

Chapter 1: Introduction

Welcome to the Heart Transplant Program

Tip

Heart transplant costs are an accepted surgery by Medicare and most insurance providers.

Welcome to the Abbott Northwestern Hospital/Minneapolis Heart Institute® Transplant Program. You have joined a small but growing number of people given this special gift.

The goal of a heart transplant is to both extend your life and improve your quality of life. The current 1-year survival rate for adults who received a new heart is 90.2 percent.

The 1-year survival rate through Abbott Northwestern Hospital's program is 91.7 percent.

Complete national and hospital-specific statistics are updated every January and July. Ask your transplant coordinator for details if you would like to see the information.

Each person's recovery and health after a transplant is unique. Some people have rejection episodes and other problems (complications). Other people will have only a few problems.

Most rejections and infections occur during the first three months but you are always at risk for complications. Your health before the transplant will also affect your health during recovery.

To have the best possible chance for a healthy life, you will need to make — and commit to — lifestyle changes:

- follow the prescribed medicine plan
- keep transplant clinic and doctor appointments
- keep scheduled lab tests
- eat healthful food
- get regular exercise
- avoid tobacco and street drugs
- protect yourself from infection.

You will need to stay in touch with the transplant center health care team. They will help with your recovery for the rest of your life.

Your Transplant Team

You will meet a variety of health care providers who will work together for your care. Each one plays a special role in your recovery.

Cardiologist (heart doctor) or advanced practice provider

He or she works with you through your regular exams in the hospital and at the transplant clinic and keeps your regular doctor informed of your progress.

Transplant surgeon

This is the surgeon who performs the transplant. He or she will examine you during your hospital stay.

Consulting doctors

They have areas of expertise and may be part of your care if needed.

Your regular (primary) doctor

Your regular doctor will work closely with your transplant center doctor. You will see your regular doctor for office visits, physical exams and health screenings.

Transplant coordinator

This is a registered nurse who will coordinate your transplant care from evaluation, to surgery, and through long-term follow-up.

He or she will tell you of any changes in your care plan, answer your questions, serve as a liaison between you and the transplant doctors, and will keep your regular doctor informed.

Pharmacist

The pharmacist will answer your questions about your medicines.

Registered nurses

Nurses will provide 24-hour care for you during your hospital stay. They will teach you about the procedures, medicines and self-care activities.

Dietitian

He or she will meet with you about heart-healthy foods that fit your needs.

Occupational therapists, physical therapists or cardiac rehabilitation therapists

They work to improve your confidence, strength and endurance after your surgery. They will create an exercise program that begins in the hospital and continues through recovery at home.

Social worker

He or she will help make arrangements for your hospital stay and return home. This includes counseling and support. He or she will answer your questions about financial concerns and community resources.

Financial operations supervisor

He or she works with you and your insurance company to answer your insurance and money concerns.

Chaplain

He or she will offer support as you work through the emotional and spiritual responses to the transplant.

Transplant Process

Getting a new heart is more than surgery — it is a process that begins when you and your health care team talk about transplant as a possible treatment option.

Exam before your surgery

You may qualify for a heart transplant when all other treatments have been tried. To see if a transplant is right for you, your doctor will schedule a health exam that includes:

- blood tests
- X-rays
- heart catheterization (a test to tell how well your heart pumps blood through your arteries)
- tests to determine your overall state of health.

During this time, you will learn about the surgery, risks and benefits, after care, and lifestyle changes you may need to make.

If you qualify, your name will be added to the United Network for Organ Sharing (UNOS), which matches available donors to waiting recipients. Your blood type, weight, medical urgency status, and any special tissue matching requirements are registered.

Waiting for a donor heart

The time waiting for a heart may seem quite long. It can range from several months to years. You will need to see your regular doctor and your transplant cardiologist for treatment while you wait.

During this time, you will likely be stressed about your lifestyle, work, family, and money. While keeping a positive outlook may be a challenge, this may be a time of great personal reflection and growth. The transplant team will help you. You are encouraged to meet other patients and attend support group meetings.

