

# Heart Transplantation: A Guide for Patients and Caregivers

Brought to you by your Heart Transplant Team



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### **Contacting the Transplant Team**

- Transplant office is open Monday-Friday from 8:00 am to 4:30 pm
- If you are having a scheduling issue or need to contact your outpatient transplant coordinator, please call (503) 216-1182, option #1

#### **Transplant Nurse On-call**

- There is a transplant nurse on-call
  - 24 hours per day
  - 7 days per week
  - 365 days per year
- If you are calling for an urgent problem during after hours or a holiday, call 503-216-1182, option 1. This will route you to the answering service, ask for the Transplant Coordinator on-call

### When to call the heart transplant team:

- Fever of 100° F or more
- When your medications are getting low
- You have signs of infection
- Dizzy or passing out
- Nausea, vomiting, or diarrhea
- When starting a new prescribed or over the counter medication
- Unable to keep down medications
- Missed medications

### **Medication List**

### Example

**Directions for Taking Your Medication** 

DRUG	Strength	Function	DIRECTIONS	Breakfast 6:00-9:00	Lunch 11:00-1:00	Dinner 4:00-6:00	Bedtime 8:00-9:00	COMMENTS
Acetaminophen (Tylenol)	500 mg	For pain	Take 1 tablet every 6 hours as needed					Do NOT take more than 3000 mg in any 24 hour period
Amlodipine	5 mg	For blood pressure	Take 1 tablet every day					
Calcium carbonate	500 mg	Calcium supplement	Take 2 tablets by mouth every night					
Cholecalciferol	1000 units	Vitamin D supplement	Take 2 tablets every day					
Docusate	100 mg	Stool softener	Take 1 tablet twice a day as needed					As needed
Famotidine (Pepcid)	20 mg	For stomach upset	Take 1 tablet twice a day					
Insulin Glargine	100 units/mL	For elevated blood sugar	Inject units under the skin with breakfast					
Insulin lispro	100 units/mL	For elevated blood sugar	Inject units under the skin three times daily with meals					See directions for sliding scale
Magnesium oxide	400 mg	Supplement	Take 2 tablets every day					Separate from immunosuppression by 2-4 hours
Multivitamin	Tablet	Supplement	Take 1 tablet every day					
Mycophenolate (Cellcept)	500 mg	To prevent rejection	Take 3 tablets twice a day					Take at 9AM and 9PM
Nystatin suspension	100,000 units/mL	To prevent thrush	Swish and swallow 5mL by mouth four times a day					For 3 months
Pravastatin	20 mg	Heart protection	Take 1 tablet every night at bedtime					
Prednisone	5 mg	To prevent rejection	Take tablets every morning					
Senna	8.6 mg	For constipation	Take 1 tablet twice a day as needed for constipation					
Sulfamethoxazole/ Trimethoprim (Bactrim)	400-80 mg	To prevent infection	Take one tablet every morning					For months
Tacrolimus (Prograf)	1 mg capsules	To prevent rejection	Take capsules in the morning and capsules in the evening					Take at 9AM and 9PM
Valganciclovir	450 mg	To prevent infection	Take 2 tablets by mouth every day					For months

### **Daily Record**

### **Vital Signs Log**

			Ten	nperatu	ıre: Call wit	h temp of	or great	er			
D	ate										
	AM										
12	2 PM										
4	PM										
8	PM										
		Bloc	d Press	ure: Cal	ll with BP le	ess than	or greater	than		<u> </u>	
8	AM										
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8	AM		<u> </u>	leart Ra	ate: Call wi	:h HR >	or <				
12	2 PM										
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12	2 PM										
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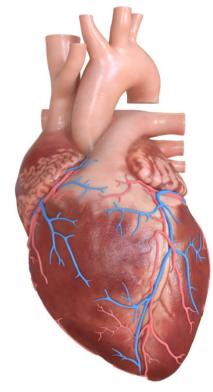
If you have symptoms of low blood sugar (feeling shaky, nervous or anxious, sweating, chills, clamminess, irritability, confusion, fast heartbeat, lightheaded or dizzy) call provider

### **Denervated Heart**

The transplanted heart is not connected to the nervous system at the time of transplant. This is also known as "denervation".

