

Heart Transplant

Fourth edition

Developed by Allina Health.

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For specific information about your health condition, please contact your health care provider.



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Table of Contents

Introduction

Welcome	5
Your Transplant Team	5

Chapter 1: Evaluation Process

Evaluation (Tests You May Need)	9
Candidate Selection	11
Where a Donor Heart Comes From	13
What to do When You Get ‘the Call’	14
What Happens if Your Health Gets Worse	14

Chapter 2: Surgery

Transplant Surgery	17
Hospital Stay	19
Discharge (Leaving the Hospital)	20
Activity Restrictions	21
Cardiac Rehabilitation.....	21

Chapter 3: Follow-up Visits

Heart Biopsy	25
Transplant Clinic	29
Annual Evaluation	30

Chapter 4: Complications (Problems)

Rejection	33
Infection.....	35
Coronary Artery Vasculopathy (CAV)	36
Cytomegalovirus (CMV) Infection	38

Chapter 5: Medications

General Information	41
Your Medications	43
Tacrolimus: Prograf	43
Mycophenolate Mofetil: CellCept (MMF)	45
Sirolimus (Rapamune)	46
Prednisone	47

Table of Contents

Sulfamethoxazole Trimethoprim (Septra, Bactrim)	48
Acyclovir (Zovirax)	49
Valganciclovir (Valcyte)	50
Voriconazole (Vfend)	51
Nystatin (Liquid)	52
Aspirin	53
Pravastatin (Pravachol), Atorvastatin (Lipitor), Rosuvastatin (Crestor)	54
Famotidine (Pepcid), Pantoprazole (Protonix, Lansoprazole (Prevacid), Omeprazole (Prilosec).....	55
Terbutaline Sulfate (Brethine)	56

Chapter 6: Life After Transplant

Lifestyle Changes.....	59
Healthy Eating	59
Routine Health Care	63
Cancer Screening	64
Immunizations (Shots)	65
Sun Protection and Skin Care	65
Travel	67
Alcohol	67
Tobacco	68
Emotional Changes	68
Sexual Issues	69
Birth Control and Pregnancy	69

Chapter 7: Special Helps

Financial Information	73
Lab Glossary.....	77
Glossary.....	80
Resources	84
Resources for Quitting Tobacco.....	85
Worksheets	86
Biopsy Results	86
Temperature, Pulse and Blood Pressure Checks	87
Schedule of Appointments	89

Welcome to the Heart Transplant Program

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

Your Transplant Team

Tip

Your evaluation, surgery and follow-up care will be done at Abbott Northwestern Hospital.

Your transplant team includes the following people.

Advanced heart failure cardiologists (heart doctors)

These doctors will oversee your care. They are part of the advanced heart failure, VAD (ventricular assist device) and transplant team at Abbott Northwestern. They are members of the Minneapolis Heart Institute®.

They help patients in the hospital and in the clinic. This means you may see different doctors at each visit. All of the doctors have special training in transplant care.

Transplant or cardiothoracic surgeon

This doctor, who specializes in surgery of heart disease, will perform your surgery and take care of your transplant-related needs after surgery.

Heart failure nurse practitioners

They will help the doctors with your care. They work in both the hospital and the clinic. This means you may see different nurse practitioners at each visit.

Transplant coordinator

This is a nurse who has specialized training in heart transplant. This person will:

- help with your transplant care from the evaluation to long-term follow-up
- teach you about your surgery and after care
- tell you results of test and procedures
- help with your clinic care
- be available for questions and concerns, and 24 hours a day for emergencies.

Social worker

This person will help you with social, emotional and financial concerns that you may have. The social worker:

- can help you prepare for some of the lifestyle changes that are part of living with a transplant
- will connect you with resources.

Chaplain

This person will be available as a support person for you and members of your care circle (family, friends and others close to you).

Pharmacist (doctor of pharmacy)

This person will:

- make sure you are taking the right medications and doses
- make sure your medications aren't working against each other (known as an interaction)
- make sure your medications are working as they should
- teach you about medications and side effects.

Palliative care team

Palliative care can help increase your ability to cope during treatment while maintaining your best physical, emotional and spiritual health possible.

Before your surgery, a member of the palliative care team will meet with you and members of your care circle. Talking about your health care goals before surgery helps guide your care.

Members of the palliative care team are available at any point in your care.

Dietitian

This person will:

- talk with you about your nutrition needs before and after surgery
- teach you about any special diet you need to follow.

Chapter 1: Evaluation Process

Evaluation (Tests You May Need)

Getting a new heart is more than surgery. It is a process that starts when you and members of your health care team talk about transplant as a possible treatment option.

The first step in the process is an evaluation. This evaluation involves testing as well as meeting. You will meet with some members of your transplant team. They will explain the criteria you need to meet to qualify for a transplant.

The purpose of these tests is to look for any conditions that need to be treated before transplant surgery. These tests could also show conditions that may not be able to be treated. This will be part of the final decision.

They will talk with you about which of these tests you need:

- blood tests**
- echocardiogram:**
This ultrasound shows your heart muscle, heart valves and the sac surrounding your heart.
- electrocardiogram (ECG or EKG):**
This test records the electrical activity of your heart.
- angiogram:**
This test shows how well your heart pumps blood through your arteries and shows any blockages or areas of narrowing.
- cardiac catheterization (right-heart cath):**
This test measures the pressures on either side of your heart. It gives information about how well your heart is pumping and how much resistance your heart has to pump against in your lungs.
- exercise stress test:**
This test checks how well your heart reacts when it is working at its hardest.
- abdominal ultrasound:**
This test uses sound waves to look at your liver, gallbladder, pancreas, spleen and kidneys.

❑ chest CT:

This test uses detailed X-ray to look at your lungs and the position of your heart inside your chest.

❑ pulmonary function tests:

These breathing tests check how well your lungs are working.

❑ colonoscopy:

This procedure uses a camera to look at your colon and rectum for polyps and signs of cancer.

❑ carotid ultrasound:

This test uses sound waves to see how blood flows through the carotid artery in your neck.

❑ dental exam

Dental clearance is needed to make sure that there are no infections in your mouth. The clearance form can be faxed directly to your dental office.

You may also need other tests such as a mammogram, gynecological exam, Pap test, and ultrasound of the blood flow in your legs.

Your role

Your commitment is very important to your recovery and success after transplant. As you begin the transplant evaluation, be honest with yourself. Are you able to:

- do all the follow-up care you need such as:
 - frequent clinic appointments and lab draws
 - timely communication with your transplant team
 - getting routine care from your primary care provider
- take your medications as directed
- follow lifestyle changes such as:
 - following a heart-healthy diet
 - getting regular exercise
 - lowering your stress.

Speak up if you have any concerns or if you need resources. Members of the transplant team want you to be successful.

Candidate Selection

After your tests, procedures and meetings are done, members of the transplant team will review the results. There are many factors that weigh in before a final decision is made.

The final decision will be one of 3 options:

- approval to be placed on the heart transplant wait list
- more information is needed before approval to be placed on the heart transplant wait list
- does not meet criteria for a heart transplant at this time.

Your transplant coordinator will call you with the results and send you a letter.

Tip

Go to unos.org to learn more about heart transplant and resources.

If the team determines that you qualify for heart transplant and that transplantation is the best next step for you, your name will be added to the United Network for Organ Sharing (UNOS). UNOS matches available donors to waiting recipients. Your blood type, size, medical urgency status, and any special tissue matching requirements are registered.

Waiting for ‘the call’

The time waiting for a heart can range from days to years. You will need to see your primary care provider and your heart failure cardiologist for treatment while you wait.

Your health before the transplant will affect your health during recovery.

Being listed for heart transplant can often leave the question, “now what?” Below are some guidelines and resources while you wait.

- **Stay healthy.**
 - Wash your hands often.
 - Eat healthful foods.
 - Wear a face covering when in public places.
 - Avoid being around sick people.
- **Get regular exercise.**
 - Go to cardiac rehabilitation (if available).
 - Go for walks.
 - Exercise as much as you are able.
- **Keep your routine clinic visits.**

Tip

Go to allinahealth.org to find a provider near your home. Check with your insurance to make sure the provider is in your network.

- Keep all routine health visits with your primary doctor and your heart failure team. This includes:
 - preventive health exams (such as colorectal cancer screening or mammogram)
 - vaccines (such as influenza or pneumonia)
 - yearly physical
 - blood pressure checks
 - regular dental checks.
- If you don't have a primary care provider, now is the time to find one. This person is a key part of the your health care team after transplant.
- **Get lab tests done.**
 - You may need to have some organ-specific labs. A member of the transplant team will call you with the results.
 - You will need to be tested for street drugs and nicotine. Using either will affect your status on the waiting list.
- **Take care of your mental health.**
 - Talk to family and friends about how you are feeling.
 - Attend a transplant support group to talk with others who have had transplants.
 - Call a transplant social worker at 612-775-5007 to learn when and where the group meets.
 - The transplant social workers are great resources if you are struggling with other mental health needs.
- **Stay in contact with transplant coordinator.**
 - Call the transplant office at 612-863-5638 and ask for a transplant coordinator if you have any changes or updates with your health.
 - The transplant coordinator will try to see you at every visit you have at Abbott Northwestern Hospital or the clinic to answer questions and check in with you.
- **Call the transplant office if you plan to travel.**
 - Call the transplant office at 612-863-5638 if you plan to travel more than 1 hour away from your home.
 - Your transplant team needs to know that you are within an available distance to get to Abbott Northwestern Hospital if a heart becomes available.

■ **Call the transplant office if you have any insurance changes.**

— Call the transplant office at 612-863-5638 if you:

- have any changes in your health insurance
- are thinking about changing your insurance.
New insurance could affect your coverage for heart transplant and post-transplant medications.

Where a Donor Heart Comes From

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 if they wish to receive contact.

Letters of thanks are usually 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.

The donation of organs depends on the donor's cause of death and medical condition, and the donor family's permission. Acceptable heart donors may be up to 55 years old, but the age is usually younger.

A donor is someone who has had a severe brain injury and cannot recover. These donors fall into 2 categories: those declared brain dead and those who donate after circulatory death.

Brain dead donors have been declared brain dead by a doctor. Brain death means that the brain has stopped working. With the help of a machine (ventilator) to breathe, the donor's body may be able to keep some organs working.

Donation after circulatory death donors (DCD) do not meet the strict criteria for brain death, but require life-sustaining medical treatment for support. If the family decides they would like to attempt donation, life sustaining measures are withdrawn.

If the donor's heart stops beating within a narrow window of time, death is declared. The heart can be recovered and restarted on a heart pump (heart in a box).

LifeSource is the organ procurement organization that serves Minnesota, North Dakota, South Dakota and part of Wisconsin.

