



Heart Transplantation

After Transplant Patient Education

DATE: OCTOBER 25, 2022 PRESENTED BY: OHSU CLINICAL TRANSPLANT TEAM

Section 1: Basics

- Contacting the transplant team
- Medication list
- Daily vital signs record log
- Denervated heart
- Immune system overview
- Immunosuppression
- Infection
- Rejection

How To Contact Us

- The transplant office is open:
 - Monday – Friday
 - 8 a.m. - 4:30 p.m.
- Call 503-494-8500 and ask for heart transplant
- After hours, call the hospital operator at 503-494-8311 and ask to page the heart transplant doctor on call
- You can also use MyChart messaging for non-urgent requests



When To Call

- Fever of 100° F or more
- Dizziness or passing out
- Nausea, vomiting or diarrhea
- Other signs of infection (chills, night sweats, tiredness, burns when you pee, drainage from your surgical cut, new body aches, flu-like symptoms)
- When you start a new medication – either prescribed or over the counter
- If you can't keep down medications or you miss a dose

Medication List

- We will give you a list of your medications before you leave the hospital (when you are discharged).

Medication List

ⓘ Reminder: Please bring all of your medications with you to your first follow-up appointment with your provider. Please bring your medication list to every office visit, Emergency Room visit, or hospitalization.

	Morning	Noon	Evening	Bedtime	As Needed
 START					
mycophenolate 500 mg Tab Commonly known as: CELLCEPT Take 3 tablets by mouth two times daily. Take with food. Indications: cardiac transplant rejection prevention Last Hospital Dose: 1,500 mg on September 21, 2022 8:21 AM This medication is very important: It prevents organ rejection.					
 START					
predniSONE 5 mg Tab Commonly known as: DELTASONE Take 7 tablets by mouth once daily. Indications: cardiac transplant rejection prevention Last Hospital Dose: 40 mg on September 21, 2022 8:31 AM This medication is very important: It prevents organ rejection.					

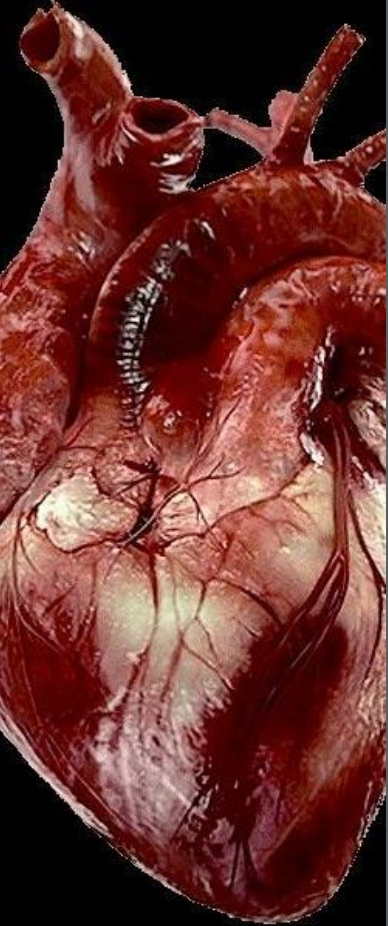


Daily vital signs record log

- We will give you a daily vital signs record log before your leave the hospital (when you are discharged).

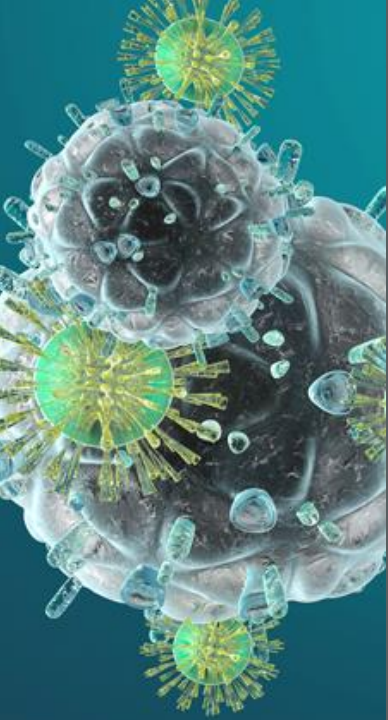
Vital Signs and Blood Sugar Record

Date																
Temperature																
8am																
12pm																
4pm																
9pm																
Blood Pressure																
8am																
12pm																
4pm																
9pm																
Pulse																