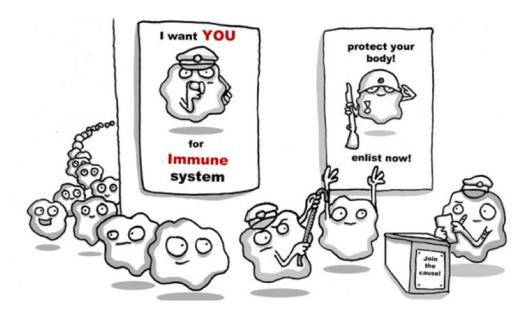
It's important to remember the following when you have a heart transplant due to the effects of denervation:

- Your normal resting heart rate may be faster
- You must warm up and cool down with exercise because you lack the immediate feedback from the central nervous system to tell your heart rate to speed up or slow down
- You may not experience "typical" signs of chest pain if you have a heart attack
- Take your time when going from sitting to standing and when getting out of bed first thing in the morning
- You will be set-up for cardiac rehab when your transplant team feels you are ready



### **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. The immune system protects you against infection from viruses, bacteria, or fungi. It also fights cells that could turn into cancer cells.



The immune system is very good at recognizing "self" from "non-self". For instance, your immune system would not attack your pancreas or lungs, because these organs look like they belong to you. It would, however, attack an organ that was donated to you from someone else because your immune system would not recognize that organ as belonging to you.

The immune system thinks the donated organ, in this case your heart, is something that could make you sick. This may lead the immune system to attack the donor organ. This is called REJECTION.

### **Immunosuppression**

Medications called immunosuppression or anti-rejection medications, are given to you to decrease the response of the immune system. These medications reduce the ability of the immune system to attack your heart.

Your immune system will never recognize your donor heart as belonging to you. Therefore, you have to take immunosuppression medications for the rest of your life. Over time, your risk of rejection becomes less but never completely goes away.

Immunosuppression medications also decrease your body's ability to fight infections. You will be more at risk of getting infections.

The most common immunosuppression medications are tacrolimus (Prograf), mycophenolate (Cellcept), and prednisone.



Tacrolimus (Prograf)



Mycophenolate (Cellcept)



Prednisone

Medication images may differ depending on the manufacturer.

### Infection

The medications you take to prevent your immune system from attacking your heart also make you more likely to get infections.

It is important to balance infection prevention with living your life. You do not need to live in a bubble but you will need to take certain precautions.

Special focus should be paid to prevention. These measures can include:

- Hand washing
- Wearing a mask for the first three months after transplant and any time a mask is recommended by the transplant team
- Avoid sick contacts
- Avoid crowds
- Avoid peak times for shopping and other activities

You should also be aware of signs of infections and report these to your transplant team right away:

- Fever of 100° F or more
- Diarrhea, nausea, vomiting
- Burning with urination
- Drainage from wounds or changes in appearance
- New onset body aches
- "Flu-like" symptoms

Fever can be the first sign your body is fighting an infection. It is important to notify your transplant team if you have a fever of 100° F or more. You might also have chills, night sweats, or general fatigue with or without a fever. Please let your transplant team know if you have any of these symptoms as they could indicate an infection and should be addressed right away.

### Infection

### **Common Infections after Transplant**

There are some common infections you may get after transplant. These include bacterial, fungal, and viral.

#### **Bacterial**

Bacterial infections can occur right after surgery. You will be given a medication called Bactrim for 3-6 months after your transplant to help prevent bacterial infections. In some circumstances you may be on Bactrim for life.

#### **Fungal**

You can also develop fungal infections after your heart transplant surgery. You can have a fungal infection in your mouth or throat, this is called thrush. You will be given a medication called nystatin for 3-6 months after your heart transplant to help prevent fungal infections.

