

Released March 2002
Revised December 2006
Revised March 2012
Reviewed May 2015
Reviewed April 2017
Reviewed May 2018



AMERICAN SOCIETY OF
TRANSPLANTATION

Getting a new heart

*Information for patients
about heart transplant*

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Getting a new heart

Facts about heart transplants

WHY IS IT IMPORTANT TO HAVE A HEALTHY HEART?

Having a healthy heart is important to your overall health because the heart pumps blood (containing oxygen and nutrients) to the rest of the body. This allows you to take part in all physical activities.

WHO CAN GET A HEART TRANSPLANT?

People get a heart transplant when they have heart failure and other treatments haven't worked.

WHAT IS HEART FAILURE?

Heart failure is a long-term problem where your heart has trouble pumping blood to the rest of your body. There are 2 types of heart failure:

- Your heart is enlarged and too weak to pump blood with enough force. This is called "systolic heart failure".
- Your heart muscle is thick and stiff, so it can't relax and fill with blood between each beat. This type is more likely in people age 70 and older. This is called "diastolic heart failure".

Both types of heart failure cause heart damage that can get worse over time:

1. As your heart grows weaker, it's less able to pump oxygen-rich blood through your body
2. As your heart tries harder to pump blood, it grows larger

When heart failure slows the flow of oxygen-rich blood to the rest of your body, you may have:

- Shortness of breath and feel tired, even when you're resting or lying in bed
- Swelling in your feet, legs, and stomach
- Feeling sick to your stomach and not wanting to eat

WHAT CAUSES HEART FAILURE?

There are 2 common causes of heart failure:

- Buildup of fatty material (plaque) in the arteries of the heart that blocks blood flow – this is called coronary artery disease
- Disease of the heart muscle (cardiomyopathy), which has many causes, including:
 - Valvular diseases – where your heart valves become stiff or have leaks
 - Infections that can cause scar in the heart valves
 - Metabolic disorders – such as thyroid disease where the heart muscle becomes weakened
 - Genetic disorders – some people are born with genes that cause heart failure
 - Sometimes, an unknown cause
- To learn more about on the causes of heart failure, visit <http://www.hfsa.org/patient/learn/> and (http://www.heart.org/HEARTORG/Conditions/HeartFailure/AboutHeartFailure/What-is-Heart-Failure_UCM_002044_Article.jsp#.Ww285Egvw2w)

HOW DO DOCTORS TREAT HEART FAILURE?

There are many treatments for heart failure. Your doctors will use the best treatment for you based on your type of heart failure, medical history, and current health. At first, your doctors will try medicines – sometimes, medicines alone can treat heart failure. If needed, doctors will use other types of treatment, such as surgery or other procedures

If these treatments don't prevent more heart damage and help your heart pump enough blood, doctors may ask you to consider getting a heart transplant.

To learn more about heart failure treatments, visit <http://www.hfsa.org/patient/learn/> and http://www.heart.org/HEARTORG/Conditions/HeartFailure/TreatmentOptionsForHeartFailure/Treatment-Options-for-Heart-Failure_UCM_002048_Article.jsp#.Ww29bEgvw2w

WHAT HAPPENS WHEN YOU DECIDE TO GET A HEART TRANSPLANT?

If you and your doctors decide that a heart transplant may be right for you, they'll help start your journey to getting a new heart. Your doctor or their staff will send your medical records to the transplant center and help you schedule a visit there.

The health care team at the transplant center will guide you through a 5-step process to:

1. Decide if you need a new heart
2. Decide if you are strong enough to get a new heart
3. If the right heart is found, prepare for your transplant surgery
4. Do the heart transplant surgery
5. Help you stay healthy after your transplant surgery

To learn more about the transplant process, visit <https://transplantliving.org/before-the-transplant>

Step 1. The transplant team decides if you need a new heart

Many heart diseases get worse very slowly. The transplant team will look at your medical records to:

- Learn about your heart failure and your overall health
- See if you are taking your medicine the right way
- Make sure you don't have other health problems that could prevent you from getting a transplant
- Make sure you will have enough help at home after you get a transplant

Next, the team will see if a new medicine, procedure, or other surgery can improve your heart condition. They want to give you every chance to get better with your own heart before they recommend a heart transplant.

