remain still for this study, it may be necessary for your child to be sedated by a doctor or nurse specialized in sedating children.

Psychosocial Evaluation

It is critically important to address the psychosocial needs of patients and families throughout the transplant process in order to promote the best possible health outcomes.

Each transplant candidate and their family will meet with a social worker and a pediatric transplant psychologist. Our psychosocial team will help to identify areas in which patients and families may require additional support.

This can include the provision of support specific to patient and parent mental health, financial stressors, or insurance barriers. They will work with patients and families to identify and utilize effective coping strategies. Sometimes, referral for more focused psychological or psychiatric treatment will be recommended to best prepare patients or families for transplantation. The transplant psychologist(s) has an outpatient psychotherapy clinic just for our transplant population to ensure quick access to care for those needing more regular intervention and support.



Our concern for the well-being of our patients and families continues throughout the evaluation, transplantation, and post-transplant periods. Thus, our social workers and transplant psychologist(s) are available throughout the entire transplant process and may continue to meet with patients and families in inpatient and outpatient settings.

Financial and Residential Considerations

Financial: The cost for heart transplant includes the cost of surgery, the hospital stay and ongoing clinic follow-up with biopsies and medicines. Adequate insurance coverage is extremely important in anticipation of transplant and for follow-up care.

When a candidate is considered for transplant, the present insurance coverage is evaluated. Our patient accounts representative will be in contact with the candidate's insurance company to determine 1) whether or not the transplant can be done in this facility and 2) what type of coverage before, during and after transplant (including medicines) there is. Many insurance companies have agreements with certain medical centers for transplant surgery and care. Although the candidate may be a patient at this hospital or clinic, his/her particular insurance may not cover transplant at the University of Michigan. That is why this needs to be determined as quickly as possible.

Candidates younger than 21 years old may be eligible for Children's Special Health Care Services in Michigan and similar programs in other states. The transplant social worker will be available to discuss these programs. Another program the candidate may be eligible for is SSI-Medicaid (through Social Security), depending upon income, assets, medical eligibility and additional factors.

For some families, fundraisers can be held to help with costs before and after transplant. The transplant social worker will be able to provide information about fundraising programs such as "Children's Organ Transplant Association" and discuss considerations for raising funds. If this is something you are considering, PLEASE DISCUSS with our transplant social worker first.

Residential: When listed and waiting for transplant the candidate must be no further than a four-hour drive away from this hospital or as negotiated with the transplant team. If the candidate presently lives further away, the transplant social worker will talk with the candidate and family about temporary relocation to this area. This could mean staying locally. This might mean some separation from the rest of the family for a long time, which can be emotionally difficult and expensive. The transplant social worker will help figure out how to best handle this with the family and what programs might be available to help with the cost of temporarily relocating here. Once transplanted, the patient can return home, but will be returning for scheduled appointments and follow-up care.

What's Next

After evaluation, the candidate's case is presented to the transplant team for an in-depth discussion covering all aspects of the evaluation. The team will then recommend the appropriate form of treatment for the candidate. The candidate and family will be informed of the team's recommendation. This generally occurs within one week after the completion of the evaluation. Candidates will then be referred to the appropriate service within the Heart Transplant Program to receive the best type of care specific to their needs.

Candidates who are not recommended for transplant will return to the care of their private physician.

If the candidate has been recommended for transplant, he/she is "activated" at the appropriate time and placed on a nationwide waiting list for donor hearts.