#### Viral

You will also be at greater risk for developing viral infections. We are particularly concerned with a virus called cytomegalovirus (or CMV) after heart transplant. This is a common virus in the community and can make you sick if you are immunosuppressed. You will be given a medication called valganciclovir for 3-6 months after transplant to help prevent a CMV infection. We will test your blood to see if you develop a CMV infection once you complete the course of valganciclovir.

### Rejection

### What is Rejection?

Rejection occurs when the body's immune system attacks the donor heart. Rejection is a normal process and can occur at any time during your life. 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. It is important that we monitor your heart routinely to make sure you are not having rejection.

### Symptoms of Rejection:

- Low grade fever
- Feeling tired or weak or not feeling "quite right"
- Rapid or irregular heart rate
- Flu-like symptoms
- Shortness of breath
- Weight gain
- Fatigue
- No symptoms

### Rejection

### **Different Types of Rejection**

### **Acute Rejection**

Acute rejection can occur at any time but is more likely to happen in the first year after transplant. We monitor you with special blood tests and Right heart catheterization and biopsy. Common reasons for acute rejection include:

- Missed Immunosuppression doses
- Low blood levels of immunosuppressive medications
- Drug interactions

Sometimes, acute rejection can occur for no reasons which is why you are monitored so closely

### **Chronic Rejection**

Chronic rejection occurs when the body's immune system slowly and continuously attacks the heart over time. This type of rejection affects the blood vessels of the heart. Over many years, this can cause the blood vessels to narrow, which decreases the blood supply to the heart muscle. This can gradually lead to a decrease in heart function.

You should 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 an angiogram, which will show if there is any narrowing of the blood vessels that supply the heart. We also monitor for this with a Dobutamine Stress Echocardiogram, which can give us information about whether your heart is getting enough blood flow.

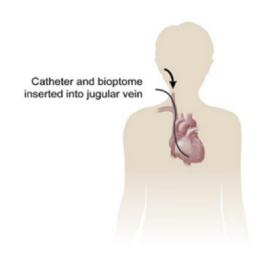
### **Antibody Mediated Rejection (AMR)**

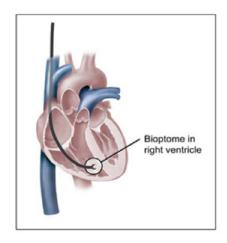
Your immune system can create antibodies that can attack the donor heart. These antibodies circulate through your blood and can cause Antibody Mediated Rejection. We monitor you for AMR with biopsies and with special blood tests.

### **Rejection Monitoring**

One way we can monitor your heart for rejection is by doing a heart biopsy. This is a procedure that is done in the catheterization lab at the hospital. A cardiologist accesses your heart through a vein in your neck or groin. The same approach is used when you have a right heart catheterization. The cardiologist uses a special tool called a bioptome to take a sample of your heart tissue. The heart tissue sample is sent to the pathology lab and a pathologist looks at it under a microscope to see if there is any evidence rejection. It can take 24-48 hours before we have the results of the biopsy. One of the coordinators will call you with your biopsy results and any medication changes.

There are also blood tests that may be used to monitor you for rejection. These tests are not used until at least 6 months after transplant or when you are off prednisone. This test is not used for everyone. Your heart transplant doctor will decide if this is a good option for you. Additionally, you will





have routine ultrasounds of your heart, or **echocardiograms**, to monitor you for rejection. Changes seen on the echocardiogram, such as decreased heart function, may lead the doctor to worry that you have rejection.

It is important to monitor your new heart for rejection. If rejection is found through monitoring, the transplant team will outline the best treatment plan for you.

### **Rejection Monitoring**

### **Biopsy Results**

The transplant team will notify you of your results and if treatment is needed will explain the next step.

