

Being Evaluated for Heart Transplant

A Guide for Patients and Their Families



VANDERBILT  UNIVERSITY
MEDICAL CENTER

Vanderbilt Transplant Center

Vanderbilt Transplant Center in Nashville, Tennessee, is one of the South's main providers of solid organ and stem cell transplantation. We offer programs in heart, kidney, heart, lung, pancreas, and bone marrow transplantation, and our outcomes are among the best in the country. Our specialists strive to return every patient to a full and active life. Our mission is to provide patients with end-stage organ failure the opportunity to lead extraordinary lives. We thank you for trusting us with your care.

As we treat you, we promise to:

- include you as the most important member of your health care team
- personalize your care with a focus on your values and needs
- work with you to coordinate your care
- respect your right to privacy
- communicate clearly and regularly
- serve you and your family with kindness and respect.

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Overview of the Transplant Process

Your heart doctor (cardiologist) has suggested that you be evaluated for a heart transplant. For you to decide if you want to consent to this evaluation, you need to understand both the risks and benefits of the evaluation, as well as transplant surgery itself. Learning about what you are agreeing to is a process called “informed consent.”

This document will help you learn what happens when a person gets a heart transplant. This process includes getting approved for new heart, waiting for a new heart, and all the other things you can expect before and after surgery.

Why do I need a new heart?

A person who needs a new heart has heart problems that cannot be fixed any other way. The most common reasons for a heart being so damaged that it needs to be replaced are:

- viruses
- other heart diseases.

What are the steps of a transplant?

A heart transplant has 4 major steps:

- evaluation and education
- waiting for a heart
- surgery
- lifelong care and follow-up.

Step 1: Evaluation and education

This 1st step includes the many tests done to see if you are healthy enough for a new heart. Having all these tests does not guarantee that you'll get a new heart.

You will also learn a lot about the transplant process, which will help you decide if transplant is the right thing for you.

During the evaluation and education phase, you will learn about:

- the risks and benefits of transplant
- alternative treatments to transplant, including VAD, medical management, and palliative care
- the evaluations and tests that are required
- the results of all the tests you have done
- how the waitlist works
- how transplant recipients are chosen
- any psychosocial or financial issues that may affect your ability to be transplanted
- the strict medical regimen that transplant recipients must follow for the rest of their lives after transplant
- current results and outcomes at the Vanderbilt University transplant program
- organ donor risk factors
- your right to refuse to have a transplant at any time, up until surgery.

Step 2: Waiting for a heart

If tests show you are healthy enough for new heart, and you meet all other requirements, you will be put on a waitlist for a donor heart.

Where donor hearts come from ...

Most hearts come from donors who are legally brain dead. This means their brain damage cannot be fixed. This damage may have been caused by stroke, tumor, or a really bad head injury.

Step 3: Surgery

As soon as you agree to have surgery, even before a heart is found, your surgeon will talk to you about the surgery and its risks. At all times, your health and safety are our main concern.

When a heart becomes available, you will have surgery. Note: there are times when patients are called in for a transplant, but for whatever reason, it is discovered that the donor heart is not suitable for transplant. If this happens, your surgery will be cancelled. Although this is disappointing for patients and their families, your health is our main concern.

Step 4: Lifelong care and follow-up

Having a transplant is just the 1st step in a lifelong process. For the rest of your life after transplant, you will be required to follow a strict medical plan. This plan will include follow-up appointments and medicines you will have to take every day for the rest of your life.



What are my treatment options besides having a transplant?

You are being evaluated for a heart transplant because you have heart problems that cannot be fixed any other way. This means that having a transplant is your only option for a possible cure.

You always have the right to decline a transplant. If you decide you do not want a transplant, your doctor will continue to manage your heart problem. Alternatives to transplant include a VAD (ventricular assist device), medical management of your heart condition, and palliative care. If you change your mind about having a transplant, we can also arrange for you to have a consult with palliative care to help you plan your goals of care.

Can I get a new heart, even with a history of alcohol or tobacco abuse or illegal drug use?

