A patient’s guide to heart transplants
Is a heart transplant in your future?

If you are waiting for a transplant or wondering if it is a possibility for you, you have a lot to consider.

**You may have asked yourself:**

- How did I get to this point?
- Why me?
- What should I do now?

This is a normal reaction in trying to cope with what is happening to you. However, there is a lot that you can do to learn more about your situation. These steps may include reading, asking questions, and talking with your family, friends, and transplant team.

Remember that you are not alone. It may be helpful to talk to other patients who’ve already had a heart transplant. Don’t hesitate to talk to your transplant team about any issues or concerns you may have. They are there to answer your questions and provide support.

This booklet may answer some of your questions and it may prompt others that you had not thought of. Learning as much as you can about the transplant process may help you be an active partner in your own care.

The information in this brochure is intended for educational purposes only. It is not intended as a substitute for speaking with your healthcare provider.

Always consult your healthcare provider or transplant team before making any changes to your lifestyle, such as changing your diet or exercise plan, or before changing your medicine routine.
Important facts about the heart and its functions

What does your heart do?
The heart is a muscular pump about the size of a fist. It is located in the center of your chest behind your sternum (the flat bone at the center of your rib cage). The heart circulates blood, carrying oxygen and nutrients to the body’s tissues and organs. Circulating blood also removes waste from the body’s cells. The waste products are then filtered through the liver, kidneys, and lungs. Each day the heart beats about 100,000 times, pumping about 2,000 gallons of blood.

What happens when the heart is not working the way it should?
A number of diseases and conditions can injure the heart. These conditions include long-standing heart muscle disease (cardiomyopathy) or cell death caused by heart attacks, coronary artery disease, valvular heart disease, heart failure, and congenital heart disease. You may have been born with some of these diseases. Most take time to develop.

Symptoms for each of these diseases are different and depend on your condition and how serious it is. They may include:

- Shortness of breath
- Irregular heartbeat
- Tiredness
- Weakness or dizziness
- Confusion
- Edema (fluid buildup in the tissues)

Diagram of your heart. Your heart pumps blood throughout your body. Proper blood flow is critical for carrying oxygen and nutrients to all of the tissues and organs in your body.
Is a heart transplant right for you?
A heart transplant may be needed if the heart:
• Is damaged
• Is not working correctly
• Cannot be treated by any other medicines or surgeries
Some patients cannot get a heart transplant for many reasons, including:
• Cancer
• Blood clotting problems
• Other health or personal issues
However, for some patients, a heart transplant may be an option. There are machines that help improve how well your heart works. Sometimes they are used to help a person until a donor heart becomes available.

How do you get a new heart?
You will receive your heart from a deceased donor. This is someone who has agreed before their death to donate his or her organs for transplant. These organs are in short supply. If this is the procedure for you, you may be put on a waiting list until a suitable heart becomes available. It is difficult to know how long the wait might be.

Types of heart transplants
Heart transplant may be an effective treatment for life-threatening heart disease that can no longer be treated by any other option. Currently, the national 1-year survival rate for heart transplant patients is about 86% for men and 84% for women. There are also risks associated with heart transplants. See page 10 for a list of some possible complications.

There are 2 very different types of heart transplant surgeries, orthotopic and heterotopic. You may want to discuss these options with your transplant team so you can decide together which one is right for you:

Orthotopic transplant This is the more common transplant. It involves removing and replacing the recipient’s heart with a donor heart. Once the donor heart is removed, the transplant must take place within 4 to 5 hours.

Heterotopic (or “piggyback”) transplant In this transplant, which is less common, the recipient’s heart is not removed. Instead, the donor heart is placed into the right side of the recipient’s chest.

“The List”—waiting for a donor organ
There is a system to help make sure that patients who need a heart transplant are given priority based on a variety of factors. This is managed by the United Network for Organ Sharing (UNOS). UNOS coordinates efforts among transplant centers in the country to allocate donated organs.
Your position on the waiting list may depend on:

**Blood type (O, A, B, or AB)** Blood type must be compatible to receive a donor organ (see the blood type chart below).

**Antibodies** These help your body fight off foreign cells that might have formed because of an earlier transplant, blood transfusion, or pregnancy.

**Crossmatch** A test done to see if there is anything in your blood that will react against the donor’s cells.

**Status** Patients may be listed by UNOS status, which indicates categories for urgency. These categories are determined based on the degree of illness of the patient who needs the transplant.