ØR	A biopsy result of ØR means that there is no evidence of rejection on your heart tissue sample. No treatment is needed. Your prednisone may be decreased with a negative biopsy result.
1R	A biopsy result of 1R means that there is one area of your heart sample that shows evidence of your immune system interacting with your heart tissue cells. Generally, no treatment is needed.  This is an expected finding.
2R	A biopsy result of 2R means that there is more than one area of your immune system attacking your heart cells. This is considered "treatable" rejection. You will likely be treated with a course of prednisone, known as a "prednisone pulse" as an outpatient. You may or may not have symptoms with this level of rejection. A repeat biopsy is done after you complete the prednisone pulse to make sure the rejection has been cleared.
3R	A biopsy result of 3R means there are multiple areas of the immune system attacking the heart cells with damage to the cells. You will likely have symptoms with this level of rejection. You will be admitted to the hospital and given intravenous (IV) medications to treat this rejection. A repeat biopsy will be done once the treatment is completed to make sure the rejection is cleared.

### **Rejection Prevention**

- Take your immunosuppression consistently every day
- Come to your clinic and biopsy appointments
- Have your labs drawn

The goal of immunosuppression is to balance between rejection and infection. You must take enough to prevent your immune system from attacking your heart while minimizing your risk of developing infections.

#### **Transplant Medications**



### Clinic and Biopsy Schedule

You will see your heart transplant team in the **Mother Joseph Plaza suite 599**. A caregiver will get your weight and vital signs. You will then see a heart transplant coordinator who will review your medication list, any recent medication changes, review your vital sign log and clinic schedule. They will also review how you are feeling. You will then see your transplant cardiologist who will do a physical examination, review all of your medications and testing and make a plan for follow up.

If you are having any incision or wound concerns, the transplant surgeon will also visit with you.

You will have your heart biopsy done at **Providence St. Vincent Medical Center** heart catheterization lab. Someone will call you before your procedure to review any medication holds and preparation instructions that are necessary.

#### **Clinic Visits**

- Weekly for the first month
- Monthly through the first year
- Every three months between years 1 and 2
- Every six months between years 2 and 3
- Yearly after year 4
- Labs every 3 months forever

You will receive a 12 week schedule when you are discharged from the hospital.

At the beginning you will have very frequent clinic follow-up and testing. The further you get out from your transplant date the less often you will see the team.

### Clinic and Biopsy Schedule

### What to bring to clinic

#### **Transplant binder**

 Your transplant binder will include your medication list, your vital signs log, education materials, and contact information of the transplant team.

#### **Medication list**

- You will be given a medication list at the time of discharge after your heart transplant
- 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

### Vital sign log

- Record your vital signs four times a day and record the readings in your binder
- You will need an automatic blood pressure cuff that goes on your upper arm (wrist cuffs are not as accurate)
- Your blood pressure cuff should also take your heart rate
- You will need a scale to weigh yourself daily
- You will need a thermometer
- You may need a glucometer

#### Pill box

- Using a pill box will help you take your medications consistently
- We will help you organize a pill box at the time of your discharge after your heart transplant surgery
- Bring your pill box to clinic along with all of your pill bottles.
   If there are medication changes we will be able to assist you in clinic

### Manual Pulse Check

It is important to know how to check your pulse manually in case your heart rate feels very fast or irregular. Your blood pressure cuff may not pick up on these changes. You can check your carotid pulse in your neck or radial pulse on your wrist.

- To check your carotid pulse: place your first two fingers on your neck to the side of your windpipe.
- To check your radial pulse: place your first two fingers on the thumb side of your wrist.

Count your pulse, or heart rate, for one full minute. Note any irregular or missed beats.



### **Vital Sign Daily Monitoring**

## Complete your daily health checks utilizing vital signs tracking record

•	<b>Blood pressure:</b> Call if blood pressure is
	greater than
	or lower than

- Heart rate: Call if heart rate is greater than\_\_\_\_\_
   or less than\_\_\_\_\_
- Temperature: Call with temperature of 100 degrees Fahrenheit or more (even if you feel ok).
- Blood sugar: Call with blood sugar greater than\_\_\_\_\_
   or less than
- Weight (once per day): Call with 2-3 pound weight gain in 24 hours or steady weight gain (1 pound per day for a week)

