

PATIENT HANDBOOK

Heart Transplant



name

phone number



Stanford Health Care has assembled this guide to help you organize and follow important information about your care.

Please bring the guide to your appointments and the hospital. It will be used to teach you about your care.

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Patient Information

My Caregiver or Emergency Contact

Name: _____ Relationship: _____

Contact Info: _____

List of Medications I Am Currently Taking

Name / Dosage:

Name / Dosage

_____	_____
_____	_____
_____	_____
_____	_____

Allergies

Name

Reaction

_____	_____
_____	_____
_____	_____

Preferred Pharmacy

Name

Address

_____	_____
_____	_____
_____	_____

Appointments & Contact Information

Pre-Operative Appointment

Date: _____

Time: _____

Location: _____

Pre-Anesthesia Appointment

Date: _____

Time: _____

Location: _____

Introduction

Welcome to the heart transplant program at Stanford Health Care. Stanford is the birthplace of heart transplant surgery in the United States.

Dr. Norman Shumway and his team at Stanford developed the basis for heart transplants in the 1960s. He also did the first successful adult heart transplant in the United States in 1968 at Stanford.

Since then, the Stanford team has developed many innovations that are now standard practice. Today, the team uses new surgery techniques, better medicines to fight rejection of the transplant, and the absolute best care for heart transplant patients.

Stanford innovations include:

- The heart transplant surgery technique
- Heart biopsy tests to see if the body is rejecting the heart
- Latest and best drugs to treat rejection
- The first successful heart-lung transplant
- The first successful heart device that is a bridge to heart transplantation

Stanford Hospital performs about 50 to 70 heart transplants each year. More than 1,750 heart transplants have been done at Stanford.

Patients range in age from newborns to adults. They have almost every type of severe heart disease.

Many patients have now survived more than 25 years. Some live more than 30. We stay in touch with patients throughout their lives.

We'll continue to offer support, education, and medical help for your transplant over the years. Don't ever hesitate to ask your transplant team questions at any time.

This manual is a guide to the transplant process. Education begins at your first evaluation and continues long after your heart transplant is complete.

Please keep this manual. It will be useful throughout your transplant care.

You play an active role in the transplant. Your concerns are important to us. Our goal is to give you and your family all the information and support you need.

What Is Heart Failure?

About 5 million Americans are living with heart failure. Although the risk of heart failure increases as we age, it affects all ages.

Heart failure happens when the heart muscle gets weak. The failing heart can't keep up with the body's need to pump blood. That allows fluid to collect in the lungs and other parts of the body.

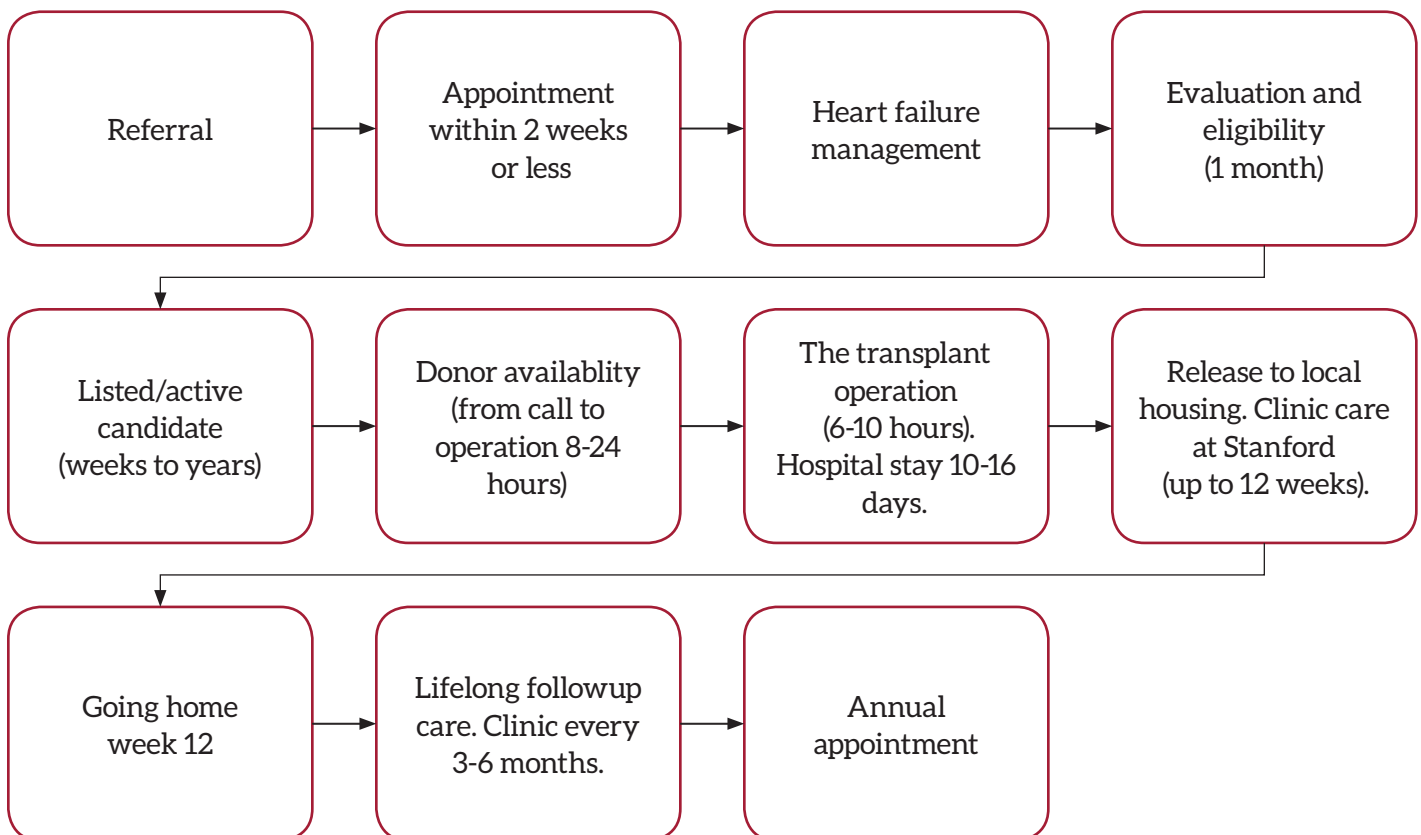
Heart failure may start slowly and get worse over time. Sometimes it happens suddenly.

The outlook for improving a weak heart depends on the cause and how severe it is. It also depends on how closely you follow the treatment plan.

Eating healthy food, taking medicine and following doctor's orders can improve your symptoms and quality of life.

Timeline

All times are estimates and cannot account for every individual.



Evaluation

Why has my doctor sent me for this evaluation?

You may be a candidate for a transplant to replace a failing heart that has not improved after other treatment. Your doctor is having you examined at Stanford to decide the best treatment for you.

While a heart transplant may be the best option, often other treatments are explored first.

Some causes of congestive heart failure, or weakening of the heart muscle, include:

- Heart attack
- High blood pressure
- Leaking or blocked heart valves
- Heart conditions present at birth
- Irregular heartbeats
- High blood pressure within the lung' blood vessels
- Alcoholism or drug abuse
- Virus infection
- Pregnancy changes
- Diabetes changes

You may have questions about your evaluation. You will have a chance to talk about them during your clinic appointments.

Social Services

The clinical social worker works closely with you and your after-transplant team. Most patients and families return to a healthy life. Sometimes you may need advice from the clinical social worker.

Help is available for you, even lifelong, after a transplant. That may start during your evaluation. It could happen while you are on the transplant list or at a clinic appointment.

Sometimes you may get help over the telephone, or while in a support group. Often it happens when you are in the hospital at Stanford.

Support may include:

- Counseling and teaching after your transplant
- Planning for a move after your transplant
- Help coordinating after-transplant care in your home community
- Mental health help to ease anxiety, depression, and stress as you adjust to your transplant
- Managing costs and keeping medical insurance
- Job issues like transition to work, school, and home activities
- Smoking, drug, or alcohol addiction checks, and relapse prevention
- Relationship issues, communication, intimacy, sexual questions
- Heart transplant and caregiver support groups
- Help writing a letter to the donor's family
- End-of-life decision-making, grief, loss, and mourning
- Any other issues that could hurt your transplant

Interpreter Services

You can call Stanford Health Care interpreter services to get help with understanding language. This help is available 24 hours a day, 7 days a week. The phone number is (650) 723-6940.

Puede llamar a Stanford Health Care servicio de interprete para recibir ayuda con el idioma. Este servicio esta disponible a diario las 24 horas, los 7 dias de la semana. El numero de telefono es (650) 723-6940.

Psychological and Social Evaluation

Getting a heart transplant is a complex effort. It's not recommended for every patient.

Psychological and social challenges can make poor results more likely. Before a transplant, the clinical social worker gives a candidate counseling and education.

Clinical social workers check how you and your caregiver handle the daily challenges from your situation. They help you start a strong coping plan with psychological support.

Your Peers Are Mentors

Mission statement: "Provide unique support and understanding through peer to peer mentoring in order to promote healthier lives and reduce isolation."

Peer mentors are people like you who have volunteered to help. They are carefully selected, trained, and supported to help you and your support circle. Together you can handle the challenges that come with your medical condition.

In the peer mentoring program, you are linked one-to-one with a mentor who shares similar health and life circumstances. Through this trusted relationship, mentors can support you in many ways. They listen to your concerns and share personal experiences. They help you find ways to cope and guide you through the health care system.



For more information please contact your transplant social worker or the peer-to-peer program coordinator at 650-474-1011.

My Heart Transplant Care Team

Your **heart failure doctor** (a cardiologist) specializes in weakened heart muscles (cardiomyopathy). This doctor has deep experience in deciding which patients will benefit from a heart transplant. He or she will make a recommendation to the Stanford heart transplant selection committee. If you are accepted, this doctor cares for you while you wait for a donor.

Your **pre-heart transplant coordinator** schedules tests and appointments during your evaluation.

Your heart failure nurse coordinator works with the heart doctor. This nurse helps you understand your illness, salt limits, and medicines. This nurse also helps with information on testing and the transplant.

Your **heart transplant clinical social worker** has specialized training to help you and your family. The clinical social worker will do a psychological and social review for your application for a transplant.

Clinical social workers help with counseling and education about the transplant. They can help you adjust to changes before and after a transplant. They also make regular checks on you after a transplant.

The **heart transplant financial counselor** works with your insurance company to explain coverage for your visits and tests here. The financial counselor makes sure your insurance company approves your treatment. If a transplant is recommended, the counselor also will find out what coverage you have for the operation, medicines, and care after the transplant. Please contact us to talk over any financial hardship.

The **inpatient transplant nurse practitioner** works with you during your transplant in the hospital. This nurse works closely with the surgeons, heart doctor, and social worker to make sure your hospital stay and recovery go as smoothly as possible. This nurse will give you and your family information to prepare you for life after the transplant.

The **after-transplant nurse coordinator** works with you after you have been released from the hospital. You will see this nurse during your clinic visits and talk to him or her often over the telephone.

He or she will support you as you recover from your transplant and will work with you after surgery. This nurse provides a lot of education and continuing care in the clinic.

The **after-transplant doctor** cares for you after you leave the hospital. This doctor specializes in medicines that prevent your body from rejecting the transplanted heart. This doctor also treats your special needs after the transplant.

The **transplant surgeon** performs your surgery. The surgeon has assistants including other doctors and nurses who specialize in anesthesia and transplant surgery. The surgeon reviews your medical history and your condition to see if you are a good candidate for transplant surgery. The surgical team cares for you while you recover from surgery.

The **physical therapist** helps restore your strength and stamina after surgery. The physical therapist also teaches safe and effective ways to increase your activity after you leave the hospital.

The **dietitian** gives you information on nutrition and eating heart-healthy food.

Stanford Health Care is a teaching hospital. It works closely with the Stanford School of Medicine. You will be seen by doctors called “fellows” because they are completing their last training in heart failure and transplantation. These fellows will see you with the faculty or staff Stanford doctors.

Heart Transplant Screening Tests

You may have some or all of the following tests:

Echocardiogram

During this test, a probe that looks like a microphone is passed over your chest. Sound waves bounce back from the heart and make a picture of your pulsing heart muscle. It also shows how the heart valves are working and if your heart is enlarged. Even if you’ve had an echocardiogram before, we may need to repeat it at Stanford.

Exercise (VO2) Test

This test shows how much oxygen your heart and lungs can send to your muscles during exercise. It is done on a treadmill or bicycle using equipment to collect exhaled air. This test is useful in showing who will benefit most from a heart transplant.

Right Heart Catheterization

This test checks the pressures in the right side of your heart. After numbing the area, a narrow flexible tube called a catheter is inserted into a vein in your neck or groin. The tube is used to measure pressure in the heart chambers and main blood vessels.

Coronary Angiogram

This test checks for blocked areas in your heart’s arteries. A tube is inserted into the blood vessel in the groin or arm and pushed to the arteries that supply blood to the heart. Dye is injected to look at the arteries and the pumping of the heart.

Laboratory tests

Blood tests can determine your blood type and whether you have been exposed to certain viruses.

Chest X-ray

This test shows an image of your lungs and heart. It can show any unusual features in your lungs and the size of your heart.

Pulmonary Function Test

This shows how well your lungs work and how much they can carry.

Carotid and Peripheral Doppler Studies

These tests look for blocked areas in the neck (carotid) and leg arteries. This test uses an ultrasound probe to produce pictures.

Colonoscopy

This test is often done to rule out colon or rectal cancer. This is done at Stanford or by your own specialist doctor.

Mammogram

This may be done to screen for breast cancer.

Dental exam

This can evaluate the health of your mouth, teeth, and gums.

Eye Exam

This looks at the blood vessels behind your eyes and your overall eye health.

Electrocardiogram (EKG)

This is a painless test that traces electrical activity in your heart.

Other tests

Depending on your age and other medical conditions, you may need more tests. Some people get tests for cancer, blood vessel disease, lung disease, and other conditions.

Each person is different. If you need extra tests, your pretransplant heart doctor will talk them over with you.

Heart Transplant Selection Committee

When your tests are done, your pretransplant heart doctor will present your case to the heart transplant selection committee. This team meets weekly.

Members of the committee include surgeons, heart doctors, nurses, and clinical social workers. They may also include nutritionists, pharmacists, physical therapists, and specialists in infections and the body's immune response. The group will discuss the best treatment for you.

Sometimes the committee decides a patient doesn't require listing at that time. If so, the patient may continue treatment medicines.

In other cases, a patient may benefit from another surgery or therapies before getting a heart transplant. Others may need to be listed for a transplant right away.

In some cases, a patient may not be a good candidate for a heart transplant. Some reasons include, but are not limited to:

- An infection that is current or recurring that can't be treated effectively
- Active cancer
- Inability to tolerate the surgery
- Serious conditions, other than heart disease, that would not improve after a heart transplant
- Unwillingness to agree to a treatment plan
- Alcohol or drug abuse
- Support system lacking
- Other risks depend on your specific medical condition. Be sure to discuss any questions with your doctor before the procedure.

The committee recommendation will be given to you and your doctor.

If you are accepted to be a transplant candidate, we will check to see if your insurance company clears you. Then we will list you on the computer system for the United Network for Organ Sharing (UNOS). Patients are listed by blood type, height, weight, and urgency.

The Categories of Urgency Are:

1A Patients who are very sick and are in the hospital. They have equipment or mechanical devices to keep their hearts beating.

1B Patients who may be in or out of the hospital. They have intravenous (IV) medicines or a mechanical device to keep their hearts working.

Status 2 Most patients who are out of the hospital and stable.

Status 7 Patients who are temporarily inactive on the transplant list.

Your pre-transplant heart doctor will talk to you about your status. That may change as your condition improves or gets worse. There are some exceptions to the status categories labeled with an E, such as 1AE, or 1BE.

The Donor Heart

Organ donors are those declared brain dead from a severe brain injury. Before removing the heart, 2 or more doctors must declare the donor brain dead. Family consent also is necessary.

The donor information is then sent to the UNOS computer. The computer produces a match list of possible recipients.

It is best to remember that you are waiting for a family to make a decision to donate, rather than waiting for someone to die. Deaths happen regardless of your need for a transplant.

The decision a family makes to donate is often the only way they can find comfort with their loss. At the same time, it gives hope to another family.

Questions About Your Donor

Personal information about your donor is kept confidential. You are still welcome to write to the donor family.

Expressing how the donor's gift will affect you and your family can help convey your thanks. We suggest that you avoid identifying information about your family.

You may send the completed letter to your transplant coordinator or social worker. They will send it to an agency to send to the donor family.

If the donor family chooses to write to you, the letter will also be sent anonymously the same way. It is usually a good idea to wait at least 6 months after a transplant to write this letter.

Advice on writing a letter to your donor family can be found on the "Transplant Living" website at: <https://transplantliving.org/community/patient-resources/contacting-your-donor-family/>

The High-Risk Donor

A high-risk donor is anyone who shows high-risk behavior that increases the chance of spreading certain infections. The infections are from viruses called HIV (the human immunodeficiency virus) or hepatitis B and C.

All donors whose hearts are offered for transplant have already been tested and found clear of HIV and hepatitis B and C. The tests use the most up-to-date technology.

At the time the organ is offered, the donor does not appear to have any harmful infections. But some of these infections, including HIV and hepatitis B and C, can be undetectable for a short time after the donor is exposed.

That means a high-risk donor has a very small chance of having such an infection that went undetected. So there is a very small chance, less than 1 percent, that you will get that infection from the donor.

You must be given this information so you are fully informed about the donor heart offered. However, the Stanford transplant team would only recommend a donor if they believe it is an acceptable offer.

The team also weighs the best option for you given the timing and your situation. Keep in mind that the risk of rejecting this heart offer may be greater than the risk of accepting it. Suitable donor hearts are often few and far between.

Please discuss this question ahead of time with your primary heart doctor.

The call to come to the hospital for a transplant may come at a difficult time. It may be the middle of the night. This is an important decision that is best made ahead of time.

Frequently Asked Questions About Infection Risks

How soon do these infections show up if they were not found in the first donor evaluation?

The incubation period (time it takes to be detected) for hepatitis C is about 8 weeks. For hepatitis B, it is about 4 months, and for HIV it's about 2-4 weeks.

Would I be checked for these possible infections? If so, how is that done? How often?

You will be tested every month after the transplant with a blood test for up to 6 months. The tests include sensitive virus tests and antibody tests.

If I get infected, how would that affect my recovery? Would that change my treatment and longer-term medical outlook?

If you were infected, you would probably get medicines to treat the infections. Most of these drugs do not affect typical transplant medicines. None of the 3 viruses should affect the heart directly. These viruses can affect other organs.

Is there treatment for these infections?