Yes. You may still be able to get a new heart, but you must do the following to stay on the waitlist:

- You must not abuse alcohol for 6 months before your evaluation.
- You must not use tobacco or illegal drugs for 6 months before evaluation. You will be tested for nicotine and illegal drugs at random during these 6 months. These tests must show no nicotine or illegal drug use.
- You must not abuse alcohol while you are waiting for a transplant.
- You must not use tobacco or illegal drugs while waiting for a transplant.
- If tests or other evidence shows that you have been abusing alcohol or using tobacco or illegal drugs, you will be required:
 - to complete a tobacco or drug rehab program
 - to be in an ongoing support rehab program. We will require written proof that you are in such a program.

Staying eligible for transplant

To remain eligible for transplant, there are some behaviors you must commit to.

To qualify for a transplant:

- **no alcohol abuse**
- **no tobacco**
- **no illegal drugs.**

The Vanderbilt Heart Transplant Program requires that you have 6 months of no tobacco or illegal drug use before you can be put on the waitlist for a heart. It is also expected that you will not use drugs or smoke for the rest of your life after transplant.

The first time you come to our office, we will test you to see if you have drugs or nicotine in your system. If these tests show that you have been using drugs or tobacco:

- we will re-test you randomly at return visits
- you may be expected to do smoking cessation counseling or another treatment program.

What happens if I don't comply with the requirements during evaluation?

A heart transplant is a valuable and limited resource. We expect you to comply with all our evaluation requirements.

- We currently follow a "3 strikes, you're out" program.
- Our "3 strikes, you're out" program means you will not be considered for a transplant at Vanderbilt if we discover 3 times that you have not followed eligibility requirements.

We will give you more information regarding the behaviors and compliance we expect from you. In order to get a new heart, you must also be committed to following the required medical regimen and all the health recommendations that we will give you after transplant.

What kind of support will I need through the transplant process?

A successful transplant requires that you have people in your life who are able to give you the support and help you will need. You cannot go through this process alone. For a heart transplant, you need 2 caregivers.

What kind of support will I need through the transplant process?

You cannot go through this process alone. A successful transplant requires that you have at least 2 people in your life who are able to give you the support and help you will need, through evaluation, your time on the waitlist, and your life after transplant.

Your support persons must be:

- able to drive
- older than 18
- reliable.

Before transplant

Your support persons:

- need to go to the psychosocial evaluation with you
- will learn everything they'll need to do for you after surgery, including at the hospital and in the long-term.

After transplant

At the hospital, your support persons will:

- be present with you when we give you your medicine, once you are out of the ICU (intensive care unit)
- learn about all your medicines, what they are used for, and their side effects
- learn how to care for your chest incision as you heal.



By the time you leave the hospital, your support persons will:

- know all about the medicines you will take and their side effects
- be able to help you take your medicines exactly how you are supposed to
- be able to help you keep track of the medicines you take by writing in your daily medicine diary the times time you take them and the doses you take
- be ready to go with you to your lab and clinic appointments and your other medical visits to discuss your condition with the doctor and report any issues you are having
- have learned about (and be able to help you watch for) signs and symptoms of organ rejection, medicine side effects, or any other medical issues, once you have left the hospital
- be ready to help you with your personal care activities, such as bathing or shaving
- will know how to check your blood sugars and give you insulin injections, if you need them.

Reliable, committed support is absolutely necessary for you to successfully go through the transplant process.

Once I start the transplant process, can I change my mind?

Yes. At any time during the evaluation process, while you are on the waitlist, or just before surgery, you can change your mind about getting a new heart.

What will happen if I change my mind about my heart transplant?

Your heart disease treatment will continue. Understand that your health is likely to get worse and how long you live may be shorter.

What happens if my transplant fails?

If your transplant fails, you may be eligible for another transplant in the future. This will depend on:

- the reason the organ failure happened
- your state of health.



Transplant Evaluation

What happens during the evaluation stage?

Getting a new heart is serious, risky surgery. You will have many tests, including 2 rounds of medical tests, to find out if you are healthy enough for a new heart. All of these tests will determine if you are medically, surgically, emotionally, and mentally able to go through a transplant. How much social support you have and your financial situation will also be considered.

During evaluation, you will meet members of the heart transplant team, including your:

- nurse practitioner
- transplant coordinator
- social worker
- transplant doctor
- transplant surgeon
- nutritionist
- pharmacist
- psychiatric nurse practitioner.

Your transplant coordinator

Your transplant coordinator will be your partner through the entire transplant process. This person will be available starting from the evaluation stage. You may contact your coordinator any time you have questions or concerns. Everything you talk about is confidential. It will only be shared with the other transplant team members as needed.