LifeSource donor coordinators work closely with the 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 team.

What to Do When You Get ‘the Call’

The transplant coordinator will call you when a donor heart is available.

If you are at home, the transplant coordinator will tell you:

- when to go to Abbott Northwestern Hospital
- which medications to take
- when to stop eating.

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.

What Happens if Your Health Gets Worse

If your health gets worse while you are waiting for a heart transplant, you may need to stay in the hospital for treatment. The transplant team will watch you closely and tell you about 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.

Chapter 2: Surgery

Transplant Surgery

Before surgery

- You will have an IV (intravenous) line placed in your arm or hand.
- You will have blood drawn and a chest X-ray.
- The surgeon and heart failure doctor will review the surgery and risks with you and members of your care circle.
- There are usually many hours of waiting between learning that a donor has been matched and the surgery.

There is close communication between the donor hospital and the heart transplant coordinator at Abbott Northwestern Hospital. When it's time for your surgery, a team of people will take you down to the operating room.

Tip

Your surgery will start when the donor heart is being transported to Abbott Northwestern Hospital.

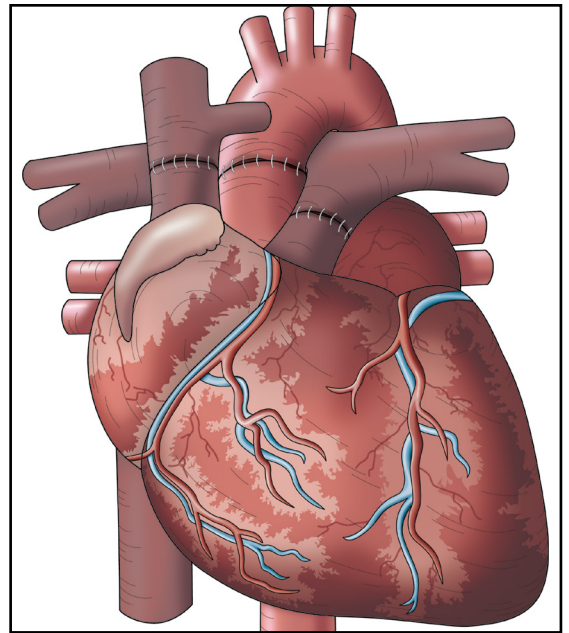
During surgery

- You will have:
 - more IVs placed in your arm or neck
 - a breathing tube placed into your airway (throat) to help you breathe
 - a urinary catheter placed in your bladder to drain your urine.
- You will be given medication to put you to sleep.
- The surgeon will make an incision in the midline of your chest and open your sternum.
- A heart-lung bypass machine will take over the work of your heart and lungs.
- Once the donor team arrives with the new heart, your heart will be removed.

Tip

Members of your care circle will be updated on the progress of your surgery.

- The surgeon sews the donor heart into place by attaching major blood vessels: aorta, pulmonary artery, superior vena cava and the inferior vena cava.
- 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 with stitches or surgical staples. (See the drawing.)
- The surgery usually takes 4 to 6 hours. It can take longer if you had a previous open heart surgery or if you have a left ventricular assist device (LVAD) in place.



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After surgery

- You will be taken to the cardiac Intensive Care Unit (ICU) to recover.
- In the ICU you will be:
 - on a breathing machine (ventilator) and unable to talk for the first few hours after surgery
 - connected to a heart catheter that monitors your vital signs continuously.
- Members of your transplant team will watch you closely.
- Once you are able to be off the ventilator and the breathing tube is removed, the nurses and physical therapist will work with you to get up and out of bed.
- A typical stay in the ICU is 2 to 4 days. Once you are well enough to have the heart catheter removed, you will leave the ICU.

Hospital Stay

Tip

Use the worksheets on pages 86-90. Bring them with you to follow-up appointments.

- You will be taken to the Telemetry Unit where your vital signs are monitored, but not as often as in the ICU.
- Members of your care circle can visit with you. They will learn how to help you take care of your new heart.
- The heart transplant coordinators will regularly visit to make sure that you understand how and when to take your medication.
- They will teach you and your care circle how to watch for complications (problems).
- Physical and occupational therapists will work with you to regain your strength. They will teach you how to move safely and how to increase your activity at home.
- The average hospital stay after heart transplant is 2 weeks but it could be longer.
- You will need to stay within 1 hour of Abbott Northwestern Hospital for 1 to 2 months after surgery. The length of time will depend on your biopsy results and overall health.

Members of your transplant team will talk with you before you leave the hospital.

- If you live outside of the local area, you will need to arrange for a place to stay. You can stay with family, friends, or at a hotel. If these are not options for you, social worker may be able to help.

Discharge (Leaving the Hospital)

While still in the hospital, you will learn about routine care, medication schedules and clinic visits. The more you learn, the better you can manage your health needs at home.

You will be discharged from the hospital once you:

- have recovered from surgery
- can manage your medication
- have no medical issues.

Before you leave the hospital, the transplant coordinator will give you education about:

your medications

- what they are (brand name and generic name)
- when to take them
- how to take them
- why you need to take them
- possible side effects
- how to use the medication list when filling your pill box (see page 74)

follow-up biopsy and clinic schedule

signs of rejection and infection (see pages 33-36)

your blood pressure

- Check your blood pressure 1 to 2 times each day at least 1 hour after you take your medications.
- Call the transplant office if your top number (systolic blood pressure) is more than 135 or less than 110.

your weight

- Weigh yourself on the same scale every morning right after you wake up.
- Call the transplant coordinator if you gain 3 pounds in 1 day or 5 pounds in 1 week.

your temperature

- Take your temperature any time you feel feverish.
- Call the transplant coordinator if your temperature stays above 100.5 F for several hours.
- Do not take any medication to lower your temperature until the transplant coordinator says it's OK.

Activity Restrictions

The guidelines below will help you know which activities you can do after surgery and those you should avoid.

Weeks 1 to 6

- Do not drive for at least 6 weeks. Your transplant teams will tell when you can drive.
- Do not lift, push or pull anything that weights more than 10 pounds.
 - For example, do not vacuum, push the lawn mower or snowblower, open or close heavy doors, or change bed sheets.
- Climb stairs only as needed. Do not carry anything while climbing stairs for at least 2 weeks.

Weeks 7 to 12

- Do not lift more than 20 pounds.
- Rest between activities.

Cardiac Rehabilitation

The goal of your heart transplant is to allow you to continue your normal life, including work, school and other activities. You should be physically able to resume your activities in about 3 to 6 months.

Cardiac rehabilitation is an important part of your recovery. It starts when you are in the hospital and continues at a rehabilitation center nearest to your home.

The benefits of regular exercise include:

- more strength and stamina
- better blood pressure control
- feel more confident and independent
- easier to maintain or lose weight
- have more energy
- lower cholesterol and triglyceride numbers
- less stiffness, soreness and discomfort.

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 want to help you reach your goals.

Warm up and cool down

The nerve that ran from your heart to your brain was cut during surgery.

Your new heart will need more time to increase speed after starting exercise and longer to return to your resting rate after exercise. It is important to warm up and cool down.

For both a warm up and cool down, walk 3 to 5 minutes at a leisurely pace before and after increasing your activity.

Signs that you are doing too much

As you exercise, check your body's responses. Stop and rest if you have any of the following:

- feel dizzy or lightheaded
- feel very tired or drained
- are short of breath (making talking difficult)
- have an upset stomach or start vomiting
- feel as if your heart is suddenly racing or pounding.

Call the transplant coordinator if any of these symptoms do not go away with rest.

Chapter 3: Follow-up Visits

Heart Biopsy

Important

Do not take your morning medications before your biopsy.

Bring your pill box with you. You will take your medications **after** the labs are drawn before the biopsy.

Tip

Keep track of your biopsy dates and results in the back of this book on page 86.

General information

In the first year after transplant you will have regular biopsies. This test is the only reliable way to tell if your body is rejecting your new heart. It can help your cardiologist find rejection in its earliest stage even before you notice any symptoms.

During a biopsy, your transplant cardiologist will take a tiny sample of tissue from the inner surface (endocardium) of your heart.

Your biopsy will be scheduled early in the morning at the Abbott Northwestern Heart Hospital. Go to the Catheterization Lab (CV Lab) on the third floor.

A pathologist will evaluate the sample within 24 hours. A heart transplant coordinator will call you with the results.

Biopsy risks

Risks of a heart biopsy are low. But it's important to tell the nurse or doctor if you have:

- shortness of breath
- chest pain
- dizziness
- weakness.

Biopsy Grading Scale

- **Grade 0R:** no rejection
- **Grade 1R:** mild rejection. The sample shows lymphocytes (white blood cells) with up to 1 area of heart cell injury.
- **Grade 2R:** moderate rejection. The sample shows 2 or more areas of lymphocytes with heart cell damage.
- **Grade 3 R:** severe rejection. The sample shows many areas of heart cell injury with other signs of heart cell damage.

Heart biopsy schedule

Your cardiologist may change the schedule based on your health or if you have an episode of rejection.

Here is the general heart biopsy schedule:

- week 1
- week 2
- week 3
- week 4
- week 6
- week 8
- week 10
- week 12 (3 months): This will include a clinic visit, testing and an angiogram. You will need someone to drive you.
- month 4
- month 5
- month 6: This will include a clinic visit and testing.
- month 9: This will include a clinic visit and testing.

After 9 months, biopsies will be done only as needed.

How a biopsy is done

- Do not take your morning medications. Bring your pill box with you.
- Arrive at the scheduled time, often early in the morning. Check in on the third floor at the Abbott Northwestern Heart Hospital.
- Staff will take you back to the prep and recovery area to get ready for the procedure.
- A nurse practitioner from your heart transplant team will meet with you.
- You will change into a hospital gown.
- You will get an IV (intravenous) line placed in your hand or arm.
- A phlebotomist will come and draw your blood.
- You will then take your morning medications.
- Staff will bring you into the CV Lab room.