### **Routine Transplant Labs**

#### **Routine Transplant Labs**

- Immunosuppression drug level (tacrolimus or cyclosporine)
- Compete Blood Count (CBC)
- Comprehensive Metabolic Panel (CMP)
- Magnesium Level
- Cytomegalovirus (CMV)

#### Immunosuppression drug level:

- Tacrolimus or cyclosporine
  - Tacrolimus or cyclosporine
  - 12 hour blood draw
  - Have your labs drawn about 12 hours after your last dose of medication
  - If you take your night time medications at 9 PM, then have your blood drawn the next day at 9 AM



#### **Medication Tips:**

- Know the names of your medications
- Know why you are taking your medications
- Know when to take your medications
- Use a pill box
- Set an alarm to help you remember to take your medications
- Take your pills with food
- Always keep a copy of your medication list with you
- Organize your medication schedule to fit with your daily routine

#### Call the transplant team

- If you are late taking your medications or if you miss a dose
- If you are unable to take your medications due to nausea, vomiting, or diarrhea
- If you run out of medications
- If you are having a side effect to the medication
- If you would like to start a new medication (prescribed or over the counter)



There are several medications you will take to prevent your body from rejecting your new heart. These are called immunosuppressants.

#### Immunosuppressant (anti-rejection) medications

- Tacrolimus (Prograf)
  - Taken 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
  - Side effects: headache, tremors, high blood pressure, kidney dysfunction, neuropathy, low magnesium
- Mycophenolate (Cellcept or Myfortic)
  - Taken by mouth every 12 hours
  - Side effects: diarrhea, nausea, loss of appetite, low white blood cell count
- Prednisone
  - This is a steroid medication
  - Some patients will only take this medication for the first six months after transplant. This will be decided by your transplant team (NEVER STOP TAKING UNLESS DIRECTED BY YOUR TRANSPLANT TEAM)
  - Side effects: high blood sugar, mood swings, insomnia, delayed wound healing, weight gain, increased appetite, stomach ulcer, retained fluid, bone loss



#### Alternative immunosuppression medications

- Sometimes your heart transplant cardiologist may change your immunosuppression medications if you are having side effects or based on the results of your biopsy
- Alternative immunosuppressant medications may include:
  - Cyclosporine
  - Sirolimus
  - Everolimus
  - Azathioprine

In addition to immunosuppressant medications, you will also be prescribed other medications to prevent infection and for the overall health of your new heart and body

- Medications to prevent infections
  - Bactrim
  - Nystatin or clotrimazole
  - Valgancyclovir (Valcyte)
- Cholesterol medications for heart health
  - Pravastatin or rosuvastatin
  - Side effects: muscle pain
- Medications for your stomach
  - Famotidine (Pepcid)

- Blood pressure medications are sometimes added if your blood pressure is high
  - Amlodipine
  - Lisinopril
  - Hydralazine
  - Losartan
- Other Supplements (Vitamins and minerals should be separated from immunosuppression medications by 2 hours.
   We recommend taking vitamins and minerals at 12 pm and 5 pm.)
  - Calcium for bone health
  - Vitamin D for bone health
  - Magnesium supplement
  - Multi-vitamin
- Over the counter medications (OTC)
  - Avoid taking NSAIDs (non-steroidal anti-inflammatory drugs)
    - Ibuprofen, naproxen
  - Avoid phenylephrine or pseudoephedrine
    - Frequently found in cold medicine
  - Avoid herbal products
    - Contact the heart transplant team if you want to take an herbal product
    - Herbal products may interact with your immunosuppressant medications

# HCV Treatment (If you received an HCV+/NAT+ Donor)

HCV+/NAT+ Donors are donors that had active Hepatitis C (HCV) discovered in their blood during the infectious disease screening process. Prior to 2017, organs from these donors would not have been transplanted. In 2017, advances in the treatment and cure of HCV have led to HCV+/NAT+ donors being utilized for transplant recipients.