What kinds of medical tests will I need?

Not every person will need all of the tests described in this section, or even the same tests. The tests you have are based on your own situation.

- Every test will be carefully explained in detail in advance.
- If a test has any risks, we will explain all these to you in advance and ask you to sign a consent form which outlines the risks in detail.

Will I need to see a lot of different doctors during my evaluation?

During the evaluation stage, you might need to see other doctors in addition to the doctors on the transplant team if you have other medical problems. For example, many patients need to be seen by a lung doctor (pulmonologist) for lung problems or a diabetes doctor (endocrinologist).



Medical tests and consultations (round 1)

The first tests and office visits you have will tell us about your overall physical health. These tests and visits include:

- a review of your health history
- urine tests
- an EKG (electrocardiogram), a test that measures the electrical activity of your heart
- a chest x-ray
- blood tests
 - We will find your blood type (so you can be matched with a heart).
 - We will check your blood to see if you are immune to or have certain viruses, including HIV (human immunodeficiency virus).

Medical tests and consultations (round 2)

Additional tests will look at your health in more detail and may include, but are not limited to:

- tests to see how well your heart works, including:
 - heart catheterization tests on both the right and left sides of the heart to check your heart pressures and look for heart disease
 - an echocardiogram to see how well your heart works overall
 - a nuclear stress test to see how well your heart works under stress.
- lung tests to see how well you breathe and to give us even more information about your heart function
- stool tests to see if you have any blood in your stool
- VO2 tests to see how much oxygen your body is using
- TB (tuberculosis) test
- a CT scan without IV contrast to help us find any scar tissue and bypass grafts you may have.

You may also have tests to see how well your liver and kidneys work.

If you're older than 50

If you're older than 50, this second set of tests will include:

- a procedure to check how well your blood moves through the carotid arteries in your neck
- a CT scan without IV contrast of your abdomen and pelvis to look for any abnormal masses or lesions in your belly
- a procedure to check how well your blood moves through the arteries in both your legs.

You will also have a colonoscopy to look for polyps and bleeding in your colon.

If you're female

If you're female, we will need the results of your last pap smear and mammogram, if they were done in the past year. You can have the results faxed to us if necessary.

If you have not had a pap smear or mammogram in the past year, you will need to have both of these tests done.

If you have diabetes

If you have diabetes, your tests will include:

- a procedure to check how well your blood moves through the carotid artery in your neck
- a CT scan of your abdomen to look for any abnormal masses or lesions in your belly
- a procedure to check how well your blood moves through the arteries in both your legs.

Dental evaluation

Dental diseases can cause infection or other problems after transplant. See your dentist to be sure any problems you have are fixed before surgery. You'll need to get a written statement from your dentist showing that any needed work has been done. You'll give this document to your transplant coordinator.

Nutrition evaluation

You'll meet with a nutritionist or dietician who will decide if you are eating as healthfully as you should be. The goal is for you to be as strong as possible for surgery. The nutritionist will help you make any diet changes you need to make.

Risk evaluation

There are many risks associated with getting a new heart. We'll talk about all of this with you in great detail. In addition to

the medical risks, getting a new heart has risks that are psychological, emotional, social, and financial.

Psychosocial evaluation

A social worker will meet with you for what is called a psychosocial evaluation. At least 1 of your designated caregivers (support persons) is required to be at this meeting. **If you come without your support person(s), the meeting will be cancelled and rescheduled.**

At this meeting, your social worker will:

- do an in-depth evaluation of your life and social circumstances, including discussions about your:
 - employment
 - financial situation
 - substance abuse history (if you have one)
 - mental health history
 - legal history.
- decide if you are able to understand and agree to the risks, benefits, and expected results of a heart transplant
- discuss the reasons you have decided to pursue a heart transplant
- decide if you and your family are able to hold up under the emotional, financial, and physical stress of this type of surgery
- determine if you will have the amount of social support you'll need through the transplant process.

What happens after the evaluations are finished?

Once all of your evaluations are complete, your case will be discussed at a patient selection committee with the heart transplant team. The team will determine if a heart transplant is the option for you. If the evaluations show you are a good candidate for a new heart, you will be put on the Vanderbilt Transplant Center Waitlist for a donor heart. You must be available at all times. Avoid traveling to areas that may not have cell phone reception.

Waiting for a Donor

Where do new hearts come from?

