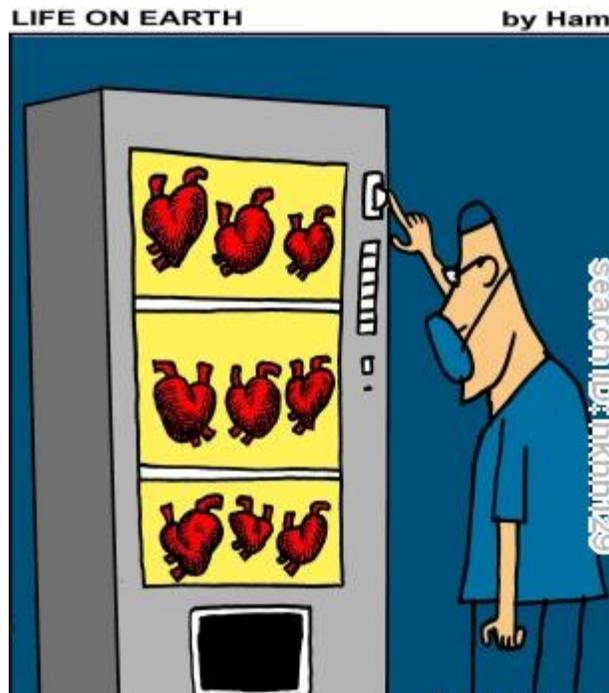


# What to Expect When you are Expecting



# Introduction

- The first successful heart transplant was done at Stanford in January 1968.
- Stanford performs 50-60 heart transplants per year in both adults and children.
- More than 1,450 heart transplants have been performed at Stanford.
- In general 85-90% of patients survive past one year and 80% survive three years.
- You and your loved ones play an active roll in the transplant process.
- Beyond the transplant surgery, we have a multidisciplinary team that has lifelong relationship with our transplant patients offering support, education and medical management.





- 5 million Americans have heart failure
- Heart failure is when the heart muscle becomes impaired
- The weak heart cannot keep up with the body's need to pump out blood
- This can be sudden, or may occur over time

# Heart Transplant Evaluation

- **Echocardiogram.** Ultrasound of your heart
- **Exercise (VO<sub>2</sub>) test.** Shows the amount of oxygen your heart and lungs can provide to your muscles
- **Right Heart Catheterization.** Measures pressures in your heart
- **Left Heart Catheterization.** Uses a dye to look at your coronary arteries
- **EKG.** Looks at your heart rhythm
- **Laboratory Tests.** Determine blood type, other organ function and exposure to certain diseases
- **Chest Xray.** Image heart and lungs
- **Pulmonary Function Test.** Determines lung function if you are/were a smoker
- **Carotid and peripheral ultrasounds.** Looks for blockages in certain blood vessels
- **Colonoscopy.** To ensure you do not have colon cancer
- **Mammogram.** To ensure you do not have breast cancer
- **Dental exam.** To evaluate your oral health
- **Eye exam**
- **Psychosocial evaluation**
- **Insurance clearance.** This includes covering the cost of the surgery as well as testing and medications after transplant
- Your doctors may decide if other studies are needed to ensure you are a good candidate for heart transplant

# Psychosocial/Psychiatric Evaluation Includes

- Performed by specialized transplant social workers
- Understanding of the transplant process
- Transplant goals, quality of life definition
- Transplant expectations
- Availability of caregivers before and after transplant
- Coping and stress management barriers/challenges
- Compliance
- Religious and/or cultural issues
- Mental status and mental health evaluation
- Substance use history
- Healthcare planning



# Selection

Once all testing and psychosocial evaluation is complete the entire transplant team comprised of surgeons, cardiologists, nurses, social workers, psychiatrists, financial counselors, and more meet to review your case.

The decision is then made to “defer”, “decline”, or “list” you.

# What does defer, decline, or list mean?

- **Defer**
  - Means the team has decided that further testing is required in order to make the decision about your candidacy.
- **Decline**
  - The team has decided that transplant is not the best option for you.
  - If you are declined for transplant your Cardiologist will explain the reasoning behind the decision as well as review alternative treatments for you.
- **List**
  - The team has decided that transplantation is the best option for you.
  - You will then be placed on the transplant waitlist.



# Heart Transplant Listing

## UNOS Status



**1A** – Patients are very sick and are in the hospital with intravenous monitoring equipment, special IV medications and/or mechanical devices helping temporarily sustain their heart function.