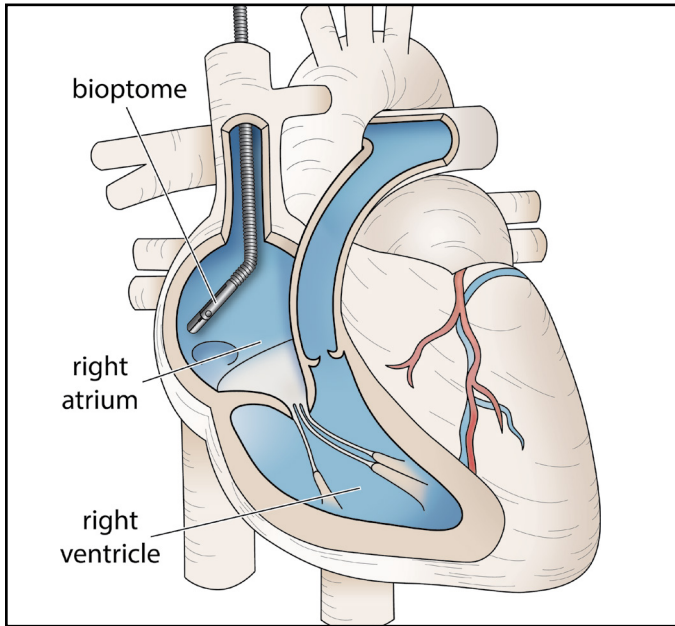
Important

If you have bleeding or a large hard swollen lump at the insertion site once you get home:

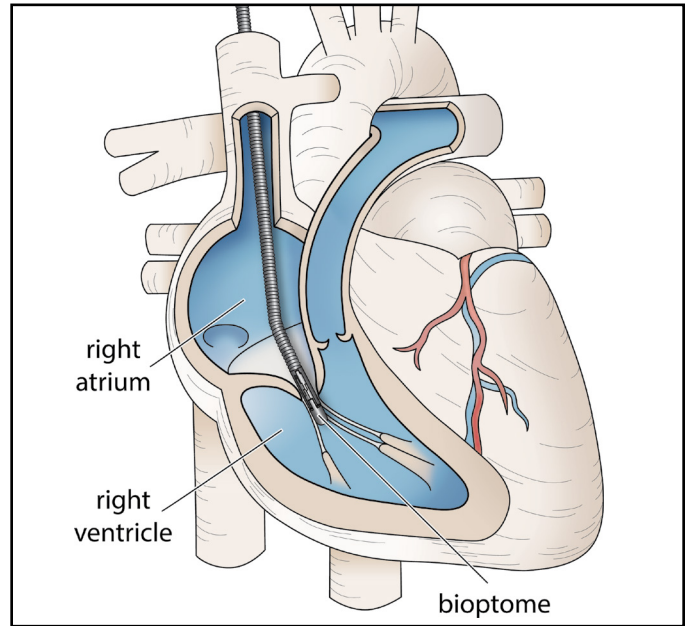
1. Hold pressure on the area.
2. Call the Transplant Office 612-863-5638.

- You will lie on an exam table.
- You may be given medication to help you relax.
- Your neck or groin will be cleaned with a special solution.
- The cardiologist will inject some numbing medication into the skin over the vein in your neck or groin.
- The cardiologist will insert a needle into your vein and put a bioptome through the needle to collect the tissue sample. (See the drawings on the next page.)
- You may feel a fluttering or tugging in your chest during the biopsy.
- The cardiologist will:
 - remove the needle and the bioptome
 - apply gentle pressure on the insertion site to stop the bleeding
 - put a small dressing or bandage on the area.
- The biopsy takes about 30 minutes.
- The transplant coordinators answer your questions and make sure that you know about any medication changes.
- You can change into your clothes and return home.
- The transplant coordinator will call you with the results.

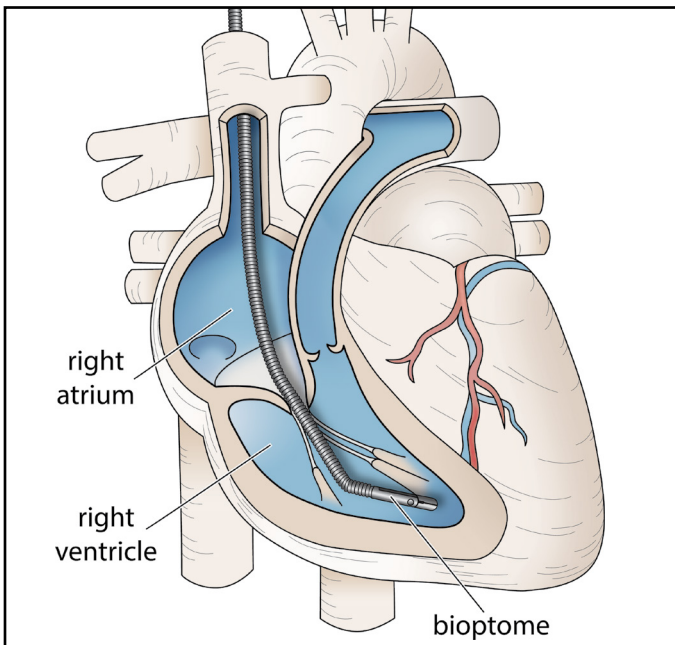
Heart biopsy



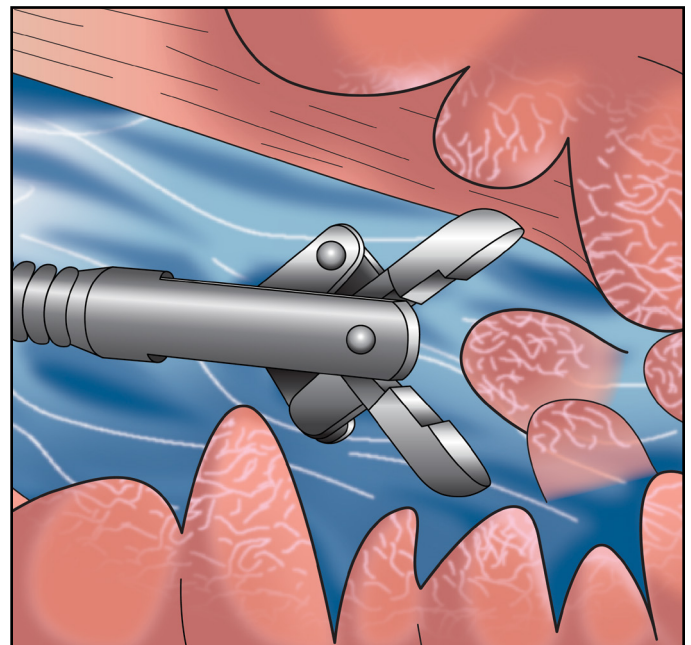
A. The cardiologist inserts a needle with a bioptome on the end. (The bioptome takes a tissue sample.)



B. The cardiologist guides the needle from the right atrium to the right ventricle.



C. The needle and bioptome are in place when they reach the inner surface (endocardium) of your heart.



D. The end of the bioptome takes a small tissue sample. The cardiologist then removes the needle and bioptome.

Transplant Clinic

Important

Call the transplant office at 612-863-5638 if you need to reschedule.

Try to call at least 24 hours before your appointment.

Clinic visits

Clinic visits start 3 months after your transplant. The clinic is located on the second floor of the Abbott Northwestern Heart Hospital. Transplant clinic is open on Tuesday and Thursday mornings.

- Do not take your morning medications.
- Bring these with you to each clinic visit:
 - a mask
 - your pill box or medications
 - your medication list
 - your weight and blood pressure worksheets
 - a list of questions.
- Arrive before your appointment time and go to the **first floor main lab** for your blood draw.
- Take your medications after your blood is drawn.
- Go to the second floor of the Abbott Northwestern Heart Hospital Clinic. Check-in at the front desk.
- Any scheduled tests, such as echo or EKG, will be done.
- Staff will take you back to the Transplant Clinic and:
 - take your weight and blood pressure
 - review your medications.
- You will see the transplant pharmacist. If you have any questions about your medications, bring all the medication bottles with you.
- A transplant doctor or nurse practitioner will give you an exam.
- Your transplant coordinator will check in with you.
- Ask questions or talk about your concerns.
- Your transplant coordinator will call you with:
 - results of labs or tests
 - any changes to your medications, if needed.

Lab draws

- For the first 3 months after the transplant, you will have lab draws every week.
- After 3 months, the labs may change to monthly if there are no issues.
- After the first year and lifelong, labs will be checked every 3 months.
- You may get these labs drawn at a convenient location near your home. Tell your transplant coordinator which lab you prefer to use so lab orders can be sent to that location.

Annual Evaluation

Important

Your yearly transplant evaluation does not replace the annual physical exam you should schedule with your primary care provider. See page 63 to learn more.

Every year, near the anniversary of your heart transplant, you will have a full evaluation.

A scheduler from the transplant office will call you to schedule this visit.

Once the appointment is scheduled, you will receive a letter confirming your appointment dates and times. You will meet with a transplant provider in the transplant clinic and have these tests:

- electrocardiogram (EKG)
- chest X-ray
- echocardiogram
- cardiac catheterization or angiogram
 - You will **not** be able to drive home after this procedure.
 - You will need someone to drive you home.
 - You will need someone to stay with you for 24 hours.
- cardiac PET scan
 - This can replace the angiogram starting at 4 years after your heart transplant if there are no concerns for coronary artery vasculopathy (see pages 36-38).

Chapter 4: Complications (Problems)

Rejection

The immune system is complicated. When healthy, the immune system's white blood cells travel throughout the body "looking" for foreign invaders like bacteria or viruses.

If a bacteria or virus enters your body, your immune system attacks it. Your immune system identifies your new heart as foreign and treats it the same.

White blood cells invade the heart tissue in an attempt to destroy it. The immunosuppressive medications you take work against this response.

About 1 in 4 people who received a new heart have a rejection episode during the first 3 to 6 months after surgery.

Rejection can happen even if you don't have symptoms.

Important

Call the transplant coordinators at 612-863-5638 if you have any concerns about your symptoms.

Signs and symptoms of rejection

- heart palpitations (abnormal or irregular heartbeats, unusually fast or slow)
- shortness of breath
- increased weight gain or swelling (3 pounds in 1 day or 5 pounds in 1 week)
- flu-like symptoms (chills, aches, headache, dizziness, upset stomach or vomiting)
- temperature of 100.5 F or higher that lasts for several hours
- difficulty sleeping while lying on your back
- decreased appetite, abdominal "bloating"
- fatigue or being very tired that does not get better with rest

How to prevent rejection

- Take all of your medications as directed.
- **Do not** stop or change doses of your immunosuppression medications without instruction from your transplant team.
- Order your medications refills early so you don't run out.
- Call the transplant office before you make any medication changes or start a new prescription from your primary care provider. Even over-the-counter medications can weaken your immunosuppression medications. This includes vitamin and herbal supplements.
- Do not drink alcohol.

Members of your transplant team look at your lab work for markers of rejection. They draw special labs to check for antibodies against your donor (DSA) as well as other blood tests that assesses the immune activity by monitoring specific genes in your white blood cells.

The only way to confirm rejection is with a heart biopsy. Routine biopsies start the first week after your heart transplant and end after your first anniversary.

Your heart transplant cardiologist will decide if you need biopsies after that time. (See page 26 for the biopsy schedule.)