Most hearts come from donors who are legally brain dead. This means their brain damage cannot be fixed. This damage may have been caused by stroke, tumor, or a really bad head injury.

How are donor hearts chosen?

Hearts are chosen if they are healthy and work well. Good heart function is the most important consideration when a donor heart becomes available. Donor hearts are not matched by sex, color, race, or culture. Organ donation is voluntary. Donation often helps families deal with grief.

How does the transplant waitlist work?

Your transplant coordinator will explain to you in detail how this waitlist works and how it is decided who gets a heart. There are three issues that are key to offering a donor heart:

- blood type
- body size and weight
- your priority status.

How long does it take to get a new heart?

The wait time for a heart is unknown and can take a very long time. It is possible for a patient to die while waiting.



What can I do to help support my heart and health while I am on the waitlist?

If your wait time seems like it may be long, your doctor may talk to you about getting a device, called a VAD (ventricular assist device). A VAD goes inside the body and is used to support heart function.

Also, follow everything your health team says you should do. This includes everything from taking your medicines to eating a healthy diet.

Can I get on the waitlist at other transplant hospitals?

Yes; you have a right to do this. Your transplant coordinator will talk to you about how to get on the waitlist at more than one transplant hospital. You'll also learn how to transfer your listed wait time from one transplant center to another so you don't lose your place on a list.

How is it decided who is highest on the waitlist?

Who has high priority on the waitlist is determined by a patient's medical needs. A patient's status on the list can change as their health and medical needs change.

There are three priority categories on the waitlist:

- Priority status 1A. These patients are the sickest and have the most urgent medical transplant needs.
- Priority status 1B. This level is not as urgent, but the patient is not in a stable condition and is still very sick.
- Priority status 2. A patient with this status needs a transplant but is stable, so getting a transplant is not as urgent as status 1A or 1B.

Do I need to stay close to Vanderbilt while I am waiting for a new heart?

- It is best if you are within a 4-hour drive from Nashville while waiting for your heart. This is because the donor heart must be transplanted within a 4-hour window to have optimal function.
- If you do live further than a 4-hour drive, you can still get on the waitlist, but you must arrange air transportation to Vanderbilt at the time the donor heart becomes available.
 - It is your responsibility to pay for these costs.
 - The transplant coordinator or social worker will give you the contact information for several air ambulance companies.
 - When you choose the companies you will use, give the names and contact phone numbers to your transplant coordinator.

We have program coverage if you need assistance at any time

A transplant surgeon, transplant doctor, and transplant coordinator are available 24 hours a day, 365 days a year to assist with patient management. Back-up coverage is available for each of these people as well. If you ever need help or assistance at any time, a surgeon or doctor can always be on site at Vanderbilt within 60 minutes.

What happens when I get the call for transplant?

While you wait for transplant, you should have your cell phone on at all times. We have one hour to reach you or your support person. If we cannot reach you, we have to move on to the next person. Once you get the call, you have 4 hours to get to Vanderbilt.

When you arrive, check into the Admitting Office located in the main lobby of the main hospital.

Important reminders:

- Have a bag packed and ready to go at all times.
- Do not eat or drink anything once you have received the call that an organ has been found.
- Remember that there is always a chance that your transplant may be cancelled.
- Bring all of your home medicines with you to the hospital as well as a list of all your current medicines.

What if Vanderbilt is not able to do my transplant?

If Vanderbilt is unable to do transplants for any reason, such as a natural disaster, we will let you know as soon as possible. If necessary, we will also refer you to another center for transplant care.

At the Hospital

What happens when I get to the hospital for surgery?

As soon as you get to the hospital, you'll be prepared for surgery then taken to the operating room.

What happens during surgery?

In the operating room:

- You'll get medicine (called anesthesia) that will make you sleep.
- You'll be asleep and not feel any pain during the procedure.
- When you're asleep, the surgery begins.
 - Your transplant surgeon will first make an incision in the middle of your chest then cut through your breast bone.
 - Your diseased heart will be taken out of your chest.
 - The new, healthy heart will be put in your chest.
 - Once your new heart is beating, your surgeon will close your chest and your incision.

How long will my surgery last?

Heart transplant surgery usually takes 6 to 10 hours.

What happens after surgery?