**Time** Every time a heart becomes available in an area, a list of patients who might be compatible with that heart is generated. The patient’s status and the amount of time spent on the waiting list contribute to his or her position on the list.

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You are only on the list when your transplant coordinator or healthcare provider confirms that you are on the list. If you are not sure that you are on the list, talk to your transplant coordinator.

You never know when a donor will be available for you, so you must stay in constant contact with your transplant coordinator. If you move or change any of your phone numbers, tell the transplant center. That way you can be reached immediately when it is your turn to receive a donor heart.

**Your transplant team and the UNOS Web site, www.unos.org, may have the most current information.**

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<thead>
<tr>
<th>Donor’s Blood Type</th>
<th>Recipient’s Blood Type</th>
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<tr>
<td>O</td>
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<tr>
<td>A or O</td>
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<td>B or O</td>
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<tr>
<td>A, B, AB, or O</td>
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</table>
What are some possible complications from a transplant?

There is always a risk of complications after a heart transplant. These may include:

- Infection
- Rejection of the new heart
- Bleeding
- Clotting leading to heart attack, stroke, lung problems, or artery blockage
- Breathing problems
- Tiredness
- Rapid or irregular heartbeats
- Dizziness
- Medicine side effects
- Death

Infection and organ rejection are two serious things that may happen. The best thing you can do to prevent rejection is to take your medicines exactly as prescribed. If you feel very tired or are short of breath, call your transplant team right away, as these could be early signs of heart rejection.

Right after transplant, the high doses of medicines you will be taking to prevent rejection also lower your body’s ability to fight infection. You may need to be very careful and stay away from crowds and people who are sick. Wash your hands often. After a while, the doses of your anti-rejection medicines may be reduced. Then the chances of infection may be less. Talk to your transplant team about the restrictions you may need to follow.
Screenings that may happen before transplant

There are a number of tests that will be done for anyone who needs an organ transplant. These tests show your overall health and help your transplant team decide if a transplant is right for you. Some or all of the following tests (and possibly more) may be required.

- **Blood tests** are done to check for certain infections and provide information about:
  - Various blood cell counts, such as white cells, red cells, and platelets
  - Blood typing (O, A, B, or AB), which will help decide your compatibility with a potential donor
  - Blood chemistries, including those that measure blood sugar
  - How well your kidneys, liver, and heart work
  - The presence of viruses and/or antibodies to viruses
    - Determining whether you may need vaccinations before the transplant

- **Panel reactive antibody (PRA) tests** measure how active your immune system is. This level is usually higher when more antibodies are being made

- **Chest X-rays** will help show the health of your lungs

- **Imaging scans** can show the size and shape of your heart and the major blood vessels around it. Some imaging scans that may be done include:
  - Computerized axial tomography (CAT/CT) of the chest, abdomen, and pelvis will help rule out the presence of other diseases or tumors
  - Multiple-gated acquisition (MUGA) nuclear scan is used to check how well the heart is supplied with blood and how well it is pumping

- **Electrocardiogram (EKG)** shows how well your heart is working and if there is any past damage

- **Urine tests** can show whether there is bladder or kidney disease or infection

- **Lung tests** (which require you to breathe forcefully into a tube) measure how well your lungs are working and how well your blood carries oxygen

### Other common tests for heart transplants

<table>
<thead>
<tr>
<th>Test Type</th>
<th>What It Measures</th>
<th>Results May Show</th>
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<tbody>
<tr>
<td>Biopsy</td>
<td>Possible organ rejection</td>
<td>• Acute rejection</td>
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<td></td>
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<td>• Chronic rejection (narrowing of the vessels of the heart)</td>
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<td>• Infection</td>
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<tr>
<td>Cardiac catheterization (coronary angiography)</td>
<td>A dye is injected through a flexible tube (catheter) into the arteries and left ventricle of the heart, and a series of X-rays are taken to:</td>
<td>• Blockage of blood flow</td>
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<td></td>
<td></td>
<td>• How well the heart and blood vessels are working</td>
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<td></td>
<td></td>
<td>• Poorly functioning valves</td>
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<tr>
<td>Echocardiogram (ECHO)</td>
<td>Creates a video of the inside and outside walls of the heart and its valves</td>
<td>• Whether the heart is pumping well</td>
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<td></td>
<td></td>
<td>• Whether the heart is larger than it should be</td>
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<td></td>
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<td>• Whether the valves are opening and closing properly</td>
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Keep a record of all your tests

You and your transplant team may use the following table to keep track of the tests you may need to have. Your transplant team can check off those that you need in the Required column. You may want to carry this booklet with you so you always have a record of what needs to happen, when it needs to happen, and when it is done. Your age, sex, and health status may determine which tests you get.