Your chance of a rejection episodes goes down over time, but it is a lifelong risk. Severe rejection can weaken your heart, cause disease in your blood vessels, and cause death.

It is important to take your immunosuppressive medications as directed for the rest of your life.

How to treat rejection

How to treat an episode of rejection depends on how severe it is and how long as it has been since the transplant surgery. Early treatment is critical to successfully reverse rejection.

Treatment options include high doses of IV steroids, increasing anti-rejection medications, or a stay in the hospital for a few days.

Your doctor will prescribe a treatment plan based on the biopsy, your history of rejection episodes, and if you have any symptoms.

Infection

The anti-rejection medications that keep your immune system from rejecting your new heart also have the side effect of lowering your immune response to infections. This means that you have a lowered ability to fight infections.

Think about all infections as potentially serious.

Symptoms of infection

Call the transplant coordinator or your primary care provider if you have any of these symptoms:

- temperature of 100.5 F or higher that lasts for several hours
- blisters, sores, new growths or lumps in your armpits groin, or elsewhere on your body
- vomiting that makes it impossible to keep down your medications
- diarrhea (4 to 6 watery stools in 24 hours)
- white patches in your mouth or throat
- sore throat
- painful or burning urination, or urine that is bloody or cloudy
- fatigue or unusual tiredness that does not go away with rest.

How to prevent infections

- **Wash your hands. This is the most important thing you can do to prevent infections.**
- Try to avoid people who are sick with infections that are contagious (can be spread).
- Wear a mask when you are in the hospital or doctor's office. Wearing a mask decreases the risk of getting an airborne infection from people with contagious infections.
- Wear a mask when around crowds of people for at least the first 3 months after transplant.
- Wear gloves when you are working in the soil.
- You may have pets, but **do not** have birds or reptiles.
- If you have a cat, do not handle the cat litter.
- Avoid farm animals.
- Hunters should not dress their animals.
- If you use well water, a 1 micron filter or bottled water for drinking and cooking is necessary.

Tip

See page 65 for a list of vaccines you should receive.

- Do not use room humidifiers.
- Get plenty of rest.
- Eat healthful foods.
- Cook meat to medium/well done to destroy bacteria.
- Take good care of your body.

Coronary Artery Vasculopathy (CAV)

One possible long-term problem after heart transplant is coronary (heart) artery disease. The type that can occur after a heart transplant is known as coronary artery vasculopathy (CAV).

CAV causes arteries that supply oxygen to your heart to thicken and narrow. It is believed to be a form of chronic (long-term) heart rejection.

If found, medications changes and close monitoring can help. But, it is the most common cause for needing re-transplantation.

How often CAV occurs

- 1 year: 8 in 100 people (8%)
- 5 years: 30 in 100 people (30%)
- 10 years: 50 in 100 people (50%)

Causes of CAV

The cause of CAV is unknown. It is believed to be caused by an immune system process, often called “chronic rejection.”

You are at risk for CAV if you:

- have high blood pressure, high lipids or high cholesterol.
 - Pravastatin (Pravachol®) or other cholesterol-lowering medications are prescribed, even if you don't have high cholesterol as this has shown to reduce the risk of CAV.
- have low immunosuppression medication levels in your blood.
 - Take your medications at the same time every day to keep your level consistent.
 - Get labs when needed to make sure you are not dropping below your goal range.
- have donor specific antibodies (DSA). These are antibodies made by your immune system to attack your donor heart.
 - These are drawn at regular times during the first year after transplant and when your transplant team suspects rejection.

How to prevent CAV

- Maintain a healthy weight.
- Get regular exercise.
- Maintain normal cholesterol levels.
- Maintain a healthy blood pressure.
- Do not use tobacco products.
- Take a small dose of aspirin every day.

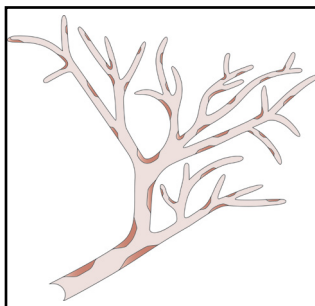
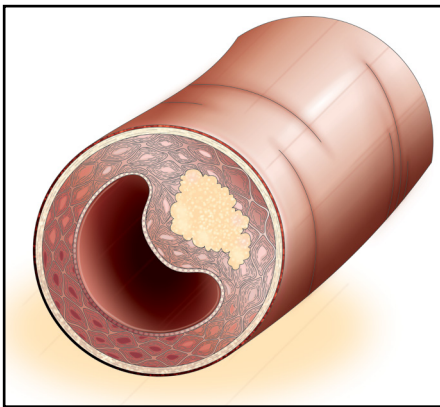
How you will be monitored for CAV

You will have screening tests every year to watch for any signs of CAV.

During the first 4 years after heart transplant, you will have an angiogram annually. After that visit the transplant team may decide to alternate a PET (positron emission tomography) scan and angiogram at your annual visits.

Your transplant cardiologist will talk about this with you.

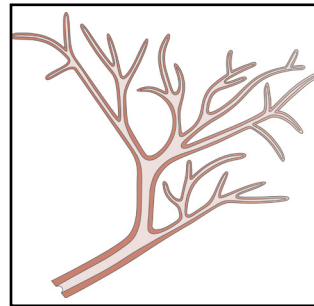
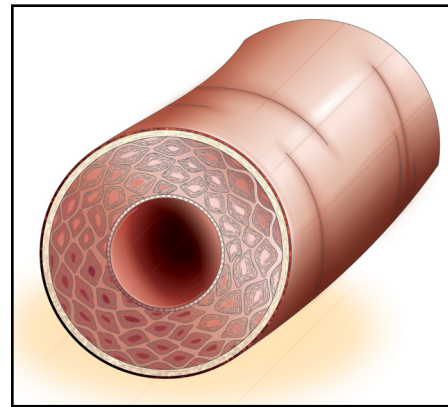
Atherosclerosis (Found in Non-transplanted Hearts)



Atherosclerosis is a blockage of the arteries and is most often caused by a gradual build-up of plaque (fatty deposits) inside the arteries.

All drawings
© Allina Health System

Vasculopathy (Found in Transplanted Hearts)



Vasculopathy is the thickening and narrowing of the arteries in your heart.

Cytomegalovirus (CMV) Infection

CMV is a common virus that infects more than half of U.S. adults by the age of 40. Most healthy people who get CMV have few symptoms and no long-term effects. Many do not even know they have had it.

CMV is a member of the herpes virus group. It is spread through close contact with an infected person's body fluids (such as saliva, urine, semen or blood). It is also common in people who have had an organ transplant.

Once you become infected, the virus stays in your body for the rest of your life without causing damage or illness. You will not get sick with CMV again unless your immune system is weak due to disease or medications.

Symptoms include:

- fever
- diarrhea
- loss of appetite
- nausea.

After heart transplant, if you or your donor are positive for CMV, you will be treated with antiviral medications for up to 9 months.

If you develop any symptoms of CMV after transplant, call the transplant coordinators. There are blood tests to check for active CMV infection and it is important to start medication treatment early.

Chapter 5: Medications

General Information

Tip

See the list of over-the-counter medications that are recommended for common issues on pages 75-76.

Taking your medications as directed is vital to your success after a heart transplant. The following pages have information about each of your medications, including their use, dose and possible side effects.

You will be taking medications to keep your body from rejecting your new heart (known as immunosuppression). You will take these medications for the rest of your life.

You may also still need to be on medications for blood pressure or fluid build-up. Your medications will be reviewed regularly.

Talk with your transplant coordinator, doctor or pharmacist if you have any questions or concerns.

What to do

- Take your medications at the same time every day. This will keep the levels of the medications in your blood consistent.
- Set alarms on your phone to help remind you to take your medications.
- If you forget a dose of your medications, take it as soon as you remember. If it is more than 4 hours, call the transplant coordinator for instructions.
- Call **your pharmacy** to get medications refilled early so you don't run out. (Most insurance providers allow for refilling medications 7 to 9 days before to running out.)
- Leave your medications at room temperature in a cool dry place. The humidity in the bathroom may affect how well they work.
- Tell a member of the transplant team if you are having any side effects from your medications.

What not to do

- Do not stop taking your immunosuppression medications without instructions from the transplant team.
 - Even if you are feeling well or had your transplant many years ago, stopping your medications can cause rejection or other serious problems.
- Do not take any medications — including over-the-counter, herbal, natural products or supplements — without checking first with the transplant team. Many medications can change the levels of the immunosuppression medications in your blood.
- Do not change the dose of your medications on your own.
- Do not take antacids (such as Tums® or Rolaids®) within 2 hours of taking your immunosuppression medications.
- Do not run out of your medications. If you run out late in the evening or on a weekend, it may be hard to find a pharmacy that can fill your prescriptions and it may cost you more.

Where to get your medications

You may get your medications filled at the pharmacy of your choice. Check with your insurance provider to see if you need to stay within a network of approved pharmacies.

Some local pharmacies do not routinely have immunosuppression medications but they can order them for you. There are also mail-order pharmacies you can use.

Allina Health Heart Hospital Pharmacy, located in the second floor skyway, has most medications in stock and can mail medications to you. Call 612-775-3100 to learn more.

Your Medications

You will get an updated medication list at each visit.
See page 74 for an example.

□ Tacrolimus: Prograf®

What it does

- It is an immunosuppressant. It helps to keep your body from rejecting your new heart.

How to take it

- Take this medication every 12 hours at the same time every day.
 - For example, if you take the first dose at 8 a.m., take the second dose at 8 p.m.
- **Do not skip a dose of this medication.**
- You can take this with or without food but try to be consistent.
- Do not eat grapefruit or pomegranate or drink their juices while taking this medication. These fruits change the way your body absorbs this medication.

Important information

- This is a lifelong medication.
- Members of your transplant team will check the levels of this medication in your blood often.
- **To get an accurate level, blood should be drawn 12 hours after the evening dose and before taking the morning dose of medication.**
 - For example, if you take your evening dose at 8 p.m., your blood should be drawn at 7:30 a.m. Take your medications right after the lab draw.

Possible side effects

- increased risk of infection
- increased risk of cancer
- kidney problems
- high blood pressure
- increased cholesterol
- increased blood glucose
- headaches, dizziness or feeling tired
- trouble sleeping or anxiety
- tremors (shaking), numbness or tingling in your hands or feet
- blurred vision or light sensitivity
- ringing in the ears
- upset stomach or diarrhea
- hair loss

❑ Mycophenolate Mofetil: CellCept[®] (MMF)

What it does

- It is an immunosuppressant. It helps to keep your body from rejecting your new heart.

How to take it

- Take this medication every 12 hours at the same time every day.
 - For example, if you take the first dose at 8 a.m., take the second dose at 8 p.m.
- **Do not skip a dose of this medication.**
- Do not open, break, cut, crush or chew this medication before swallowing it.