After surgery, we will take you to the ICU (intensive care unit), where we will watch over you as you wake up and begin to recover. You will have various machines connected to you after surgery:

- Breathing machine (ventilator) with a breathing tube. One end of the tube is connected to the breathing machine. The other end goes into your mouth and down your throat. The machine helps you breathe until you can do so on your own. The breathing tube is usually removed in 4 to 8 hours after surgery.
- Chest tubes. These tubes are placed in your chest through your skin. They are used to help drain blood and fluid from your chest as you heal. These tubes are usually removed 2 to 3 days after surgery.
- IV tubes. These tubes go under the skin into your veins. They are used to give you medicine. These may be in your hands, arms, or neck.
- Urinary catheter. This tube carries your urine from your bladder into a container. It will be removed when you can go to the bathroom on your own.
- Pacer wires. These temporary pacer wires will be hooked to a pacemaker. The pacer wires will be removed the day before you leave the hospital.

We will move you to a regular hospital room when you are ready.

How will I feel after surgery?

Pain

After surgery you can expect to feel pain.

This may include:

- gas pains
- sore throat
- soreness
- backaches
- chestbone pain
- incision pain.

Most heart transplant patients are usually pain-free 2 weeks after the surgery. However, some people continue to have pain for a longer period of time.

Confusion

You may be confused for a short time after surgery because of the medicines you are taking.

How long will I be in the hospital?

Heart transplant patients are usually in the hospital for 7 to 10 days. However, this may change depending on how sick you were before your transplant and if you had any trouble during surgery. You will be able to leave the hospital when your doctor is confident that it is safe for you to leave.

Arrange a ride from the hospital

Your support person will need to make sure you have a ride from the hospital. You will not be allowed to leave on your own.

When You Leave the Hospital

When you leave the hospital, you will still be recovering. Because of this, you will need to stay in the Nashville area for at least 6 weeks after surgery. Your support person will need to be with you during this time.

Depending on your circumstances, your recovery time may be even longer. Your transplant cardiologist and nurse will tell you when you can safely leave the Nashville area.

Short-term care

Your short-term care will include:

- appointments with your doctor to see how your new heart is working
- blood work and possible scans to see how your new heart is working
- cardiac rehab 3 to 4 times a week for 4 to 6 weeks so you can learn to exercise with your new heart
- learning about a heart-healthy diet
- smoking cessation classes, if you used to use tobacco.



Biopsies

After transplant, you will begin to have biopsies of your heart. Biopsies let us know as soon as possible if your body has started to reject your new heart. You will have biopsies in both the short- and long-term.

How often you have cardiac biopsies will depend on the results

- After surgery, your biopsies will be done in the cardiac cath lab 1 time a week for the first 2 weeks. If there are no signs of rejection, you will then have biopsies done according to the schedule below. You will follow this schedule for as long as you show no signs of rejection.
- If you have a biopsy that shows that your new heart is being rejected, you will have to have biopsies more often.

Cardiac biopsy schedule (as long as there are no signs of rejection):

- Year 1
 - Biopsy 1
 - Two weeks later: Biopsy 2
 - Four weeks later: biopsy 3
 - Four weeks later: biopsy 4
 - After biopsy 4, you will have the next biopsy 6 weeks later. You will then have a biopsy every 6 weeks for the rest of the year.
- Year 2: You will have a biopsy every 3 to 4 months.
- Year 3: You will have a biopsy every 6 months (2 times during the year).
- Year 4 and after: You will have a biopsy 1 time each year, at a rate of every 12 months.

Long-term follow up with the transplant team

Though every effort will be made to transition your routine medical care to your primary care doctor, you will be followed in the transplant clinic for the rest of your life.

Follow up typically involves:

- frequent lab work
- a clinic visit once a year.

If you develop complications, you may need to be seen more often by the transplant team.

Risks and Potential Complications of Transplant

Heart transplant surgery is very complex and the risks are high. Your doctor cannot know exactly how your body will respond to a transplant until it happens. It is never fully known how the problem that caused your original heart problems will affect your transplant.

The success of a heart transplant will also be affected by:

- how sick you were before surgery
- how well you follow the rigorous treatment plan prescribed by the transplant team
- conditions surrounding the donor, such as the donor's health history and the condition of the organ when it is received in the operating room for surgery.

What are the risks associated with a heart transplant?

Risk of interrupted surgery

Sometimes a surgery is cancelled. This can happen if the surgical team decides a patient has become too much of a high risk. It can also happen if the donor heart does not seem healthy enough to use.