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

**Status 2** – Patients are out of the hospital and stable.

**Status 7** – Patient is temporarily inactive on the transplant list.

*\*\*\*Your status may change as your condition improves or deteriorates.\*\*\**

# How long will I wait for my heart?

- There are many factors that affect how long an individual will wait for their heart
  - Blood type
  - Height/weight
  - UNOS status
  - How long you have been on the transplant waiting list
  - Preformed antibodies
- There is no way to truly predict how long you will wait for your transplant.

# Potential Donor

- A donor is an individual who is declared “brain dead” by two separate physicians.
- The donor family generously decides to consent making the donor organs available for transplant.
- The donor information is transmitted to the “donor network” and a recipient “match list” is generated
- While waiting, you need to keep yourself as healthy as possible.
  - Continue your medications as prescribed
  - Follow diet recommendations
  - Stay as active as possible



# How should you prepare yourself?

- Communication

- Ensure you have a working cell phone for when a donor heart becomes available
- Make sure we have *all* your phone numbers so we can contact you easily when a heart becomes available
- Check all your answering machines/voicemails often especially if you are somewhere with limited phone service
- You must let the transplant team know if you will be unavailable for any reason whatsoever.

- Finances

- Check with your insurance provider and Stanford's financial counselors to make sure your transplant is covered
- Check with your insurance provider to ensure all medications you will be on after transplant are covered and what the cost to you will be
- You will stay in a hotel/motel near Stanford for at least 3 months after transplant. We help arrange special rates for you, however there will be some cost to you. Make sure you are prepared for this expense.



# How should you prepare yourself?

- **Emotional Preparation**
  - It is important to stay positive and help manage stress well prior to transplant
  - Support groups can help. Stanford hosts a monthly support group for patients and families
  - Our social workers can offer a number of other resources to help you during this trying time
- **Support Person**
  - Make sure you have a few support people identified to help you during the immediate transplant period.
  - The presence of at least 1 support person is a requirement for transplantation.
  - It may be helpful to create a schedule with them as someone will need to be with you 24/7 for the first 3 months at least.
  - Stanford also offers a monthly support group for caregivers. Your Social Worker will provide you with this information



## When a donor becomes available...

- You will be contacted by the surgeon when a donor becomes available
- The surgeon will ask if you have had any recent infection...cough, cold, fever, nausea, vomiting, diarrhea. It is important to be completely honest as an infection can complicate transplant
- Once you have been called, you may not have anything else to eat or drink
- You must come to Stanford IMMEDIATELY
- Once at Stanford you will get an IV, chest x-ray and will be seen by the surgeon and anesthesiologist
- The surgeon will review risks of the operation with you and your family

# Timing Etc.

- Donor Team
  - Team of surgeons who go to the donor's hospital
  - They will review the donors records and examine the donor to make sure it is a good match for you
- It is very important to minimize the amount of time the donor heart is outside of the body
  - The donor team will be at the donor hospital at the same time the transplant team will be working on you

# “Dry Run”

- On occasion the donor team discovers that the donor will not be a good match for you causing us to cancel the transplant.
- Though rare, sometimes the transplant needs to be cancelled after you have already gone to the operating room and have “gone to sleep” for your surgery.
- Although this may be extremely disappointing for you and your family the surgeons have determined that it is just not safe to proceed with the transplant.

# The Surgery



- An incision is made in the midline of your chest
- A heart-lung bypass machine will take over the work of the heart and lungs
- Your diseased heart will be removed and replaced by the healthy donor heart

# Immediately after your Heart Transplant

- You will be taken to a bed in North ICU to recover immediately after the transplant
  - You will be connected to a ventilator to help you breathe while you awaken from your surgery. This will be discontinued when you can breathe independently
  - You will have a special catheter in one of the big veins in your neck that will monitor the pressure in your new heart
  - You will have many IV's and IV pumps delivering medications
  - Chest Tubes will be present to drain fluids from your chest
  - You will have a catheter in your bladder to drain your urine
  - Medications to suppress your immune system and monitoring of your transplanted organs begin
  - Most patients are in the ICU for 2-3 days after your transplant depending on the pace of your recovery



