

# Chapter 7: Special Helps

## Financial Information

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.

The costs of the transplant can be divided into:

- evaluation
- surgery
- after-surgery care.

Sources to pay for medical expenses include health insurance or COBRA benefits, Medicaid or Medicare, CHAMPUS (Civilian Health and Medical Program of the Uniformed Services), charitable organizations, fundraising, or medical assistance programs.

Other costs include living expenses while you are away from home and transportation to and from the hospital for appointments, tests, surgery or follow-up care. These costs are usually not covered by insurance. They are your responsibility.

### General guidelines

- **Read your insurance plan.**
  - Know if your insurance plan:
    - has “approved providers.” (You may need to receive care at a certain hospital or clinic.)
    - requires “pre-certification” for hospital stays, or “prior authorization” for appointments or procedures
    - requires a referral from your regular doctor before you can go to the transplant center.
  - Following your insurance requirements will help make sure that your care will be covered.
  - Call your insurance provider if you have any questions about your coverage.

- **Call the transplant office if you change insurance plans or if your insurance ends.**
  - Changing plans will affect the benefits you receive.
  - Be sure you know how any changes will affect your care. (For example, you may be required to change doctors.)
  - The financial operations supervisor will fill out the authorization for the surgery. This is done when you are accepted and listed on the national transplant list.
  - The financial operations supervisor will coordinate with your insurance company.
    - He or she will coordinate information and get updated approvals for the heart surgery while you are on the transplant list.
    - **Important:** Tell the financial operations supervisor of any changes with your insurance as soon you know about them.
- **Organize your insurance papers.**
  - Create a filing system for papers including your insurance policy and any information you receive.
  - File bills and receipts by provider in the order in which they occur.
- **Talk with your insurance provider and transplant coordinator.**
  - Complete your insurance provider's requirements.
  - Talk to the transplant coordinator about any "pre-certification" requirements before any hospital stay.
  - Check with your insurance plan or regular doctor to get any required "prior authorizations" or "referrals."
  - Your clinic may require that lab work or other services be done at a certain hospital or clinic.
  - Tell the transplant coordinator when you talk about scheduling a hospital stay, appointment, procedure or test. Your transplant health care team will work closely with your regular doctor and clinic to coordinate your care.

- **Call right away if there is a problem with any bill.**
  - Call the phone number on the bill if you have a question or problem with a medical bill. This may help prevent a future problem.
  - If calling the provider does not solve the problem, call the transplant financial operations supervisor at 612-863-3652.
  - Keep notes of all phone conversations you have.
    - Write down the date and time of your conversation, name of the person you spoke to, and a brief summary of what you talked about.
- **Ask for help when needed.**
  - The financial operations supervisor and social worker are available to help with your questions, concerns or problems.
  - They will work with you or your family members to find financial resources or resources that may be available.
  - Finish any applications or paperwork required.

## **Common Questions After Surgery**

### **When can I drive?**

You may drive 6 weeks after your surgery.

### **How much activity can I do? How much can I lift?**

- You may do light housework.
- Do not, push, pull or lift anything that weighs more than 10 pounds for the first 6 weeks.
- After 6 weeks, do not lift anything that weighs more than 20 pounds.

### **How often do I need heart biopsies?**

In general, biopsies are scheduled as follows:

- once a week for the first month after surgery
- every 2 weeks for the next month (2 to 3 months)
- every 4 weeks (4 to 6 months)
- every 3 months (6 months to 1 year after surgery).

## **What happens if I have rejection?**

It depends on the degree of rejection. It may be corrected with be an adjustment in your medicines. Or, you may need to stay in the hospital and have special IV medicines. Together, you and members of your health care team will decide what treatment you should have.

## **How long will I take prednisone?**

### **How do I taper off it?**

How long you take prednisone depends on your biopsy results. In general, you will be off prednisone by 6 months.