Important information

- This is a lifelong medication.
- Tell a member of your transplant team if you have unusual bruising or bleeding while taking this medication.

Possible side effects

- increased risk of infection
- increased risk of cancer
- upset stomach or diarrhea
- loss of appetite or stomach pain
- lowered white blood cells, red blood cells or platelets

□ Sirolimus (Rapamune®)

What it does

- It is an immunosuppressant. It helps to keep your body from rejecting your new heart.

How to take it

- Take this medication once each day in the morning.
- You can take it at the same time as tacrolimus (Prograf).
- If you take cyclosporine, take sirolimus at least 4 hours after your cyclosporine dose.
- **Do not skip a dose of this medication.**
- You can take this with or without food but try to be consistent.
- Do not eat grapefruit or pomegranate or drink their juices while taking this medication. These fruits change the way your body absorbs this medication.

Important information

- You may switch to this medication if you have coronary artery vasculopathy (CAV) after transplant.
- **To get an accurate level, blood should be drawn 24 hours after the last dose and before taking the next dose of medication.**
 - For example, if you take your dose at 8 a.m., your blood should be drawn at 7:30 a.m. Take your medication right after the lab draw.

Possible side effects

- increased risk of infection
- problems with wounds healing
- lung issues, trouble breathing
- mouth sores or ulcers
- increased cholesterol
- headache
- sleeping problems
- skin rash or acne
- high blood pressure
- upset stomach, vomiting, diarrhea or constipation
- lowered white blood cells, red blood cells or platelets

□ Prednisone

What it does

- It is a steroid that prevents your body from rejecting your new heart.

How to take it

- Take this medication at the same time every day.
 - Can be dosed as a twice daily or once daily medication. Follow the prescribed instructions given to you by the transplant coordinator.
- **Do not skip a dose of this medication.**
- Take this medication with food.

Important information

- This medications will be tapered during the months after transplant.

Possible side effects

- increased risk of infection
- upset stomach, heartburn, ulcers
- red or dark tarry stools
- water retention and bloating
- weight gain
- puffiness in the face
- increased appetite
- increased blood glucose
- muscle weakness or cramping
- mood changes, anxiety or depression
- weak bones (osteoporosis)
- problems with wound healing
- skin infections
- cataracts (cloudy vision)

❑ Sulfamethoxazole Trimethoprim (Septra[®], Bactrim[®])

What it does

- It is given to help prevent bacterial infection (specifically a type of pneumonia called pneumocystis pneumonia).

How to take it

- Take this medication once each day in the morning or as directed.
- Drink a lot of liquids when you take this medication.
- If you take warfarin, you are at an increased risk for bleeding.

Important information

- You will take this medication for 1 year after transplant.

Possible side effects

- headaches or confusion
- shaking
- upset stomach, vomiting, diarrhea, stomach pain
- loss of appetite
- kidney problems
- increased sensitivity to sunlight, sunburn
- blood in urine
- skin rash, itching

❑ Acyclovir (Zovirax®)

What it does

- It helps prevent or treat herpes simplex (cold sores) and more serious viral infections.

How to take it

- Take this medication once each day in the morning.
- Drink a lot of liquids when you take this medication.

Important information

- You will take this medication for 3 months after transplant (if needed).

Possible side effects

- headaches or confusion
- shakiness or feeling shaky
- skin rash, itching
- fever of 100.5 F or higher
- chills
- kidney problems
- lowered white blood cells
- upset stomach, vomiting, diarrhea, stomach pain

□ Valganciclovir (Valcyte®)

What it does

- It is an anti-viral medication that helps prevent and treat CMV (cytomegalovirus) infection.

How to take it

- Take this medication once each day in the morning.
- Take this medication with food.
- Do not break, crush or chew the tablets.

Important information

- You will take this medication for up to 9 months after transplant, if needed.

Possible side effects

- lowered white blood cells, red blood cells or platelets
- upset stomach, vomiting, diarrhea
- headaches
- trouble sleeping

❑ Voriconazole (Vfend®)

What it does

- It is an anti-fungal medication that helps prevent infections from fungus.

How to take it

- Take this medications every 12 hours at the same time every day.
 - For example, if you take the first dose at 8 a.m., take the second dose at 8 p.m.
- Take this medications 30 to 60 minutes before you eat.
- Do not eat grapefruit or pomegranate or drink their juices while taking this medication. These fruits change the way your body absorbs this medication.

Important information

- You will take this medication for up to 90 days after transplant, if needed.

Possible side effects

- headache
- dizziness
- blurred vision
- light sensitivity
- ringing in your ears
- having hallucinations (seeing things that are not real)

❑ Nystatin (Liquid)

What it does

- It is an anti-fungal medication that helps prevent or treat thrush (candidiasis), a yeast infection in your mouth.

How to take it

- Take this medication 4 times each day after meals and at bedtime.
- Rinse your mouth with this medication for 10 to 15 seconds and swallow it.
- Do not eat or drink for 15 minutes after your dose.

Important information

- You will take this medication for up to 3 months after transplant.

Possible side effects

- mouth irritation
- bad or odd taste in your mouth

□ Aspirin

What it does

- It is a medication that prevents clots by keeping platelets from clumping together.

How to take it

- Take this medication once each day in the morning.
- Take this medication with food.

Important information

- This is a lifelong medication.
- You do not need to stop taking aspirin before a biopsy or angiogram.

Possible side effects

- upset stomach
- bleeding problems

□ Pravastatin (Pravachol[®]), Atorvastatin (Lipitor[®]), Rosuvastatin (Crestor[®])

What it does

- It is a medication that reduces the amount of cholesterol your liver makes.

How to take it

- Take this medication one time each day.

Important information

- This is a lifelong medication you need to prevent coronary artery vasculopathy (CAV).

Possible side effects

- muscle aches or pains
- rash, itching
- chest pain
- upset stomach, diarrhea, stomach pain

❑ **Famotidine (Pepcid®), Pantoprazole (Protonix®), Lansoprazole (Prevacid®), Omeprazole (Prilosec®)**

What it does

- It is a medication that helps prevent stomach ulcers.

How to take it

- Take this medication 1 to 2 times each day.

Important information

- You will take this medication as long as you take prednisone.

Possible side effects

- headache
- dizziness
- drowsiness (feeling sleepy)
- upset stomach, diarrhea or constipation
- rash

❑ Terbutaline Sulfate (Brethine®)

What it does

- It is a medication used to increase your heart rate.

How to take it

- You may take this medication up to 3 times each day.
- Follow instructions from your transplant team on how often to take this medication.

Possible side effects

- tremor (shaking)
- dizziness
- nervousness

Chapter 6: Life After Transplant

Lifestyle Changes

After your transplant it is important to make lifestyle changes:

- Get regular exercise.
- Eat a healthful diet that is low in fat and cholesterol foods. Do not add salt to foods. Follow guidelines from your dietitian.
- Do not eat grapefruit and pomegranates or drink their juices. They change how well your medication works.
- Do not eat raw or uncooked fish, meat or poultry.
- You can use clean hot tubs and swimming pools after you have fully recovered and your incision is healed. (This includes the drive-line site if you have had an LVAD.)

Healthy Eating

Eating is one of life's necessities — and certainly one of its pleasures. Eating nutrient-rich foods in appropriate portion sizes with regular physical activity is core to overall good health. But eating too much, too often, leads to excess body fat.

Carrying excess weight is related to diabetes, gallbladder disease, high blood pressure, higher cholesterol and triglycerides, and adds significantly to increased risk of developing transplant heart disease.

Finding your healthiest weight is a personal matter. There are tools such as Body Mass Index (BMI) that can help you determine if your weight is hazardous to your health.

BMI is a measure of body fat based on height and weight that tells if you are underweight, normal, overweight or obese. According to the National Institutes of Health, BMI ranges are:

- underweight: 18.5 and lower
- normal: 18.5 to 24.9
- overweight: 25 to 29.9
- obese: 30 and higher

No matter how heavy you are, losing weight and keeping it off are goals that you can achieve. It takes commitment and a well-thought-out plan.

Before you try a weight loss plan you have read or heard about, be sure it is nutritionally sound. Too often people are looking for a quick fix or easy solution to a complex problem. Guidelines to consider in choosing a diet plan:


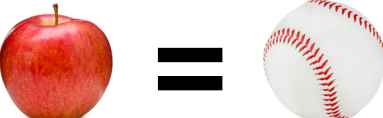
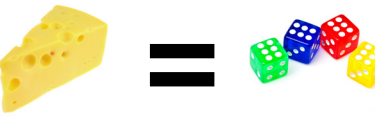
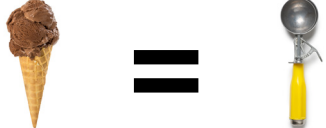
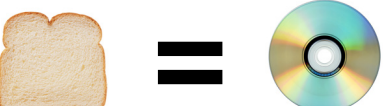
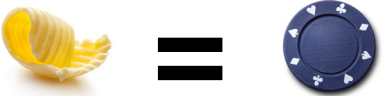
- Are there fewer calories in the weight loss plan than you normally eat?
- Does the plan include heart healthy foods of vegetables, fruits, whole grains, low fat dairy, dried beans and peas, nuts and seeds, and lean poultry, meat and fish?
- Is it low in saturated fats, trans fats, cholesterol, salt (sodium), and added sugar?
- Is the diet made up of appealing food that you will enjoy eating not only today but the rest of your life?
- Are the foods easily available and affordable?
- Does the diet recommend changes that in your eating habits that fit into your lifestyle?

A well-balanced diet is only part of the equation for weight loss success. The other part is a healthy level of activity.

Activity will be different for each person after heart transplant, but, in general, 30 minutes of activity that gets your heart rate up a day is recommended.

If you need help tailoring a diet to your health needs, a registered dietitian can design a healthy eating plan to help you prioritize and realize your goals.

Portion Sizes

<p>3 ounces of meat is about the size and thickness of a deck of playing cards.</p>	
<p>1 medium apple or 1 cup of raw vegetables is about the size of a baseball.</p>	
<p>1 ounce of cheese is about the size of 4 stacked dice.</p>	
<p>1/2 cup of ice cream or 1/2 cup of cooked pasta is about the size of an ice cream scoop.</p>	
<p>1 slice of bread or 1 6-inch tortilla is about the size of a DVD.</p>	
<p>1 teaspoon of butter is about the size of a poker chip.</p>	

Limit cholesterol and fats

Cholesterol and saturated fats are found in animal products such as meats, dairy products and eggs. Saturated fats raise your blood cholesterol more than anything else in your diet.