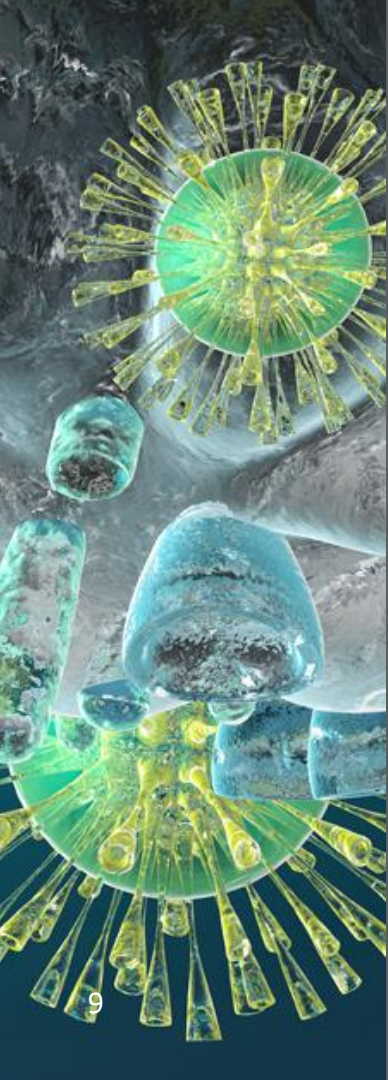
Denervated Heart

- Denervation: your new heart is not connected to your nervous system at the time of transplant
- Due to denervation:
 - Your normal resting heart rate may be faster
 - You must warm up and cool down when you change positions and exercise
 - You may not get “typical” signs of chest pain if you have a heart attack



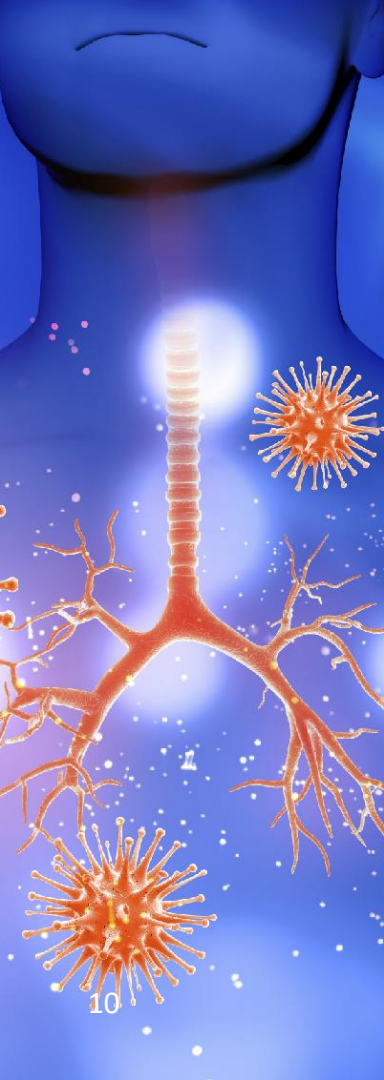
Immune System Overview

- Your immune system is like your own private army that protects you from infection by foreign invaders
- It is made up of cells, tissues and organs
- It protects you from infection from viruses, bacteria or fungi. It also fights cells that could turn into cancer cells



Immune System Overview

- The immune system is very good at recognizing “self” from “non-self”
 - Your immune system would not attack your native organs because they look like they belong to you
 - It would attack a donated organ because your immune system would not know that it belongs to you
 - Rejection happens when your own immune system attacks a donor organ that it does not recognize



Immunosuppression

- Immunosuppression or anti-rejection medications – lower the response of your immune system
- These medications make it harder for your immune system to attack your (new) heart
- Your immune system will never recognize your donor heart as belonging to you
 - You **MUST** take immunosuppressive medications for the **REST OF YOUR LIFE**
- Over time, your risk of rejection becomes less but never none



Immunosuppression

- Immunosuppression medications also lower your body's ability to fight infections
- You will be more at risk of getting infections
- The most common immunosuppression medications:
 - Tacrolimus (Prograf)
 - Mycophenolate (Cellcept)
 - Prednisone



Infection

- The medications you take to keep your immune system from attacking your heart also make you more likely to get infections
- You must balance preventing infection with living your life
- You do not need to live in a bubble, but you will need to take some safety measures
- Focus on prevention



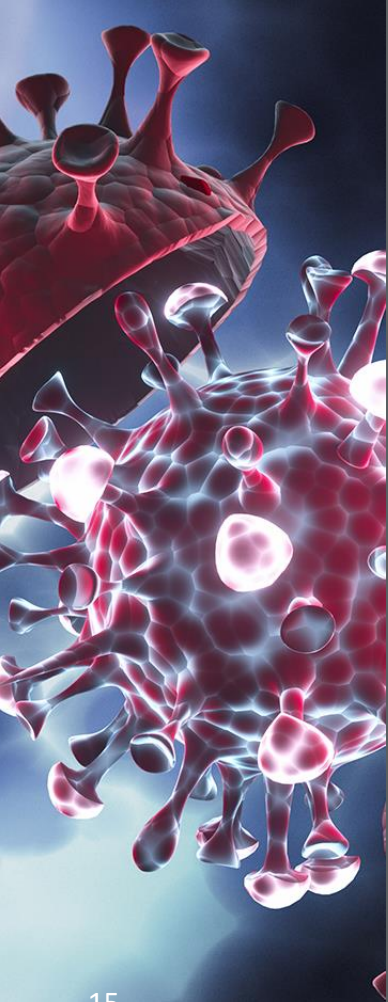
Infection Prevention

- Wash your hands
- Wear a mask:
 - For the first 3 months after transplant
 - Any time your transplant team tells you to
- Avoid sick people
- Avoid crowds
- Avoid busy times for shopping and other activities