# Once stable you will be transferred to the step down ICU

- You will most likely be in a private room once on the step down unit so family can visit, or even spend the night in your room with you
- You will receive your own set of medications which the nurse will start to teach you and your support people your new regimen
- Physical and occupational therapists will work with you to build up your strength
- A dietician will meet with you to discuss heart healthy diet now that you have a new heart
- You will continue with blood draws and chest x-rays that monitor response to medications and your recovery
- As you near discharge the transplant coordinator will teach you and your caregivers about your transplant, how to recognize potential complications and how to contact the transplant team

# Discharge

- Once you are doing well from a medical perspective and have learned your medicines in hospital, you will be discharged to an apartment/motel located very near Stanford hospital.
- You will stay in that apartment/motel for **3 months**
- You **must** have a caregiver/support person staying with you for this 3 month duration
- Please ensure you have an alternate person available should your primary caregiver become sick
- Our social workers will work with you to find accommodation that is affordable for you

# Heart Transplant Complications

- Rejection
- Infection
- Graft Coronary Artery Disease
- High Blood Pressure
- Diabetes

# Rejection

- Rejection is your body's attempt to fight off a "foreign invader"
- Since your new heart is "foreign" your immune system will try to get rid of it
  - Special white blood cells seek out the heart and attack it
- In order to prevent rejection you take medications called immunosuppressants. These weaken your immune system helping your body to accept your new heart
- You will need to take immunosuppressants for the rest of your life
- Up to half of all heart transplant patients have at least one episode of rejection in the first year
- The highest risk of rejection is during the first 6 months
- You will ALWAYS be at risk for rejecting your heart; however the risk does decrease over time
- If rejection is left untreated your heart will no longer function



# Infection

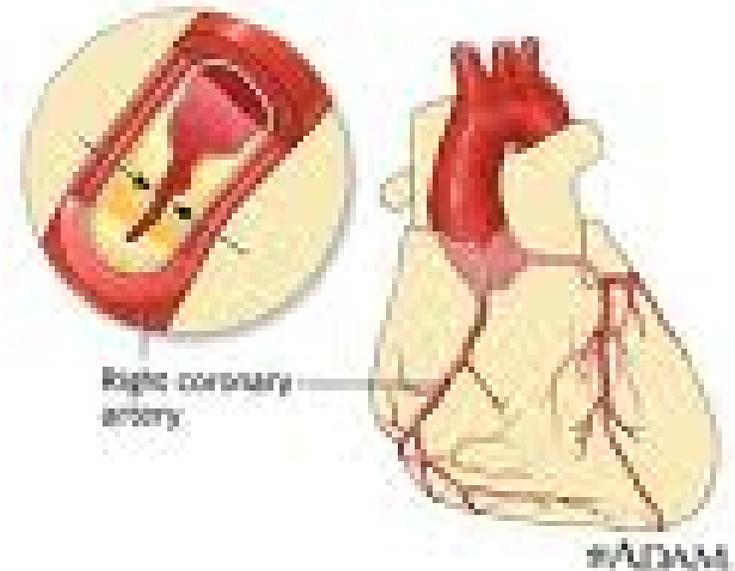
- Since you will take medications to weaken your immune system, you will be more susceptible to infections
- Be aware of symptoms and seeking treatment immediately.
- Hand washing is essential
- Wear your mask for the first 3 months
- Stay away from sick people
- Antibiotics before dental procedures
- Avoid “live” vaccines
- Avoid cleaning up after your pets
- Follow food safety guidelines
- Report all signs and symptoms of infection to the transplant team
- All infections are potentially serious

# Diabetes

- May be a side effect of some of your anti-rejection medication
- Symptoms include increased thirst, urination, confusion and eye problems
- If you have diabetes before transplant, it may be a little more difficult to control after transplant
- Some patients who do not have diabetes before transplant may find that they have diabetes after transplant likely due to medications
- It is important to keep your blood sugars well controlled to decrease risk of infection, improve nutrition and promote heart health

# Coronary Artery Disease

- In transplanted hearts, coronary artery disease (CAD) is not the same as native CAD.
- It is called graft vasculopathy, because it generally involves the entire length of artery starting at the most distal end of the artery and progressive upward. This is known as distal tapering or pruning.
- The only cure is re-transplantation
- Current therapies include a medication called Rapamune or some lesion can be opened with angioplasty.