HIV cannot be cured but the virus can be suppressed. Hepatitis B cannot be cured but it can also be suppressed. Hepatitis C can be cured more than 95 percent of the time.

What is high-risk behavior?

High risk behavior has been defined by U.S. health officials as:

- Men who have had sex with another man in the last 5 years
- People who have injected nonmedical drugs in the last 5 years
- People who have received blood-clotting products for hemophilia or related clotting disorders
- Men and women who have had sex in exchange for money or drugs in the last 5 years
- People who have had sex in the last 12 months with anyone known or suspected to have HIV infection
- People who have been exposed in the last 12 months to known or suspected HIV-infected blood. They can be exposed through skin injection or by touching an open wound, a skin cut, or mucous membrane
- Prison or jail inmates. This group reflects the challenge of ensuring inmates give informed consent to be tested. Also, inmates have a higher risk of HIV infection

Waiting Time

How long you wait for a donor will depend on your UNOS status, your blood type, and size. It also depends on how long you have been waiting on the list.

You may wait a few days or more than a year. The donor's body must be close to your own height and weight. Your pre-transplant heart doctor will talk to you about how long you may have to wait.

You may wait at home or in the hospital. This depends on whether you need IV medicine and devices to support your heart. The heart transplant team's goal is to make the most of your treatment and enhance your quality of life during this time.

Hearts can be transplanted only for a short time after being taken from the donor. You may be asked to move temporarily to be near the hospital.

You will need a cell phone so you can be called right away if a donor heart becomes available. Always tell the pre-heart transplant coordinator about any trips you take out of the area.

While waiting, keep yourself as healthy as possible. Continue to take your medicine as prescribed. Follow diet recommendations.

Stay as active as possible by walking or exercise program approved by your heart doctor. It is also a good idea to see your dentist and your primary care doctor when recommended.

Weigh yourself every morning

It's a good idea to weigh yourself every morning, after going to the bathroom and before eating breakfast. Wear similar clothes each time.

Keep a record of your weight. If you gain 2 pounds or more in one day, or 3 to 5 pounds in one week, notify your doctor. This may show fluid build-up—a possible symptom of heart failure--rather than a weight increase from fat.

Avoid:

- Heavy cleaning like vacuuming, sweeping, or mopping
- Isometric exercises or weight lifting
- Raking leaves or garden hoeing
- Playing golf, tennis, basketball, football, or soccer.
- Smoking and smoking environments
- Ask your doctor whether you should drive.
- Talk to your heart doctor about having alcoholic drinks. In some people, alcohol can poison the heart muscle cells and weaken your heart. Alcohol also makes the heart more vulnerable to irregular heart rhythms.

Life while waiting

Above all, continue to live your life by seeing family and friends. Continue doing what you enjoy.

You will be invited to join a support group led by our clinical social worker. The group members are other patients waiting for transplants. People who have received transplants and their families are also part of the group.

This group can provide valuable information and may give you emotional support. A separate support group for caregivers is also available.

Once you are on the transplant list, our staff will need a way to contact you any time of the day or night. You must be ready to come right away.

With cell phones, it should be easy to reach you as soon as a potential donor is found. To help you prepare, here are a few tips:

A cell phone is essential. But you'll need more. Give the transplant team a list of telephone numbers for the homes of friends and family or wherever you visit often.

Check your cell phone, answering machine, or voicemail often. This is especially important if you are someplace where it is hard to reach you.

Mental Health In Heart Transplant Patients

A heart transplant often changes a person's life. Like people with other long-term medical problems, heart transplant recipients have a higher risk of mental health problems.

About half of patients with severe heart disease have anxiety or depression. About 63 percent of heart recipients develop anxiety or depression during the first year after the transplant.

A clinical social worker will care for you after the heart transplant. The social worker can check for feelings of depression and anxiety after the transplant.

You may be helped by seeing a psychiatrist or a therapist if you have difficult feelings. Please feel free to speak to your transplant team if you want someone to talk to.

It is important to stay positive and be aware of the very natural stress that comes from having heart failure.

Learning everything you can about your condition, your transplant, and what to expect can make you feel less worried or afraid. If you can, talk with people who have had transplants. Be sure to ask members of your transplant team any questions you may have.

Support groups can be very helpful for you, your family and friends. Stanford hosts a monthly support group for both patients and caregivers. Patients waiting for a donor organ are especially welcome to attend. Our clinical social workers also offer resources to help you cope and manage stress in a positive way.

Paying For Your Transplant

Check with both your insurance provider and Stanford's financial counselors to ensure you get full benefit from your insurance coverage and limit your out-of-pocket costs.



To reach one of our transplant financial coordinators, please call (650) 498-6334

Financial planning begins when your doctor sends you for a transplant evaluation. The pre-transplant coordinator is notified that you are a potential candidate for a transplant. The next step is to check your financial status. Another step is to check for insurance approval. The financial coordinator will tell you and your doctors about any financial issues. This may mean explaining current insurance benefits or counseling to get insurance coverage.

Sometimes this planning may lead you to another transplant center because of insurance contracts. We are ready to counsel patients who have no insurance, or limited insurance, for a heart transplant.

We're with you all the way.

Once your benefits are clear and insurance approvals are set, you are scheduled for any appointments and procedures you need. While you think over transplantation and take care of your medical condition, we handle the insurance coordination.

When all your tests are done, you will be presented to the transplant selection committee. If the committee agrees, you will be listed on the UNOS wait list.

At that time, we will coordinate approvals for transplantation. This includes all insurance plans that cover you. Approvals are obtained for all procedures you might need after the transplant.

We are also ready to help if you are adding, changing, or losing insurance coverage. We ask you to call us before you make any changes in health insurance. We'll help keep information accurate and get approvals in time for your care.

Financial Help at Stanford

Stanford Health Care has financial help available to patients who don't have insurance or don't have enough insurance. We will help you find out if you qualify for financial help.

There may be programs that help pay for your medical services. You can get more information or find out the cost for hospital services by calling the number listed below.

SHC Patient Financial Advocates

Patient Financial Services

2690 Hanover Street

Palo Alto, CA 94304

Customer Service: (800) 549-3720

Web: <http://stanfordhospital.org/forPatients/financial/financialHardship.html>

Your social worker will help you plan the expected costs of housing and medicine.

Fundraising For Your Heart Transplant

HelpHopeLive

HelpHopeLive works with families to build grass-roots fundraising campaigns for people facing transplantation. Money is sent to and held by HelpHopeLive in honor of patients. Money is given to those who apply and show financial need.

Web: www.helphopelive.org

You can contact HelpHopeLive at (800) 642-8399.

National Foundation for Transplant

The National Foundation for Transplant (NFT) was started in 1983, in Memphis, TN. It has become an organization that helps transplant candidates with fundraising.

After your first conversation with a fundraising consultant, NFT will send you a packet of information, including an application.

You may sign-up for NFT's fundraising program by calling (800) 489-3863 and asking to speak with a fundraising consultant.

Web: <http://www.transplants.org>

You may also contact them at info@transplants.org

Paying for Medicine

Check your insurance prescription plan to find out what your co-payment will be for prescription medicine. The cost may be different for generic and name-brand medicine. What can look like a low co-payment can actually add up to several hundred dollars a month.

It is important that you know what bills you will be expected to pay each month. If you have Medicare, you will need to make sure you enroll in Medicare part D – the prescription program.

Most drug companies have patient assistance programs to help people who cannot afford to buy their medicine. The following websites offer a list of patient assistance programs with information on rules and forms. Please verify that you qualify for these programs by reviewing the website.

RxAssist

Web: www.rxassist.org

Partnership for Prescription Assistance

Web: www.pparx.org/en

Transplant Financial Resources

The following organizations provide financial help to transplant candidates or recipients and their families.

This is a sample list only and not an endorsement. For more information, visit UNOS.org.

American Kidney Fund

6110 Executive Blvd., Suite 1010
Rockville, MD 20852
800-638-8299
www.kidneyfund.org

The fund provides limited grants to needy dialysis patients, kidney transplant recipients, and living kidney donors. Grants help cover the costs of health-related expenses, transportation and medication. The fund provides information and support for kidney donation and transplantation, plus general information on kidney disease.

American Liver Foundation

39 Broadway, Suite 2700
New York, NY 10006
800-465-4837
www.liverfoundation.org

This foundation is a voluntary agency dedicated to fighting disease through research, education, and patient self-help groups. The group acts as trustees for trust funds.

American Organ Transplant Association

21175 Tomball Parkway #194
Houston, TX 77070

713-344-2402
www.aotaonline.org

This private nonprofit group provides reduced or free airfare and bus tickets to transplant recipients and their families. AOTA publishes a newsletter for its members. Patients interested in these services must be sent by their doctors. The association also helps to setup trust funds and do fundraising. No administration fee is charged.

Air Charity Network

National headquarters
4620 Haygood Road
Virginia Beach, VA 23455

877-621-7177
www.aircharitynetwork.org

Through its members, this network gives people access to free airline flights to health care facilities or distant destinations. It helps those in a family, community, or national crisis.

Children's Organ Transplant Association

2501 W Cota Drive
Bloomington, IN 47403

800-366-2682
www.cota.org

This national nonprofit agency raises money for people and their families to help with transplant expenses. It works with adults as well as children. All funds raised go to the individual. No administrative fees are collected.

HelpHopeLive (formerly NTAF)

Two Radnor Corporate Center
100 Matsonford Road, suite 100
Radnor, PA 19087

800-642-8399
www.helphopelive.org

Packing For the Hospital and Recovery

Every patient is different so it is hard to know how long you will need to stay in the hospital. Timetables also differ for how long you will need to recover outside the hospital. Most patients stay in the hospital's intensive care unit (ICU) for 1 to 3 days.

Then you are moved to the step-down ICU for another 7 to 10 days before leaving the hospital.

You will be asked to stay in the area for 10 to 12 weeks after you leave the hospital. You maybe ready to go home earlier, but it is always better to plan ahead.

During the first month after your hospital stay, you need to have someone with you most of the time. This guideline depends on your progress. It is generally safe for your caregiver to leave you alone for brief periods.

While waiting for a donor, pack a small bag to carry you through the first few days in the hospital. A friend may bring more articles later. Some people instead want to pack enough in advance for the full hospital stay.

Checklist for packing

- ☐ **Bring only the personal items you will need during your stay.** That includes a robe, reading material, 1 or 2 checks, and \$10 or less in cash. Small devices like shavers and hair dryers are OK except in the ICU.
- ☐ **Bring pajamas if you don't like hospital gowns.** Tops should be button down or zip-front, so the nurses can change bandages and check cords on your chest. Short sleeves or baggy sleeves are better to place IV tubes in an arm.
- ☐ **Bring slippers or slip-on shoes for walking around the hospital.** You may want to bring something roomier than usual because swollen feet and ankles are common after surgery.
- ☐ **Bring athletic shoes or sneakers** for physical therapy when you start moving.
- ☐ **Bring a list of medicines, doses, and allergies.**
- ☐ **Bring a journal.** Writing about your experience is a great way to adjust to the transplant experience. It may be helpful to gather your thoughts and put your emotions on paper.
- ☐ **Have a copy of your advance health care directive.** If you have not already done so, please send a copy of this document before or when you are listed for a transplant. For more information about this, please ask your social worker or transplant coordinator.
- ☐ **If you're a reader, bring a good book.** You may not feel like reading right after the transplant. When you're ready, reading may be a good way to ease anxiety.

- ☐ **Bring a music device (like a cell phone).** The ICU and step-down units can be noisy. Music that you enjoy may calm you so you can rest or fall asleep. Music may ease anxiety and restlessness.
- ☐ **Pack comfortable clothes** like sweats or jeans for your recovery. If no one is returning home to get your personal items BEFORE you leave the hospital, you may plan to pack a few days' worth to tide you over.
- ☐ **Bring contact lists of people you want notified or who you want to call.** Starting a phone tree, where 1 or 2 folks call others, is a good way to ease the stress on your family fielding calls from numerous people.
- ☐ Many people use “apps,” or applications, on a phone or online, that allow you or your family to post progress that can be seen by invitation only. Computers are available in the hospital for email.
- ☐ **Bring enough medicine to get you back home if it's a “dry run.”** Plan for unexpected delays such as trouble getting travel arrangements.
- ☐ **Bring a camera or cell phone.** Some patients like to have photos taken in the hospital to make scrapbooks or to get pictures of the transplant team.
- ☐ **Bring photos of family or inspiring friends** to have around you for comfort or support.
- ☐ **Include bathroom items** and products you “can't live without” such as a favorite foot cream, lotions, shampoos, or other items to comfort and pamper yourself.
- ☐ **Bring spiritual or cultural items** such as prayer books, rosaries, or scripture.
- ☐ **Bring your cell phone and charger.** Ask where you can use it. You are not allowed to use your cell phone in many parts of the hospital. Long-distance calls from your hospital room phone are not allowed.
- ☐ **Bring eyeglasses** – many people find it difficult to use contact lenses right after the transplant operation.
- ☐ **Bring any essential medicines.** Bring information to obtain refills at local pharmacies and medical insurance cards.

Hospital Checklist For Caregivers

- ☐ **Enough clothes for the hospital stay or to last until backup helpers arrive.** Be sure to include a warm sweater or sweatshirt. The ICU waiting rooms are routinely chilly.
- ☐ **Comfortable walking shoes.** Many support people walk to lower stress and get fresh air to cope.
- ☐ **Contact information** so you can reach people supporting you emotionally--and other helpers.
- ☐ **A cell phone and charger.**
- ☐ **Spiritual or cultural aids** like prayer books, rosaries, or scripture.
- ☐ **Phone trees, email addresses or contacts of people** for information sharing.
- ☐ **Checkbook or ATM cards and credit cards.**
- ☐ **Toothpaste and toothbrush, and hairbrushes.** You may be in the ICU waiting room overnight.
- ☐ **Eyeglasses, reading glasses and backup contact lenses with solution.**

Please leave valuables such as jewelry, a lot of cash, or electronics at home. The hospital cannot be responsible for the loss or damage of your personal belongings in your room.

Appliances, except shavers and hair dryers, are not allowed in patient rooms for safety reasons. Don't bring medicine from home unless your doctor told you to.

No smoking

Stanford Hospital & Clinics does not allow smoking anywhere. This includes the hospital entrances, courtyards, and most outdoor areas.

Your Caregiver or Support Person

Your caregiver is an essential member of your transplant team. Caregivers are usually family members or friends who are able to rearrange their schedules to become your partner during your transplant journey. You will need a caregiver as soon as you leave the hospital to continue recovering.

For many patients, finding a caregiver is easy. The caregiver is a nonworking partner or spouse, family, or friend willing to support you throughout the transplant process. For others, the choice is more complicated if there is no readily available person.

Be prepared to pick someone—or people—who can be with you at appointments before your transplant. They also must make a 24/7 commitment to you for 3 months after your transplant. They must be able to handle the uncertainty and stress that come with recovery from major surgery.

Getting ready for a transplant can take days, weeks, and possibly months. During that time, your caregiver should be ready to go with you to key appointments. Your caregiver(s) should learn how to navigate various clinics and offices at Stanford.

They should learn about any special conditions for you. They need to know what caregiver tasks they'll have to do after the transplant. Your caregiver will be asked to sign a pledge to accept these tasks before you are released from the hospital after the transplant.

The caregiver's role is a full-time job. Caregiving requires someone who is dependable and reliable. Changes in your treatment plan, schedule, or health can be stressful for the caregiver. They may feel concern, frustration, and fatigue.

There are many after-transplant topics the staff will want to talk over with you and your caregiver before you are released. A major topic will be medicines. When you leave, you and your caregiver must follow a medicine plan more complex than anything you have ever had. The stakes are high.

Organizing your medicines into a plan so you can manage them will fall mostly on your caregiver. Before you leave the hospital, the staff can help you and your caregiver organize this plan. This will remove much of the mystery and give you confidence.

What are your caregiver's responsibilities?

- Protecting your need for recovery
- Talking with family and friends
- Giving emotional support
- Shopping for food
- Preparing meals
- Checking and writing down fluid intake
- Reviewing medicines and getting prescriptions refills
- Watching for symptoms and reporting them
- Doing housecleaning and laundry
- Going with you to a clinic visit and finding the right labs and offices
- Transportation

There is no way to completely protect you and your caregiver from the challenge of being on your own the first 24 to 48 hours after leaving the hospital. Before your first clinic appointment, careful preparation can reduce uncertainty and mystery.

Day or night, you will always only be a phone call away from expert help. Your caregiver is the key to guiding you to success after a transplant.

Adult Heart Transplant Program Caregiver/Support Person Agreement

Transplantation includes many challenges and risks. Patients must have a capable and committed caregiver or support person available to help them before and after the transplant. This requirement helps patients get the best results from the transplant.

I, _____, understand my full assistance, commitment, and cooperation to the patient, _____, are required to achieve the best care.

To meet that goal, I agree to give the following support care after transplantation:

- Attend hospital teaching sessions when the patient is hospitalized or when the patient has reached the top of the waiting list, or when asked.
- Drive the patient to all appointments on time before and after the transplant.
- Go with the patient to all clinic appointments before and after the transplant. I understand this could include other medical appointments, such as blood tests, for the transplant.
- Help with fill and or refill prescription medicines.
- Monitor medicines.
- Help shop for groceries, cooking meals, and tasks.
- Monitor the patient's condition after leaving the hospital. This includes taking temperatures and helping with daily living,
- It also means calling the doctor for any concerns at any time. Be prepared to get the backup support person to move the patient back to the hospital if required.
- Give emotional support and companionship before, during, and after the transplant.

I understand the above list is not final. There could be more unexpected tasks added in the future.

If, for whatever reason, I am unable to provide the required care I agree to discuss my situation with the patient and the transplant clinical social worker. I will do my best to find another support person who is able to fulfill these responsibilities.

If no other caregiver can be found before the transplant, the patient may be temporarily put on hold on the transplant wait list while another caregiver can be found.

I have received education and teaching on my caregiver or support person roles and responsibilities. I agree to carry out these duties to the best of my abilities.

_____ Patient Name (print)	_____ Patient Signature	_____ Date
_____ Caregiver Name (print)	_____ Caregiver Signature	_____ Date
_____ Caregiver Name (print)	_____ Caregiver Signature	_____ Date

Spiritual Services

The spiritual care staff helps patients find comfort and support within their own faith traditions. Staff and volunteers, as well as community resources, are available for all heart transplant patients.

Whether you are a Stanford Health Care patient, family member, friend, or staff member, spiritual care service is here with compassion to support you with:

- Listening
- Open-hearted talk about hope, gratitude, fear, connection, and meaning
- A calm presence
- Prayers and blessings
- Connecting you to your religious or spiritual tradition through our staff, volunteers, and community resources

Phone: 650-723-5101

Fax: 650-725-8907

Email: spiritualcare@stanfordhealthcare.org

When a Donor Comes Available

You will be contacted by the surgeon once a potential donor becomes available. Keep all phone numbers current with the transplant coordinator to prevent delays in reaching you.