If your surgery is cancelled:

- you will return home and continue to wait for a new heart
- you will not lose your place on the waiting list.

Risk of rejection

The chance that your body will reject your new heart is always possible. The risk is highest the first year after your transplant. The good news is that rejection is usually treatable. Treatment may be provided at home or may require that you go to the hospital.

Your body will never develop a tolerance to the new heart. This means you have to take medicine to keep your immune system from attacking your heart. **You will have to take these medicines for the rest of your life.**

Risk of complications from your lifelong, anti-rejection medicines

Anti-rejection medicines are critical to preventing organ rejection. You will take them for the rest of your life after transplant. However, these medicines do have potential complications, including:

- increased risk of cancer
- high blood sugar levels
- damage to other organs, including your kidneys
- high blood pressure
- increased risk of infection
- increased risk of bone disease.

Risk of pain, bleeding, or injury

Transplant surgery can cause pain, bleeding, or damage to other organs in the belly.

Risk of sickness or infection

This surgery can cause sickness and infection, including:

- feeling sick to the stomach
- fevers
- pneumonia
- infections of the bladder
- infections to other organs in the chest.

Risk of blood clots

This surgery may cause you to have blood clots in your legs. This is dangerous since clots can travel to your lungs and make it hard for you to breathe.

To prevent blood clots from forming, you may be given special devices, such as plastic boots that inflate and deflate to keep the blood in your legs flowing during and after surgery.

Risk of nerve damage

This surgery can cause nerve damage, which can cause numbness, weakness, paralysis, or pain in your body. Most of the time these symptoms last only a short time and go away on their own. In rare cases they can last for extended periods or even become permanent.

Increased cancer risk

You will have a slight increase in the risk of getting certain kinds of cancers (skin and some lymph cancers). This is caused by the medicines you will take for the rest of your life to keep your body from rejecting your new heart.

Risk of disease or infection from the donor

The risk of catching a transmittable disease or infection from your donor is very rare. All donors are carefully tested for transmittable diseases and infections, including HIV, Hepatitis C, and Hepatitis B. However, you need to know that no organ transplant is completely free of this risk, even though this risk is low.

If you catch a disease or infection, you could end up with a serious illness. The situation would be complicated by the fact that after transplant, you will be taking medicines that weaken your immune system.

More about elevated risk donors

During the screening process, we may find that your potential donor has a higher than normal risk for having a transmittable disease or infection. This type of donor is often called a "PHS elevated risk donor." If we find that your donor has an elevated risk, we will discuss this with you to help you decide if you wish to accept the organ for transplant.

Increased heart disease risk

After surgery, you will have a greater risk of getting serious heart disease.

Risk of death

Like any surgery, there is the risk of death. This is especially true with heart transplant surgery given how serious it is.

Anesthesia risks

This surgery will be done under general anesthesia that will make sure you sleep and feel no pain during surgery. Any time general anesthesia is used there are a number of known risks. An anesthesiologist will explain these to you and give you a separate consent form to sign.

The risks of being on a heart-lung bypass machine

During surgery, your body will be attached to a machine (called a cardiopulmonary bypass machine) that moves blood through your body and carries oxygen to all your organs. Your transplant surgeon will explain the risks of being attached to this machine. These risks will be outlined on the surgical consent form that you sign for heart transplant.

The risks of blood transfusion

You may need to receive blood during or after this surgery. Even though all blood is carefully checked for HIV, hepatitis, and other diseases, anytime you receive blood, there is the risk of being infected.

Risks of pregnancy caused by transplant medicines

There are some transplant medicines that you should never take if you are pregnant or actively trying to become pregnant. These include mycophenolate mofetil or mycophenolic acid. These medicines may increase the risk of birth defects or pregnancy loss.

- If you are a woman of childbearing age who has not had a hysterectomy, you must use an acceptable form of birth control. Talk to your doctor about the best birth control options for you.
- If at any time you want to try to become pregnant, talk to your doctor in advance so you can begin taking alternative transplant medicines. Never stop taking any transplant medicines without talking to your doctor first.

Risk of transplant failure

If your transplant fails for any reason, you may be placed on the United Network for Organ Sharing (UNOS) list to wait for another heart. During this waiting time, it is possible that you could die.