# Hypertension

- A common complication post transplant is high blood pressure.
- The kidneys are affected by your immunosuppression, so they tell your brain to constrict blood vessels.
- This in turn causes your B/P to elevate. You will most likely be on medication to control your blood pressure

# Caring for you and your new heart



# Home Monitoring

- You will need a scale, upper arm blood pressure cuff and thermometer when you are discharged
- You will chart your weight, blood pressure and temperature daily and report these vital signs to the transplant team frequently
- It is important that you take these measurements at the same time every day
- Make sure when doing your daily weight that you have the same amount of clothes on or no clothes on

# Clinic Follow Up

- As a new transplant patient you will be seen very frequently by the post transplant team
  - Twice a week for the first month (Monday & Thursday)
  - Weekly-biweekly until month 3
  - Monthly until 6 months
  - Every 2 months until one year
  - Every 4 months until year 3
  - Every 6 months until year 5
  - Annually > 5 years
  - At each clinic visit, you will get lab work done including drug levels of your immunosuppressants.

We may ask you to come in for an extra clinic visit if you are not feeling well or we are concerned about your heart function in any way.

# Lab Tests

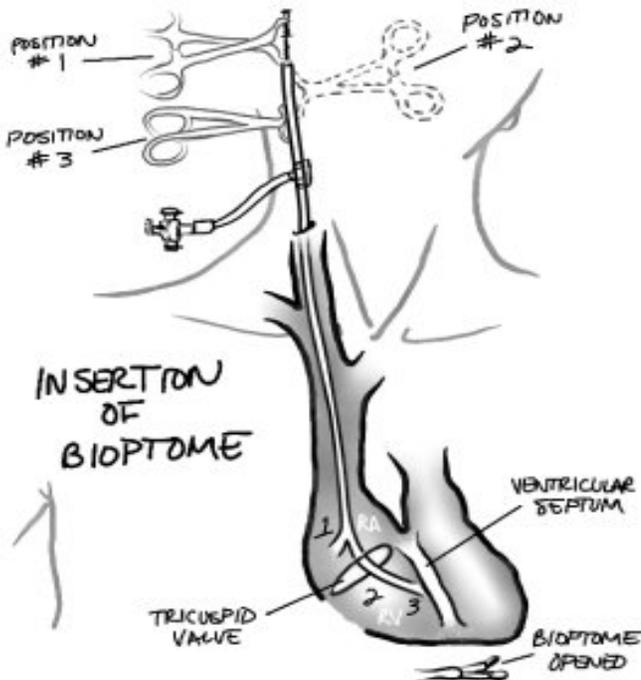
- You will have blood drawn regularly at every clinic visit and when directed by the transplant team
- Lab tests are looking for :
  - White blood cell count which can indicate infection or a side effect of medication
  - How well your kidneys and liver work
  - Your level of immunosuppression
  - How much sugar is in your blood
  - How much cholesterol and lipids are in your blood
  - How thin your blood is

# Echocardiogram and Biopsy Schedule

- As part of your routine screening you will get an echocardiogram and biopsy to ensure your heart is functioning well
  - Every week for 4 weeks (beginning 2 weeks after your transplant)
  - Every 2 weeks until month 3
  - Monthly until month 6
  - Every 2 months until 1 year
  - Every 3-4 months until year 3
  - Every 6 months until year 5
  - Biopsies are typically discontinued after year 5

We may ask you to come in for an echocardiogram and/or biopsy if you are not feeling well or we are concerned about your heart function in any way.

# Heart Biopsy



- You will get a local anesthetic in your neck
  - A long tube (catheter) called bioptome is passed through a small puncture wound in your neck down into your heart
  - A special type of x-ray called fluoroscopy helps guide the catheter to your heart
  - The doctors take 5-6 tiny samples of heart tissue
  - The tissue samples are then sent to the pathology lab to look for rejection
  - Results are usually available within 24-48 hours
- Used to diagnose rejection
  - Performed in the Cath lab and will usually take 30 mins



# Routine Health Care

- It is essential that you have a primary care provider before transplant
  - You will have many other health needs outside of your heart transplant that you will need to see a general internist for including disability issues.
  - You will need to keep up regular health maintenance screenings such as colonoscopy, mammogram, prostate exam, pap smear, skin checks. With immunosuppression, you are more at risk for cancers so screenings are essential
- If you live a long distance from Stanford, it may be in your best interest to have a cardiologist nearer home. We can often communicate with the cardiologist to help guide care
- Dental health is important to avoid infection. Some transplant medications can cause gum problems. Ensure you have regular dental check ups and remember you need antibiotics before any dental work