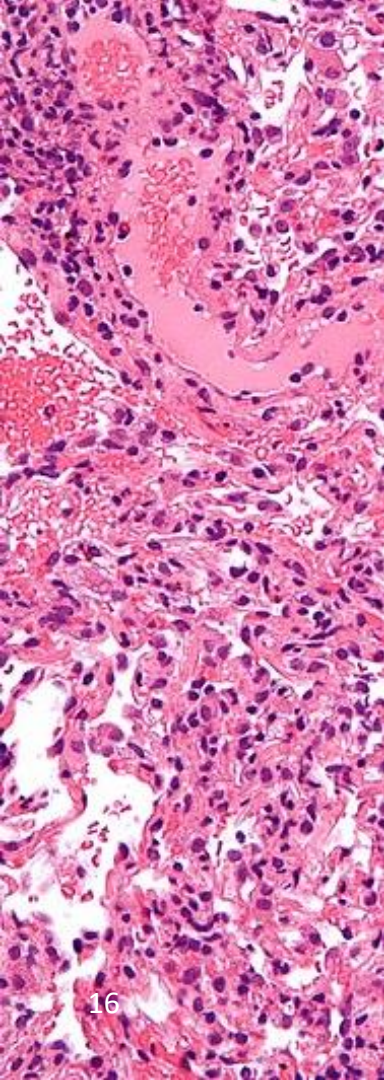
Infection Signs and Symptoms

- Call the transplant team right away if you get:
 - Fever of 100° F or more and/or chills, night sweats and tiredness (fatigue) without fever
 - Diarrhea, nausea, vomiting
 - Burning when you pee
 - Drainage from your surgical cuts or changes in their appearance
 - New body aches
 - Flu-like symptoms



Common Infections: Viral

- You will also be more likely to get viral infections
- The biggest worry is a virus called cytomegalovirus (CMV)
- CMV is common and makes you sick if you are immunosuppressed
- We will give you a medication called valganciclovir for 3-6 months after transplant to help prevent a CMV infection
- We will test your blood when you are done taking valganciclovir to see if you get a CMV infection



Rejection

- Rejection is when your body's immune system attacks the donor heart
- Rejection is a normal process and can happen at any time
- You must take lifelong immunosuppression medications to prevent your immune system from attacking the heart
- Rejection can cause your transplanted organ to fail
- You may have heart failure symptoms if you have rejection or you may have no symptoms at all
- We must monitor your heart regularly for signs of rejection



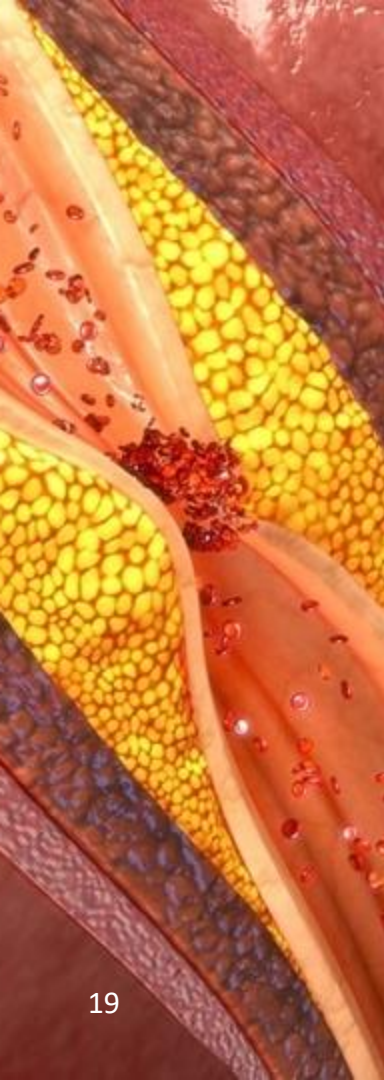
Rejection: Symptoms

- Low grade fever
- Feeling tired, weak or not feeling “quite right”
- Fast or irregular heart rate
- Flu-like symptoms
- Shortness of breath
- Weight gain
- **No symptoms**