Tests and evaluations

<table>
<thead>
<tr>
<th>Blood/Urine</th>
<th>Test Required</th>
<th>Date Scheduled</th>
<th>Completed</th>
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<tbody>
<tr>
<td>Alpha fetoprotein (AFP)</td>
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<td>Blood typing</td>
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<td>Coagulation profile</td>
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<td>Complete biochemical and liver profile</td>
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<tr>
<td>Complete blood cell count (CBC)</td>
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<tr>
<td>Drug and alcohol screening</td>
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<td>Lipid profile</td>
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<td>Renal function</td>
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<td>Urinalysis</td>
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<tr>
<td>Virology studies</td>
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<tr>
<th>Cancer Screening</th>
<th>Test</th>
<th>Required</th>
<th>Date Scheduled</th>
<th>Completed</th>
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<tr>
<td>Colonoscopy</td>
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<td>Mammogram</td>
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<td>Pap smear</td>
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<td>Upper endoscopy (EGD)</td>
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<tr>
<td>Prostate-specific antigen (PSA)</td>
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<thead>
<tr>
<th>Imaging/Function</th>
<th>Test</th>
<th>Required</th>
<th>Date Scheduled</th>
<th>Completed</th>
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<tbody>
<tr>
<td>Cardiac catheterization</td>
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<td>Cardiac (thallium) stress test</td>
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<td>Chest X-ray</td>
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<td>CT/CAT scan</td>
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<td>Echocardiogram (ECHO)</td>
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<td>Electrocardiogram (EKG)</td>
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<tr>
<td>Magnetic resonance imaging (MRI)</td>
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<tr>
<td>MUGA</td>
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<td>Nuclear bone scan</td>
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<tr>
<td>Pulmonary function test</td>
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<tr>
<td>Ultrasound of chest, abdomen, and pelvis</td>
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<tr>
<th>Other</th>
<th>Test</th>
<th>Required</th>
<th>Date Scheduled</th>
<th>Completed</th>
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<tr>
<td>Dental examination</td>
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<td>Heart biopsy</td>
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What does all this testing mean?
Most of the tests are done to help your transplant team decide how to improve your chances of getting the best results from your heart transplant. These tests and discussions will show if:

- Your disease can be treated effectively with a heart transplant
- There are any problems, such as blocked or closed blood vessels, that could get in the way of a successful transplant
- Your kidneys, lungs, and liver are strong enough for a transplant
- There are emotional and family issues to deal with

Is everyone a candidate for a heart transplant?
Not everyone is a candidate for a heart transplant. The following may prevent a person from receiving a transplant*:

- Severe liver, kidney, or lung disease
- Advanced cancer
- Use of alcohol, street drugs, or tobacco
- HIV-positive and/or AIDS
- History of not following medical instructions

The most important consideration is that you are healthy enough to have the transplant.

Who are the members of your transplant team and what do they do?
It is important for you to know the medical professionals who will be taking care of you and what they do. Each team is different, but your team may include these people:

**The transplant surgeon** The transplant surgeon does the transplant. He or she also checks your health before the transplant to make sure you’re healthy and after the transplant to make sure your new organ is working well.

**The transplant doctor** The cardiologist is the heart doctor who checks all nonsurgical aspects of your care, such as rejection episodes and medicines after transplant. You will see this doctor often. Ask as many questions as you want.

**The consultant doctors** Many medical specialists are involved to make sure you get the care you need. Depending on the type of organ transplant, your doctors may include nephrologists (doctors who treat kidney disease), cardiologists (doctors who treat heart disease), infectious disease specialists (doctors who treat contagious diseases), hematologists (doctors who treat blood disease), oncologists (doctors who treat cancer), anesthesiologists (doctors who manage anesthesia), psychiatrists/psychologists (doctors who treat mental illnesses), pulmonologists (doctors who treat lung disease), and hepatologists (doctors who treat liver disease).