# MEDICATIONS



# General Points

- You will likely be discharged on 10-15 medications that you will take one or multiple times a day
- Your list of medications will likely decrease the further you are out from transplant
- NEVER stop or change the doses of your medications unless instructed by the transplant team
- Take all your medications exactly as directed
- You will have an individualized regimen
- Your medications will be reviewed at every clinic visit. Make sure you bring an updated list with you
- Do not take any new medications or supplements without the transplant teams approval
- Report any adverse effects of your medications
- Notify the transplant team if there is any reason you are unable to take your medications
  
- **REMEMBER** – transplant medications keep your heart functioning!!

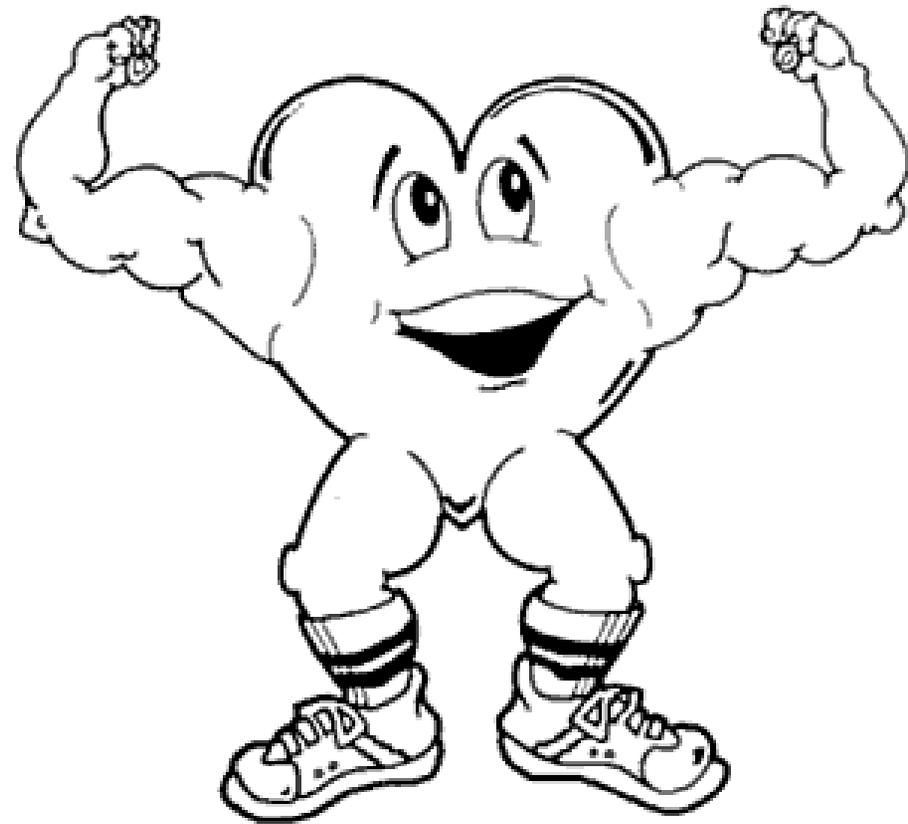
# Immunosuppressants

- Cyclosporine (Gengraf)
  - Side effects: Risk for infection, pungent odor, high blood pressure, worsening kidney function, elevated cholesterol, headache, risk of infection, gum growth
- Prograf
  - Side effects: Risk for infection, high blood pressure, worsening kidney function, diabetes, high blood pressure, tremor
- Mycophenolate (Cellcept)
  - Side effects: Risk for infection, nausea, vomiting, diarrhea, low white blood cell count
- Prednisone
  - Side effects: Risk for infection, high blood sugar, weight gain, weakened bones, skin changes, nausea or vomiting, abdominal pain
  - This medication is usually slowly decreased over your first year after transplant

# Commitment to Health

- Transplant is a gift of life that requires commitment to living healthily
- Take all drugs as prescribed
- Monitor vital signs and weights daily
- Attend all clinic visits
- Regular exercise
- Healthy eating
- Health care maintenance

**The Stanford Heart Transplant team has a lifelong commitment to you to get you through this process by providing information and support.**



# Pictures

\* Please note that some of these pictures are somewhat graphic. Please use your discretion as to whether you choose to view these or not