Members of the team will talk to you about a heart transplant and what it requires physically, mentally, and financially.

Step 2. The team decides if you are strong enough to get a new heart

If the team decides you need a new heart, they'll have you schedule a visit for a complete evaluation (check) of your physical health, mental health, and finances, such as insurance coverage.

Physical health check

The team may do many tests, including on your:

- Heart
- Arteries and veins
- Kidneys and bladder
- Stomach, esophagus, gallbladder, and intestines
- Lungs
- Teeth and gums
- Brain and nervous system
- Prostate, if you are a man
- Breasts and cervix, if you are a woman
- Blood and bone marrow

Mental health check

A social worker, psychologist, or other member of the transplant team will:

- Make sure you are not addicted to alcohol or drugs
- See if you have emotional problems that could interfere with your health or your ability to manage medicines, doctor visits, and other health needs after a transplant
- Make sure you have support from a caregiver who can help you in the first few months after the transplant with medicines, travel to the transplant center, and other needs

Financial check

An insurance specialist will review your insurance to make sure your policy covers the transplant surgery and the medicines you will need afterwards.

If the transplant team decides you're strong enough to get a heart transplant, they'll support you while you wait for a new heart. They'll add your name to the list of people waiting for a heart transplant. This wait can take a long time and depends on:

- Your body size
- Your blood type
- How sick you are

The team will also schedule regular visits to check your health and help you learn to eat healthy foods and be active. You will

also have regular visits with your regular doctor. If you have any changes in your health, let your regular doctor and the transplant team know about them. These changes could affect your ability to stay on the waiting list.

To learn about transplant programs, visit: <https://www.srtr.org/about-the-data/comparing-transplant-programs/>

Step 3. The team prepares for your transplant surgery

When a new heart is found for you, a member of the transplant team will call you to come to the hospital. To prepare for your transplant surgery, the team will:

- Do a final check to make sure you're strong enough for the surgery
- Check the donor heart to make sure it's the right match for you

Next, doctors will take you to the operating room and give you an anesthetic to put you to sleep and medicines to prevent your body from rejecting the new heart. Usually, they also need to give you blood to replace lost blood and reverse the effect of any blood thinners in your body.

Step 4. The team does your heart transplant surgery

Your transplant team will do surgery to remove your heart and place your new heart in its place through an incision (cut) in the opening in your chest.

The surgeon will sew your new heart's main arteries (the aorta and pulmonary arteries) to yours and will close the opening in your chest.

Right after surgery, the team will take you to a recovery room. You'll stay in the hospital until your doctor feels you're ready to go home. That will depend on your overall health, how well your new heart is working, and how easily you learn to take care of your new heart.

To learn more about what happens after heart transplant, visit <https://transplantliving.org/after-the-transplant/>

Step 5. The team helps you stay healthy after surgery

In the weeks and months after your transplant surgery, you can help your new heart work its best by doing these **3 important things**:

- Take your transplant medicines exactly the way the doctor tells you to

- Go to all of your visits at the transplant center and your doctor's office. **They will watch for warning signs that your body may be rejecting the new heart.**
- Take care of your health. This includes eating healthy foods, being active most days of the week, and resting when needed.

Take your transplant medicines

After your surgery, you will take strong medicines to keep your body from rejecting your new heart. Your body's immune system protects you from germs and other foreign things that can make you sick. Your immune system will think your new heart is foreign and will try to reject it. This can damage your heart.