Risk of additional medical problems

Other things that can happen include:

- injury to structures in your chest
- pressure sores on the skin caused by the position of your body during surgery
- burns caused by the electrical equipment used during surgery
- damage to your arteries and veins
- heart attack
- stroke
- seizures
- a scar at your chest incision.

Psychosocial risks

Having a transplant can be very stressful emotionally and psychologically, as well as physically. After transplant, there is the risk you may develop psychosocial health problems, including:

- depression
- post-traumatic stress disorder (PTSD)
- generalized anxiety
- anxiety about having to depend on others
- feelings of guilt.

There are many resources to help you if you have any of these issues. Let us know if you need any help at any time.

Financial risks

Getting a transplant can affect you financially, both now and in the future:

- During the evaluation process you may find out that you have some health problems that you didn't know about.
 - You may have to spend money to treat these problems.
 - Some of these problems could also affect your ability to get health or life insurance, depending on what they are.
- Getting a heart transplant may affect your ability to get life or health insurance in the future. Insurance companies may identify you as having a pre-existing condition and refuse payment for medical care, treatments or procedures.

Common Medicines for Transplant Recipients

As a transplant recipient, you will need to take various medicines for the rest of your life. You will get medicines to help your body accept your new organ. These are known as “immunosuppressive drugs” or “anti-rejection medicines.”

After transplant, patients usually go home taking 2 or 3 types of anti-rejection medicines. This is in addition to their other medicines. Anti-rejection medicines help your body accept the transplanted organ by lowering your body’s natural reaction, which is to attack foreign tissue. At first, you will take large doses of these medicines. The amount you take will gradually be lowered as your body accepts the new organ.

It is important that you ALWAYS take your medicines exactly as directed.

- You need to know the names of these drugs, how much you are taking, and what the pills look like.
- Your nurse will help you and your support person learn all about your medicines so you can take them yourself in the hospital and at home.
- Failure to take these drugs or skipping doses can cause your body to reject your new organ.
- It will be necessary for you to take all your medicines on a strict schedule.

Common medicines

The two most common anti-rejection medicines for transplant patients are:

- Tacrolimus (Prograf)
- Mycophenolate (Cellcept)

These medicines are very effective at lowering the risk of rejection, but they also have a number of potential side effects including:

- lower ability to fight infection
- increased risk of certain cancers
- increased risk of birth defects
- nausea or diarrhea
- high blood sugars.

There are additional side effects as well. We will talk with you about them.

After transplant, you will have to take anti-rejection medicine for the rest of your life. Once you are transplanted, we will give you more detailed information about the specific medicines you will be on and instructions on how to take them.

Prednisone

At our center, most transplant patients do not have to take prednisone long-term. But, if you were on prednisone before transplant, or if you are at a high risk of rejecting the transplanted organ, you will be sent home on a daily prednisone dose.

Your Life after Transplant

Prevent infection

The medicines you will take for the rest of your life will make you more prone to getting infections. The good news is that with good habits, you can stay healthy.

Some of these things you will need to do for the rest of your life. Other restrictions may be lifted in time. Your transplant doctor or nurse will tell you when some of these restrictions may be lifted.

Tips to prevent infection:

- Stay away from people who are obviously sick with the flu or a cold.
- Try to avoid children with chicken pox or strep throat.
- Wash your hands with soap and water before you eat and after you go to the bathroom.
- Shower or bathe regularly. Wash your incision as you would any other part of your body. Do not use lotions or powders on your incision.
- Clean cuts and scrapes right away with soap and water; then apply an antiseptic and a bandage.
- Do not, under any circumstances, change the litter in the cat box or birdcage without wearing gloves. This could cause a serious infection. Avoid cat scratches.

- Do not garden, dig in the dirt, or mow the lawn for 6 to 8 weeks after your transplant without gloves. Doing so could cause a serious infection.
- Keep your fingernails and toenails clean and trimmed. If your toenails are hard to manage or are ingrown, see a foot specialist.
- Talk to your doctor about getting the injected flu and pneumonia vaccines. Neither vaccine contains live viruses. Both vaccines are safe for you to have.
- Do not get any vaccine that contains live virus, such as the shingles, smallpox, polio, or nasal influenza vaccine.
- Talk to your doctor if someone in your house is going to get a live virus vaccine, such as the oral polio vaccine, and you have not already been vaccinated for that virus.
- Do not smoke. And do not expose yourself to second-hand smoke.
- Avoid community whirlpools.
- Avoid swimming in lakes or ponds.