The surgeon will ask if you have had a recent infection like a cold or flu. Tell the doctor if you have signs of infection such as fever, cough with sputum, flu-like symptoms, or diarrhea. It is important to be completely honest.

An existing infection could cause complications after a transplant. The medicines you will receive for the transplant could prevent you from fighting infection. That might make it dangerous to proceed with surgery. If you have an infection that makes it unsafe to go through with surgery, the heart will go to the next candidate on the list.

Once you are called, do not have anything more to drink or eat. You will be asked to report to the hospital immediately. The surgeon will tell you where to go once you arrive at Stanford.

Once you have been admitted to the hospital, you will be connected to an IV. You will have your blood drawn and receive a chest x-ray. The surgeon and an anesthesiologist will see you and take your medical history.

The surgeon will go over the procedure with you. He or she will review the risks of the operation with you and your family.

Heart Transplant Surgery

When it is time for your operation, a team of anesthesia doctors will take you to the operating room. There they will place special IV tubes for you to receive fluid during your surgery.

They will give you medicine to help you relax. Then they will place a breathing tube into your airway to help you breathe during your operation. You will also have a tube placed to drain your urine during the surgery.

While this is happening another team of surgeons will be at the donor's hospital. The team will check the donor's heart to make sure that it is a good match for you.

Sometimes they discover information that makes the donor heart unacceptable for you. In that case, your transplant will be cancelled. Though this is rare, there is always a very small chance that the surgery may not take place.

Sometimes the transplant can even be cancelled at the last minute after you have gone into the operating room. This can be very difficult and disappointing for you and your family. Canceling your transplant is done only when it would be unsafe to proceed.

If the heart transplant is done, a cut will be made down the middle of your chest. A heart-lung bypass machine will take over the work of your heart and lungs. Your diseased heart will be removed and replaced with a healthy donor heart.

The doctors will leave a small piece of the top of your heart and back of your heart. They also leave the big blood vessels that bring blood to and from the heart.

The operation usually lasts between 5 and 6 hours. It can last longer if you have had previous open-heart surgery or have a left ventricular assist device (LVAD) in place.

What if I had a ventricular assist device (VAD) or artificial heart?

If you had a VAD, also called mechanical circulatory support (MCS) before you had the heart transplant, you may have a higher risk for bleeding after the transplant. Your surgery may also take a little longer because your VAD will have to be removed.

After the transplant, you will no longer have a driveline.

If you had other devices before the transplant, including an internal cardiac defibrillator (ICD) or a pacemaker, that will be removed by the surgeon.

Risks of the Procedure

Complications may occur with any surgery. Potential risks for heart transplantation include, but are not limited to:

- Infection
- Bleeding during or after the surgery
- Blood clots that can cause heart attack, stroke, or lung problems
- Breathing problems
- Kidney failure
- Coronary artery vasculopathy (CAV), similar to coronary artery disease
- Your body may reject your new heart. Rejection is a normal reaction of the body to a foreign object or tissue. When a new heart is transplanted into someone's body, the immune system reacts to what it sees as a threat and attacks the new heart.

To allow the transplanted heart to survive in your body, you must take medicines to trick the immune system into accepting the heart. The medicines that prevent or treat rejection have side effects.

The exact side effects depend on the specific medicines. The doses may be lowered. Still, you will need to take these medicines for the rest of your life to avoid rejection.

How Successful Are Heart Transplants?

Survival after a heart transplant has improved over the last 20 years. Each transplant patient faces specific risks depending on his or her particular condition. Your doctor will talk over these risks with you. In general, 85 percent to 90 percent of patients survive at least one year and 80 percent survive 3 years.

Survival times for each transplant program in the United States are available online at www.ustransplant.org. The survival times for every heart transplant program in the country are on this site. The information is updated in January and July.

As of June 2016, the survival rate for adult heart transplant patients at Stanford Hospital after one month is 96 percent. After one year it is 91 percent, and at 3 years it is 86 percent.

Many patients at Stanford have survived more than 20 years. Two of the most important reasons for long-term survival are taking medicine properly and getting good follow-up care.

2

After-Surgery Care

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After-Surgery Care

This section of the binder is about taking care of yourself after your transplant. It has information to help you get used to your new daily routine for health care.

That means learning your medicines. It also means checking yourself for possible complications.

You'll be part of a big team effort to ensure your transplant success. The teamwork between you, your family or caregivers, and the transplant team is vital.

We will work closely with you from the first time you are seen for a transplant. We'll continue to stay with you throughout your hospital stay. We'll keep in touch after your release while you return for follow-up visits.

However, YOU are the most important member of the team. Your jobs include:

- Getting a healthy lifestyle. That includes eating heart-healthy food, getting regular exercise, and managing stress.
- Taking all your medicines on time.
- Checking for signs of infection, rejection, or other complications.
- Talking regularly with the transplant team.
- Returning to the transplant clinic regularly and having your blood tests done.

What to Expect When You Are in the Hospital

Intensive Care

During your surgery, your family will be in the waiting area for the intensive care unit (ICU) for heart surgery. When the operation is over, the surgeon meets with your family to tell them about the surgery.

You will be taken to the heart-chest (cardiothoracic) ICU to recover. Doctors and ICU nurses trained to recognize any problems will watch you closely.

While you are in the ICU, expect:

- A breathing machine (ventilator) will help you breathe for the first 8 to 24 hours while the anesthesia wears off. You can communicate with your nurse and family by nodding your head or writing on a tablet.
- A special tube (called a catheter) will be in one of the big veins of your neck to check the pressure in your new heart. Other tubes in your arms deliver medicine and fluids.

- A tube in your bladder will drain your urine. It is very important to check your urine flow to make sure your kidneys are working normally.
- Two or 3 tubes coming out of your chest will drain liquids that may collect in your chest from the operation. The tubes will be removed when the liquid slows or stops. A bandage will cover the cut in your chest for the first 24 to 48 hours. The bandage will be removed if there is no liquid draining.
- Two temporary wires may come through the skin below the cut in your chest. These wires can be attached to a pacemaker if your new heart needs the help. The wires will be removed before you are released from the hospital.
- You may get out of bed and sit in a chair the day after your surgery. If you have pain, don't be afraid to ask for pain medication.
- Reducing your pain will allow your body to move more easily. That helps you recover faster. A physical and occupational therapist also will be ready to work with you.
- Your blood will be tested each day to adjust the dose of the anti-rejection medicine that keeps your body from rejecting the heart transplant. These tests will also check your kidney, liver, and other body systems.
- When you are breathing on your own, you will learn to use a breathing exercise machine, held in your hand. This machine can prevent pneumonia. It is important to use this machine and to cough and deep-breathe every hour. It may be uncomfortable the first few days. Practicing makes it easier.
- Your doctors will order chest X-rays every morning to check your lungs. It is common to be slightly short of breath after the surgery.
- Remember, you may have received a lot of liquids, medicines, and blood products during the operation. As you begin to move, your body will naturally get rid of the extra fluid. You may also get medicine to get rid of the fluid.
- Many of your medicines will change after your heart transplant. You may no longer need to be on warfarin (Coumadin), but you will have new anti-rejection medicine.
- Everyone who enters your room will wash their hands with soap and water or hand gel. This protects you from getting infections that are more likely because of your anti-rejection medicine.

Information For Visitors

Visiting Hours

ICU for heart surgery: Visiting hours are open. Visitors may be asked to leave for periods if a patient has medical needs. Sometimes they must leave while medical tasks or treatments are done.

General care units: Visiting hours are open.

Visitors who have colds or flu should not visit because that poses a risk to your health. That's also true for visitors who have been exposed to chicken pox, tuberculosis, mumps, measles, or any other infectious disease within the past 3 weeks.

To send cards or mail to patients, please address mail to:

Stanford Health Care
ATTN: (Patient's name)
300 Pasteur Drive
Stanford, CA. 94305

Mail will be delivered to your room. After you are released from the hospital, mail will be sent to your home.

Gift balloons: Only Mylar balloons may be brought into the hospital because of the risk of latex allergies.

Dining: See page 107.

Banking: Two ATM machines are located within the hospital. Both are in the rear of the hospital near the cafeteria and emergency department.

Step-down ICU

Most patients stay in the ICU for 2 to 5 days, depending on how fast you recover. Once you are stable, you will be moved into a private or semi-private room in the step-down ICU.

- If you are in a private room, your family members can visit as much as they want. One person can even spend the night in the room with you.
- Your family is invited to spend as much time as possible at your bedside in the step-down ICU. This is where you and your family will learn how to take care of your new heart, as well as your new medicine plan.
- Your nurse and the transplant pharmacist will teach you the new plan for taking your medicines. You will receive your own set of medicines, and a complete list of them.
- Whenever it is time to take your medicine, your nurse will bring your supply and ask you to pull out the correct medicine and dose based on your list. The nurse will also teach you what the medicines do and the correct way to take them.
- You will continue to have regular blood tests and X-rays to check your response to the medicine and track your recovery.
- A dietitian will teach you about nutrition and eating heart-healthy food.
- As you near the time for leaving the hospital, the transplant coordinator will teach you about taking care of your transplant. That includes how to recognize potential complications. The transplant team will also monitor you for the potential complications.
- You may be released from the hospital when you have recovered from surgery and have no outstanding medical issues. By then you must be knowledgeable about your medicines, and have met with the transplant coordinator for education.

Your transplant team will do their best to make sure that you learn how to take care of yourself and your new heart. They will continue to be there for you and to help with any questions or problems you may have.

Still, you are the most important person taking care of your health. You must make every effort to follow your medical plan.

Potential Complications

Complications can occur after any surgery. Special complications are linked with transplantation. Your medical team is aware of most things that can happen.

We know how to prevent complications and how to treat them if they occur. Still, your role in checking your health and following a healthy lifestyle is important. Taking your medicine is critical.

Your Body's Response: Rejection

In a healthy body, white blood cells circulate through the blood looking for foreign invaders like bacteria or viruses. If a foreign invader enters your body, perhaps through a skin cut, your body's immune system automatically sees it as a threat and attacks it.

Unfortunately, your body responds to a new heart as if it is foreign. Your immune system treats it the same as it would a bacteria or virus. Rejection is your body's attempt to protect you by attacking a foreign protein that has entered your body.

Preventing rejection requires medicine called immunosuppressants. These anti-rejection medicines help your body to accept the new heart by weakening or suppressing the immune system.

Even with these powerful drugs, rejection can still occur at any time. Up to half of all heart transplant patients have at least one rejection episode within the first year.

The highest risk of rejection occurs during the first 6 months after your transplant. Over time, the risk decreases. Still, you will always have a risk for rejection. You will need to take your anti-rejection drugs for the rest of your life.

Recognizing Rejection

Acute rejection is a common problem after a heart transplant. It often happens early after the transplant.

Most of the time, patients who have a rejection will not have any symptoms. The rejection episode is detected by a test called a heart biopsy. When symptoms of rejection do occur, they can be very subtle.

Rejection can be life-threatening if it not recognized and treated early. It is critical that you report any of the following symptoms to your transplant team immediately:

- Excessive fatigue or weakness
- Drop in blood pressure
- Sudden weight gain

- Shortness of breath
- Swelling in hands or feet
- Bloating, nausea, or vomiting
- Irregular or fast heartbeats
- Fever of 99.0 degrees or higher
- New onset of aches and pains

Treating Rejection

Having an episode of rejection can be discouraging, but remember that they are common. Most rejection episodes can be reversed if they are found and treated early. Treatment for rejection depends on how severe it is.

The treatment may include giving you high doses of steroid drugs called SoluMedrol, delivered by tubes or IV's through your veins. Or it could mean changing the doses of your anti-rejection medicine, or adding new medicine.

Severe or persistent rejections may require treatment with more powerful medicines. One option is plasmapheresis, a procedure that removes antibodies from your blood.

Early treatment is critical to reversing rejection. Do not try to treat your symptoms yourself. Call your transplant team immediately if you have any concerns or any of the symptoms.

Antibody Mediated Rejection (AMR)

You are not a genetic match with your donor, so that increases the risk you will develop antibodies to the transplanted heart. They are called “donor specific antibodies (DSA's).”

This form of rejection is not common, and is treated differently than the type of acute rejection already described. It requires filtering your body's lymphatic system, followed by drugs delivered to your veins to modify the immune system.

If your donor specific antibodies remain high or cause health problems, you may receive ongoing drugs delivered to your veins by visiting the infusion clinic.

Gene Expression Profiling

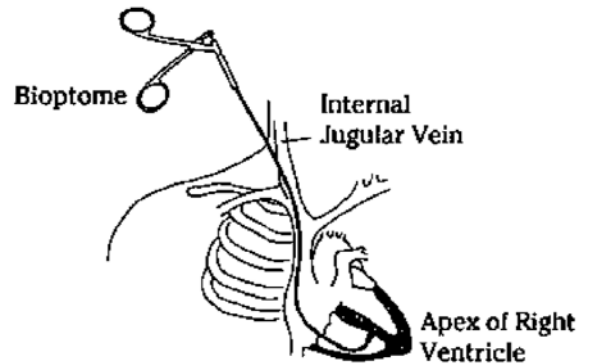
About 6 months after your transplant, you MAY be able to have a special blood test that looks for rejection. Patients are eligible based on their history of rejection and individual clinical rules. The tests are performed at some labs and at Stanford Health Care.

The test looks for certain genes that are expressed in the bloodstream during rejection. The results are described with a score of 0-40. If your score is greater than 34, there is a small chance you may be experiencing rejection and need a heart biopsy within 5 days of testing.

Heart Biopsy

The only way to diagnose or confirm a rejection is by doing a heart biopsy. This procedure gets tiny samples of your new heart to look for signs of rejection.

Routine biopsies begin about 2 weeks after your transplant and then as ordered by your transplant heart doctor. The biopsies will be done less often as time goes on as long as you are not experiencing frequent episodes of rejection.



The procedure takes about 30 minutes, although the entire process may take a few hours. A doctor will give you a local anesthetic to numb an area around your neck. A long tube is passed through a small opening made in your neck, then down into your heart. Sometimes the tube will be placed through a vein in your groin if the neck veins aren't possible.

A type of X-ray called fluoroscopy helps the doctors guide the tube into your heart. Once it reaches your heart, the doctors remove 5 or 6 tiny samples of your heart to examine.

They will look for white blood cells to decide if your body is rejecting the heart. The results are usually ready within 24 to 48 hours. The transplant coordinator will tell you the results as soon as possible.

After the biopsy, gentle pressure will be applied to the opening in your neck or groin. The doctors and nurses also will watch the area for bleeding.

Tell the nurses or doctors if you have either bleeding or swelling at the opening.

Also tell them right away if you feel short of breath or have unusual chest pain after the biopsy. Those symptoms may be signs of more serious complications.

You may be released soon after the procedure, but asked to remain within the hospital for about 30 minutes to ensure you are not experiencing complications.

Emergency patients and unexpected procedures in this busy unit may increase your overall appointment length by up to a few hours.

After your biopsy, do not lift heavy objects for 24 hours. That effort may cause bleeding at the biopsy site.

Grading Heart Rejection

The presence and severity of acute (cell-based) rejection is graded by a scale based on the results of your biopsy.

Grade	Definition	Treatment
Grade O	No rejection	None
Grade 1 R	Mild rejection	This type of rejection is so mild and harmless that it requires no treatment.
Grade 2 R	Moderate rejection	Steroid drugs (similar to prednisone) will be delivered to your veins in the hospital or at a clinic once a day for 3 days. Another biopsy will be done in about 2 weeks to make sure the treatment worked.
Grade 3 R	Severe rejection	The treatment is similar to what's given for a grade 2 rejection. Stronger medicines may be used to destroy the white blood cells that are attacking your new heart. You may have to stay in the hospital if your heart function has been affected.
Grade AMR	Rejection by antibodies to the donor heart	You will be connected to a machine that will remove the antibodies in your blood. This procedure is plasmapheresis. You may be given other medicines delivered to your veins to suppress the white blood cells that generate the antibodies in your blood. You may have to stay in the hospital.

Infections

The anti-rejection medicines that keep your body from rejecting your new heart have the unfortunate side effect of weakening your immune system. You may no longer be able to fight off infections the way you used to.

You can reduce infections by avoiding exposure to infections. Being aware of the symptoms and seeking treatment immediately also help. Now that you have received a transplant, think of all infections as potentially serious.

At least for the first few months, we recommend that you avoid crowds where you could be exposed to infections. If you leave home in the first few months, wear a mask.

Recommendations you should follow indefinitely include:

Washing your hands and using anti-bacterial soap or gel often.

This is especially important after using the bathroom and before meals. It's also important before and after changing bandages on wounds, and after coughing or sneezing. People around you also should follow these guidelines.

- Staying away from sick people. If you have to be around someone who is sick with a cold or flu, that person should follow guidelines to wash their hands often and use separate drinking glasses.
- Taking antibiotics before all dental procedures.
- Getting annual flu shots.
- Avoiding outside animals that roam outside. It's also wise to stop cleaning fish tanks, cat boxes, and bird cages. Let your transplant team know if you have any pets at home and they can tell you how to avoid common infections from your pets.
- Avoiding plants and soil for the first few months after your transplant to avoid germs in the soil. Later, wear protective gloves if you garden or dig in the soil.
- Avoiding "live" vaccines such as those for polio, German measles, smallpox, and mumps. Tell your doctor if you or anyone you live with needs a vaccination.
- Following food safety guidelines. Anything that contaminates food can be especially problematic for people who have transplants.
- Avoid raw meats, including poultry. All meat, seafood, and poultry should be cooked to medium. Pink meat is not acceptable.
- Use only pasteurized dairy products and stick to fully cooked eggs or pasteurized egg substitutes. Wash fruits and vegetables with chlorinated water, even if they have a non-edible peel. Make sure countertops and cleaning products are clean to avoid cross-contamination.

You probably won't have any major complications from common cold and flu viruses. Still, it's wise to treat all symptoms of infection seriously. Call the transplant team right away if you have any of the following symptoms:

- Fever of 100.0 degrees or higher
- Abdominal pain
- Cough
- Diarrhea
- Difficult breathing
- Earache
- Headache
- Nausea
- Painful urination
- Runny nose
- Skin blisters or sores, especially in the mouth
- Sore throat
- Swelling, redness, soreness, or draining fluid from any cuts
- Vomiting

Some infections that can be especially risky include:

- A type of pneumonia called *Pneumocystis carinii*, that is more likely in people who have weak immune systems. Symptoms may include a mild cough and fever that don't get better.
- A virus infection called cytomegalovirus (CMV). This has flu-like symptoms including aching joints, headaches, nausea, vomiting, shortness of breath, diarrhea, fatigue, fever, and night sweats. Treatment may require a hospital stay.
- An infection from herpes-simplex virus type 1 and 2. This is a family of viruses that usually infects the skin, eyes, lungs or genital areas.
- Type 1 may cause blisters or cold sores around the mouth. Type 2 is associated with genital sores.
- Herpes can't be cured but there are effective treatments. Fluid-filled sores in the mouth or genital area, as well as fatigue, are the usual symptoms. Women also may have vaginal discharge.
- Herpes zoster, more commonly called shingles, appears as a rash or blisters, usually on the upper body.