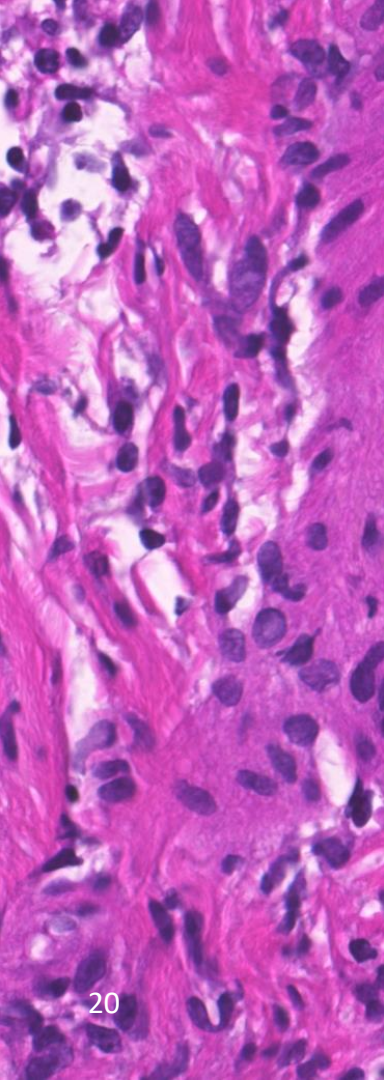
Rejection: Acute

- Acute rejection can happen at any time but is more likely in the first year after transplant
- We monitor you with special blood tests, right heart catheterization and biopsy
- Common reasons for acute rejection
 - Missed immunosuppression doses
 - Low blood levels of immunosuppressive medications
 - Drug interactions
- Acute rejection can happen for no reason. This is why we monitor you so closely.



Rejection: Chronic

- Chronic rejection is when your body's immune system slowly attacks the heart over time
- It causes your heart's blood vessels to narrow. This decreases the blood supply to the heart muscle.
- This can slowly lead to decreased heart function
- Let your transplant team know if you have chest pain or feel more short-of-breath with activity
- We monitor you for chronic rejection with angiograms and/or perfusion echocardiograms



Rejection: AMR

- Your immune system can create antibodies that can attack the donor heart
- These antibodies are in your blood and can cause Antibody Mediated Rejection (AMR)
- We use biopsies and special blood tests to check you for AMR

Section 2: Prevention

- How to prevent rejection
- How we can watch out for rejection
- Clinic and biopsy schedule
- Daily vital signs
- Regular labs
- Medications
- HCV treatment



How to Prevent Rejection

- Take your immunosuppression every day
- Come to all clinic and biopsy appointments
- Get your lab draws on schedule
- Balance between rejection and infection
 - Take enough medication to prevent your immune system from attacking your heart, but try not raise your risk of infections by too much



How to Watch for Rejection

- One way is by doing a heart biopsy
 - We go through a vein in your neck or groin to get to the heart (just like when you have a right heart catheterization)
 - We take a sample of your heart tissue and send it to the lab
 - We get the results in 24-48 hours



Biopsy Results

Result	Meaning
0R	No sign of rejection. You do not need treatment.
1R	1 area of your sample shows signs of your immune system interacting with your heart tissue cells. This is to be expected. You do not need treatment at this time.
2R	2 or more areas of your heart cells are being attacked by your immune system. This is a treatable rejection. We will most likely treat you with a course of prednisone and another biopsy. You may or may not have symptoms.
3R	3+ areas of your heart is being attacked by your immune system. The heart cells are damaged. We will likely admit you to the hospital for intravenous (IV) medications and another biopsy. You likely have symptoms.



Clinic and Biopsy Schedule

- Clinic at OHSU Center for Health and Healing, Building 1 on the South Waterfront campus
 - During visits, we will:
 - Get your weight and vital signs
 - Review your medication list and any new changes
 - Review your vital sign log and clinic schedule
 - Do a physical exam
 - Build a follow-up plan
- Heart biopsies at OHSU's heart catheterization lab on Marquam Hill



Clinic Schedule

- Sample clinic schedule (yours is unique to you)
 - Weekly for the first month
 - Monthly through the first year
 - Every 3 months between years 1 and 2
 - Every 6 months between years 2 and 3
 - Yearly after year 4
 - Labs every 3 months forever
- We will give you a 16-week schedule before you leave the hospital after transplant
- You will start with very frequent clinic follow-up and testing. This will decrease over time.

A close-up photograph of a person's hand holding a silver pen, writing on a white grid-patterned notepad. The background is slightly blurred, showing a blue patterned surface. The lighting is soft and focused on the hand and pen.