## **When can I return home?**

Returning to your home will depend on the biopsy results and your overall health. In general, you should be ready to return home three weeks after surgery.

## **How long do I need to wear a mask?**

Wear a mask for the first 3 months or until your prednisone is 30 milligrams a day or less for each dose.

## **When can I be around a large group of people?**

Wear a mask at all times when you are around a large group of people, such as at church, shopping malls or sporting events for the first three months after surgery.

## **What happens if a family member gets sick?**

Family members should wash their hands and avoid kissing or coughing on you until they get better.

## **Can I get the flu shot?**

Do not get a flu shot for the first 3 months after surgery or after an episode of rejection. Family members or friends who are close to you should have a flu shot every year.

## **When can I find out who the donor is?**

Information about the donor will not be shared with you due to confidentiality.

## **When can I write to the donor's family?**

You can write to your donor family through the donor program.

## Lab Glossary

Test	What it is	Normal range
<b>Albumin</b>	It is a protein made in your liver. This blood test checks how well your liver is working.	3.5 to 4.8 gm/100 ml
<b>Alk p-tase (alkaline phosphatase)</b>	It is an enzyme in your body. This blood test can help tell how well your liver is working.	40 to 120 mu/ml
<b>AST (aspartate amino transferase)</b>	It is an enzyme in your body. This blood test can help tell how well your heart, liver and kidneys are working.	5 to 45 mu/ml
<b>Bicarbonate</b>	It is a test that helps control the amount of acid in your blood. This blood test checks the acidity level of your blood.	22 to 32 mEq/liter
<b>Bilirubin</b>	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.	0.0 to 1.5 mg/100 ml
<b>BUN (blood urea nitrogen)</b>	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.	5 to 25 mg/100 ml
<b>Calcium</b>	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.	8.5 to 10.5 mg/dl
<b>Normal lab values are different from lab to lab, depending on your age and sex.</b>		

Test	What it is	Normal range
<b>Chloride</b>	It is an electrolyte and works with sodium to influence your water balance. This blood test checks the chloride in your body.	95 to 111 mEq/liter
<b>Cholesterol</b>	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.	110 to 199 mg/100 ml
<b>CPK (creatinine phosphokinase)</b>	It is an enzyme found in your heart, muscles and brain tissue. This blood test checks for heart and muscle injury.	47 to 220 IU/L
<b>Creatinine</b>	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.	0.5 to 1.3 mg/dl
<b>Creatinine clearance</b>	This is a 24-hour urine test to check your creatinine level. This test checks how well your kidneys are working.	75 to 115 ml/min
<b>Glucose</b>	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.	65 to 110 mg/dl
<b>HDL (high density lipoprotein)</b>	It is the "good" cholesterol that carries cholesterol from your blood to your liver. This blood test checks the HDL level in your body.	36 to 75 mg/100 ml
<b>Normal lab values are different from lab to lab, depending on your age and sex.</b>		

<b>Test</b>	<b>What it is</b>	<b>Normal range</b>
<b>Hematocrit</b>	Hematocrit means “to separate blood.” This blood test tells the percentage of red blood cells in your blood.	38 to 50 percent
<b>Hemoglobin</b>	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.	Women: 12 to 15 g/100 ml Men: 14 to 16.5 g/100 ml
<b>INR (international normalized ratio)</b>	It is a measure of your blood’s clotting ability. This blood test checks how well your body responds to medicine like warfarin.	0.7 to 1.2 For anticoagulant therapy: 2.0 to 3.5
<b>LD (lactic acid dehydrogenase)</b>	It is an enzyme found in your kidneys, heart, brain liver, lungs and muscles. When any of these are injured, the lactic acid gets into your blood. This blood test measures the amount of lactic acid in your body.	90 to 225 mu/ml
<b>LDL (low density lipoprotein)</b>	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.	60 to 130 mg/100 ml
<b>Magnesium</b>	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.	1.8 to 2.6 mg/100 ml
<b>Phosphorus</b>	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.	2.4 to 4.7 mg/dl
<b>Normal lab values are different from lab to lab, depending on your age and sex.</b>		