- Varicella zoster or chicken pox, like herpes zoster, may appear as a rash or blisters. Even if you do not have symptoms, call the transplant team immediately if you are exposed to someone with chicken pox, if you have not previously had it.
- A yeast infection called candida can occur in the mouth or throat. It can also occur at the surgical incision, in the respiratory or urinary tract, the eyes, or even the blood stream. Candida can infect the vagina as well as the esophagus.
- A yeast infection in the mouth can cause a condition called thrush. Symptoms include white patchy sores, a white film on the tongue, and difficulty swallowing.



It's wise to wear a HEPA filter mask anytime you are outside of your home until 3 months after the transplant. For 3 to 12 months after the transplant, doctors recommend wearing the HEPA mask or another mask, called N-95, while going to and from Stanford clinic appointments.

These masks protect you from soil or dust from heavy construction. They also protect you from close contact to soil or dust during yard work or gardening. The Techno Mask, allergy masks, and paper surgical masks do not provide acceptable protection against *Aspergillus* spores.

Please wear your mask! You have a higher risk of getting infections of the lungs and airways.

Other Complications

Heart artery disease

One of the main complications following the first year after a heart transplant is graft coronary artery disease, or coronary artery vasculopathy (CAV). This condition causes blocked blood vessels.

You can help prevent this condition by taking your medicine and sticking to heart healthy habits. This means controlling blood pressure and weight, and eating low-cholesterol food.

It also means doing a reasonable amount of exercise. Strive to do 30 minutes of walking per day.

You will have a baseline angiogram about 6 weeks after your transplant unless the doctor decides otherwise. An angiogram is a test that looks at your heart's blood vessels through a very small tube inserted into the vessels. Blocked areas that can be reached by the tube may be removed, compacted with a balloon, or opened up by a device called a stent.

Every year for the first 5 years after your heart transplant, you will have an angiogram with an annual examination.

High blood pressure

Even if you did not have high blood pressure before your transplant, you may have it afterward. This can be due to anti-rejection medicine. Other medicines are available to help you control this condition.

Diabetes

Diabetes can be a side effect of some of your anti-rejection medicines. Warning signs include thirst, increased urination, confusion, and eye problems.

Diabetes usually can be controlled by making healthy changes to your lifestyle, or with medicine or insulin.

If you are overweight or have a family history of diabetes, you are more likely to develop diabetes after your transplant. You also are more likely to get diabetes if you are African American or Hispanic.

During the transplant process, everyone's blood sugars are different and sometimes unpredictable. Often the disease progression and medicines used to treat the disease may cause blood sugars to run higher or lower than usual.

During the transplant surgery and afterward for several months a person's blood sugar may be irregular. Often, immediately and for several months after transplant, the medications that prevent and treat rejection can cause blood sugar to be abnormal or high.

Some people who did not have diabetes before their transplant may find that they now have high blood sugars. For those who had diabetes before getting a transplant, diabetes may be harder to control.

The medicines that you take to prevent rejection may cause blood sugars to go up. To prevent dehydration and reduce the risk of infection, it is important to keep blood sugars within the goal that the transplant team and your primary doctor recommend. This will help with healing and recovery; and allow you to feel better during the transplant process.

Good blood sugar levels are also important to decrease the risk of infection, improve nutrition, and promote heart health. Controlling diabetes is one of the most important things you can do to ensure the success of your transplant.

The Transplant Diabetes Program at Stanford Health Care has been developed to meet the needs of both candidates waiting for transplants and for those who have received transplants. This program offers support and education for the best possible transplant results.

We understand that diabetes affects each person differently. Because of this, we help create treatment programs for the special needs of each person.

Individuals (before and after transplant) and their families are welcome to contact the Transplant Diabetes Program and to enroll in the classes and programs provided. For more information about dates, times, and location, contact us by:

- Calling 650-498-4526.
- Logging onto our website at www.stanfordhospital.com/transplantdiabetes

Anxiety and Depression

A heart transplant is major surgery that may be life-changing. It is common to feel intense emotions, including depression and anxiety.

These emotions can also be a side effect of some of your medicines. Your clinical social worker can look at your situation and talk about ways to handle these issues.

See section on mental health on page 17 of this handbook.

Going Home

Checklist

- ☐ Read your hospital-release teaching manual.
- ☐ Meet with the transplant coordinator for your education for leaving the hospital.
- ☐ Know how to weigh yourself, take your blood pressure and temperature, and check your blood sugar if necessary.
- ☐ Know the signs of transplant rejection.
- ☐ Know the signs of infection.
- ☐ Know all your medicines including names, doses, schedule and purpose.
- ☐ Be able to take your medicines correctly with little or no help from your nurse or caregiver.
- ☐ Know how to contact the transplant team with questions or to report a problem or change in your condition.
- ☐ Discuss your temporary housing options with your clinical social worker. Options will take into consideration distance from home, how you are doing, and method of transportation.
- ☐ Receive a complete 30-day supply of all your medicines before leaving the hospital. Your first prescriptions will be filled at a pharmacy near the hospital based on what your insurance allows. Once you are ready to move home, your prescriptions can be sent to a pharmacy near your home.

Keeping Your New Heart Healthy

You will receive a chart when you are released from the hospital. You will be asked to use this chart to write down your temperature, pulse, blood pressure, and weight. Make sure you know how to do this accurately before you go home.

Bring your chart with you when you return for check-ups. You will need to get a home blood pressure recording device so you can use it at home. This device is sold in most drugstores.

Pharmacy care package: If you are not a Kaiser patient, you will need to order or will receive the following list of items from the pharmacy when you leave the hospital.

- ☐ Blood pressure monitor
- ☐ Weight scale
- ☐ Pill box (slots divided by days of week and time of day--morning, noon, evening, bedtime)
- ☐ Pill cutter/crusher
- ☐ Thermometer

Your transplant coordinator can check the results of your home device against a clinic device to ensure accuracy. The top number, called the systolic number, is the first “pumping” sound you hear when you take your blood pressure. The bottom number, or diastolic, is the beat when the sound changes.

You will need to learn what your normal blood pressure is so that you can respond to any abnormal changes. Notify your doctor if your systolic blood pressure (top number) is more than 160 or less than 100, or if your diastolic pressure is more than 95 .

- Record your temperature every morning, but also any time you feel sick or cold or experience other symptoms. Call your doctor immediately if your temper goes higher than 100.0 degrees.
- Don't use products such as aspirin, or Advil (Also called NSAIDs or non-steroidal anti-inflammatory medicines) unless your doctor prescribes them because they may interact with your other medicine. Tylenol is usually the best over the counter pain reliver.
- Pulse – If you're taking any medicine that affects your heart rate, your nurse will teach you how to check your pulse at home. Notify your doctor if your pulse is faster than 140 or slower than 60.
- Weight – Weigh yourself every morning after going to the toilet. If you gain more than 2 pounds a day, you could be starting to retain fluid, so notify your doctor.

Clinic Visits

When you leave the hospital, you will receive a schedule of follow-up clinic visits. At these visits, you will get lab tests, heart biopsies, echocardiograms and other tests. These visits help us to track your progress and find complications as early as possible.

Generally, you will be seen once or twice a week, on a Monday or Thursday, for the first 3 weeks after discharge. Afterward, your clinic visits will be less often as long as you are not having problems. The transplant team will determine how often you should go to the clinic. In general, you will go:

- 1-2 times a week for 2-4 weeks
- Every other week for one month
- At least once per month through month 6
- Every other month until month 12
- Every 3-4 months until two years after transplant
- Life time follow up as directed
- Clinic Visit will be modified based on how you are doing.

When you come to the clinic:

- You will meet with the post-transplant nurse coordinators, and if needed the social worker and dietitian.
 - You will review your medicines with them.
 - Bring your med action list schedule with you and health record logs.
 - Keep a list of questions as you think of them so you can talk about them at your clinic visit.
- The cardiologists will perform a physical exam.

A transplant coordinator will call you the next day if there are any changes to your medicine.

Bring your medicine list, your binder of information, and this handbook with you to follow-up visits. You will be told about routine lab tests. They will keep track of your blood count, kidney and liver function, medicine levels, or special tests you might need.

Lab Tests

You will have lab tests at each checkup. These are often blood and urine tests.

The tests include:

- A complete blood count (CBC), which measures your white blood cell count (WBC). That can indicate an infection or side effects from medicine.
- A chemistry panel, a comprehensive metabolic panel (CMP) or a basic metabolic panel (BMP) that tell how well your kidneys and liver are working. They measure levels of creatinine (sCR) and blood urea nitrogen (BUN), the waste products your kidneys remove from the blood.
- Medicine levels: How much anti-rejection medicine is staying in your bloodstream and for how long. This measures levels of tacrolimus, (TAC) or cyclosporine (CSA), or other anti-rejection drugs. High levels could lead to toxicity or too much suppression of your immune system. Low levels may lead to transplant rejection. It is important to have your blood drawn 12 hours (plus or minus one hour) after the last dose of tacrolimus or cyclosporine the night before. This blood draw is called the trough level (lowest level) of the day. It is what the doctors use to adjust your dose of medications. Take your medications after your blood draw.
- Sugar (glucose) levels in your blood.
- Cholesterol and lipid levels (HDL, LDL) in your blood.
- INR, PT/PTT. These tests are done if you are taking blood thinners or anti-clotting drugs. They measure how well your blood clots. This helps prevent too much bleeding if you are injured.

Lab results will be placed for you to see on MyHealth after a doctor has looked at the results. Remember that lab results are reviewed in connection with your individual situation. One person's lab values are compared to normal in the general population. But the results are also compared with what is "normal" for each individual transplant patient.

Additional tests and procedures

Your transplant team may perform any of the following tests to keep watch on your transplant:

Echocardiogram (ECHO)

This test uses sound waves to check the size, shape, and motion of your heart. It also checks your heart valves, the heart's pumping, and any fluid in the sac around your heart.

A gel is applied to the chest. Then a wand with a ball on the end of it will be placed on your chest and moved around to get the pictures of your heart. This test is usually done on the same day as biopsies. It also measures your heart's ejection fraction (%EF), another measure of how well your heart pumps blood.

Right heart catheterization (RHC)

A tube called a catheter is used to check the pressure in the heart. After numbing the area, the tube is inserted into a vein in the neck and moved into the right side of the heart. Pressure is measured for your heart chambers, main blood vessels and valves. A special tube called a Swan Ganz catheter is used to document these pressures in your heart.

Left heart catheterization (LHC)

A tube is inserted in the left heart yearly to check for blocked arteries in your heart.

A tube goes into the blood vessel (artery) in the groin or arm. Then it's pushed to the left side of the heart. Dye is injected to look at the arteries and the pumping of the heart. This test is done in a lab.

Bone density scan (DEXA scan)

This test will check your bones for osteoporosis, which is calcium loss in your bones from taking steroids.

Electrocardiogram (EKG)

This test measures the electrical voltages in your heart by placing 12 electrodes on your skin.

Staying Healthy After You Leave the Hospital

Anti-rejection medicines interfere with your body's defenses against infections. That means you'll need to protect yourself from infection after your surgery.

Follow these steps to prevent infections:

- Wash your hands often with anti-bacterial soap or hand gel.
- Keep your hands away from your face and mouth.
- Stay away from people with colds or other infections.
- Ask friends to visit only when they are well.
- If you have a wound and must change your own bandage, wash your hands before and after.
- Wash your hands after coughing or sneezing. Throw tissues into the trash immediately.
- If someone in your family is ill with a cold or flu, ask them to help protect you. They can use separate drinking glasses, cover their mouth when coughing, and wash their hands often.
- Avoid animal waste. Stay away from animals that roam outside. Do not clean bird cages, fish or turtle tanks, or cat litter.
- The cat litter box should be covered and taken out of your home before it is changed. That's because the feces of some animals contain parasites and can cause infections. Fish tanks can grow fungus and can be infectious. All of these organisms can infect you after your transplant.
- Avoid vaccines that have live viruses. They include the vaccines for measles, mumps, German measles, yellow fever, smallpox, chicken pox, Shingles and the Sabin oral polio vaccine.

If you or any family member needs to receive any vaccinations, tell your transplant team or doctor.

Heart Transplant Nutrition

Best Ways To Eat To Keep Your New Heart Healthy

Short-term tips following surgery

After surgery, your body needs extra calories and protein to promote healing and recovery. You'll need enough calories and protein to overcome the stress of surgery and the side effects of some medicine.

You may feel less hungry or notice a change in taste because of the new medicine you will be taking. If your appetite is poor, here are some tips to eat well:

- **Eat more small high-calorie or protein meals or snacks.** Do this every 2 to 3 hours instead of 3 large meals per day.
- **Add high-calorie or protein drinks or powders** (Ensure, Boost, Orgain, Nepro).
- **Drink nutrient-dense fluids such as milk, supplements, or shakes and smoothies** to help meet calorie and protein needs.
- **Stand and walk whenever possible.** That will improve your appetite, bowel function, blood circulation, and maintain your muscle and bone strength.
- **Include some protein food each time you eat.** Protein foods include yogurt, cottage cheese, nuts, beans, tofu, lentils, peanut butter, lean meats, seafood, and eggs.
- **If you are underweight or have unplanned weight loss, work with your nutritionist.** Ask for strategies to increase your high calorie and protein foods to gain weight.

Long-term nutrition after your transplant

Some medicines that prevent transplant rejection have side effects related to nutrition. Common complications include weight gain, high blood pressure, high lipid levels and resistance to insulin.

Unhealthy eating habits, combined with lack of exercise, can promote metabolic syndrome and cardiovascular disease. Your choice of food and lifestyle are powerful tools to prevent long term complications. This can protect your new heart transplant.

Tips to keep your new heart healthy

Stick to a healthy weight

Weight gain can happen after a transplant. Culprits include unhealthy eating habits, bigger appetite from steroid drugs, no exercise, and changes to your body's metabolism (how it burns calories).

The most dangerous place to add weight is around your waist. Extra calories, saturated fats, and carbohydrates contribute excess fat around your middle.

Ways to promote healthy weight:

- Track your food and drink choices with a food log.

Seeing your daily meal and drinking habits can help keep you accountable. A food log helps you think first before choosing food and drinks.

- Using smart-phone apps like Myfitness Pal, Lose it, and Smart People can help. Or use a food journal.
- Increase nutrient dense foods

Eat at least 5 servings of fresh fruits and fresh vegetables daily.

- Decrease “empty calorie” foods
 - Reduce soda, juice, cookies, candy, sweetened coffee drinks, high starch (rice or pasta), and snack foods (chips, cookies, crackers).
 - Remember 1 can of soda has 10 teaspoons of sugar.
- The best cooking methods are baking, broiling, poaching, grilling, or steaming foods.
- Eat less, with smaller portions at meals and limited snacks between meals.
- Get moving.
 - Consider tracking your steps or physical activity with an exercise tracking device.
 - Exercise 45 minutes to one hour daily.

Fats

For years, fats have been getting a bad rap. Many people think food fat causes heart attacks, weight gain, and high cholesterol. Now it's not that clear cut.

The **type** of fat you eat is important. For more than 10 years, studies have shown us that all fats are **not** created equal. Some fats can protect your heart, improve blood sugars, and lower high cholesterol.

Here are 2 types of heart-healthy fats that can help to lower you LDL “bad” cholesterol. They can also raise HLD (the “good” cholesterol), reduce unhealthy triglycerides, and promote stable blood sugars:

- Unsaturated fats

The best sources of unsaturated fats include olive oil, canola oil (also a good source of omega-3s), most nuts and nut butters (almonds, cashews, pumpkin seeds, pistachios), avocados, and peanuts.

- Omega 3 fatty acids
 - Fish sources include salmon, mackerel, sardines, herring, anchovies, rainbow trout, and white albacore tuna canned in water.
 - Plant sources are canola oil, flaxseed, flaxseed oil, walnuts, walnut oil.

Meal tips to increase healthy fats in your diet:

- Sprinkle 1-2 tablespoons of ground flaxseed or chopped nuts on yogurt or cooked oats.
- Use canola oil for baking and cooking.
- Make homemade salad dressing with walnut or avocado oil.
- Buy salad dressing, mayo or margarine made with canola or olive oil.
- Swap out cheese with avocado on sandwiches and salads.
- Add avocado or nut butter to smoothies.
- Try salmon burgers instead of beef burgers.
- Try salmon salad sandwiches instead of tuna salad sandwiches

Balanced heart-healthy meals can provide up to 35 percent of overall calories from fat (roughly 80 grams per day in a 2000-calorie diet). Fat sources should be mostly unsaturated and from omega 3 sources.

Blood sugar control

Some people who did not have diabetes before their transplant may find they have high blood sugar after transplant. For those with diabetes before transplant, your diabetes maybe more difficult to manage.

Your anti-rejection medicine may make your blood sugars go up. It is important to keep your blood sugars under good control. That's true in the short term after surgery, to help healing and recovery. It's also true long term, to lower stress on your new heart.

What are carbohydrates?

Carbohydrates are sugars and starches that your body uses for energy. Foods high in carbohydrates include breads, crackers, cereals, pasta, rice, grains, potatoes, corn, beans, milk, fruits, and cakes.

When you eat them, carbohydrates are absorbed from your digestive tract into your bloodstream, raising your blood sugar.

Amount of carbohydrates

Your total daily carbohydrate intake should be based on how active you are. If you are physically active, you may eat more carbohydrates to fuel your body.

If you are mostly sedentary, you don't need as much fuel. On days you are active you would eat a bit more, and on days that you don't exercise you would eat a bit less.

Slow or fast carbohydrates

Fast carbohydrates

Carbohydrates have a fast and high impact on blood sugar if they are digested and absorbed quickly. White bread, pasta, or sweets cause blood sugar levels to rise quickly.

When you eat fast carbohydrates, your blood sugar levels rise very quickly. Soon after, your body clears the sugar from your blood. This can leave you with very low blood sugar levels. This roller-coaster ride of sugar levels leaves you more tired and hungry and especially hungry for carbohydrate-rich foods.