What to Bring to Clinic

- Your current medication list
 - You will be given a medication list at the time of discharge from the hospital
 - Medication changes are common after transplant
 - Please keep your medication list up to date with all the medication changes made by your transplant team
 - Do not take any medications other than those on this medication list without consulting a member of the transplant team



What to Bring to Clinic

- Your recent vital sign log
 - Write down your vitals signs in your log 3 times a day
 - You need:
 - An automatic blood pressure cuff that goes on your upper arm. No wrist cuffs – they are not as accurate. The cuff should also take your heart rate
 - A scale to weigh yourself daily
 - A thermometer
 - A glucometer (maybe)



Vital Signs Daily Tracking Log

- Blood pressure
 - Call if greater than _____ or lower than _____
- Heart rate
 - Call if greater than _____ or less than _____
- Temperature
 - Call if 100° F or more (even if you feel OK)
- Blood sugar
 - Call if greater than _____ or less than _____
 - Call Endocrinology with blood sugar issues
- Weight
 - Call if you gain 2-3 pounds in 24 hours
 - Call if you gain 1 pound per day for a week



Regular Transplant Labs

- Immunosuppression drug level (tacrolimus or cyclosporine)
 - Get your labs drawn about 12 hours after your last dose of medication
 - For example: If you take your night medications at 9 p.m., get your blood drawn the next day at 9 a.m.
 - Bring your morning medications with you to the lab. Take them after the blood draw.
- Complete Blood Count (CBC)
- Comprehensive Metabolic Panel (CMP)
- Magnesium
- Tacrolimus Level



Medication Tips

- Know:
 - The names of your medications
 - Why you are taking them
 - When to take them
- Use a pill box
- Set alarms, post reminders and ask your support person to help you remember to take your medications
- Take your pills with food
- Always keep a copy of your medication list with you
- Set your medication schedule to fit with your daily routine



Medication Tips

- Try to use Creekside (OHSU mail order pharmacy)
- Order refills early enough for the pharmacy to process and mail
- Use your phone's alarm clock to remind you to take your medications
- **Do NOT miss doses**



Medications: When To Call

- Call the transplant team if:
 - You are late taking your medications
 - You miss a dose
 - You are unable to take your medications due to nausea, vomiting or diarrhea
 - You have a side effect to the medication
 - You would like to start a new medication (prescribed or over the counter)
 - You have trouble getting refills through your pharmacy

Medications: Tacrolimus

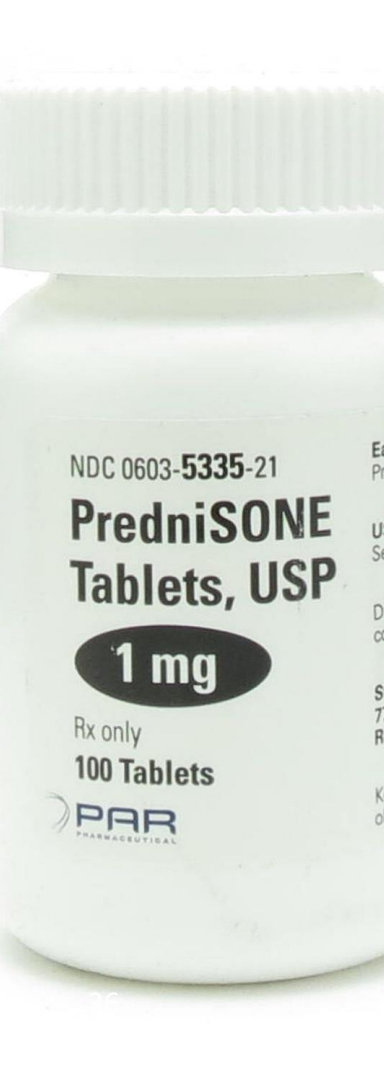
- Generic version of Prograf
- It is an immunosuppressant (anti-rejection) medication
- Take by mouth every 12 hours (or as directed by your transplant team)
- We will check your blood levels and may change your dose if the level is too high or too low
- Possible side effects: headache, tremors, high blood pressure, kidney problems, neuropathy, low magnesium levels



Medications: Mycophenolate

- Generic version of Cellcept or Myfortic
- It is an immunosuppressant (anti-rejection) medication
- Take by mouth every 12 hours
- Possible side effects: diarrhea, nausea, loss of appetite, low white blood cell count





Medications: Prednisone

- A steroid medication
- In transplant, it is used as an immunosuppressant (anti-rejection) medication
- You may only take it for the first 6 months after transplant. Your transplant team will decide.
- Possible side effects: high blood sugar, mood swings, trouble sleeping (insomnia), taking longer for wounds to heal, weight gain, increased appetite, stomach ulcer, bloating (retained fluid), bone loss



Medications: Other

- We will also prescribe other medications to prevent infection and for the overall health of your new heart and body
 - To prevent infections
 - Bactrim
 - Fluconazole
 - Valgancyclovir (Valcyte)
 - For cholesterol and heart health
 - Pravastatin or rosuvastatin
 - Possible side effects: muscle pain
 - For your stomach
 - Famotidine (Pepcid)

Medications: Other

- Blood pressure medications if your blood pressure is high
 - Such as: amlodipine, lisinopril, hydralazine, losartan
- Supplements
 - Take vitamins and minerals spaced 2+ hours between immunosuppression medications (12 p.m. and 5 p.m. are often good times)
 - Take Calcium and Vitamin D for bone health
 - Magnesium
 - Multi-vitamin