Limiting foods like butter, cheese, whole milk, ice cream and fatty meats will lower your blood cholesterol level and your risk of developing heart disease.

Limit sodium (salt)

Eating foods low in sodium will help control your blood pressure. It will also help keep your body from holding (retaining) extra fluid. As a result, your heart will not have to work as hard.

Avoid eating salty foods and do not add salt to your food.

It is important to make — and stick with — these changes to decrease your risk of long-term problems.

A dietitian can meet with you to talk about how to plan your meals. Call the transplant office to set up an appointment.

Medication may increase your appetite

Even if your weight was not a problem in the past, having an increased appetite is a common side effect of prednisone. You may find yourself feeling hungry more often and eating more than you realize.

To avoid weight gain:

- Eat smaller portions.
- Eat less often.
- Avoid eating foods that are high in calories (such as sweets, desserts and extra fats).
- Try to eat only when you are hungry, not out of habit.
- Get enough exercise.

Routine Health Care

General schedule

It is important to have regular checkups with health care providers between transplant clinic visits.

Your transplant team will share updates with your primary care provider. Tell a member of your transplant team if you change primary providers or clinics. Your regular checkup schedule is:

Checkup (Screening)	How Often
physical exam	once a year
dental cleaning and exam	every 6 months
eye exam	once a year
skin exam (dermatology)	once a year

Yearly physical exams

Get a complete physical exam by your primary care provider once a year. This exam is important so your provider can check your overall health and find any developing problems.

Taking prednisone increases your chance for osteoporosis. This is a disease that causes your bones to become thin and weak. Prednisone therapy increases the chance of developing this condition, so your provider will want you to have a bone density scan to check the health of your bones.

Your regular transplant clinic checkups focus on transplant-related problems. They should not replace a complete physical exam.

Dental care

Wait 6 months after your transplant to have your first dental checkup.

See your dentist every 6 months for checkups and cleanings. Gum disease and mouth infections can turn into more serious infections.

Before you go to the dentist — even for a routine checkup — you need to take an antibiotic (medication) to prevent any bacteria (germs) from turning into an infection. Call the transplant office at 612-863-5638 to have a prescription sent to your pharmacy.

Eye exams

Schedule an exam with your ophthalmologist (eye doctor) within the first year after transplant. Have eye exams every year after that.

Immunosuppressive medications may cause problems for your eyes such as cataracts (cloudy lenses) and eye infections that can cause serious changes in the retina.

Cancer Screening

The immunosuppressive medications put you at a greater risk for developing cancer. For this reason you should have regular preventive cancer screening.

Below is the screening schedule according to the “Journal of Heart and Lung Transplant.”

Screening	How Often
skin cancer	adults: every year
prostate and testicular cancer	men (males at birth): every year
colon and rectal cancer	adults: every year with a colonoscopy every 5 to 10 years (starting at age 45)
cervical cancer (Pap smear and pelvic exam)	women (females at birth): every year starting at age 18 or when sexually active
breast cancer (mammogram)	women (females at birth): mammogram every year starting at age 40
If you have a personal or family history of cancer, talk with your provider about what screening schedule is right for you.	

Immunizations (Shots)

There are vaccines available to protect you from common diseases and illnesses.

After your transplant, you should not receive any “live vaccine” such as chickenpox or the oral polio vaccine. These can cause a serious infection in people who take immunosuppressive medications.

Because children receive live vaccines, do not change any diapers as they may contain some of the vaccine.

Call your transplant coordinator if you are exposed to any disease that can be spread such as chickenpox, measles or mumps.

The recommended schedule for vaccinations is:

Vaccine	Age/How Often
Influenza	■ Every year for everyone.
COVID-19	■ For adults starting at age 18 who don't have proof of vaccination or evidence of a past COVID-19 infection. ■ This is a 1- or 2-dose primary series, and booster for some.
Tetanus booster (Td or Tdap)	■ For adults. After one dose of Tdap starting at age 11 years, have a Td or Tdap every 10 years.
Herpes zoster (RZV) (shingles)	■ For adults age 50 and older. This is a 2-dose series.
Pneumonia (PCV13)	■ For some adults age 65 and older. Talk with your health care provider about if this vaccine is right for you.
Pneumonia (PPSV23)	■ For adults age 66 and older. This is given in 2 doses, 5 years apart.

Sun Protection and Skin Care

After your transplant, see a dermatologist (skin doctor) within 6 months. See a dermatologist for skin exams every year after that.

If you do not have a dermatologist, talk with your primary care provider or transplant coordinator.

Be alert to any changes in your skin

Finding changes early makes a difference.

- Look at your skin regularly. Notice any change in existing or new skin growths.
- Call your primary care provider or dermatologist if you notice any changes such as sores or darkened areas.

Apply sunscreen often

- Use a “broad spectrum” or “complete blocker” sunscreen with an SPF of 30 or higher all year round.
- Apply sunscreen about 30 minutes before going out during the day and re-apply every 2 hours. Make sure you re-apply if you are sweating from activities or swimming.

Protect yourself from the sun

- Never sunbathe.
- Never use tanning beds.
- Find shady areas outside.
- Wear hats with brims.
- Wear lightweight long-sleeved shirts and long pants, if possible.
- Avoid being in the sun during the peak hours of 10 a.m. to 2 p.m.
- Talk with your dermatologist about other ways to protect yourself from skin cancer.

Acne and dry skin

Acne and dry skin are the two most common skin problems after a heart transplant. They are side effects of prednisone.

Both conditions should start to clear as your dose is reduced. Talk to your dermatologist if you have severe acne.

Travel

- Do not travel outside the U.S. for the first year after your transplant.
- You may travel within the U.S. by car or plane 6 months after your transplant.
- When flying, carry several days worth of your medication with you. Do not put all your medications in your checked luggage.
- Bring extra medication with you in case your return gets delayed. Most insurance providers allow for an extra medication refill for travel.
- Bring an updated medication list with you.

Call your local international travel clinic if you are planning on traveling outside of the U.S. They will talk with you about shots you may need and how to avoid infection.

It is also good to know where the closest transplant centers are while you are traveling. Visit srtr.org/transplant-centers to learn more.

Alcohol

Having alcohol on rare occasions is OK, but it is best to not drink at all.

If you have a history of alcohol dependence, you cannot drink.

Alcohol may affect how well your immunosuppression medication works (how it is absorbed and stays in your blood).

It is important to talk with your transplant coordinator and primary care provider about your alcohol use.

Tobacco

You cannot use any tobacco products after your transplant. This includes smoking, vaping, chewing and any other product that contains nicotine.

Using tobacco increases your risk of the following:

- heart problems (complications)
- coronary artery vasculopathy (CAV) and chronic (long-term) rejection
- lung problems such as pneumonia
- an infection of your surgery site (incision)
- blood clots.

See page 85 for resources to quit using tobacco.

Emotional Changes

Tip

Talk with your chaplain, social worker or both for free, one-on-one counseling.

Although you are excited to go home, you may be feeling some anxiety. This is normal. Some of the changes you may see include:

- becoming confident in your new heart
- coping with actual or potential rejection episodes
- getting used to changes in how you look
- having emotional ups and downs
- learning how to live “healthy” and “well” again.

During the weeks after you return home, it is common to feel some emotional letdown. The joy of the initial period can fade while you are going through your recovery.

The changes after your transplant can also affect your family. Changes can cause added stress and make communication more difficult.

Consider joining a transplant support group. Hearing that you are not alone in what you are going through, and that others struggle with similar issues, are important in your recovery and rediscovering the joy of a full life.

Call the transplant social worker at 612-775-5007 to learn more about the support group.

Sexual Issues

Resuming sexual activity

One major concern many people have is when they can resume sexual activity. In general, if you can walk up a flight of stairs without problems, you may have sexual activity.

You may find that some of the medications, as well as your own emotional responses to your transplant, may affect your sex life. If you are having problems, talk about it at your clinic visits. Treatment is available.

Birth Control and Pregnancy

When you resume sexual activity, use 2 forms of birth control to avoid an unplanned pregnancy right after the transplant.

If you are considering getting pregnant, talk with your cardiologist, obstetrician/gynecologist and transplant coordinator. You will need special medical care, planning and close follow-up.

Immunosuppression medication can have very high risk of birth defects, so your medications would need to be changed months before pregnancy.

You should also have:

- stable immunosuppression levels
- no heart or kidney problems
- normal blood pressure or high blood pressure that is under control
- normal blood glucose levels or diabetes that is under control
- overall good health.

Important: The pill, ORTHO EVRA® patch, and the NuvaRing® may affect how well your medications work. Talk with your cardiologist or transplant coordinator **before** you start any of these birth control methods.

To learn more, contact the National Transplantation Pregnancy Registry at transplantpregnancyregistry.org or toll-free at 1-877-955-6877.

Chapter 7: Special Helps

Financial Information

Tip

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

You may have concerns about your insurance and the cost of the surgery and recovery. These concerns can be overwhelming. Thinking about money issues before surgery can help relieve some stress.

- Before you start the heart transplant evaluation at Abbott Northwestern Hospital, staff members will check your insurance coverage to make sure the hospital is an approved provider under your plan.
- Know what your insurance policy covers.
 - Read your insurance plan to find out what is covered and what might need a “pre-certification” or “prior authorization.”
 - Follow your insurance requirements to help make sure that your care will be covered.
 - Call your insurance provider if you have questions about coverage. The phone number should be on your card.
- Call the transplant office at 612-863-5638 if you change insurance plans.
- Call the transplant financial operations supervisor at 612-863-3652 or a social worker at 612-775-5007 if you have questions, concerns or problems. They will work with you and your family to find resources that may be available.