Important points to remember if your donor was HCV+/NAT+:

- You will develop HCV infection
- We will monitor your blood weekly for development of HCV
- When HCV is detected, we will start treatment
- Treatment will last for 8-12 weeks
- We will monitor your blood to make sure you are cured
- 95% of patients will be cured with the first treatment course
- We partner with the Pharmacotherapy clinic to treat your HCV
- HCV is transmitted through blood and body fluids
- To prevent transmission of HCV before you are cured:
  - Avoid sharing razors or toothbrushes
  - Use barrier protection with sex
  - Universal precautions with dressing changes or wound care
  - Safety with needles used for insulin or other medications

### **Nutrition After Transplant**

You may have a decreased appetite after your heart transplant surgery. Try to eat small, frequent meals and increase your protein intake as you are healing from surgery. You should continue to adhere to a "heart healthy" diet after your heart transplant. Limit salt, fat, and sugar in your diet. Try to eat at least 5 servings of fruits and vegetables daily and increase your dietary intake of fiber. Limit your fluid intake to 2 liters per day immediately after your heart transplant. You may be able to increase your fluid intake over time. There are certain foods that can interfere with your immunosuppression medications, such as grapefruit, pomegranate, and acai berries. You should avoid eating these foods. A dietitian is available to you to discuss and nutritional concerns you may have.



### **Food Safety**

Safe food handling is especially important after a heart transplant because your immunosuppressed status puts you at greater risk for developing a food borne illness. Always wash your hands before and after handling food. Avoid raw or undercooked foods.



#### Dairy:

- Drink only pasteurized milk and milk products including cheese and yogurt
- Some soft cheeses are not made with pasteurized milk and should be avoided
- Hard cheeses, such as parmesan and cheddar, processed cheeses, cream cheese, mozzarella and soft cheeses clearly labeled "made from pasteurized milk" are ok to eat

#### Fruits, Vegetables and Nuts:

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



### **Food Safety**

#### **Poultry and Meats:**

• Eggs: avoid raw or undercooked eggs

(no runny egg yolks or foods made with uncooked eggs like Caesar dressing or hollandaise sauce)

- Avoid raw or undercooked meats and seafood
- Hot dogs should be thoroughly heated
- Store meat in the bottom of your fridge



#### Avoid cross-contamination

- Keep meat and vegetables separate in your grocery cart and in the fridge
- Use a separate cutting board for meats and vegetables
- Keep cooked and raw foods separate
- Keep cold foods cold and hot foods hot
- Avoid buffets and salad bars
- Leftovers should be re-heated to steaming hot
- Clean kitchen surfaces (bleach solution works well)

### **Food Safety**

### Four Steps to Food Safety





Wash hands for 20 seconds with soap and water before, during and after preparing food and before eating.

Wash utensils, cutting boards and countertops after each use with hot, soapy water.

Rinse fresh fruits and vegetables under running water — but not meat, poultry or eggs.

#### **SEPARATE**



Use separate cutting boards and plates for produce and for meat, poultry, seafood and eggs.

When grocery shopping, keep raw meat, poultry, seafood and their juices away from other foods.

Keep raw meat, poultry, seafood and eggs separate from all other foods in the fridge.



Use a food thermometer.

Keep food hot after cooking (at 140°F or above).

Microwave food thoroughly (to 165°F).



Refrigerate perishable foods within two hours.

Never thaw or marinate foods on the counter.

Know when to throw food out.

#### **Additional Resources:**

Food Safety and Inspection Service <a href="https://www.fsis.usda.gov">https://www.fsis.usda.gov</a>

#### Foodsafety.gov

Academy of Nutrition and Dietetics <a href="https://www.eatright.org/homefoodsafety">https://www.eatright.org/homefoodsafety</a>

Sign up for important FDA news and information, especially food recalls <a href="https://www.fda.gov/about-fda/contact-fda/get-email-updates">https://www.fda.gov/about-fda/contact-fda/get-email-updates</a>

#### **Exercise**

- Warm up before and cool down after exercise
- Participate in a cardiac rehabilitation program
- 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 physician will determine the timeline for return to work and activities
- The timeline varies for each recipient