Medications to Avoid

- Avoid these over-the-counter medications:
 - ⊗ NSAIDs (non-steroidal anti-inflammatory drugs)
 - They will damage your kidneys
 - Do NOT take ibuprofen, Advil, naproxen
 - ⊗ Phenylephrine or pseudoephedrine
 - Often found in cold medicines
 - ⊗ Herbal products
 - Contact the heart transplant team if you want to take an herbal product
 - They may interact with your immunosuppressants



HCV Treatment

- If your donor was HCV+/NAT+:
 - You will get an HCV infection
 - We will watch for HCV weekly in your blood
 - When we detect HCV, you will start treatment
 - Treatment will last 8-12 weeks
 - We will watch your blood to make sure you are cured



HCV Treatment

- If your donor was HCV+/NAT+:
 - 95% of patients are cured with the first treatment course
 - HCV is transmitted through blood and body fluids
 - To prevent spreading HCV before you are cured:
 - Do NOT share razors or toothbrushes
 - Use condoms
 - Be very careful with wound care and changing bandages
 - Practice safety with needles, such as those used for insulin

Section 3: Healthy Heart

- Nutrition after transplant
- Food safety
- Lifestyle
- Preventive care
- Immunizations
- Sun safety
- Mental health and wellbeing
- Your donor family



Nutrition After Transplant

- You may be less hungry after your heart transplant surgery
- Try to eat small, frequent meals.
- Increase the amount of protein you eat as you heal from surgery
- Keep following a “heart healthy” diet after your transplant – limit salt, fat and sugar
- Try to eat 5+ servings of fruits and vegetables a day
- Increase the amount of fiber in your diet
- Do NOT drink more than 2 liters per day right after transplant
 - You may be able to increase this over time



Nutrition After Transplant

- Do NOT eat these foods that can interfere with your immunosuppression medications
 - ⊗ Grapefruit
 - ⊗ Pomegranate
 - ⊗ Acai berries
- Our dietitian can talk to you about any nutritional concerns you may have



Food Safety

- Your immunosuppressed status puts you at greater risk for getting a food borne illness
- Handle food safely
- Always wash your hands before and after handling food
- Do NOT eat raw or undercooked foods



Food Safety: Dairy

- Drink only pasteurized milk and milk products like cheese and yogurt
- ⊘ Do NOT eat: soft cheeses that are not made with pasteurized milk
- ☑ You can eat: hard cheeses (like parmesan and cheddar), processed cheeses, cream cheese, mozzarella and soft cheeses clearly labeled “made from pasteurized milk”



Food Safety: Eggs and Meat

- Eggs

- ⊗ Do NOT eat raw or undercooked eggs

- ⊗ NO runny egg yolks

- ⊗ NO foods made with uncooked eggs, like Caesar dressing or hollandaise sauce

- ⊗ Do NOT eat raw cookie dough made with eggs

- Meat

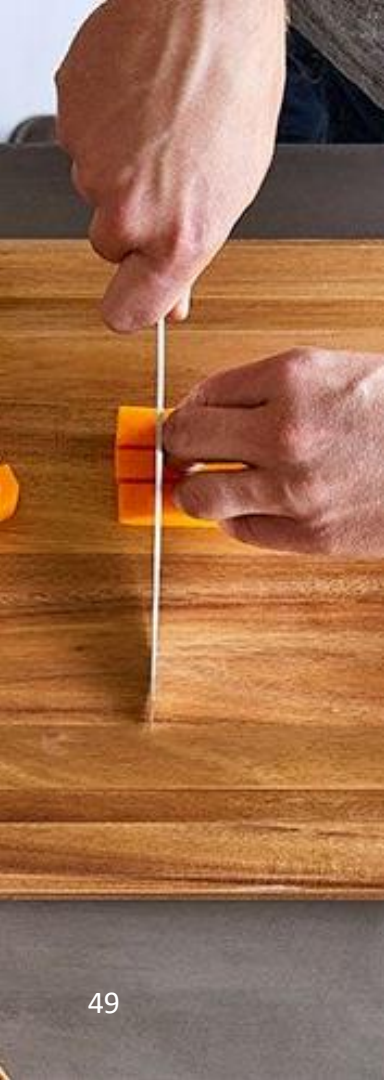
- ⊗ NO raw or undercooked meat or seafood

- Store meat in the bottom of your refrigerator



Food Safety: Other

- Always clean fresh fruits and vegetables well before eating
- ⊘ Avoid unpasteurized juices



Food Safety: Cross-Contamination




- Keep meat and vegetables separate in your grocery cart and in the fridge
- Use a separate cutting board for meats than you do for vegetables
- Keep cooked and raw foods separate
- Keep cold foods cold and hot foods hot
- Avoid buffets and salad bars
- Re-heat leftovers until they are steaming hot
- Clean kitchen surfaces (bleach solution works well)

Food Safety

“Is it *done* yet?”

You can't tell by *looking*. Use a **food thermometer** to be sure.