Example of a Medication List You Will Receive When You Go Home

Patient's Medication List – as of Date				
Medication Name, Dose, and Indication	8:00 am	1:00 pm	8:00 pm	Bedtime
Tacrolimus (Prograf) 1 mg capsule Take 1 capsule (1 mg) every 12 hours. → Anti-rejection	1		1	
Mycophenolate mofetil (Cellcept) 250 mg capsule Take 4 capsules (1000 mg) every 12 hours. → Anti-rejection	4		4	
Prednisone 5 mg tablet Take 6 tablets (30 mg) twice daily on *** and *** Take 5 tablets (25 mg) twice daily on Take 4 tablets (20 mg) twice daily on Take 3 tablets (15 mg) twice daily on Take 2 tablets (10 mg) twice daily *** and CONTINUE then as directed. → Anti-rejection	X		X	
Valganciclovir (Valcyte) 450 mg tablet Take 1 tablet (450 mg) daily. → Prevent CMV infection	1			
Sulfamethoxazole/Trimethoprim (Bactrim, Septra) 80-400 mg tablet Take 1 tablet (80-400mg) daily. → Prevent infection	1			
Nystatin Swish and Swallow suspension Swish and swallow 5 ML four times per day → Prevents thrush infection	5 ml	5ml	5 ml	5ml
***Voriconazole (Vfend) 200 mg tablet** Take 1 tablet (200 mg) twice daily → Prevent infection				
Aspirin 81 mg tablet Take 1 tablet (81 mg) daily. → Heart health	1			
Pravastatin (Pravachol) 40 mg tablet Take 1 tablet (40 mg) daily. → Cholesterol			1	
Pantoprazole (Protonix) 40 mg tablet Take 1 tablet (40 mg) daily. → Prevents stomach ulcer	1			
***Amlodipine (Norvasc) 5 mg tablet Take 1 tablet (5mg) daily. →Blood pressure	1			
***Hydralazine ** mg tablet Take 1 tablet (**mg) three times daily. →Blood pressure	1	1	1	
***Terbutaline 5 mg tablet Take 1 tablet (5 mg) three times daily → Increase heart rate	1	1	1	
Calcium + Vitamin D (Os-Cal + D) 500 mg-400 unit tablet Take 2 tablets daily with meals. → Calcium supplement		2		
***Insulin NPH (Humulin/Novolin) Inject ** units SQ every AM and ** units every PM → High blood sugars	XX units		XX units	
***Insulin aspart (Novolog) Inject SQ up to four times daily dose by sliding scale → High blood sugars	X	X	X	X
Acetaminophen (Tylenol) 325 mg tablet Take 1-2 tablets (325-650 mg) every 8 hours as needed for pain. No more than 4000 mg (12 tabs) 24 hrs. → Pain	As needed			
Polyethylene glycol (Miralax) 1 packet or capful Take 1 pack/cap (17 grams) daily for constipation → Laxative, constipation	As needed			
Oxycodone-acetaminophen (Percocet) 5 mg-325 mg tablet Take 1-2 tablets every 6 hours as needed for severe pain. → Pain	As needed			
Sennosides-docusate (Senokot S) tablet Take 1-2 tablet twice daily as needed. → Laxative, constipation	As Needed			

***** Medications that are for Heart Rate, Blood Pressure or Blood sugar control are totally dependent on patient condition**

Over-the-counter Medicines to Use After a Heart Transplant

Brand names and ingredients can change. Use the generic name (in parentheses) as the key for using these medicines. Call your clinic or pharmacist if you have questions or concerns.

Condition	Medicine	Condition	Medicine
aches, pains, headache	<ul style="list-style-type: none"> <input type="checkbox"/> Tylenol® (acetaminophen) — Take 650 mg to 1,000 mg every 6 hours as needed. — Do not take more than 3,000 mg in 24 hours. ■ Do not take ibuprofen (Advil®, Motrin®) or naproxen (Aleve®). 	constipation	<ul style="list-style-type: none"> <input type="checkbox"/> Citrucel® or Unifiber® (methylcellulose) <input type="checkbox"/> Colace® (docusate sodium) <input type="checkbox"/> ex-lax® Maximum Strength Stimulant Laxative (sennosides) or Senokot® (senna) <input type="checkbox"/> Fiber caplets or FiberCon® (calcium polycarbophil) <input type="checkbox"/> Metamucil® (psyllium)
acne	<ul style="list-style-type: none"> <input type="checkbox"/> Cetaphil® Gentle Skin Cleanser <input type="checkbox"/> CeraVe™ Hydrating Cleanser <input type="checkbox"/> Glytone® (benzoyl peroxide) or generic 	cough, cold	<ul style="list-style-type: none"> <input type="checkbox"/> Vicks® DayQuil™ Cough Suppressant Soothing Tropical Blend (dextromethorphan hydrobromide) <input type="checkbox"/> Delsym® 12-Hour Extended-release Suspension (dextromethorphan polistirex) <input type="checkbox"/> Coricidin® HBP Chest Congestion and Cough (dextromethorphan, guaifenesin) <input type="checkbox"/> Mucinex® (guaifenesin) <input type="checkbox"/> Adult Robitussin® Peak Cold Cough and Chest (dextromethorphan, guaifenesin) ■ Do not take phenylephrine, pseudoephedrine, or combination products containing ibuprofen.
allergy	<ul style="list-style-type: none"> <input type="checkbox"/> Claritin® (loratadine) <input type="checkbox"/> Benadryl® (diphenhydramine) <input type="checkbox"/> Zyrtec® (cetirizine) 	cramps	<ul style="list-style-type: none"> <input type="checkbox"/> magnesium oxide or magnesium chloride ■ Do not take magnesium at the same time as Cellcept® (mycophenolate mofetil).

Condition	Medicine	Condition	Medicine
diarrhea	<input type="checkbox"/> Imodium® (loperamide)	sleep problems	<input type="checkbox"/> Unisom® SleepTabs® (doxylamine succinate) <input type="checkbox"/> Tylenol® PM (acetaminophen, diphenhydramine HCl)
heartburn, indigestion	<input type="checkbox"/> Maalox® tablets or Roloids® or Tums® (calcium carbonate) <input type="checkbox"/> Pepcid® AC (famotidine) <input type="checkbox"/> Zantac® (ranitidine) <input type="checkbox"/> Prilosec® OTC (omeprazole) if taking long-term <input type="checkbox"/> Prevacid® OTC (lansoprazole) if taking long-term	sore throat	<input type="checkbox"/> Cepacol® Maximum Strength Sore Throat Spray or Sucrets® Lozenges (dyclonine hydrochloride) <input type="checkbox"/> Chloraseptic® Lozenges (benzocaine) or spray (phenol) Do not take longer than 2 days. <input type="checkbox"/> Halls® or Robitussin® or Vicks® (menthol) lozenges (dextromethorphan hydrobromide)
rash	<input type="checkbox"/> Aveeno® Soothing Bath Treatment (colloidal oatmeal) <input type="checkbox"/> Caladryl® Clear® lotion (pramoxine, zinc acetate) or calamine lotion (calamine, zinc oxide) <input type="checkbox"/> Cortaid® 1% (hydrocortisone) cream <input type="checkbox"/> Gold Bond® Medicated Anti-itch Cream (menthol, pramoxine) <input type="checkbox"/> Benadryl® (diphenhydramine)		

Lab Glossary

Test	What it is
Albumin	It is a protein made in your liver. This blood test checks how well your liver is working.
Alk p-tase (alkaline phosphatase)	It is an enzyme in your body. This blood test can help tell how well your liver is working.
AST (aspartate amino transferase)	It is an enzyme in your body. This blood test can help tell how well your heart, liver and kidneys are working.
Bicarbonate	It is an electrolyte that helps control the amount of acid in your blood. This test checks the acidity level of your blood.
Bilirubin	It is made when red blood cells break down at the end of their life cycle. Your liver filters it out of your body. This blood test checks how well your liver is working.
BUN (blood urea nitrogen)	It is a waste product in your blood. Your kidneys filter it out of your body. This urine test checks how well your kidneys are working.
Calcium	It is needed for your muscles to tighten, heart to work, blood to clot, and nerves to work. This blood test checks the calcium level in your body.
Chloride	It is an electrolyte and works with sodium to influence your water balance. This blood test checks the chloride in your body.
Cholesterol	It is a fat substance made in your body and found in certain foods. It is important for energy, making hormones, making bile acids and cells. High levels can cause clogged arteries and a higher risk of heart disease. This blood test checks the total cholesterol in your body.
CPK (creatinine phosphokinase)	It is an enzyme found in your heart, muscles and brain tissue. This blood test checks for heart and muscle injury.
Creatinine	It is a waste product in your blood. Your kidneys filter it out of your body. This blood test checks how well your kidneys are working.

Lab Glossary

Test	What it is
Creatinine clearance	This test measures creatinine levels in both a sample of blood and a sample of urine from a 24-hour urine collection. The results are used to calculate the amount of creatinine that has been cleared from the blood and passed into the urine. This calculation allows for a general evaluation of the amount of blood that is being filtered by the kidneys in a 24-hour time period.
Glucose	It is the energy source that helps your body cells to live. It is formed when your food digests (breaks down). Your body makes insulin to keep the glucose level in check. This blood test checks the glucose level in your body.
HDL (high density lipoprotein)	It is the “good” cholesterol that carries cholesterol from your blood to your liver. This blood test checks the HDL level in your body.
Hematocrit	Hematocrit means “to separate blood.” This blood test tells the percentage of red blood cells in your blood.
Hemoglobin	It is the main part of red blood cells. It helps deliver oxygen to your cells. This blood test measures your blood’s hemoglobin level.
INR (international normalized ratio)	It is a measure of your blood’s clotting ability. This blood test checks how well your body responds to medication like warfarin.
LD or LDH (lactic acid dehydrogenase)	It is an enzyme involved in energy production, and is found in almost all of your body’s cells. The highest levels are in the cells of your heart, liver, muscles, kidneys, lungs, and in blood cells. This test is used to help detect a condition causing tissue damage, such as a blood or liver disease, and to monitor its progress.
LDL (low density lipoprotein)	It is the “bad” cholesterol that carries cholesterol to your body’s cells. High levels of LDL can narrow blood vessels. This blood test checks the LDL level in your body.
Magnesium	It is a mineral you need for energy, to build proteins, help your muscles work, and help your blood clot. This blood test checks the magnesium level in your body.

Lab Glossary

Test	What it is
Phosphorus	It is a mineral you need for bones and body cells to live and grow. This blood test checks the phosphorous level in your body.
Platelets	These blood cells are needed to help your blood clot. When levels are low, you can have bleeding that is difficult to stop. This blood test checks the level of platelets in your body.
Potassium	It is an element (electrolyte) that helps your heart maintain a regular heartbeat. Your kidneys control the amount of potassium in your blood. This blood test checks the level of potassium in your body.
Protein	It is important to keep your cells and muscles healthy. This blood test checks the level of protein in your body.
PSA (prostatic specific antigen)	It is a protein that is made by the prostate gland in men. When a man's prostate is enlarged or has prostate cancer, the PSA level can become high. This blood test checks the level of PSA in your body.
Sodium	It is an element (electrolyte) that causes your body to hold (retain) fluid. Your kidneys control the amount of sodium in your blood. This blood test checks the level of sodium in your body.
Triglycerides	It is a fat substance made in your liver. It is important for giving you energy. High levels can cause clogged arteries and a higher risk of heart disease. This blood test checks the triglyceride level in your body. It may mean you are having problems with your liver or pancreas.
TSH (thyroid stimulating hormone)	This blood test is done to see how well your thyroid gland is working.
Uric acid	Uric acid is a waste product in your blood. Your kidneys filter it out of your body. This test checks the level of uric acid in your blood.
White blood cell count	These blood cells help your body fight off infections. This blood test checks the level of white blood cells in your body.