- Fast carb foods
 - Refined grains: white rice, white pasta, white bread, cereals or breakfast bars with added sugars
 - Fruit juices
 - Sweets like cake, candy, cookies, and pie
 - Sugary foods like regular soda, fruit drinks, and sherbet
 - Starchy vegetables like corn, white potatoes, and peas

Slow carbohydrates

High-fiber carbohydrates take longer to be broken down during digestion. That means they stay in your stomach longer. They cause a slow and steady sugar release into your blood, promoting better blood-sugar control. They tend to keep you fuller for longer compared to fast carbohydrates.

- Slow carb foods
 - Whole grain bread with at least 5 gms of fiber, coarse grains, quinoa, barley, brown rice
 - Non-starchy vegetables, beans, lentils, sweet potatoes
 - Some fruits including apples, pears, and berries.

High-fiber fruits and vegetables make you feel full longer. They are the richest in nutrition of all carbohydrates. They also have the lightest impact on blood sugar and insulin levels.

Limit salt

After surgery, your long term goal is to limit salt intake to 2000 milligrams (mg) per day. This helps control your blood pressure control and prevents you from retaining water. Aim for fresh, unprocessed foods as much as possible.

Avoid these high salt foods:

- Packaged or frozen foods with more than 140 mg of salt (sodium) per serving. Fresh foods tend to be much lower in sodium.
- Frozen meals should have less than 600 mg of sodium per serving.
- Canned foods (canned vegetables, chili, spam, sardines).
- Processed or cured meats (bacon, ham, sausage, pepperoni, hot dogs).
- Processed cheeses (CheeseWiz, Velveeta, Queso).
- High-salt sauces: Marinades, barbeque sauce, Worcestershire sauce, soy sauce, oyster sauce, fish sauce, ketchup, bouillon cubes, relish, salad dressings such as ranch, blue cheese, Italian, and French.

Bone health

Long term use of the drug prednisone interferes with your body's absorption of calcium. That makes bones more fragile and easy to break. **You can keep your bones stronger by getting regular exercise plus adequate calcium and vitamin D.**

- Healthy adults aged 19 and 50 should aim to get 1,000 mg calcium per day.
- Older adults (especially women) need more, because bones lose calcium as we age. After age 50, healthy adults should get 1,200 mg calcium per day.

High-calcium foods:

300 mg calcium per serving	<ul style="list-style-type: none"> 1 cup milk (fatfree, lowfat, chocolate, and buttermilk) 1 cup nonfat or lowfat yogurt 1 cup calcium-fortified soy milk or rice milk 1 cup calcium-fortified orange juice 1½ oz lowfat natural cheese (such as cheddar, mozzarella, or Swiss) 2 oz processed cheese (such as American) 1 cup ready-to-eat pudding 1 cup macaroni and cheese
200 mg calcium per serving	<ul style="list-style-type: none"> 3 oz canned salmon (with soft bones) 3 oz sardines (with soft bones) 1 cup calcium-fortified cereal 1 oz feta cheese
150 mg calcium per serving	<ul style="list-style-type: none"> 1 cup cottage cheese ½ cup tofu (made with calcium) 1 slice calcium-fortified bread
100 mg calcium per serving	<ul style="list-style-type: none"> ½ cup frozen yogurt or ice cream ¼ cup almonds ½ cup cooked greens (beet greens, turnip greens, kale, collards, spinach) 1 English muffin ½ cup soybeans
50 mg calcium per serving	<ul style="list-style-type: none"> 1 medium orange ½ cup cooked broccoli ½ cup canned white beans 1 medium baked sweet potato

Note: if you are lactose intolerant, consider lactose-free versions of dairy product or calcium-fortified plant-based milks.

Magnesium

Cellcept and Prograf are anti-rejection medicines that can reduce your body's ability to absorb magnesium. Aim to eat more food rich in magnesium.

Foods rich in magnesium

Food	Amount	Magnesium (mg)
Pumpkin seeds	1 oz	151
Cereal, 100% bran	½ cup	110
Halibut	3 oz	90
Spinach: fresh, frozen	½ cup	80
Swiss chard, cooked	½ cup	76
Nuts: almonds or cashews	1 oz	75
Soybeans	½ cup	74
Tofu, firm	½ cup	73
Mixed nuts, dry roasted	1 oz	67
Soy milk	1 cup (8 oz)	61
Black beans	½ cup	60
Potato, backed with skin	1 medium	50
Peanut butter	2 tablespoons	50
Okra, frozen	½ cup	47
Brown rice, cooked	½ cup	40
Avocado	½ fruit	35
Banana	1 medium	30
Oatmeal, cooked	½ cup	30
Milk	1 cup (8 oz)	27

Food Safety

Food safety is especially important after transplant surgery. You have a higher risk for illness from food carrying infections while you are taking anti-rejection drugs. Foods can carry bacteria, viruses, fungi, and parasites.

Following food safety guidelines can help. Here are some tips to prevent infections from the foods that you eat.

- Dairy: Drink only pasteurized milk and use only pasteurized milk products. Check the labels on cheese and yogurt.
- Eggs: Use pasteurized eggs and egg products for recipes that call for raw or undercooked eggs. Cook unpasteurized eggs until the yolk is firm, or eat omelets, scrambled, or hard-boiled eggs.
- Avoid raw and undercooked meats and seafood.
- Always wash fresh fruits and vegetables well before eating.
- Keep cold foods cold and hot foods hot.

*Additional detailed food safety guidelines are provided in your patient binder

Potassium

Some medicine can lead to high potassium in your blood. If so, you may need to eat food lower in potassium **temporarily**. **When advised**, avoid high-potassium foods like bananas, potatoes, tomatoes, oranges, prunes, avocados, pumpkin and squash.

Taking medications

Water, Ensure, or applesauce are tolerated best with taking medicines.

Food to avoid

Skip the grapefruit, acai, and pomegranate.

These foods can interfere with your medicine.

Loss of Nerve Supply

Heart transplant surgery cuts the nerves that ordinarily guide your heart rate. This causes your new heart to beat faster than your previous heart when you are resting.

The “resting rate” of a transplanted heart usually ranges between 90 and 110 beats per minute. While this rate is faster than normal, it allows your heart to work normally. You still have the capacity for a vigorous life.

Any change in your transplanted heart’s rate depends on adrenaline and related hormones in your blood. These affect your heart rate through your blood’s circulation system, instead of nerves guiding the heart.

The heart’s response to hormones in the blood is slower. When your body responds to something that increases adrenaline, like exercise, it may take up to 10 minutes until the heart picks up the message through blood rather than from direct electrical brain impulse. The hormones circulating in blood also may take up to an hour to fall so the heart rate can return to normal after exercise.

Another effect of the cut nerves is that you may not feel chest pain if the blood flow in the arteries of your new heart get blocked. You may feel some discomfort from the healing chest wall muscles or strain from exercise.

Exercise: The Key

Getting Strong After a Heart Transplant

All people who have major surgery and a long hospital stay tend to lose muscle, fitness, and balance. Physical activity and exercise are important to your recovery.

Cardiac rehabilitation is generally divided into 3 phases.

Phase I

This begins within 24 hours after surgery, when you are asked to sit in a chair or stand and walk around the ICU. The physical therapist will gradually increase your exercise and walking.

The occupational therapist will help you return to doing your own trips to the bathroom, grooming, and dressing. The therapists will teach you about safety, breathing techniques, and how to save your energy.

It is important to remain active while you are in the hospital. During phase I, you can start a paced program of exercise, with movement followed by rest. Exercising consistently and often is more important than how much you do. You are, after all, recovering from major surgery.

By the time you leave the hospital you should be walking in the hospital hallway 3 times a day. You will need to continue an exercise program when you return home. Your exercise routine should include warm-up and cool-down activities, aerobic exercise, and strength training.

Warm-up and cool-down:

Warm-up and cool-down activities are especially important for people who have had a heart transplant. The transplanted heart has lost nerve connections, which means it gets no direct signal from the nervous system.

The heart will not respond quickly to changes in activity. Your heart rate will increase more gradually in response to exercise. It will slow down more gradually in response to rest. About 5-10 minutes of warm-up and cool-down activities are best.

Aerobic exercise:

Walking and cycling on a stationary bike are the best ways to exercise right after surgery.

Later on, you may be able to do other exercises and sports when your endurance and strength improve. Your chest also needs to heal first. Check with your doctor and transplant team if you have any questions.

Phase II

Phase II starts several weeks after you leave the hospital. Once you are home, continue to walk about 5 minutes 4 times per day.

Lengthen your walks by 1 to 2 minutes every few days. Try to make some progress each day. Once you are able to walk 10 minutes at a time you may change your routine to 3 walks a day.

Once you are able to walk 15 minutes at a time you may decrease to 2 walks per day.

At this point you are ready expand your exercise program by going to a rehabilitation center.

This center has trained personnel who will give you medical supervision. Your physical activity can be expanded with information about nutrition, medicine, and how to exercise safely.

Phase II often lasts 3 months and is usually covered by your insurance. You are likely to see dramatic improvements in your strength and ability to move during Phase II. Ask your transplant team about how you can get a referral to one of these local programs.

Continue your walking programs on your off days. **Your goal is to eventually walk without a break for 30-60 minutes.**

Do not rush the process. Your body needs time to get used to increased activity. It may take several months to see major improvement in your muscles.

- Schedule walks when you are rested.
- Avoid walking or any strenuous movement right after meals.
- Begin on flat surfaces.
- Avoid exercising when it's too hot or too cold.
- Walk with a partner if it's more enjoyable.
- Remember to wear comfortable shoes.

As with any exercise, stop if you feel dizzy or lightheaded. Stop if you feel chest pain, muscle cramps, or irregular heartbeats. Feeling unusually short of breath, sweating heavily or feeling extremely tired are also signs to stop.

Keeping an exercise log will help you see progress. (See the chart below.) Set a specific time to walk each day so that it becomes part of your daily routine.

Phase III

This phase is a long-term program that you will continue for the rest of your life. You may set up your own exercise routine at home, at a local gym, or a cardiac rehab center.

Your contacts from your phase II rehab center and the transplant team can help you find a phase III center. Most phase II centers allow you to continue with a phase III program at the same place. An ideal exercise plan would be 30-60 minutes of physical activity most days of the week.

Chest safety limits

The breastbone in your chest will need time to heal from surgery. To make sure it heals, you need to follow these rules for 12 weeks from the day of your surgery:

- Do not lift, push, or pull anything more than 10 pounds.
- Do not use your arms to push or pull yourself up from bed.
- Hold a pillow against your chest to cough. Take deep breaths if your breastbone hurts with these activities.
- Do not twist or turn your trunk too far. Use a “log roll” motion to get in and out of bed.
- Stop any activity that causes pain or clicking in your breastbone.
- Do not drive for 6 weeks after surgery. You may resume driving when a doctor feels you are ready.
- As a passenger in a car always wear a seat belt. If it is uncomfortable, you may put a small pillow between the seat belt and your chest.

After 12 weeks the chest has healed well enough to handle any level of physical activity, so these limits no longer apply.

Home Exercise Program

Exercise Log My goal is 30-60 minutes a day

[illegible]

How hard you exercise should be guided by the scale below. This scale rates how hard you feel your body is working (“perceived exertion”).

Rating of perceived exertion (RPE) scale	
10	Max effort Feels almost impossible to keep going. Completely out of breath, unable to talk.
9	Very hard Very difficult to keep exercising this hard. Can only speak a few words.
7-8	Vigorous Borderline uncomfortable. Short of breath. Can speak a sentence.
4-6	Moderate Breathing heavily but can maintain short conversation. Still somewhat comfortable but becoming noticeably more challenging.
2-3	Light Feels like you can maintain for hours. Easy to breathe and carry a conversation.
1	Very light Hardly any exertion. Watching TV, etc.

While you exercise, rate how hard you feel you are working on this 1-to-10 scale. The ideal level of exercise is 6 or “moderate intensity.” At this level, you should feel that you are breathing heavily but you are still able to have a short conversation.

If you rate your workout at 2-3 (“light”), try to increase the pace or length of the exercise. If you rate your workout at 7-8 (“vigorous”), you should slow down or stop.

Strengthening exercise

Strength training improves your skeletal muscle. This helps to reverse the muscle and bone weakness that can come from taking corticosteroid medicine.

The body areas most affected by weakness are the muscle groups around your shoulders, hips, and thighs. Weakness in your legs may limit your ability to walk or move around.

Be patient, stick to your chest-safety rules, exercise regularly, and ask for help whenever needed.

During the first 12 weeks after surgery you may begin strengthening exercises. You can start with light weights, 1 to 5 pounds each, for your arms. Avoid movements that could stress your chest healing.

There is no specific weight limit for your legs. The load should allow you to do 12-15 repetitions comfortably. This should have a low risk of injury and avoid too much soreness.

Begin with 1 set and progress to 2 to 3 sets of 12 to 15 repetitions per exercise session.

- Begin with 1 set and progress to 2 to 3 sets of 12 to 15 repetitions per exercise session.
- You can alternate days when you work your arms and legs to minimize soreness and muscle fatigue.
- Exercise large muscle groups before small muscle groups.
- Raise weights with slow, controlled movements. Extend your arm or leg completely when lifting.
- Breathe out during the hard exertion part of the lift.
- Avoid straining.
- Stop exercise if you get dizzy, lightheaded, unusually short of breath, or feel chest pain.

Building your energy

There are some simple tips that will help you reach your goals:

- Plan each day to do only what you can realistically finish.
- Allow a 30-minute rest period after each meal and strenuous activity.
- Pace yourself. Allow plenty of time to complete each task.
- Rest before you are really tired.
- Increase your routine gradually.

Transplant Olympics

(Optional)

When you are back in shape, consider competing in the Transplant Olympics. The games are a multi-sport festival event to help promote organ and tissue donation.

The purpose is to show the world that transplantation is a treatment that does indeed work. Go to www.transplantgamesofamerica.org for more information.

Resuming Regular Activities

Your transplant team will probably wait at least 12 weeks after surgery to give you permission to drive. A car accident could seriously harm the healing of your chest.

Your surgery and your previous heart condition may slow your reflexes and your stamina. Also, your time away from driving has an impact. You may need to ease back into driving, working up to longer drives.

The team will work with you to decide when you can return to your normal activities. How soon depends on your work, how your healing is going, and other factors.

Sex, Fertility And Pregnancy

Both men and women can resume sexual relations after a heart transplant. Practices and positions that put stress on the chest wound should be avoided for 3 months.

That's also true for lifting heavy weights and swimming with overhand strokes. After 3 months the breastbone is healed or "knit" and can handle normal stresses.

The usual advice for "safe sex" is even more important for heart transplant patients. Drugs you take to prevent your body from rejecting the new heart also suppress your immune system. That leaves you more vulnerable to infections.

Check with your transplant team if you have any worries about this. If you do not have a regular sex partner, you will need to use condoms to reduce your risk.

You can talk over specific questions with the doctors or nurses in the transplant clinic. Sexual concerns after a heart transplant are common. Yet many people are reluctant to talk about them.

The topic is sensitive. Yet not talking openly with your doctor or nurse can cause delays in getting care, medicine, and treatment. The best advice is to tell them so that they can help.

Problems with getting an erection for sex are common in men who have heart disease. That's also true for those who are taking medicine for high blood pressure. Tell your primary care doctor or your transplant doctor as soon as possible. They can send you to the right person so you can get treatment soon.

Fertility and pregnancy

The transplant procedure itself does not hurt fertility for either men or women. That's also true for the drugs needed after surgery.

We suggest women delay having a child for a year after a heart transplant. By then, their health is usually stable.

Women who may be able to have children should see their doctor (obstetrician or gynecologist) within 3 to 6 months after a transplant. That doctor can talk over birth control options with them.

Each woman has individual issues like age, gynecologic history, and medical conditions like high blood pressure and diabetes. For them, pregnancy should be planned and managed by a medical team.

A specialized team can include obstetricians working with heart transplant doctors. They can coordinate drug doses and watching for signs of organ rejection.

Prescription drug levels can change during pregnancy, so women will need to be checked closely. As a rule, there is no evidence that the drugs commonly used cause babies to be abnormal.

The one exception to this rule is the drug mycophenolate (Cellcept). So far it has shown some hints of abnormalities in the babies of mothers taking it. This drug will usually be replaced with another before a woman gets pregnant. Do not stop taking this drug unless directed by a doctor.

Babies of women with transplants are often born a few weeks premature and somewhat small. They grow and develop normally. A genetic counselor is available to talk over any questions at the Stanford Center for Inherited Cardiovascular Disease.

Fertility is not hurt in men who have heart transplants. Also, there is no known increase in abnormalities in the children they father.

The methods for birth control available to men and women who have transplants are the same as for anyone. One exception for women is the IUD (intrauterine devices). With this, the risk of infection from an implanted device can be significant.

Skin and Hair

Transplant patients generally don't need special skin care unless they develop an unusual skin condition or rash. Showering and bathing with regular soap is generally okay. Use mild soap and lotion after bathing if your skin is dry.

To avoid shaving cuts, use an electric razor. If you have a nick or small cut, clean it every day. If you get larger cuts you may need to visit your doctor.

Transplant patients are more likely to develop skin cancers. It is critical that you protect your skin from ultraviolet sun rays by:

- Avoiding the sun between 10 a.m. and 3 p.m. That's when ultraviolet rays are the strongest.
- Wearing protective clothing, including a hat, when outdoors.
- Applying sunscreen and lip balm daily to uncovered areas of your body, even when it is cloudy or rainy. Remember to re-apply sunscreen because it wears off.
- Using skin products with a skin protective factor (SPF) rating of at least 30.

You may have to wait until your dose of prednisone medicine is lowered to have a hair permanent or to dye your hair. This medicine is likely to change the texture of your hair.

Adding harsh chemicals may make your hair brittle and more likely to break. Your hairdresser will probably suggest a good conditioner to help with this.

Your medicine also may cause more hair to grow on your face. Carefully follow the instructions for using a hair-removal cream to avoid irritating your skin.

You also may try bleaching, waxing, or electrolysis to remove hair. Your transplant team can offer other suggestions.

Alcohol and Smoking

Many of the medicines you are taking can harm your liver when combined with alcohol. Avoid wine, beer, and other alcoholic drinks. Talk this over with your transplant team if you have any questions.

Smoking can be especially damaging for heart patients. Don't start smoking after your surgery or resume it if you smoked before.

Smoking can add to your already increased risk of cancer, heart disease, and other complications. Please talk to your transplant team if you need help to stop smoking.

Travel

Always keep your medicine with you when you travel. Also take along a letter from the transplant team verifying that you are a transplant patient.

If you're planning to visit a foreign country, check with your transplant team about what to do if vaccinations are required. Some could harm you.

If you go to parts of Africa or Mexico, for example, find out what vaccinations you need to take. Also think about how far you'll be from a 21st century hospital and your health insurance.