USDA Recommended Safe Minimum Internal Temperatures

					
Beef, Veal, Lamb Steaks & Roasts	Fish	Pork	Beef, Veal, Lamb Ground	Egg Dishes	Turkey, Chicken & Duck Whole, Pieces & Ground
145 °F	145 °F	160 °F	160 °F	160 °F	165 °F

www.IsItDoneYet.gov

USDA Meat & Poultry Hotline: 1-888-MPHotline (1-888-674-6854)

 United States Department of Agriculture
Food Safety and Inspection Service

USDA is an equal opportunity provider and employer.
Slightly Revised April 2007



Food Safety: 4 Steps to Food Safety

1. Clean	2. Separate	3. Cook	4. Chill
Wash hands for 20 seconds with soap and water before, during and after preparing food. Also before eating.	Use separate cutting boards and plates for produce (fruits and vegetables) than you do for meat, poultry, seafood and eggs	Use a food thermometer	Refrigerate fresh (perishable) foods within 2 hours
Wash utensils, cutting boards and countertops after each use with hot, soapy water	When grocery shopping, keep raw meat, poultry, seafood and their juices away from other foods	Keep food hot after cooking (at 140* F or above)	Never thaw or marinate foods on the counter
Rinse fresh fruits and vegetables under running water. Do NOT rinse meat, poultry or eggs.	Keep raw meat, poultry, seafood and eggs separate from all other foods in the fridge	Microwave food fully (to 165* F)	Know when to throw food out



Lifestyle: Exercise and Work

- Exercise
 - Warm up before and cool down after exercise
 - Talk to your team before starting an exercise program
- Returning to work or school
 - Everyone’s timeline for recovery and going back to work or school will be different
 - Talk with your team about when you will be ready
 - Your transplant doctor will set your timeline for return to work and activities



Lifestyle: Driving and Gardening

- Driving
 - You can usually start driving again 6-8 weeks after transplant
 - You must be off pain medication before you start driving again
- Gardening
 - Do NOT garden for 6 months after transplant
 - Avoid compost piles and wet leaf piles
 - Wear gloves when you work in the soil
 - Wear a mask if you will be around dirt being blown into the air
 - Wash your hands after gardening



Lifestyle: Animals and Pets

- Wash your hands after petting or playing with your pet
- Try to keep your pet from biting or scratching you
- Do NOT let your pet lick your face or mouth
- Avoid cleaning litter boxes or picking up animal waste
 - If this is not avoidable: wear gloves, wear a mask and wash your hands well after
 - Have someone clean the litter box daily and change the litter often



Lifestyle: Animals and Pets

- Do NOT have contact with these pets after transplant since they can spread disease
 - Caged birds
 - Reptiles and amphibians
 - Baby chicks and ducklings
 - Hamsters and guinea pigs



Lifestyle: Swimming

- 3 months after transplant – you may swim in a chlorinated pool if your wounds are healed
- 6 months after transplant – you may swim in the ocean, large lakes and rivers
- Do NOT swim in ponds or small lakes
- Check to see if there is any contamination before you go (algae or bacteria warnings)
- Do NOT use public hot tubs
- Always wear sunscreen



Lifestyle: Travel

- Do NOT fly for 6 months after transplant
- Clean your tray table and seat on an airplane
- You may be able to travel outside the U.S. after 1 year
- Wear an N95 mask when traveling and in crowded spaces
- Discuss any travel plans with your transplant team. Tell them if you will travel to an area without transplant services.
- Check the CDC web site to see if there are any outbreaks in the area you will be visiting
- Go to a travel clinic if you need any vaccines. NO live vaccines



Lifestyle: Drinking Water

- Tips to avoid waterborne illness
 - Test well water every year for cryptosporidium, giardia and coliform bacteria
 - City tap water is treated for cryptosporidium. Pay close attention to “boil water” recommendations from your local government.
 - If you are unsure about a water source, bring it to a rolling boil for 1 full minute before drinking



Lifestyle: Drinking Water

- Do NOT drink water directly from lakes or rivers
- Try NOT to swallow water while swimming in lakes, rivers or pools
- Do NOT drink tap water while visiting countries with poor sanitation. This includes ice cubes and accidentally swallowing water during showers.