Glossary

AlloMap™: a blood test that assesses immune activity by monitoring specific genes in your white blood cells. This can tell your health care team if you have an overactive immune system that could damage your heart.

Angiogram: an X-ray test used to show the size and shape of arteries and veins of the organs and tissue. A special X-ray contrast is injected into your bloodstream.

Angioplasty: a procedure that opens blocked or narrowed blood vessels.

Antibiotic: a medication used to fight infection from germs (bacteria).

Arrhythmia: a heart rhythm that is not normal.

Atherosclerosis: a hardening of your heart's arteries. A build-up of plaque (fatty deposits) inside your artery makes the artery wall less flexible. (It's like sludge that builds up in a water pipe.) Blood cannot flow through the artery as well as it should.

Biopsy: a procedure to remove a sample of tissue, cells or fluid.

Body mass index (or, BMI): this is a measure of body fat based on your height and weight. The BMI will tell you if you are underweight, normal weight, overweight or obese. If you are athletic and have a muscular build, your BMI might not be accurate.

Bone mineral density test: a type of X-ray used to tell how thick your bones are.

Cardiac catheterization: a flexible tube (catheter) is placed into the heart. This procedure can be used to measure pressures on either side of your heart to see if there are any problems with the valves. It can also help your health care team tell how much resistance your heart has to pump against in the lungs.

Carotid ultrasound: a test that uses ultrasound (sound waves) to track a record of echoes as they contact the carotid artery in your neck. This test is used to look for narrowed or blocked blood vessels.

Cholesterol: a white, waxy substance that occurs naturally in the body and is found in foods from animals. A diet high in cholesterol can cause your heart to work harder and narrow your blood vessels.

Claudication: this means your leg muscles are not getting enough blood. You feel pain in your calves when you walk.

Colonoscopy: a procedure to look at your colon using a thin, flexible scope.

Coronary angiogram: an X-ray contrast is injected through a catheter into the arteries and left ventricle of your heart. A series of X-rays will show any blockages of blood flow, show how well your left ventricle is working, and show if you have leaky valves.

CT (or, CAT): a scan of your chest, abdomen and pelvis. It can help rule out the possibility of other diseases or tumors.

Cytomegalovirus (CMV): a common virus (germ) that can cause an infection.

Diabetes: a disease that keeps your body from using glucose well. It occurs when your body has trouble moving the glucose from your blood into your cells where it breaks down. This causes the glucose level in your blood to rise and it acts like a poison.

Echocardiogram: an ultrasound of the heart that shows the pumping action, size and valves of the heart. Pictures of the heart appear on a screen and are recorded on tape.

Ejection fraction: this is the percentage of blood in your heart that is ejected with each beat. A healthy heart will eject 60 percent or more.

Electrocardiogram (EKG, ECG): a test that uses sticky electrodes placed on your chest, arms and legs. The machine records electrical activity of your heart as a series of wave lines on a moving strip. This shows your heart's rhythm and rate.

End-stage renal disease: this is kidney failure that cannot be cured. Dialysis or transplant is needed to keep you alive.

Holter monitor: a test that records your heart rate and rhythm for 24 hours. You wear a small, portable device around your neck. This will not interfere with normal activity.

Hyperlipidemia: this means you have extra fat in your blood.

Hypertension: this is high blood pressure; a reading of 130 or higher (top number) or 80 or higher (bottom number). It is caused by too much fluid in the blood vessels or narrowing of the blood vessels.

Hypothyroidism: your thyroid gland does not make enough thyroid hormone. This is common after transplant.

Immunosuppressant: a medication that suppresses the natural response of your body's immune system. You need this medication so your body does not reject your new heart.

IV (intravascular) ultrasound: This ultrasound used sound waves to make an image of your arteries. Your health care team can see the condition of your arteries.

Mammogram: an X-ray image of your breast which is used for look for tumors or lumps.

MRI: a test that uses radio waves and a magnet. MRI uses a magnetic field to make three-dimensional (3-D) images of your internal organs. MRI has a greater depth than X-rays. This means the MRI can help your health care team find problems that may have been hidden in other tests.

Osteopenia: this is a decrease in the thickness of bone.

Osteoporosis: this is a disease in which the bones become extremely brittle and can break.

Pacemaker: this is a small electronic device that is placed near the heart. It will make your heart beat regularly.

Pap test: a screening test to help find cancer if the cervix or uterus.

Peripheral artery disease (PAD): this happens when plaque (fatty deposits) clog the arteries in your legs. This reduces the blood flow to your legs and feet.

PET scan: This is a scan of your heart that used X-ray contrast to show any problems with your heart.

Pneumocystis pneumonia: a form of pneumonia that caused by the yeast-like fungus (*Pneumocystis jirovecci*). Is is often found in the lungs of healthy people and is usually not a cause for disease. It can cause lung infections in people with a weakened immune system.

Rejection: this is your body's natural immune system response to a foreign object. In this case, the foreign object is your new heart.

Renal: this is the medical word for kidney.

Shingles: a virus (germ) that causes painful sores along your spinal or cranial (head) nerves.

Sleep apnea: a condition in which you stop breathing for brief moments during sleep.

Steroid: a medication used to treat swelling (inflammation).

Stent: a procedure that opens a blocked or narrowed blood vessel with a small spring-like tube.

Transesophageal echocardiogram (TEE): a special echocardiogram that takes ultrasound images of your heart from a wand that is placed in your throat. A small transducer is mounted on the end of a small flexible tube that you swallow. This test gives excellent pictures of your heart because the heart lies next to your esophagus.

Transplant vasculopathy (CAV): a narrowing or tapering of your new heart's arteries. This is usually a sign of an ongoing (chronic) rejection and is difficult to change.

Resources

- **Allina Health**
allinahealth.org
- **Abbott Northwestern Hospital heart transplant**
allinahealth.org/hearttransplant
- **American Heart Association**
americanheart.org
- **Department for Health and Human Services**
organdonor.gov
- **Donate Life America**
donatelife.net
- **LifeSource**
life-source.org
- **Medic Alert**
medicalert.org
- **Medicare**
medicare.gov or 1-800-638-6833
- **National Transplantation Pregnancy Registry**
transplantpregnancyregistry.org
- **Organ Procurement and Transplantation Network**
optn.org
- **Prescription for Transplant Information**
transplantliving.org
- **Scientific Registry of Transplant Recipients**
srr.org or srr.org/transplant-centers (to find a transplant center)
- **United Network for Organ Sharing**
unos.org

Resources for Quitting Tobacco



Product-specific Resources

- financial aid Nicotrol® inhaler
 - 1-844-989-PATH (7284)
 - pfizerrxpathways.com
- Plant Extracts aromatherapy
 - 1-877-999-4236
 - plantextractsinc.com

Allina Health (if you had a recent hospital stay)

- Tobacco Intervention Program at Abbott Northwestern Hospital
 - 612-863-1648
- Tobacco Intervention Program at Mercy Hospital
 - 763-236-8008
- Tobacco Intervention Program at River Falls Area Hospital
 - 715-307-6075
- Tobacco Intervention Services at Allina Health United Hospital – Hastings Regina Campus
 - 715-307-6075
- *United Hospital Lung and Sleep Clinic Tobacco Cessation Program
 - 651-726-6200
- *Penny George™ Institute for Health and Healing (LiveWell Center) tobacco intervention coaching
 - 612-863-5178

Other

- Quit Partner
 - 1-800-QUIT-NOW (1-800-784-8669) or quitpartnermn.com
 - My Life, My Quit™ (ages 13 to 17): text “Start My Quit” to 36072 or call 1-855-891-9989 to talk with a coach
 - American Indian: 1-833-9AI-QUIT or aiQuit.com
 - Spanish: 1-855-DEJELO-YA (1-855-335-3569) or quitpartnermn.com/es
 - asiansmokersquitline.org
- online tobacco cessation support
 - smokefree.gov
- American Lung Association/Tobacco Quit Line
 - 651-227-8014 or 1-800-586-4872
- *Mayo Clinic Nicotine Dependence Center’s Residential Treatment Program
 - 1-800-344-5984 or 1-507-266-1930

*There may be a cost to you. Check with your insurance provider.

Worksheets

Biopsy Results

Date	Result	Comments
Week 1		
Week 2		
Week 3		
Week 4		
Week 6		
Week 8		
Week 10		
Week 12/Month 3		
Month 4		
Month 5		
Month 6		
Month 9		



Learn more about the Allina Health account



Easy appointment scheduling
In-person and virtual visits,
appointment reminders and updates



Care for the whole family
Gain access to another person's
account (proxy access)



Virtual care options
On-demand urgent care and
scheduled virtual visits



Prescriptions and billing
Manage payments, order refills and
track prescriptions



Info all in one place
Health records, lab results and
appointment notes



**Communicate with your
care team**
Send and review messages

Make health care easier with an online, all-in-one way to manage care.

Get started at
AllinaHealth.org/account

Allina Health 

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Nondiscrimination in Health Programs and Activities

Affordable Care Act – Section 1557

Allina Health complies with applicable federal civil rights laws and does not discriminate on the basis of race, color, national origin, age, disability, gender identity or sex. Allina Health does not exclude people or treat them differently because of race, color, national origin, age, disability, gender identity or sex.

Allina Health:

- provides free aids and services to people with disabilities to communicate effectively with us, such as:
 - ◊ qualified sign language interpreters, and
 - ◊ written information in other formats (large print, audio, accessible electronic formats, other formats)
- provides free language services to people whose primary language is not English, such as:
 - ◊ qualified interpreters, and
 - ◊ information written in other languages.

If you need these services, ask a member of your care team.

If you believe that Allina Health has failed to provide these services or discriminated in another way on the basis of race, color, national origin, age, disability, gender identity or sex, you can file a grievance with:

Allina Health Grievance Coordinator
P.O. Box 43
Minneapolis, MN 55440-0043
Phone: 612-262-0900
Fax: 612-262-4370
GrievanceCoordinator@allina.com

You can file a grievance in person or by mail, fax or email. If you need help filing a grievance, the Allina Health Grievance Coordinator can help you.

You can also file a civil rights complaint with the U.S. Department of Health and Human Services, Office for Civil Rights, electronically through the Office for Civil Rights Complaint Portal, available at <https://ocrportal.hhs.gov/ocr/portal/lobby.jsf>, or by mail or phone at:

U.S. Department of Health and Human Services
200 Independence Avenue, SW Room 509F, HHH Building
Washington, D.C. 20201
1-800-368-1019, 800-537-7697 (TDD)

Complaint forms are available at <http://www.hhs.gov/ocr/office/file/index.html>.





allinahealth.org