Most tourist destinations and overseas business trips are fine. It is when you get into remote places and encounter risks like hepatitis, malaria, and other diseases that we would be concerned.

Another issue for travelers who have transplanted hearts is time-zone changes. They must be taken into account when you take your medications.

Remember to space your medicine for the same timing and sequence as you have at home. You also may have to consider food and how to keep clean in other countries.

Routine Health Care

You will continue to have annual check-ups at the transplant center. Still, your day-to-day medical care will usually return to your regular **primary care doctor**.

Make an appointment once you return home to bring your doctor up to date. You can fill in him or her on your condition and review your records.

Give your transplant team this doctor's name and contact information.

Tracking Your Health

You are the one most likely to notice any changes in your health because you are living with your transplant. You may detect side effects from medicine or other complications.

By the time you leave the hospital, you will know the risks that come with a transplanted heart and the medicine for it. It also is your job to make sure that your other health care providers aware of it. That includes your pharmacist, primary doctor, and dentist.

Give them contact information for the transplant team in case they have questions about your care.

Dental Care

Dental health is important for people with heart transplants. Dental problems such as abscesses or mouth pain can be major problems because of your weaker immune system.

Preventive care is more important than ever. Some transplant medicines also cause gum problems. It is critical to tell your dentist that you have a heart transplant.

Telling your dentist is important even before the most routine tooth maintenance care. An antibiotic is usually prescribed to prevent any chance of infection from a dental procedure.

Dentists should take steps to prevent heart infection when you get:

- Teeth cleaning or implants where bleeding may occur
- Teeth pulled
- Gum treatment including surgery, scaling and root planing, probing, and recall maintenance
- A root canal or surgery only beyond the apex
- Antibiotic fibers or strips placed below the gums
- Orthodontic bands

Please ask your nurse for a wallet card to give your dentist before any dental procedure.

Medicines

You will have a medicine plan that matches your individual needs. It will be adjusted to reflect your body's needs and response.

This chapter provides an overview of possible medications and side effects that you may take. It is not intended to include everything. You may not receive all of the medications discussed in this section before you leave the hospital.

Please consult your doctors, pharmacists, or nurses with any questions about your medications.

The transplant pharmacist will give you a detailed list of your medicines. They will also give you a schedule of when to take them. All this will be part of the education you get before you leave the hospital.

Guidelines for taking medicine

- Get to know your medicine plan. It is set up for you as an individual, adjusted to your body's needs and response.
- Take your medicine precisely as planned at the same time every day. Try not to miss any doses and stick to your prescribed schedule.
- Never stop taking your medicine or change the doses without your transplant team's approval.
- If you miss a dose, take it as soon as possible. If it is almost time for your next dose, do not take the missed dose and don't take a double dose. If you accidentally miss a dose, call your transplant team.
- Do not stop taking or change the dose of any medicine without talking to your transplant team first.
- Do not blindly follow the directions on your prescription bottle. Doses can and will change. If your transplant team changes a dose on a medication, follow the new dose (not the dose on the prescription bottle).
- Call your transplant team if you are having side effects from your medicine.
- Call your transplant team if you are vomiting or having diarrhea.
- Store your medicine out of reach of children.
- Store medicine in a cool, dry place away from any heat or humidity.

Refills

- Do not wait until the last minute to call your drugstore for refills. Call for refills about 2 weeks in advance. This allows time for troubleshooting if there is a problem.
- Consider enrolling in automatic refills. Ask your pharmacy for details.

Other important take-home points

- Learn BOTH the generic and brand names of each medicine.
- If your medicine schedule does not work well for your life, check with your team pharmacist, nurse coordinator, or doctor for advice.
- Do not take any NEW medicine or supplements without your doctor's approval. This includes over-the-counter drugs (including appetite control, asthma, colds, cough, allergy or dietary supplements), alternative medicine, and herbals.
- Do not take grapefruit or grapefruit juice, St. John's Wort, cat's claw, or echinacea.
- Store all your medicine away from heat, humidity, and direct sunlight. Avoid areas of the bathroom, the car, and next to a window that get direct sunlight. Remember your medicines are comfortable where you are comfortable.
- Keep your medicines in their original containers unless restocking your weekly pill box. The label on the container shows the expiration date, the prescribing doctor and the original prescription date.
- Report any signs of an infection (fever, nausea, diarrhea, night sweats, chills).
- Report dizziness or fainting immediately to your nurse or doctor. Give them the name of the blood pressure medicine and other medicine you take.
- Check your blood pressure and weight regularly after you leave the hospital.

Side note if you are readmitted to the hospital

- Do not be surprised if your medicines are not timed the same way they are timed at home. It is alright. Some medicines are timed because of how the hospital operates.
- If you're wondering why one or more of your home medicines have not been resumed when you are admitted to the hospital, feel free to ask your doctor.
- Some medicines may not be ordered in the hospital on purpose. This may be explained by your current condition and may be restarted later.

What Kind of Medicine Will You Be Taking?

People with heart transplants must take many different medicines, each for a specific reason. Your transplant coordinator or pharmacist will review your medicines when you receive your transplant.

The following classes of medicines are the most commonly prescribed. Please review and get to know them BEFORE your transplant.

The medicines fall into 6 groups and may include others:

- **Immunosuppressants:** Drugs that shut down your body's immune responses. Otherwise, the immune system would damage your new heart.
- **Anti-infectives:** Drugs that prevent infections because your immune system is weakened.
- **Drugs to prevent heart disease and high blood pressure:** These medicines prevent coronary artery disease and regulate blood pressure.
- **Diabetes medicines:** Drugs to help your body control your blood sugar. Sometimes the immunosuppressants we give you cause your body to get new diabetes or worsen your existing diabetes.
- **Acid-reducing medicines:** Drugs to prevent acid reflux (heartburn) and stomach ulcers.
- **Vitamins, minerals, and nutritional supplements:** These can help your body to heal, absorb good nutrition, and continue good function.

Anti-rejection Medicine

Generic name: Tacrolimus

Brand names: Prograf, Astagraf XL, Envarsus XR

Category: Immunosuppressant (anti-rejection medicine)

How should you take this medicine?

- Immediate release form: Take with or without food, but be consistent. Always take with food or always take on an empty stomach.
- Extended release form: Take on an empty stomach 1 hour before or 2 hours after a meal.
- If taken once daily, take in the morning. If taken twice daily, doses should be 12 hours apart

Your lab test

- A simple blood test can show the tacrolimus drug level in your body. This will help your medical team decide whether you are taking too little or too much of this drug. To obtain the right drug level, you should skip the morning dose of tacrolimus before your blood test on lab days.
- Lab tests should be done about 12 hours after your previous dose.
- Bring your tacrolimus with you to the lab so that you can take it right after your blood has been taken.
- Unless told otherwise, do not wait for your lab results to come back before taking tacrolimus. Take it right after your blood has been taken.
- Lab tests take some time before they produce a result. If we have to change your dose based on your lab tests, we will let you know later on.

Side effects

- | | | |
|----------------------------|-------------------------|-----------------------|
| • Worse kidney function | • Higher risk of cancer | • Eyesight changes |
| • High blood pressure | • Anemia | • Diarrhea |
| • New diabetes | • Seizures | • Nausea and vomiting |
| • Higher risk of infection | • Headache | • Abdominal pain |
| • High cholesterol levels | • Tremors | • Hair loss |

Generic name: Cyclosporine

Brand names: Gengraf, Neoral, Sandimmune

Category: Immunosuppressant (anti-rejection medicine)

How should you take this medicine?

- Take with or without food, but be consistent.
- A strong odor may be released when the capsules are removed from their protective packet. This is only an alcohol-based preservative and the odor will fade quickly. It has no effect on the medicine.
- The blister packs containing the medicine should NOT be opened until you are ready to take the capsules. They can lose effectiveness when they are left exposed to the air.

Warning: There is more than one brand of this drug. Do not substitute one brand for another.

Your lab tests:

- We will check the cyclosporine drug level in your body with a simple blood test. This will help us decide whether you are taking too little or too much of this drug. To find the right drug level, your morning dose should be skipped before your blood test on lab days.
- Lab tests should be done about 12 hours from your previous dose.
- Bring your cyclosporine with you to the lab so that you can take it right after your blood has been taken.
- Unless your doctor says otherwise, do not wait for your lab results to come back before taking cyclosporine. Take it right after your blood has been taken.
- Lab results take some time before they result. If we have to make a dose change based on your lab results, we will let you know later on.

Side effects

- | | | |
|-----------------------------|-------------------------|----------------------|
| • Worse kidney function | • Higher risk of cancer | • Eyesight changes |
| • High blood pressure | • Anemia | • Diarrhea |
| • New diabetes | • Seizures | • Nausea or vomiting |
| • Higher risk of infection | • Headache | • Abdominal pain |
| • Higher cholesterol levels | • Tremors | • Hair loss |

Generic name: Mycophenolate

Brand names: Cellcept, Myfortic

Category: Immunosuppressant (anti-rejection medicine)

How should you take this medicine?

- Take on an empty stomach, ideally 1 hour before or 2 hours after meals.
- Delayed release tablets (Myfortic) should not be crushed, cut, or chewed.
- A liquid form is available if you cannot swallow the pill.
- Do not take antacids, cholestyramine, colestipol, or iron within 2 hours of this medicine.

Your lab tests:

Unlike some other drugs, we do not check drug levels of this medicine. You can take your usual morning dose of mycophenolate before morning lab tests.

Side effects

- | | | |
|----------------------|--|-------------------------------------|
| • Nausea or vomiting | • Anemia (low number of red blood cells) | • Extra fluid retained in your body |
| • Diarrhea | • Higher risk of infections | • Cough |
| • Stomach cramps | • Lower white blood cell count | • Higher risk of cancer |
| • Indigestion | | |

Generic name: Prednisone

Category: Immunosuppressant (anti-rejection medication)

How should you take this medicine?

- Take with or without food.

Side effects

- | | | |
|-------------------------------------|-------------------------------------|----------------------------------|
| • Psychosis | • Trouble sleeping | • Emotional changes, mood swings |
| • Round face (moon face) | • Stomach ulcers | • Weight gain |
| • Extra fluid retained in your body | • Bone weakening | • Muscle weakness |
| • Diabetes | • Necrosis | • Skin acne |
| • Nervousness | • Eye problems: glaucoma, cataracts | • Higher blood pressure |

Generic name: Sirolimus

Brand name: Rapamune

Category: Immunosuppressant (anti-rejection medicine)

How should you take this medicine?

- Take with or without food, but be consistent. Always take with food or always take on an empty stomach.
- If you are taking sirolimus with cyclosporine, sirolimus should be taken 4 hours after oral cyclosporine.
- Tablet: Do not crush, split, or chew.
- Solution: Mix with at least 2 ounces of water or orange juice (no other liquid) and drink immediately. The cup should then be refilled with water or orange juice, stirred, and the remaining contents drunk immediately.

Your lab tests:

We will check the sirolimus drug level in your body by performing a simple blood test. This will help decide if you are taking too little or too much of this drug. You should not take your morning dose of sirolimus on the day you get blood tests at the lab.

- Lab tests should be done about 24 hours after your previous dose.
- Bring your sirolimus with you to the lab so that you can take it right after your blood has been taken.
- Unless told otherwise, do not wait for your lab results to come back before taking sirolimus. Take it right after your blood has been taken.

Side effects

- | | | |
|--|---|---|
| • Delayed wound healing | • Headache | • Swelling from excess fluid in your body |
| • Higher cholesterol and triglycerides | • Pain | • Higher risk of infections |
| • Extra fluid retained in your body | • Nausea | • Higher risk of cancer |
| • Mouth ulcers | • Some lung conditions (pneumonitis, pneumonia, pulmonary fibrosis) | • More urinary protein |
| | | • Worsening kidney function |

Generic name: Everolimus

Brand name: Zortress

Category: Immunosuppressant (anti-rejection medicine)

How should you take this medicine?

- Take with or without food, but be consistent. Always take with food or always take on an empty stomach.
- Tablet: Do not crush, split, or chew.

Your lab tests:

- We will check the everolimus drug level in your body regularly by doing a simple blood test. This will help decide if you are taking too little or too much of this drug.
- You should not take your usual morning dose of everolimus on days you get your blood test in the lab.
- Blood tests should be done about 12 hours from your previous dose.
- Bring your everolimus with you to the lab so that you can take it right after your blood has been taken.
- Unless told otherwise, do not wait for your lab results to come back before taking everolimus. Take it right after your blood has been taken.

Side effects

- | | | |
|--|--|---|
| • Delayed wound healing | • Headache | • Swelling from extra water retained in your body |
| • Higher cholesterol and triglycerides | • Pain | • Higher risk of infections |
| • Extra fluid retained in your body | • Nausea | • Higher risk of cancer |
| • Mouth ulcers | • Lung conditions (pneumonitis, pneumonia, pulmonary fibrosis) | • More urinary protein |
| | | • Worsening kidney function |

Generic name: Azathioprine

Brand name: Imuran

Category: Immunosuppressant (anti-rejection medicine)

How should you take this medicine?

- Take with or without food.

Your lab tests

- Unlike some other drugs, we do not check drug levels of this medicine. You can take your usual morning dose of azathioprine before getting a blood test at the lab.

Side effects

- | | | |
|----------------------|------------------------------------|-----------------------------|
| • Nausea or vomiting | • Lower count of red blood cells | • Liver damage |
| • Diarrhea | | • Higher risk of infections |
| • Rash | • Lower count of white blood cells | • Higher risk of cancer |
| • Muscle pain | | |

Anti-infection Medicine

Generic name: Valganciclovir

Brand name: Valcyte

Category: Antiviral

This medicine can prevent or treat a virus infection called cytomegalovirus (CMV). People usually take it for a year after their transplant.

How should you take this medicine?

- Take with food for better absorption.
- Do not break or crush tablets.

Side effects

- Nausea or vomiting
- Shaky movements (tremors)
- Low number of white blood cells
- Diarrhea
- Anemia (low number of red blood cells)
- Lower number of cells that help blood clotting (platelets)
- Abdominal pain

What should you avoid while taking this drug?

You should not drive a car or operate other dangerous machinery until you know how this drug affects you. It can cause seizures, sleepiness, dizziness, unsteady movements, and confusion.

Generic name: Acyclovir

Brand name: Zovirax

Category: Antiviral medicine

This medicine can prevent or treat virus infections. People usually take it the first year after a transplant.

How should you take this medicine?

- Take with or without food.

Side effects

- Nausea or vomiting
- or having overall pain
- Lower number of platelets (cells that help blood clotting)
- Diarrhea
- Headache
- Feeling generally unhealthy
- Itching

Generic name: Sulfamethoxazole-Trimethoprim (SMX-TMP)

Brand names: Bactrim, Septra

Category: Bacteria fighting medicine

This medicine can prevent or treat some kinds of pneumonia or other types of bacterial infections. People usually take it for one year after a transplant.

How should you take this medicine?

- Take with or without food.
- Take with an 8-ounce glass of water.
- Do not take this medicine if you are allergic to sulfa drugs.
- Do not take this if you know you are deficient in G6PD (glucose-6-phosphate dehydrogenase).

Side effects

- | | | |
|----------------------|------------------------|--|
| • Nausea or vomiting | • Sun-sensitive skin | • Low number of white blood cells |
| • Diarrhea | • Itching | • Lower number of platelets (cells that help blood clotting) |
| • Abdominal pain | • Rash | • Hepatitis (rare) |
| • Loss of appetite | • High potassium level | |

Alternative medicine if you unable to take this drug:

- Atovaquone (Mepron®)
- Dapsone

Generic name: Itraconazole

Brand name: Sporanox

Category: Antifungal medicine

This medicine can prevent or treat fungal infections. People usually take it for 3 months.

How should you take this medicine?

- When you drink this drug mixed in a fluid, it should be taken on an empty stomach about 1 hour before or 2 hours after meals.
- Capsules should be taken with food.
- Never start or stop this medicine without your doctor's approval. It can have serious effects on other drugs that your doctor needs to consider.

Warning: The fluid form of this medicine should not be mixed up with the capsule version.

Side effects

- | | | |
|----------------------|-----------------------|-----------------------|
| • Nausea or vomiting | • Headache | • Nerve damage (rare) |
| • Diarrhea | • Hearing loss (rare) | |
| • Abdominal pain | • Liver damage (rare) | |

Generic name: Clotrimazole

Brand name: Mycelex

Category: Antifungal medicine

This medicine can prevent or treat a virus infection called thrush. Most people take it while also taking a steroid drug (like prednisone).

How should you take this medicine?

- Take 3 times a day after your 3 big meals of the day.
- Take the lozenge version of this medicine, which dissolves in the mouth, after meals.
- Do not crush or chew the lozenge. Let it dissolve and coat your mouth.

Side effects

- Itching

Medicines That Prevent Heart Disease and High Blood Pressure

Generic name: Pravastatin

Brand name: Pravachol

Category: Lipid-lowering medicine

This medicine helps lower cholesterol. It also helps prevent or treat clogging or disease in the heart blood vessels. It can be taken lifelong if needed

How should you take this medicine?

- Take this medicine once daily at night.
- Take it with or without food.

Side effects

- Muscle weakness or pain
- Fatigue
- Diarrhea
- Joint pain
- Dizziness
- Headache
- Nausea or vomiting

Additional safety note: Contact your doctor right away if you notice any unexplained muscle pain, soreness, weakness, or brown urine.

Generic name: Aspirin

Category: Salicylate, inflammation fighter

This medicine can relieve pain, fever, and inflammation. It is also taken in low dose to prevent strokes and heart attacks

How should you take this medicine?

- Take with food to avoid upset stomach

Side effects

- Upset stomach
- Heartburn
- Nausea or vomiting

Generic name: Carvedilol

Brand name: Coreg, Coreg CR

Category: Lowers high blood pressure

This medicine is used to lower high blood pressure.

How should you take this medicine?

- Take with or without food.
- Don't crush, chew or divide the extended-release capsules and their contents.

Side effects

- Dizziness
- Feeling tired or drowsy
- Diarrhea
- Weakness
- Headache
- Nausea or vomiting
- Blurred vision
- Back pain or joint pain

Generic name: Lisinopril

Brand names: Prinivil, Zestril

Category: Lowers blood pressure

How should you take this medicine?

Take with or without food.

Side effects

- Low blood pressure
- Dizziness
- Higher serum creatinine, a sign of possible kidney problems
- Higher potassium levels
- Cough

Acid-reducing Medicine

Generic name: Famotidine

Brand name: Pepcid

Category: Histamine blocker

This medicine can prevent or treat heartburn, acid indigestion, and sour stomach. It also can prevent stomach ulcers.

How should you take this medicine?

- Take without regard to meals.