Test	What it is	Normal range
<b>Platelets</b>	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.	140 to 440 thou/cu mm
<b>Potassium</b>	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.	3.5 to 5.3 mEq/liter
<b>Protein</b>	It is important to keep your cells and muscles healthy. This blood test checks the level of protein in your body.	6 to 8 gm/100 ml
<b>PSA (prostatic specific antigen)</b>	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.	0 to 4 mg/ml
<b>Sodium</b>	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.	135 to 145 mEq/liter
<b>Normal lab values are different from lab to lab, depending on your age and sex.</b>		

Test	What it is	Normal range
<b>Triglycerides</b>	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.	40 to 199 mg/100 ml
<b>TSH (thyroid stimulating hormone)</b>	This blood test is done to see how well your thyroid gland is working.	0.34 to 5.60 UIU/ml
<b>Uric acid</b>	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.	2.5 to 8 mg/dl
<b>White blood cell count</b>	These blood cells help your body fight off infections. This blood test checks the level of white blood cells in your body.	4.5 to 11.0 thou/cu mm
<b>Normal lab values are different from lab to lab, depending on your age and sex.</b>		

## 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.

**Aneurysm:** a balloon-like bulge in an artery. Arteries carry oxygen-rich blood to your body. An aneurysm can be caused by disease or injury.

**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 medicine used to fight infection from germs (bacteria).

**Aortic ultrasound:** an ultrasound test to record of ultrasound echoes as they contact the aorta. This test is used to look for aneurysms.

**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.

**Benign prostatic hypertrophy (or, BPH):** this means your prostate gland is larger than normal due to extra growth of prostatic tissue.

**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.

**Cataract:** a film over the lens of your eye that causes vision problems or blindness.

**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 (or, 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 (or, 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.

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

**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 medicine that suppresses the natural response of your body's immune system. You need this medicine 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 of the cervix or uterus.

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

**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 medicine used to treat swelling (inflammation).

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

**Transesophageal echocardiogram (or, 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:** 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

If you find information on a website, show it to your transplant coordinator. If you find a website that asks for you to register or that sells information or products and you are unsure about it, ask your transplant coordinator.

- **Allina Health**  
allinahealth.org
- **LifeSource**  
life-source.org
- **United Network for Organ Sharing**  
unos.org
- **Medic Alert**  
medicalert.org
- **American Heart Association**  
americanheart.org
- **Medicare**  
medicare.gov or 1-800-638-6833
- **The Organ Procurement and Transplantation Network**  
optn.org
- **Your Prescription for Transplant Information**  
transplantliving.org
- **Find Out How to Become an Organ and Tissue Donor**  
www.donatelife.net
- **Department for Health and Human Services**  
organdonor.gov
- **National Transplant Assistance Fund**  
transplantfund.org
- **International Transplant Skin Cancer Collaborative**  
itscc.org

## Resources (Quitting Tobacco)



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

### Allina Health

- 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
- \*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](http://quitpartnermn.com)
- Minnesota Department of Health  
— [health.state.mn.us/quit](http://health.state.mn.us/quit)
- online tobacco cessation support  
— [smokefree.gov](http://smokefree.gov)
- American Lung Association/Tobacco Quit Line  
— 651-227-8014 or 1-800-586-4872
- Chantix® GetQuit Support plan  
— 1-877-CHANTIX (1-877-242-6849) or [get-quit.com](http://get-quit.com)
- financial aid for Chantix® or Nicotrol® inhaler  
— 1-866-706-2400 or [pfizerhelpfulanswers.com](http://pfizerhelpfulanswers.com)
- \*Mayo Clinic Nicotine Dependence Center's Residential Treatment Program  
— 1-800-344-5984 or 1-507-266-1930
- Plant Extracts aromatherapy  
— 1-877-999-4236