Contacting the Heart Donor's Family

Information about the donor will be kept confidential.

After your transplant, you may be able to talk to your donor family through letters. Your letters are sent to LifeSource and forwarded to the donor family.

Letters of thanks are much appreciated by donor families. Your transplant team can give you a LifeSource brochure, "Writing to Donor Families," to help guide you.

If the donor and recipient families agree, there may be a meeting at a future time.

Where a donor heart comes from

A donor is someone who has had a severe brain injury and cannot recover. The donor has been pronounced brain dead by a doctor.

Brain death means that the brain has stopped working. With the help of a machine (respirator) to breathe, the donor's body may be able to keep some organs working. The donation of organs depends on the donor's cause of death and medical condition, and the donor family's permission.

Donors may be up to 60 years old, but the age is usually younger. LifeSource is the organ procurement agency that serves Minnesota, North Dakota, South Dakota and part of Wisconsin.

LifeSource donor coordinators work closely with donor hospital staff to determine whether a patient meets criteria to be an organ donor and provides information to the donor family, offering the option of organ donation.

Once the family gives permission for donation, the donor coordinator follows national UNOS guidelines to place organs with waiting candidates.

Organs are placed in order of medical urgency and the amount of time each patient has been waiting. The transplant center of each candidate is contacted, and donor information is reviewed with the transplant surgeon.

What you need to do when a donor heart is available

- If you are at home, you will receive a phone call or a page. You will need to travel right away to Abbott Northwestern Hospital. **Important: Do not eat or drink anything after you receive this call.**
- If you are already in the hospital, your nurse or doctor will tell you so that you can call your family.

The surgery may be canceled at any time during this process. If this happens, the transplant coordinator or doctor will talk with you and your family about what happened.

Care Circle

Members of your care circle include your family members, friends or others close to you.

They are not part of your health care team.

Transplant Surgery

What happens if your health gets worse

If your health gets worse, you may need to stay in the hospital for treatment. The transplant team will watch you closely and keep you informed of any changes.

If you are too ill to receive a donor heart, the team will be there to support you and talk about your options for medical care.

There is close communication between the donor hospital and Abbott Northwestern Hospital. When the donor heart is ready to be transported, your surgery has already started:

- The surgeon opens your breast bone.
- A heart-lung bypass machine delivers oxygen to your blood and circulates the blood to the body so the old heart can be removed.
- The surgeon sews the donor heart into place by attaching it to these vessels:
 - major blood vessels (aorta and pulmonary artery)
 - superior vena cava and inferior vena cava.
- The surgeon may make changes if needed.
- As blood is allowed to flow into the donor heart, it will often start to beat on its own. Sometimes, an electrical shock is used.
- The surgeon will close your chest and you will be taken to the Cardiovascular Intensive Care Unit.
- Transplant surgery takes 4 to 6 hours.
- Members of your care circle will be updated on the progress of your surgery.

Hospital stay

After several days in the Intensive Care Unit, you will be moved to an Intermediate Care Unit until you are ready to go home.

You can expect to be in the hospital 1 to 2 weeks, or longer if needed.

Recovery at home

Once you return home, you will have many appointments at the transplant clinic for biopsies, checkups and blood tests. If you live outside the Minneapolis-St. Paul area, you may need to stay in the local area for up to several weeks before returning home.

During the first few weeks to months at home, you will be able to regain independence and confidence.

It is important to remember that the goal of the transplant is to allow you to continue your normal life, including work, school and other activities. Most patients are physically able to resume these activities within three months.

Reaching all of your goals may take longer than you think. Talk with members of your transplant team about your goals, progress and any problems you have along the way. They will help you achieve the highest quality of life possible.

Follow-up directions

There are many new things to learn and guidelines to follow. Sticking with these changes can be difficult. Your transplant team members believe in your ability to make your transplant a success.

Here are some tips for your success:

- It is important that you take your medicines as directed.
- Keep all clinic and lab appointments.
- Call your transplant coordinator if you:
 - need information about tests or procedures
 - have questions, problems or concerns.
- Remember: your health care team is here to help you.