Getting a New Heart

Information for Patients about Heart Transplant

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The information presented and opinions expressed herein are those of the authors and do not necessarily represent the views of the Society.
When you have a heart transplant, there is a lot to do before and after the operation. Before the operation, you will work with the transplant team to complete an evaluation. After the operation, you will need to see your transplant team to make sure your heart keeps working well and you stay in good health. How long a new heart lasts depends on many factors. Some of these factors you can control, some you cannot control.

You will work together with the transplant team to keep you and your new heart healthy.

**What is Heart Failure and What Causes it?**

There are two main reasons for heart problems.

- One is caused by plaque building up in the arteries of the heart. This is called coronary artery disease.
- The other is caused by disease of the heart muscle. This condition is called idiopathic cardiomyopathy. We do not know what causes it.

In both cases, as the heart grows weaker, it is less able to pump oxygen-rich blood through the body. As it tries harder to pump blood, it grows larger. We call this an enlarged heart. After a while, the enlarged heart has to work so hard that it just wears out. Soon it cannot pump even the smallest amount of blood.

A weak, enlarged heart can cause you to feel short of breath and tired, even when you are quiet, such as when resting or at night in bed. Your feet, legs, and stomach may swell, and you may feel sick to your stomach and not feel like eating.

**How is Heart Failure Treated?**

There are several options for treating heart failure. Your doctors will first try medical therapy. In some cases, medicines alone can successfully treat heart failure.

If needed, your doctor may use other methods of treatment. These are:

- **Pacemakers**: These devices are used to treat a heart that beats too slowly. Some of the newer pacemakers are even better at helping the heart pump as it should.
- **Angioplasty**: This is a procedure that opens clogged arteries.
- **Repair the heart valve**: This procedure can often make your heart function much better. If doctors cannot repair the valve, they may be able to replace it with an artificial (man-made) valve.
- **Cardiac size reduction**: During this procedure, your doctor removes a piece of the heart muscle from an enlarged heart. This makes your heart smaller, which allows it to pump more efficiently and vigorously.
- **Coronary artery bypass**: Doctors use blood vessels from other places in your body to "bypass" (go around) the blockages in your heart’s arteries. This can help restore blood flow to your heart muscle.
- **Ventricular assist devices (VAD)**: These are mechanical pumps that surgeons insert to help the heart pump blood.
If these therapies fail, transplantation is the only other option for patients who have the most advanced forms of heart disease; these patients have no other choice.

The best treatment for your heart failure will depend on your medical history, health status, and personal situation. You and your doctors will figure out which treatment is best for you.

**What Happens When You Get a Heart Transplant?**

There are five steps to getting a heart transplant. Your transplant team will:

1. Decide if you need a new heart.
2. Decide if you are healthy enough to receive a new heart.
3. Prepare you for your operation. This can take a long time, and there is no guarantee that a heart will be found.
4. Perform a heart transplant operation.
5. Help you stay healthy after your operation.

### Step 1. Your Transplant Team Decides If You Need a New Heart

Many heart diseases get worse very slowly. Sometimes one treatment will work where another did not. Because of this, the transplant center will first determine which therapy is best for your condition.

Sometimes a new drug or therapy can improve your heart condition. The transplant center will do its best to make sure you have every chance to get better and live longer with your own heart before they recommend a heart transplant.

### Step 2. Your Transplant Team Decides If You Are Healthy Enough to Receive a New Heart

Before you have a heart transplant, a team of health care professionals will talk to you about what may happen if you get a new heart. What happens can depend on your physical health, your mental health, and how easy it will be for you to get the transplant medicines you will need.

There are four parts to this phase.

1. **First** you will visit a transplant center. You, your doctor, a nurse, or a social worker can schedule this visit. Your doctor’s office will send your medical records to the transplant center before your appointment. Your records should show that you are taking your medicine properly and are on a restricted diet. Your records will also confirm that you have no medical conditions that can keep you from receiving a transplant.
2. **During this visit, your physical health will be evaluated.** The transplant team will do a complete evaluation of your physical health. They may do more tests to evaluate your:
   - heart
   - kidneys and gallbladder
   - stomach, esophagus, and intestines
   - lungs
   - bladder
   - teeth and gums
   - brain and nervous system
   - prostate, if you are a man
   - breasts and cervix, if you are a woman

   The transplant team may order other tests as well.

3. **Then, your mental health will be evaluated.** You may need to see a social worker or psychologist to make sure you are not addicted to alcohol or drugs. It is also important to make sure you have no emotional problems that can interfere with your health.

4. **Finally, you will see an insurance specialist.** An insurance specialist will review your insurance to make sure your policy covers the transplant operation and the medicines you will need after your transplant.

   If the transplant team decides you are a good candidate for the operation, they will work with you to find a new heart.

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**Step 3. Your Transplant Team Prepares You for Your Operation**

This step involves finding a new heart for you. Sometimes this can take a long time. How long it takes depends on your body size, your blood type, and how sick you are.

While waiting for your operation, you will have regular visits with your doctor and transplant team. They will monitor your health, and they will work with you to make sure you are eating and exercising properly. You need to let them know of any changes in your health.

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**Step 4. Your Transplant Team Performs a Heart Transplant Operation**

Most heart transplant surgeries are done with a method called orthotopic. Your heart is removed, and the donor heart is sewn in place. Once the new heart is in place, the donor's main arteries—the aorta and pulmonary arteries—are sewn to yours.