**The transplant nurse** The transplant nurse is responsible for many duties, some of which include:

- Organizing your evaluations
- Checking lab results
- Educating you before and after your transplant
- Giving you discharge instructions
- Keeping all your medical information

Think of him or her as the person who will coordinate your care and keep track of how you are doing throughout the transplant process.

**The physical therapist** He or she may give you an exercise plan to help you keep your muscles strong, control your weight, and keep up a normal activity level after your transplant.

*Each transplant center has its own criteria for potential transplant candidates. Be sure to check with your center about the particular factors that might exclude you from being considered for an organ transplant.
The dietitian/nutritionist The dietitian/nutritionist is trained in diet and nutrition. This team member will help you with meal planning and any dietary changes that you may need before and after your transplant.

The financial coordinator This member of the team is trained to help patients and their families deal with finances. He or she can also tell you about ways to get help with medical coverage.

The social worker The social worker can help you deal with any emotional issues, and can help you plan your return to work and other activities. He or she may also help you find a place to live. In addition, he or she can help with finding transportation, financial resources, and getting your medicines.

The pharmacist This member can help coordinate your prescriptions before and after your transplant. He or she also may inform you about how the medicines work and how they affect you.

Other team members There may be other doctors, nurses, and coordinators who are part of your transplant team, depending on your needs. Everyone is working together on your behalf. These other team members may include physician's assistants (PAs), operating room and intensive care nurses, nurse practitioners (NPs), medical residents, procurement coordinators, case managers, and transplant assistants.

You One of the most important members of the transplant team is you. You are encouraged to share your feelings, ask questions, and discuss issues that are important to you.
Tips for staying healthy before transplant

Physical health

• Being active and working your muscles to the best of your ability can help. Tell your transplant team about any physical limitations
• Talking to your nutritionist or dietitian can help you eat healthy, well-balanced meals. You can also talk to your dietitian about trying to lose weight if necessary
• Do not drink alcohol or use street drugs. You may not be able to get a transplant if you smoke, so ask your transplant team if you need help quitting
• See a doctor to get treatment for other healthcare problems, including high cholesterol, high blood pressure, and diabetes

Discuss your physical activity limitations with your transplant team.

Emotional health

• Talk to your transplant team to help you stay as mentally healthy as possible. If you are having trouble coping, consider counseling
• Your transplant team may tell you about support groups and antidepressant medicines
• Try to stay in touch with the people you care about
• Try to let people help by asking them to do things like picking up groceries, running errands, and cooking meals

Always consult your healthcare provider or transplant team before making any changes to your lifestyle, such as changing your diet or exercise plan, or before changing your medicine routine.
Staying prepared and proactive

- Finding out about your financial options by talking to someone at your transplant center may help you make financial plans to minimize stress and prepare you for your future.

- Before your transplant, try to arrange for someone to:
  - Take you to the transplant center when the call comes
  - Prepare food and care for you after the transplant
  - Go with you to the center for your follow-up visits and help keep track of your medicines
  - Run errands and do housework for you when you’re not able to

Transplant recovery

Before your transplant, your transplant team will discuss the transplant and possible risks with you in detail. During the transplant, you will be placed on a heart-lung machine. The machine will take over the work of your heart and lungs. The transplant may take 4 to 12 hours or longer. Your surgeon will keep your family informed during the transplant.

Once your new heart is in place and all the blood vessels are reconnected, you will be removed from the heart-lung machine and taken to the intensive care or cardiac care unit to begin your recovery. You will stay in that unit for about 2 to 3 days.

When you first wake up after the transplant, you may feel drowsy and a little sore. You may need to be in the hospital for 7 to 16 days, but a longer stay is sometimes needed.

Tips to help keep your heart healthy

Medicines after transplant

To your body, the new heart may seem like something that doesn’t belong. Your body’s protective immune system may recognize your new heart as foreign. This is why you may need to take a number of medicines for the rest of your life. They are called “anti-rejection” or “immunosuppressive” drugs. Before you leave the hospital, your transplant team may help you understand what your medicines are for, and how and when to take them.

Follow-up lab tests

It is also important that you have follow-up lab tests done as frequently as advised by your transplant team. The transplant team can check the health of your new heart and make sure that the medicines are working.

Your transplant team after transplant

Always tell your team about anything that has happened to change your health. If you have any questions, call your transplant team and ask them. They are there to help you.