### **Driving**

- You can usually start driving again 6-8 weeks after transplant
- You must be off pain medication before you start driving again





#### **Animal Contact and Pet Safety**

- Wash your hands after petting or playing with your pet
- Try to prevent 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 and mask, and wash your hands well afterwards
  - Clean the litter box daily and change the litter frequently
- Some pets should be avoided after transplant due to the spread of disease
  - Caged birds
  - Reptiles and amphibians
  - Baby chicks and ducklings
  - Hamsters and guinea pigs
  - Exotic pets, such as monkeys and ferrets, or wild animals like raccoons

#### Gardening

- Avoid gardening for 6 months after transplant
- Avoid compost piles or wet leaf piles
- Wear gloves when working in the soil
- Wear a mask if you think you will exposed to dirt being blown into the air
- Wash your hands after gardening



#### **Swimming**

- May swim in chlorinated pool after 3 months, if your wounds are healed
- May swim in the ocean, large lakes, or rivers after 6 months
- Avoid swimming in ponds or small lake
- Check to see if there is any contamination before you go (i.e. algae or bacteria warnings)
- Avoid hot tubs



#### **Travel**

- Avoid air travel for 6 months after transplant
  - Clean your tray table and your seat on the airplane
- International travel may be ok after one year
  - Discuss any travel plans with your transplant physician, especially if traveling to an area that does not offer transplant services
  - Check the CDC web site to see if there are any outbreaks in the area you will be visiting
  - Go to the travel clinic if you need any immunizations or vaccines; no no live vaccines

#### Smoking and recreational drug use

- Smoking is bad for your new heart
  - If you required smoking cessation support during your pre-transplant journey, we highly recommend you continue
  - Constricts blood vessels and decreases the availability of oxygen to the new heart
  - Do not smoke!
- Cannabis use
  - Discuss with your transplant team before using any cannabis products as cannabis can interact with your immunosuppression medications
  - Edible products may be okay to use after discussing with your transplant physician
- Alcohol
  - Avoid drinking alcohol after transplant
  - Alcohol can interact with your immunosuppression
  - If you are drinking alcohol, please tell the transplant team

#### **Drinking water**

Caution should be used to avoid waterborne pathogen

- If you have a well or drink well water, please have a sample checked for any waterborne pathogens
- Municipal tap water is treated for Cryptosporidium, although you should pay close attention to "boil water" recommendations from your local government
  - Bring water to a rolling boil for one full minute before drinking
  - Have well water tested at least yearly for cryptosporidium, giardia, and coliform bacteria
- You should not drink water directly from lakes or rivers
  - Avoid inadvertently swallowing water while swimming in lakes, rivers, or pools
- Avoid drinking tap water while visiting countries with poor sanitation
  - This includes consuming ice cubes or unintentionally swallowing water during showers



#### Sexual activity and family planning

- Sexual desire is sometimes decreased as a result of chronic illness
- You may notice sexual desire returns after your transplant
- Listen to your body when deciding when to have sex after transplant
  - It is usually best to wait 6-8 weeks after your heart transplant when you are off sternal precautions
  - Discuss any concerns regarding sexual activity with your doctor or coordinator, including issues with impotence (the inability to have sex)
- Safe sex
  - It is important to practice safe sex to decrease the risk of contracting sexual transmitted infections (STI)
  - Safe sex practices include:
    - Having sex with only one partner
    - Using a latex condom every time you have sex
- Family planning
  - Pregnancy is not recommended for women after heart transplant
    - Mycophenolate (one of your immunosuppression medications) can harm the fetus and is classified as as a class D medication during pregnancy or lactation. This means studies have shown evidence of harm.
    - Other complications include high blood pressure, hyperemesisgravidum, blood clots, and increased risk for rejection
  - Male transplant recipients can have decreased sperm production and sperm abnormalities which can result in birth defects
  - It is important to discuss family planning with the transplant team prior to pregnancy



### **Preventative Care**

#### Local primary doctor

- You should have a local primary care doctor
- He or she can manage chronic conditions (diabetes) or acute infectious illnesses (cold or flu) and immunizations