- When the right heart is found, the nurse coordinator will call you and you will go to the hospital. The transplant doctors will check the donor heart while you are being evaluated. You will be given medications before and during the operation to prevent your body from rejecting the new heart. If the donated heart is the right match for you, you will be taken to the operating room and put to sleep with an anesthetic.
A transplant surgeon will prepare your chest cavity so your heart can be removed. At the same time, the new heart will be removed from the donor and sent to your hospital. This heart will be placed in your chest through the opening in your chest cavity. This is called a sternotomy.

After the operation, you will be taken to a special unit for recovery. You will stay in the hospital until your doctor feels you are ready to go home. How long you stay will depend on your health and how well your new heart is working. It will also depend on how quickly and easily you learn to take care of your new heart.

**Transplant Medicines**

After your operation, you will take strong medicines to keep your body from rejecting your new heart. Your immune system protects you from foreign invaders, and your body will think the new heart is a foreign invader. So your immune system will try to reject your new heart. This can damage it. Because of this, you will take immunosuppressants (im-u-no-su-pres-ants), also called anti-rejection medicines. These drugs suppress the immune system enough to keep your transplanted heart healthy.

That’s why these medicines are called immunosuppressants or anti-rejection drugs. Your body will remember that the heart once belonged to someone else, so you will need to take these drugs for as long as you have the transplant. For more information on transplant medications, please visit the AST Patient Education Brochures section of the AST website at [www.myAST.org](http://www.myAST.org).

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**Step 5. Your Transplant Team Helps You Stay Healthy After Your Operation**

It is very important that you keep yourself healthy after your transplant. Here are a few important reminders:

- After you leave the hospital, make sure you go to the transplant center often. Also be sure you go to all your doctor appointments. **This very is important!** You will only have to do this for a few months.
- Take your medicines properly. **This is extremely important!**
- Watch your weight and be sure to get some exercise on a regular basis.
- Be sure to tell the staff at the transplant center if you have problems keeping your appointments or taking your medicines.

**Your Doctor Appointments**

If your body begins to reject your new heart, you may not know it. Some patients may have signs, but most do not recognize them. If your body is rejecting the new heart, your doctors and nurses will know it. **This is why it is so important to go to all your medical appointments.** Your health care providers watch closely for signs of rejection and side effects from the medications. But, they must examine you and test your blood to know for sure.
Your doctor and transplant staff will watch for these signs:

1. **Rejection**: The risk of rejection never goes away. You will always need anti-rejection drugs. Your doctor may lower the dosage, but you should never skip or stop taking the drugs. A biopsy of the heart is the best way to know if your body is rejecting your new heart. Your doctors will do this many times for the first year after your transplant. After that, they will biopsy your heart, but less often.

2. **Infection**: Immunosuppressant drugs can increase the chance of getting infections. These infections can be treated. However, you need to tell your doctor if you have a fever, unusual pain, or any other new feelings. The risk of infection will go down when your doctor lowers the dosage.

3. **High blood pressure**: High blood pressure is a common problem after transplant. It can damage your new heart and cause strokes and heart attacks.

4. **Diabetes Mellitus**: Anti-rejection medications can cause diabetes. If you had diabetes before your transplant, you may find it harder to control your blood sugar level after your transplant.

5. **High cholesterol**: Your anti-rejection medication can also cause high cholesterol. There are some medications called statins that control cholesterol and help prevent rejection because they also control inflammation.

6. **Heart disease**: Some forms of heart disease can come back in the transplanted heart. Your doctor and transplant staff will monitor you for signs of this problem.

7. **Cancer**: Anti-rejection drugs can raise the risk of getting cancer, especially blood cancer and skin cancer. Although blood cancer, called lymphoma, can be fatal, your doctor can lower the risk by lowering the dose of anti-rejection drugs. Your transplant team will suggest getting screened for cancer early and on a regular basis. They will recommend you regularly:
   - Get a colonoscopy
   - Get a mammogram
   - Get a pap smear, or prostate exam
   - See a dermatologist

8. **Osteoporosis**: This is thinning of the bones. Being ill, eating a poor diet, being inactive, or taking prednisone and other anti-rejection drugs can cause osteoporosis. Your doctor will most likely order a bone density test and may put you on drugs that prevent osteoporosis.

9. **Cataracts**: Prednisone (a steroid medication) and other drugs can cause cataracts, which are cloudy spots on the lens of your eye. You cannot prevent cataracts, but they can be surgically removed. Your doctor will ask you to see an eye doctor (ophthalmologist) at least once a year to get checked for cataracts and glaucoma. Glaucoma is pressure in the eye that can damage your vision.

10. **Kidney disease**: The main medicines used to treat rejection, and many of the medicines used to treat infection, can hurt your kidneys. Your doctors will try to make sure you have enough medicine to prevent rejection of your new heart, but not so much that it hurts the kidneys. Sometimes this is hard to do. If you are older, or if your kidneys have already been injured by illness or medications, you may have permanent kidney damage. This can cause your feet to swell and your body to retain fluid. You may feel very tired and not feel well overall. Kidney disease is a serious problem. You will need to go for regular blood tests. These tests make sure the levels of your anti-rejection medications are not too high or too low.