Side effects

- Headache
- Dizziness
- Diarrhea or constipation

Bone-strengthening Medicine

Generic name: Alendronate

Brand name: Fosamax

Category: Bisphosphonate

This medicine can prevent and treat fragile bones (osteoporosis).

How should you take this medicine?

- Take with 6 to 8 oz. of plain water first thing in the morning. Do not take with mineral water or with other beverages.
- Stay upright (do not lie down) for at least 30 minutes and until after first food of the day (to reduce irritation of the food pipe to your stomach).
- The tablet should be swallowed whole, so do not chew or suck it.

Side effects

- Headache
- Acid backing up from your stomach to your mouth
- Muscle and skeletal pain
- Abdominal pain

Vitamins, Minerals, and Nutritional Supplements

Ferrous sulfate

This supplement can help treat low red blood cell levels (caused by anti-rejection medicine).

How should you take this?

- Take with food, especially orange juice (to help your body absorb it).

Side effects

- Upset stomach
- Constipation
- Black stool

Calcium and vitamin D

These vitamins help maintain bone strength because steroid drugs can weaken them.

How should you take this?

- Take with food.

Side effects

- Stomach or gut distress

Magnesium plus protein

This supplement can help keep healthy levels of magnesium in your body. Anti-rejection medicine can cause low magnesium levels.

How should you take this?

- Take with or without food.

Side effects

- Diarrhea

Multivitamins are general nutritional supplements

How should you take this?

- Take with or without food.

Side effects

- Stomach or intestinal distress

Potassium chloride

These tablets can help keep healthy potassium levels in your body. Potassium levels can drop from taking other drugs used to reduce excess water in your body (like furosemide).

How should you take this?

- Take with food and water to reduce risk of irritation of the stomach or intestine

Side effects

- Abdominal discomfort
- Passing gas (flatulence)
- Diarrhea
- Nausea or vomiting

Quick Reference to Medicines

Generic medicine name	Brand medicine name	Purpose
Aspirin	—	Blood thinner
Acyclovir	Zovirax	Antiviral agent
Alendronate	Fosamax	Prevents and treats bone-thinning
Azathioprine	Imuran	Prevents rejection
Carvedilol	Coreg, Coreg CR	Controls blood pressure; heart medicine
Clotrimazole	Mycelex	Antifungal (anti-thrush) drug
Cyclosporine	Gengraf, Neoral, Sandimmune	Prevents rejection
Everolimus	Zortress	Prevents rejection
Famotidine	Pepcid	Reduces stomach acid
Itraconazole	Sporanox	Antifungal drug
Lisinopril	Prinivil, Zestril	Controls blood pressure; heart medicine
Mycophenolate	Cellcept, Myfortic	Prevents rejection
Pravastatin	Pravachol	Helps lower cholesterol. Helps fight cardiac blood vessel disease
Prednisone	Deltasone	Prevents rejection
Sirolimus	Rapamune	Prevents rejection
Tacrolimus	Prograf, Astagraf XL, Envarsus XR	Prevents rejection
Trimethoprim-sulfamethoxazole (TMP/SMX)	Bactrim, Septra	Prevents fungal infection linked to pneumonia
Valganciclovir	Valcyte	Antiviral drug (prevents and treats CMV infections)

Your Commitment to a Healthy Life

A heart transplant is a gift of life. It requires you to make a personal commitment to living a healthy lifestyle.

Taking care of your transplant means you will be responsible for maintaining your new heart. To do this, you will have to:

- Take all of the drugs as prescribed.
- Check your blood pressure, heart rate and weight every day.
- Go to all your scheduled clinic visits.
- Start exercising regularly and eating healthy food.

The Stanford transplant team is committed to helping you by providing information and support. Please do not hesitate to ask any of our team members for more information.

The Patient and Family Advisory Council (PFAC)

The council's goal is to bring patients and families together with members of the health care system. Patients and families may advise health care leaders and team members on pertinent topics. The PFAC:

- Involves the patient and family perspectives on the overall patient care experience
- Is committed to address the concerns of patients and families
- Acts as advisors and advocates to enhance care for the heart transplant population. PFAC holds a seat at the Heart Transplant Quality Council.
- Identifies patient and family-centered care strategies at Stanford Health Care. This includes reviewing patient education materials and influencing staff education. It may mean acting as a sounding board for improving programs and facility design.
- Supports the heart transplant community through informative newsletters, an annual reunion and symposium , educational manuals, websites and peer-to-peer mentorship.

Peer-to-Peer Mentoring Program (P2P)

Mission statement: “Provide unique support and understanding through peer-to-peer mentoring in order to promote healthier lives and reduce isolation.”

Peer mentors are carefully selected, trained, and supported volunteers. They help other patients and their support circle with the challenges of a disease or medical condition.

The patient is linked 1-to-1 with a mentor who shares similar health and life circumstances. Through a trusted relationship, mentors provide support in many ways.

Mentors listen and share personal experiences. They also serve as resources for building coping strategies. They can guide patients in negotiating with health care systems.

For more information please contact your transplant social worker or the peer-to-peer program coordinator at 650-474-1011.

Research Studies

Clinical research studies are done to answer specific questions. Sometimes the question is about a new drug or a medical device's safety and effectiveness. Or the study may look at a new way to detect complications.

Research studies fall into 2 groups: observational studies or clinical trials.

In observational studies, information is collected from patients to understand specific conditions. For example, what factors are linked to long-term survival after a heart transplant? Observational studies may also collect information on new tests that can detect rejection or other heart transplant complications in their early stages.

In clinical trials, patients are placed in groups that get either a new medicine or a placebo. (A placebo is a pill or liquid that looks like the real medicine but does not have any active ingredients in it.) Clinical trials are done to see if new treatments are safe and effective for heart transplant complications.

Clinical research studies bring together scientists and doctors from many areas across Stanford University. To ensure the studies meet the highest ethical standards, the Institutional Review Board (IRB) is responsible for oversight.

Please feel free to talk over these studies. You can check with the heart transplant team or the heart transplant research nurse coordinator at 650-724-2883.

Resources

Stanford Heart Transplant Website

1. Type www.stanfordhealthcare.org into your web browser.
2. Type “Heart Transplant” into the search window.
3. Select “Heart Transplant” from the options.
4. You will see the “Heart Transplant–Heart Replacement” page. Use the labels on the left side to find different topics.
5. The “What to Expect” tab contains multiple sub-topics. Make sure to read through all of them to get all the information.

Lab Locations

There are several locations available for blood tests. Please check out the SHC Blood Draw Sites and Locations page on the web for up-to-date locations, addresses, phone numbers and hours.

Marguerite Shuttle System

Marguerite is Stanford's free public shuttle service. The shuttles can take you around campus and to nearby transit, shopping, dining, and entertainment.

Marguerite is free and open to the public. No ID is required. The main shuttle lines cross the campus Monday through Friday all year (except University holidays).

All buses are accessible to wheelchairs and have bike racks.

For maps, shuttle schedules, and routes of service check the Marguerite Shuttle website.

Glossary

Advance directive: A document h a person uses to either state choices for medical treatment or designate someone to make treatment choices if the person should become unable to make decisions. Most often the term refers to formal, written documents, but it can also be used to include spoken statements by the patient.

Allograft (allogeneic graft or homograft): An organ or tissue transplanted from one individual to another of the same species, i.e. human to human.

Antibody: A protein substance made by the body's immune system in response to a foreign substance, for example a previous transplant, blood transfusion, or pregnancy. Because the antibodies attack the transplanted organ, heart transplant patients must take powerful drugs that suppress the immune system (called immunosuppressive drugs).

Antigen: A foreign molecule or substance, such as a transplant, that triggers an immune response. This response may be the production of antibodies.

Anti-hypertensive drug: A drug that reduces hypertension (high blood pressure).

Atherosclerosis: A disease in which fatty deposits accumulate on the inner walls of the arteries, causing narrowing or blockage that may result in a heart attack. Commonly known as "hardening of the arteries."

Attending or Primary physician: The doctor who has the main responsibility for your care while you are in the hospital during heart transplantation. There may be other doctors caring for you such as consulting doctors, resident doctors, and medical students.

Biopsy: The removal of a sample of tissue via a small needle. The tissue is removed for examination to determine a diagnosis.

Blood typing: A test that can help establish compatibility between 2 different types of blood. Blood types include A, B, AB, or O.

Blood urea nitrogen (BUN): A waste product regularly removed by the kidneys and eliminated in the urine. Regular testing of the BUN level serves as an indicator of how well the kidney is functioning.

Breathing tube (endotracheal tube): A temporary tube put into the nose or mouth. Anesthesia or air and oxygen pass through the tube allowing artificial breathing.

Cadaveric donor: An individual who has recently passed away of causes not affecting the organ intended for transplantation. Cadaver organs usually come from people who have willed their organs before death by signing organ donor cards. Permission for donation also can be given by the deceased person's family at the time of death.

Catheter: A thin, flexible instrument used to introduce or withdraw fluids from the body. A catheter also may be used to monitor blood pressure.

Caregiver: the primary person assisting in the management of your illness: this may include a family member, a medical worker, or allied health professional, who assists in the management of an illness or disability.

Categories for urgency in heart transplantation:

1A – Patients are very sick and are in the hospital with intravenous (IV) monitoring equipment or mechanical devices helping to temporarily sustain heart function.

1B – Patients may be in or out of the hospital and have IV medications or a mechanical device stabilizing heart function.

Status 2 – Most patients are out of the hospital and stable.

Status 7 – Patients are temporarily inactive on the transplant list.

Chest X-ray: This is used to view the lungs and lower respiratory tract. A chest X-ray may be used for diagnosis and therapy.

CPR (cardiopulmonary resuscitation): This procedure uses cardiac and respiratory equipment and medicine possibly to restore the heartbeat and/or breathing.

Compliance: This is the act of following orders and adhering to rules and policies, including taking prescribed medicine after transplant.

Complication: This is the occurrence of diseases or medical problems simultaneously in the body.

Coronary angiography (also called cardiac catheterization): This procedure allows pictures to be taken of the arteries supplying the heart with blood (the coronary arteries). Angiography shows blockages in the arteries.

Creatinine: This is a waste product in the blood, removed by the kidneys and eliminated in the urine. Regular testing of the creatinine level serves as an indicator of how well the kidneys are functioning.

Crossmatch: This test establishes the compatibility or closeness of blood between the organ donor and recipient. A positive crossmatch shows that the donor and patient are incompatible. A negative crossmatch means there is no reaction between donor and patient and that the transplant may proceed.

Cyclosporine level test: This blood test measures the amount of cyclosporine in the blood. Based on the amount of cyclosporine measured, a doctor decides what dose of cyclosporine is appropriate for a patient.

Cytomegalovirus (CMV): This is a common virus that may be present without symptoms in healthy people, but can be a serious condition if present in transplant patients.

Dialysis: This is an artificial means of cleansing the blood of waste products and removing fluids from the body when the patient's own kidneys are unable to continue this process.

Diastolic: This is the lower number in a blood pressure reading that indicates the pressure in the heart when the muscle is relaxed (the point of least pressure).

Diuretic: This kind of drug helps the body get rid of excess water by increasing the amount of urine the body excretes.

DNR order (Do Not Resuscitate order): This is an advance directive that means no CPR is to be done when the heart and lungs stop.

Donor: This is a person who gives an organ, tissue, or blood to another person. A compatible donor is a person who has the same tissue and blood types as the person who receives the organ, tissue, or blood.

Durable power of attorney for health care: This is a written advance directive in which individuals name someone else (the "agent" or "proxy") to make health care decisions for them when they are unable to speak for themselves.

Echocardiogram: This imaging procedure creates a moving picture outline of the heart's valves and chambers using high-frequency sound waves that come from a hand-held wand placed on your chest or passed down your throat. Echo is often combined with Doppler ultrasound and color Doppler to evaluate blood flow across the heart's valves. Doppler senses the speed of sound and can pick up abnormal leakage or blockage of valves.

Electrocardiogram (EKG or ECG): This test records on graph paper the electrical activity of the heart via small electrode patches attached to the skin. An EKG helps a doctor determine the causes of abnormal heartbeat or detect heart damage.

Glucose: This is blood sugar. Manufactured by the body from carbohydrates, protein, and fat, glucose is the main source of energy for all living organisms.

Graft: This is a transplanted tissue or organ (such as a heart, lung, or liver).

Heart transplantation: Heart transplantation is a treatment option for irreversible, life-threatening heart diseases that cannot be managed by other medical or surgical methods.

Herpes: This is an infection for which transplant patients are at risk. It appears as small sores on the skin, lips or genitals. When there are no sores, the herpes virus lays dormant (not causing infection) in the body.

Hypertension: This is another name for high blood pressure.

HLA system (Human leukocyte antigens): There are three major genetically controlled groups: HLA-A, HLA-B and HLA-DR. In transplantation, the HLA tissue types of the donor and recipient are sometimes an important part of the selection process. This depends on the recipient's antibodies.

Histocompatibility antigens: These are molecules found on all nucleated cells in the body that characterize each individual as unique. These antigens are inherited from parents. Human leukocyte antigens determine the compatibility of tissues for transplantation from one individual to another.

Hospice: This is a program that provides care for the terminally ill in the form of pain relief, counseling, and support, either at home or in a facility.

Hydration: This means providing fluids by any means to prevent dehydration.

Immune response: This is the body's defense against foreign objects or organisms, such as bacteria, viruses, or transplanted organs or tissue.

Immune system: This is the body's response mechanism for fighting against bacteria, viruses, and other foreign substances. If a cell or tissue (such as bacteria or a transplanted organ) is recognized as not belonging to the body, the immune system will act against the "invader." The immune system is the body's way to fight disease.

Immunosuppressant drug: This kind of drug prevents the immune system from responding to cells that it recognizes as foreign to the body. Such drugs prevent the immune system from recognizing that a transplanted organ, such as a heart, is not the organ a person had when he or she was born.

Immunosuppression: This is the artificial suppression of the immune response, usually through drugs, so that the body will not reject a transplanted organ or tissue. Drugs commonly used to suppress the immune system after transplant include prednisone, azathioprine (Imuran), mycophenolate mofetil (CellCept), and cyclosporine (Neoral).

Infectious disease team: This team of doctors help control the hospital environment to protect you against harmful sources of infection.

Intensive care unit (ICU): This special nursing area is devoted to providing continuous and immediate care to seriously ill patients.

Intravenous (IV): This is the delivery of drugs, fluids, or food directly into a vein.

Informed consent: This is a process of reaching an agreement based on full disclosure. Informed consent has components of disclosure, comprehension, competence, and voluntary response. Informed consent often refers to the process by which someone decides to donate the organs of a loved one.

Legal guardian: This is a person charged (usually by court appointment) with the power and duty of taking care of and managing the property and rights of another person who is unable to take care of their own affairs.

Life-sustaining treatment: This is medical treatment given to a patient that prolongs life and delays death.

Living will: In this written advance directive, an individual states which health care decisions should be made if the individual becomes unable to make these decisions.

Medical student: This is a student in the third or fourth year of medical school training. The student doctor assists the primary and resident doctors in daily care of patients.

Noncompliance: This is failure to follow instructions given by health care providers, such as not taking medicine as prescribed or not attending follow-up appointments.

NOTA: The National Organ Transplant Act, passed by Congress in 1984, outlawed the sale of human organs and initiated the development of a national system for organ sharing and a scientific registry to collect and report transplant data.

Organ preservation: Between procurement from a donor and heart transplantation, organs require special methods of preservation. The length of time that organs and tissues can be kept outside the body vary, depending on the organ, the preservation fluid, and the temperature.

Palliative care: This is medical treatment intended to control suffering and discomfort (such as pain medicine or treatment of an infection). These treatments will not cure the patient.

Panel reactive antibody (PRA): This the percentage of cells from a panel of donors with which a potential recipient's blood serum reacts. The more antibodies in the recipient's blood, the higher the PRA. The higher the PRA, the less chance of getting a good crossmatch.

Patient advocate: A patient advocate acts as a representative for individuals requiring assistance with their health care needs. The advocate is someone who acts as a liaison between the patient and the health care provider.

Physical therapist: This expert can recommend exercises to help you maintain flexibility and regain your strength.

Pre-transplant evaluation: This is a series of interviews and tests for patients who are being considered for a transplant. It is the second step in the transplant evaluation process. After this evaluation, the transplant team decides if a transplant is a suitable treatment.

Pre-transplant screening: This is a series of interviews and physical examinations for patients who are being considered for a transplant. Pre-transplant screening is the first step in the transplant process to discover if a patient has any condition that would immediately rule him or her out for a transplant.

Proxy: This is a person appointed to make decisions for someone else, as in a Durable Power of Attorney for Health Care (also called a surrogate or agent).

Pulmonary function tests (PFTs): These tests measure the volume of air that is inhaled and exhaled. The PFTs also measure gases, such as oxygen and carbon dioxide, in the lungs.

Recipient: This is a patient who receives an organ, tissue, or blood from another person.

Rejection: In this process, the body tries to get rid of a transplanted organ or tissue by producing antibodies. Immunosuppressive drugs help to prevent rejection.

Resident physician: This is a doctor who works closely with the primary physician to manage a patient's daily care. The resident is a licensed medical school graduate doing further training in one of the specialties of medicine.

Retransplantation: Due to organ rejection or transplant failure, some patients return to the waiting list. Reducing the number of retransplants is a critical concern when examining ways to maximize a limited supply of organs.

Sensitization: Potential recipients are "sensitized" if there are antibodies in their blood, usually because of pregnancy, blood transfusions, or previous rejection of an organ transplant. Sensitization is measured by PRA. Highly sensitized patients are more likely to reject an organ transplant than unsensitized patients.

Side effect: This is an unintended effect of a drug on tissues or organs other than the drug benefits.

Status: This is the indicated degree of medical urgency for patients awaiting transplants.

Survival rates: These rates indicate the percentage of patients or grafts (transplanted organs) that are still alive or functioning at a certain point after a transplant. Survival rates are often given at 1-, 3-, and 5-year increments. Policy modifications are never made without examining their impact on transplant survival rates. Survival rates improve with technological and scientific advancements. Developing policies that reflect and respond to these advances in transplantation will also improve survival rates.

Systolic: The top number in a blood pressure reading that indicates the force of the heart muscle's contractions as blood is pumped through the heart's chambers.

Thrush: This is a yeast infection for which transplant patients have a higher risk. It can occur in the mouth or vagina.

Tissue typing: This test evaluates the compatibility or closeness of tissue between the organ donor and recipient.

TPN (total parenteral nutrition): This special intravenous (IV) solution provides hydration, vitamins, minerals, and calories to sustain life. This IV is usually inserted into a large vein in the neck area.

Transplant coordinator: This is a registered nurse who coordinates all of the events leading up to and following your transplant. The transplant coordinator helps arrange your pre-transplant tests and helps find a suitable donor.