To protect your new heart, you will take immunosuppressants (im-u-no-su-pres-ants), also called anti-rejection medicines. These medicines suppress (calm) the immune system enough to keep your new heart healthy. Your immune system will always treat your new heart as foreign, so you'll need to take anti-rejection medicines for the rest of your life.

To learn more about transplant medicines, visit the AST Patient Education Brochures section of the AST website at www.myAST.org and UNOS Transplant Living (<https://transplantliving.org/after-the-transplant/preventing-rejection/>)

Go to your medical visits

After you get a new heart, it's very important to go to all visits with your regular doctor and the transplant team. Tell them if you have trouble taking your medicines or getting to visits. Your doctors need to:

- Recognize warning signs that your body is rejecting your new heart – signs that you may miss
- Watch for side effects from the medicines you take
- Examine you and test your blood to know for sure if there are problems

Your doctor and transplant staff will watch for these warning signs and side effects:

Rejection of your new heart: To help prevent rejection:

- Never skip or stop taking the medicines
- Go to all of your visits so doctors can test for rejection, such as using biopsy – doctors take a small sample of your heart tissue to look at it under a microscope. They'll test many times in the first year after surgery, then will test less often after that.

Infections: Anti-rejection medicines can raise your chance of getting infections. These infections can often be treated, but you need to tell your doctor right away if you have a fever, unusual pain, or any other new symptoms. The chance of infection will go down when it's safe enough for your doctor to lower the dose (amount) of medicines you take.

High blood pressure: This is a common problem after transplant. It can damage your new heart and cause stroke or heart attack.

Diabetes mellitus: Anti-rejection medicines can cause diabetes. If you already had diabetes, you may find it harder to control your blood sugar level after your transplant.

High cholesterol: Your anti-rejection medicines can cause high cholesterol. Doctors may give you medicines called statins to lower your cholesterol. These medicines may help prevent rejection because they also lower inflammation (swelling) in your body.

Heart disease: Some forms of heart disease can come back in your new heart. Your doctor and transplant team will check for signs of this problem.

Cancer: Anti-rejection medicines can raise your chance of getting cancer, especially blood cancer (lymphoma) and skin cancer. Blood cancer can be deadly, but doctors can lower the risk by lowering the dose of anti-rejection medicines.

Your transplant team will suggest you get screened (tested) for cancer soon after the transplant surgery, and on a regular basis. They will recommend you regularly get a:

- Colonoscopy
- Mammogram and a pap smear, if you're a woman
- Prostate exam, if you're a man
- Skin cancer check

Osteoporosis: Anti-rejection medicines can cause osteoporosis or thinning of the bones. Your doctor will order a bone density test and may have you take medicines that help prevent bone thinning.

Cataracts and glaucoma: Your doctor will ask you to visit an eye doctor at least one time a year to get checked for eye problems such as:

- Cataracts – cloudy spots on the lens of your eye. Anti-rejection medicines can cause these. You can't prevent cataracts, but an eye doctor can remove them.
- Glaucoma – pressure in the eye that can damage your vision

Kidney disease: Anti-rejection medicines and many infection medicines you take after a transplant can damage your kidneys. Doctors will try to give you enough medicine to prevent rejection of your new heart, but not so much that it hurts your kidneys. Sometimes this is hard to do.

If you already have kidney damage, you may have permanent kidney damage. This can cause:

- Swelling in your feet and extra water in your body
- Tiredness and feeling unwell overall

Tell your doctor if you have these symptoms, because kidney disease is a serious problem. You will need to get regular blood tests to make sure your anti-rejection medicine levels are not too high or too low.

LIVING WITH A HEART TRANSPLANT

After surgery, you must be closely checked at the transplant center. For most patients, the transplant can mean they're trading in one set of problems (their heart disease) for a new set of problems (rejection, immunosuppression, and its risks).

Ideally, your heart will work better after a transplant, and you will enjoy life and live longer. Most heart transplant patients can be active, travel, go to school or work, and share daily life with friends and family.