Lifestyle: Sexual Activity

- Sexual desire sometimes goes down with chronic illness
- Your sexual desire may return after your transplant
- Listen to your body when deciding when to have sex after transplant
- Wait 6-8 weeks after your heart transplant before you have sex. This is when you are off sternal precautions.
- Talk to your transplant team about any concerns you may have about sexual activity



Lifestyle: Family Planning

- We do not recommend that women get pregnant after heart transplant
- Mycophenolate (one of your immunosuppression medications) can harm the fetus. It is a class D medication for pregnancy and breast feeding – meaning studies show signs of harm.
- Other pregnancy complications: high blood pressure, severe nausea and vomiting (hyperemesis gravidum), blood clots, increased risk for rejection



Lifestyle: Family Planning

- Men can have decreased sperm production and sperm abnormalities after transplant. This can cause birth defects.
- Talk to your transplant team about family planning before pregnancy



Preventive Care

- General care
 - You need a local primary care provider (PCP) to manage chronic conditions (diabetes), spreadable illness (cold or flu) and immunizations
- Eye care
 - 6 months after transplant – start yearly eye exams
 - Prednisone can cause blurred vision. Do NOT change your vision prescription until you are on low dose Prednisone
 - Call your PCP or eye doctor if you have any changes in vision, eye pain, sensitivity to light, dark spots in your vision or other eye concerns



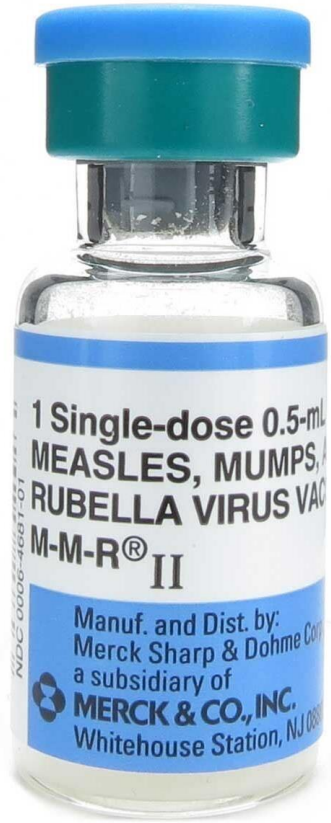
Preventive Care

- Dental care
 - Prevent dental disease by:
 - Brushing 2+ times a day
 - Flossing 1+ times a day
 - Cleaning dentures after every meal
 - Seeing your dentist every 6 months
 - Take antibiotics (amoxicillin or clindamycin) 1 hour before any dental work or cleaning
 - Wait 6 months after transplant before any dental procedures



Preventive Care

- Skin care
 - See a dermatologist 1+ times a year
- Prostate care
 - Get recommended screens for prostate cancer
 - Your PCP may recommend a blood test for prostate cancer screening
- Digestive health
 - Get recommended coloscopy screens for colon cancer (generally ages 45+ and/or those with personal or family history of colon cancer)



Preventive Care

- Vaccines

- ⊘ Do NOT get any vaccine that is classified as LIVE
 - Always make sure caregivers know you are a transplant recipient and cannot get LIVE vaccines
- ⊘ Common LIVE vaccines: oral polio, measles, mumps, rubella, yellow fever, smallpox, inhaled flu vaccine, and shingles (Zostavax)
 - It is best to wait 3+ months after heart transplant before getting a vaccine



Preventive Care

- Vaccines you should get:
 - Yearly flu shot for you and your family
 - Pneumonia vaccine
 - COVID-19 vaccine
 - Immunizations needed before travel
 - Talk to your transplant team, infectious disease doctor or travel clinic for recommendations



Preventive Care: Sun

- Immunosuppression medications increase your risk of cancer, mainly skin cancer
- Be safe to avoid skin cancer:
 - Wear sunscreen of 30+ SPF every day and reapply often
 - Wear sunglasses, broad brimmed hat, long sleeved shirt and long pants when you are outside
 - Stay in the shade when you can
 - Try NOT to go outside 10 a.m. – 4 p.m., when the sun's rays are strongest



Preventive Care: Sun

- See a skin doctor (dermatologist) every year for a skin check
- Do NOT use tanning booths
- We may need to lower your immunosuppression if you get skin cancer
 - This may increase your risk of rejection



Preventive Care

- Mental health and wellbeing
 - The transplant journey is an emotional process
 - Everyone feels this differently
 - Some may feel anger, frustration, guilt and depression after transplant. This is normal.
 - Side effects of medications (mainly prednisone) can increase feelings of emotional distress
 - Talk to your transplant team and loved ones if you are struggling with your emotions
 - We have a social worker who can help guide you



Your Donor Family

- A donor family's privacy should be respected.
 - Do NOT try to find out about the donor
 - Do NOT contact the family outside of proper channels
- You CAN write to your donor family
 - It is a way to show thanks for the gift of life you received
 - Many find comfort in acknowledging this gift
 - The act of writing can help you process the transplant journey and the many complex emotions with it
 - Your transplant social worker will guide you and manage this process once you are ready
 - All communication is anonymous, unless both parties agree to share contact information



Your Donor Family

- Guidelines for writing your donor letter
 - Show sympathy for the loss of their loved one
 - Include your first name, job and hobbies
 - Include family information (support people, children, grandchildren, pets)
 - Tell them how the transplant impacted your life
 - Include a photo of yourself or family members
 - Do NOT include any contact information in your letter
- You can give your letter to the transplant social worker in clinic or mail it to the clinic



Thank You