Transplant surgeon: This staff physician performs the transplant surgery. The transplant surgeon follows your progress while you are in the hospital and monitors your post-transplant care after you are discharged.

Tube feeding (enteral feeding): This is a temporary artificial method of providing food through a tube inserted into the stomach. This food is in a liquid form and contains calories, vitamins, and electrolytes. Enteral feeding may be necessary when food cannot be taken by mouth.

UNOS: The United Network for Organ Sharing is the national nonprofit agency that establishes and enforces regulations to ensure equality in organ transplantation and fairness in distribution of donor organs.

U.S. Scientific Registry of Transplant Recipients: This is a database of post-transplant information. Follow-up data on every transplant are used to track transplant center performance, transplant success rates, and medical issues impacting transplant recipients. UNOS facilitates the collection, tracking, and reporting of transplant recipient and donor data.

Ventilator: This machine is used to assist or control breathing (may be called a respirator).

Waiting list: After evaluation by the transplant physician, and after committee presentation, a patient is added to the national waiting list by the transplant center. Lists are specific to both geographic area and organ type: heart, lung, kidney, pancreas, intestine, heart-lung, kidney-pancreas.

This Heart Transplant Patient Guide was reviewed by the Heart Transplant Patient and Family Advisory Council 2017.

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Additional Information

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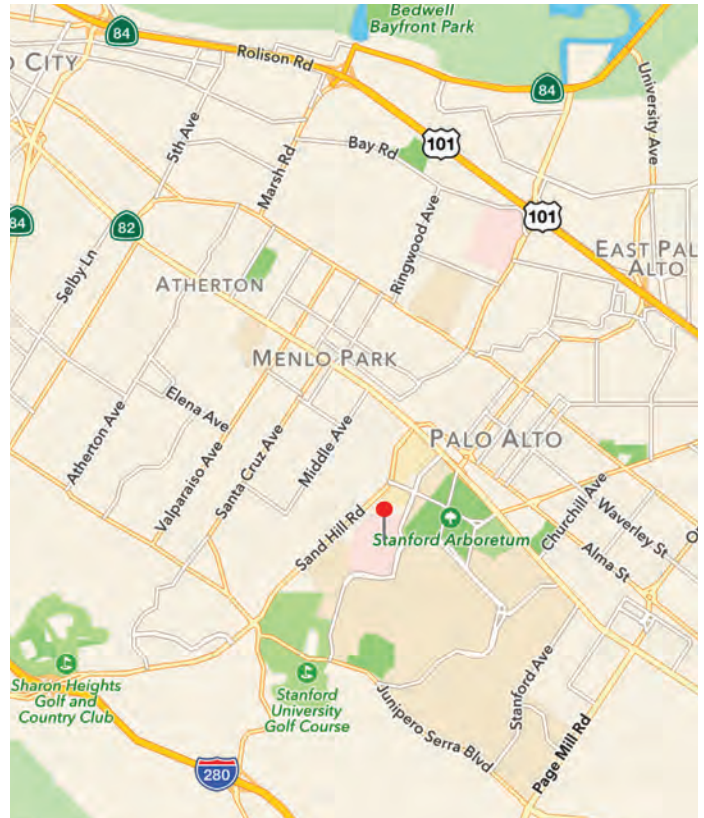
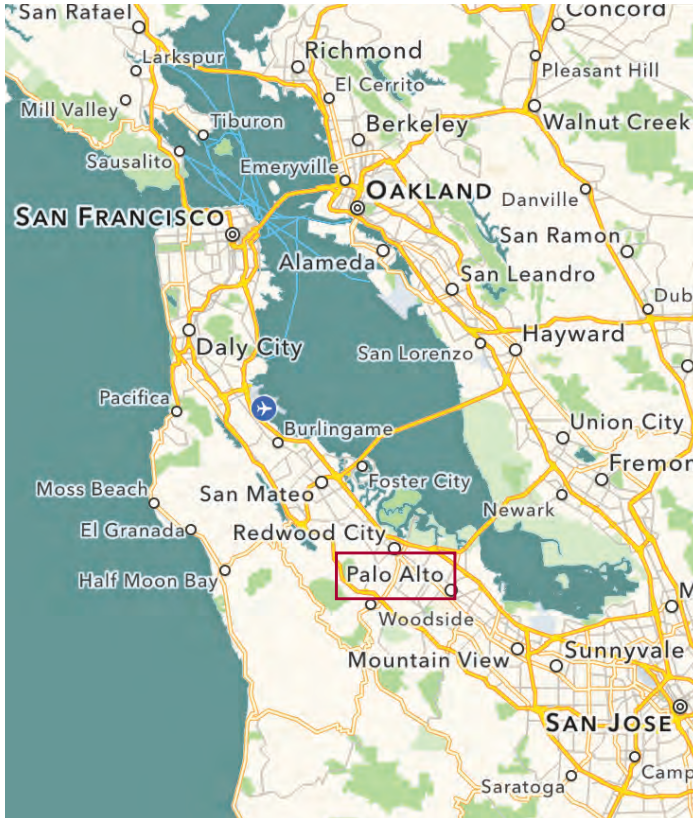
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Map & Directions

Stanford Main Hospital • 300 Pasteur Drive • Palo Alto, CA • 94304



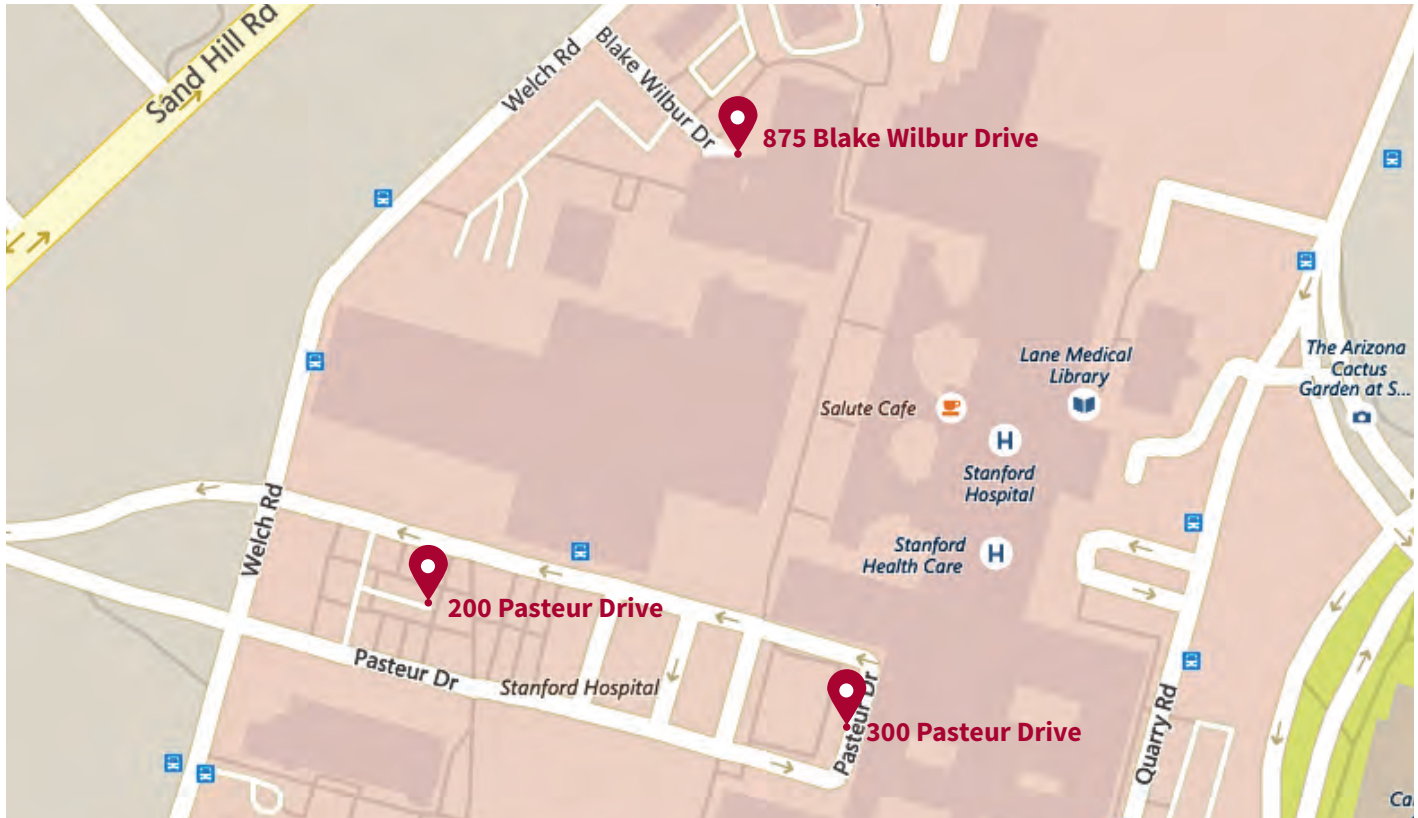
From Highway 101 North/South

- Exit Embarcadero Road West
- Follow Embarcadero Road for about 2 miles
- Cross El Camino Real (Embarcadero Road becomes Galvez Street)
- Turn right on Arboretum Road
- Turn left on Quarry Road
- Turn right on Welch Road
- Turn left on Pasteur Drive
- Pasteur Visitor Garage is 1st driveway on left (please note the parking garage is underground)
- Continue straight for valet parking

From Interstate 280 North/South

- Exit Sand Hill Road East
- Follow Sand Hill Road for about 2.5 miles
- Turn right on Pasteur Drive
- Cross Welch Road
- Pasteur Visitor Garage is 1st driveway on left (please note the parking garage is underground)
- Continue straight for valet parking

Parking



Valet Parking

Main Hospital

300 Pasteur Drive, Palo Alto, CA

Available Mon–Fri • 5:30 a.m. – 7:30 p.m.

First hour	Free
1 – 8 hours	\$10
Daily Max	\$15

Cancer Center & Ambulatory Surgery Center

875 Blake Wilbur Drive, Palo Alto, CA

Available Monday – Friday • 5:30 a.m. – 5:30 p.m.

First hour	Free
1 – 8 hours	\$12
Daily Max	\$15

Cash and all major credit cards accepted. Pickup available until 11:30 p.m.. After Hours pickup is available by calling 650-736-7855. *Prices subject to change

Self-Parking

Pasteur Visitor Garage – PS4

200 Pasteur Drive, Palo Alto, CA

Available 7 days a week, 24 hours a day.

First hour	Free
1 – 2 hours	\$2
2 – 3 hours	\$3
3 – 4 hours	\$4
4 – 5 hours	\$6
5 – 6 hours	\$7
6 – 7 hours	\$8
7 – 8 hours	\$10
Daily Max	\$12

Cash and all major credit cards accepted.

*There is free parking for Medi-Cal patients on the day of discharge. Present your card to the parking attendant to obtain the discount.

Hotels

Stanford Health Care does not endorse any of the hotels listed. Please identify yourself as a Stanford patient or guest in order to receive a POSSIBLE discount. No Stanford discount is guaranteed. Hotels may also offer Senior or AAA members discounted rates.

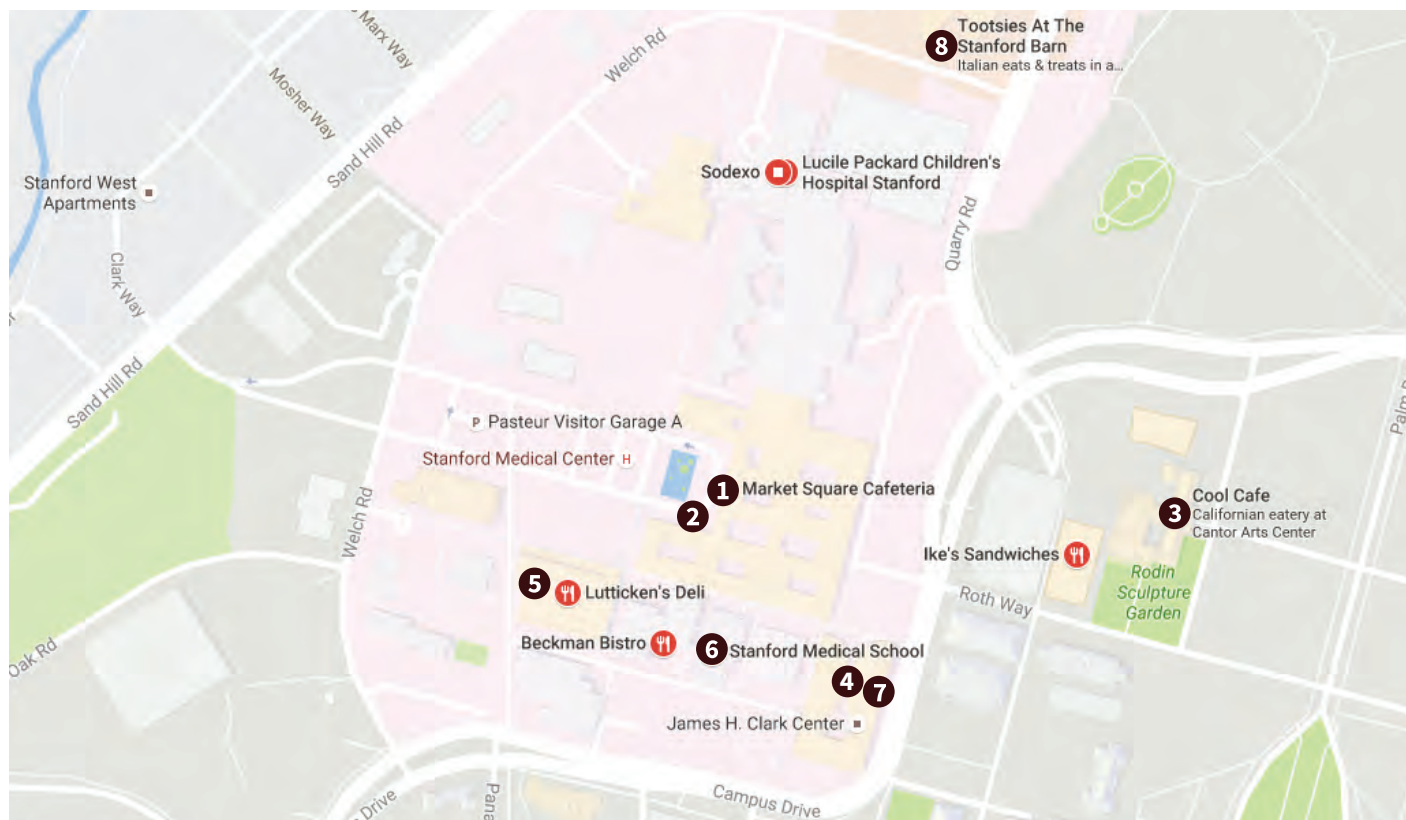
All amenities listed are subject to change – please confirm amenities when making your reservation.

Distance (Miles)	Hotel/Address	Phone	Rates
1.0	Best Western Plus Riviera , 15 El Camino Real, Menlo Park	650.321.8772	\$\$\$\$
1.2	Stanford Park Hotel , 100 El Camino Real, Menlo Park	650.322.1234	\$\$\$\$
1.5	Stanford Inn , 115 El Camino Real, Menlo Park	650.326.5500	\$\$\$\$
1.5	Sheraton Palo Alto Hotel , 625 El Camino Real, Palo Alto	650.328.2800	\$\$\$-\$\$\$\$
1.5	Westin Hotel , 675 El Camino Real, Palo Alto	650.321.4422	\$\$\$-\$\$\$\$
2.0	Cardinal Hotel , 5 Hamilton Ave., Palo Alto	650.323.5101	\$\$\$\$
2.0	Stanford Guest House , 2575 Sand Hill Rd., Menlo Park	650.926.2800	\$\$\$\$
2.0	The Cowper Inn B&B , 705 Cowper St., Palo Alto	650.327.4475	\$\$\$-\$\$\$\$
2.0	Menlo Park Inn , 1315 El Camino Real, Menlo Park	650.326.7530	\$\$-\$\$\$\$
2.0	Travel Lodge , 3255 El Camino Real, Palo Alto	650.600.8515	\$\$\$
2.0	Creekside Inn , 3400 El Camino Real, Palo Alto	650.493.2411	\$\$\$\$
2.0	Atherton Park Inn , 2834 El Camino Real, Redwood City	650.366.2000	\$\$\$\$
2.1	Garden Court Hotel , 520 Cowper St., Palo Alto	650.322.9000	\$\$\$\$
2.1	Hotel California B&B , 2431 Ash St., Palo Alto	650.322.7666	\$\$
2.4	Stanford Motor Inn , 3305 El Camino Real, Palo Alto	650.493.3153	\$\$-\$\$\$\$
2.6	Stanford Terrace Inn , 531 Stanford Ave., Palo Alto	650.857.0333	\$\$\$-\$\$\$\$
2.8	Coronet Motel , 2455 El Camino Real, Palo Alto	650.326.1081	\$\$-\$\$\$\$
2.8	Rosewood Sand Hill , 2825 Sand Hill Rd., Menlo Park	650.561.1500	\$\$\$\$
2.9	Red Cottage Inn & Suites , 1704 El Camino Real, Menlo Park	650.326.9010	\$\$\$-\$\$\$\$
3.1	Hotel Parmani , 3200 El Camino Real, Palo Alto	650.493.9085	\$\$\$\$

Room Rates: \$ = under \$90 \$\$ = \$90 – \$100 \$\$\$ = \$100 – \$200 \$\$\$\$ = \$200+

Places to Eat

Please see corresponding numbers on the map above for more specific location.



1. Market Café

(Main Cafeteria)
300 Pasteur Dr.
Daily: 7 a.m. – 7 p.m.

2. Outdoors Carts

300 Pasteur Dr.
M-F: 8 a.m. – 3 p.m.

3. Cantor Arts Ctr.

328 Lomita Dr.
W-Sun: 11 a.m. – 5 p.m.
Thu: open until 8 p.m.

4. Clark Center

1st Floor, 318 Campus Dr.
M-F: 8:30 a.m. – 10 a.m.
& 11 a.m. – 7 p.m.

5. Center for Clinical Science Research (CCSR)

1st fl, 269 Campus Dr.
M-F: 7:30 a.m. – 4 p.m.

6. Li Ka Shing Center

1st Floor, 291 Campus Dr.
M-Th: 7 a.m. – 7 p.m.
Fri: 7 a.m. – 5 p.m.

7. Clark Center

3rd Floor, 318 Campus Dr.
M-Th: 7 a.m. – 7 p.m.
Fri: 7 a.m. – 7 p.m.

8. Stanford Barn

700 Welch Road
M-F: 6:30 a.m. – 4 p.m.
Sat: 10 a.m. – 4 p.m.



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