#### **Dental Care**

- Dental disease can be prevented by:
  - Brushing at least twice a day
  - Flossing at least once a day
  - Cleaning dentures after every meal
  - Routine dental care every 6 months is recommended
- Antibiotics (amoxicillin or clindamycin) should be taken one hour prior to any dental work or cleaning
  - Your dentist or transplant team can prescribe this
- We recommend no dental procedures until 6 months after transplant

#### Eye care

- Yearly eye exams are recommended
- Call your primary care doctor or eye doctor if you have any changes in vision, eye pain, sensitivity to light, dark spots in your vision or other vision concerns

### **Dermatologist**

You should see a dermatologist at least once a year

#### **Prostate screening**

- Screens for prostate cancer
- Your PCP may also recommend a blood test for prostate cancer screening

### Colonoscopy

- Screens for colon cancer
- Recommended for both men and women over age 45
- You may need a colonoscopy earlier than age 45 if you have a family history of colon cancer
- Repeat screening is based on gastroenterologist's recommendation

### **Immunizations**

#### Vaccines to avoid

- Any vaccine that is classified as **LIVE** should not be administered:
- Always make sure caregivers are aware you are a transplant recipient and cannot receive live vaccines including:
  - Oral polio
  - Measles
  - Mumps
  - Rubella
  - Yellow fever
  - Smallpox
  - Inhaled flu vaccine
  - Shingles (Zostavax)
- Generally, it is best to wait at least three months after heart transplant before getting a vaccine

#### Recommended vaccines

- Yearly flu shot for you and your family
- Pneumonia vaccine
- COVID-19 vaccine
- Immunizations needed before travel
  - Discuss with your transplant team, infectious disease doctor, or travel clinic for recommendations



### Sun Exposure

- Immunosuppression medications increase your risk of cancer, especially skin cancer
- It is important to take precautions to avoid the development of skin cancer
  - Wear sunscreen of at least 30 SPF every day and reapply frequently
  - Wear sunglasses, a broad brimmed hat, and long sleeve shirt and long pants when you are outside
  - Stay in the shade whenever possible
    - See a dermatologist (skin doctor) every year for a skin check
    - Avoid being outside when the sun's rays are strongest (between 10 AM and 4 PM)
    - Do not use tanning booths
    - Your immunosuppression may be decreased if you develop skin cancer



### Mental Health and Wellbeing

- The transplant journey is an emotional process
- Everyone experiences this differently
- Some people may feel anger, frustration, guilt, and depression after their heart transplant
  - These feelings are normal
- Side effects of medications, especially prednisone, can increase feelings of emotional distress
  - Talk to your transplant team and loved ones if you are struggling with your emotions after transplant
- The transplant team has a social worker available to help guide you



### **Your Donor Family**

- Please respect the privacy of the donor family and do not try to find information about the donor on social media or try to contact the family outside of the proper channels
- Writing to your donor family is a way to express gratitude for the gift of life you received
- Many transplant recipients find comfort in acknowledging this gift
- The act of writing can help the recipient and recipient's family process the transplant journey and the many complex emotions surrounding it
- The transplant social worker will help provide guidance and coordination for this process if you are ready
- All correspondence is anonymous unless both parties agree to disclosure
- You can give your letter to the transplant social worker in clinic or mail it in to the clinic
- Guidelines for writing your donor letter
  - Acknowledge and express sympathy for the loss of their loved one
  - Include your first name, occupation, and hobbies
  - Include family information (support people, children, grandchildren, pets)
  - Tell the donor family how the transplant experience impacted your life
  - Include a photo of yourself or family members
  - Do not include any contact information in your actual letter
- You can give your letter to the transplant social worker in clinic or mail it to the clinic

#### **Our Mission**

As expressions of God's healing love, witnessed through the ministry of Jesus, we are steadfast in serving all, especially those who are poor and vulnerable.

#### **Values**

Compassion, Dignity, Justice, Excellence, Integrity