If you want to have a child

Women

If you decide to become pregnant after your transplant, it is very important to discuss this with your transplant doctor or nurse in advance. Some of the medicines you will be on may not be safe for you to take during pregnancy.

Avoid pregnancy:

- for 1 to 2 years after your transplant
- at all times if you are taking the medicine mycophenolate.

Men

Although men may father children at any time, talk to your doctor before trying to conceive to be sure the medicines you are taking, such as mycophenolate, will not affect the baby.



Medicare and Financial Considerations

If I have Medicare, can I have my transplant at Vanderbilt?

Vanderbilt Transplant Center is currently Medicare-approved. However, the center is audited every 3 to 5 years for continued approval. If Vanderbilt loses Medicare approval, Medicare will no longer pay for transplants at this center. We will keep you informed about our status, and let you know if we become deficient in any Medicare requirements at any time.

Paying for your medicines

Without your proper medicines, your body will reject your new organ. You will need to be able to pay for your medicines or have enough prescription drug coverage at the time of your transplant. Without adequate drug coverage, your estimated costs for your medicines are about \$5,000 a month (\$60,000 a year) for the rest of your life. Because these costs are so high, it is important that you inform us of any changes in your drug coverage. It is also important that you always have pharmacy coverage.

If Medicare pays for your medicines

If Vanderbilt Transplant Center ever loses Medicare-approved status, your ability to have your immunosuppressive drugs paid for may be affected. Our financial counselor will talk with you about these details so you can make the best decision for you.

Fundraising

If you anticipate that you will have any major costs that may not be covered by your insurance (including prescription co-pays, travel, and lodging), we encourage you to consider doing some fundraising. Call the numbers below and to begin the process of fundraising as soon as possible.

These organizations have been able to make quite a difference in the lives of many of our patients. They are often able to help patients before, during, and even years after their transplants.

Two organizations that help transplant patients raise money:

- NFT (National Foundation for Transplants): (800) 489-3863
Transplants.org
- Help Hope Live (Formerly National Transplant Assistance Fund):
(800) 642-8399
HelpHopeLive.org

Your financial coordinators

Your financial coordinators will keep everyone at Vanderbilt informed about your current insurance coverage, will get all the necessary authorizations and approvals required from your insurance throughout the process, and will help you in any way possible with your insurance questions and concerns. We know this can be a lot of information to process all at one time. Please don't hesitate to call us.

Notify your financial coordinators immediately if:

- you begin or end the coverage you have through COBRA
- you obtain any new insurance
- any of your current insurance policies change or end
- there are any changes in your Medicare Part D coverage.

Learn more:

- Medicare
Medicare.gov
- Centers For Medicare and Medicaid Services (CMS)
CMS.gov
- Social Security Administration
SSA.gov

Resources and Patient Tools

United Network for Organ Sharing

You may get more information about transplantation from the United Network for Organ Sharing (UNOS).

- The UNOS website: **UNOS.org**.
- The UNOS toll-free patient phone line: 1-888-894-6361. This phone line:
 - is to help transplant candidates, recipients, donor, and family members understand the way organs are matched with patients who need them
 - can be used to find data, information, and statistics about transplants
 - can be used to talk about any problems you have at your transplant center or with the overall transplant system.

National and local transplant data

During your evaluation meeting, your transplant coordinator will provide you with copies of the current data about national and Vanderbilt-based transplants. This information will help you learn about the number of transplants performed both nationally and at Vanderbilt, including the results of the transplants.

Information sharing

As you go through the transplant process, members of your transplant team may access and share your medical information as permitted by law and Vanderbilt University Medical Center policies.

If you do end up getting a new heart, information about you, which will include your identity, will be shared with the United Network for Organ Sharing (UNOS). This information may also be sent to other transplant-related agencies or companies as permitted or required by law.

Information sharing is an important part of overall transplant program success, both nationally and locally. As a person who gets a transplant, it is expected that you agree to postoperative and long-term follow-up tests with the knowledge that this information will be shared.

Learn more:

American Heart Association
Heart.org

Coalition of Donation
ShareYourLife.org

National Foundation for Transplant
Transplants.org

National Transplant Assistance Fund
TransplantFund.org

United Network of Organ Sharing
UNOS.org

Vanderbilt Heart Transplant Program
VanderbiltHealth.com/transplant



