Health Facts for You

Heart transplant medicines

LWHealth

Taking Your Medicines

Why is it important to take your medicines?

You **must** take your medicines exactly as the directions or health care provider says. If you do not take your medicines, it can lead to increased risk of organ rejection and loss.

- Do not stop a medicine without talking to the transplant team.
- Take the right amount of medicine prescribed for you
- Take your medicines at the right time of day
- Do not take medicines that are not prescribed.

If you are concerned about paying for your medicines, please let us know. The pharmacy team will check pricing with your insurance before you leave the hospital after transplant.

If your medicines become difficult to pay for after transplant, discuss with your transplant team.

Transplant medicines are not common, so they may not be in stock at all pharmacies.

- We will fill the first month of your medicines in our outpatient pharmacy, as long as your insurance is accepted, to make sure you can take your medicines right away.
- If you use your local pharmacy for refills, let them know a week before you run out of pills so they can order the medicines and fill them.
- When you are traveling (this includes traveling to clinic visits), bring a few extra days of medicines with you in case of delays or other travel complications.
- If you are using mail order for your medicines, plan ahead for holidays and weekends. Keep your mailing

address up to date with your mail order pharmacy to prevent delays in shipment.

If side-effects are serious or bothersome, call your transplant coordinator right away to discuss ways to manage them. **Do not stop** taking your medicines unless your transplant coordinator or doctor tells you to.

What if I miss a dose of medicine? If you miss a dose, follow the "Half-Way" Rule.

- If you are less than "half-way" to your next dose, take your missed dose.
- If you are more than "half-way" to your next dose, skip it and continue with your next scheduled dose
- **Never** use extra medicine to make up for a missed dose.
- Call your transplant coordinator if you miss a dose of anti-rejection medicine.

How should I store my medicines?

Store your medicines in a cool, dry area out of reach of children. Bathrooms, kitchens and cars are not good places because of changes in heat and humidity.

Who should know about my medicines?

Tell **ALL** of your healthcare providers that you are on anti-rejection medicines, including:

- Dentists
- Doctors or surgeons
- Pharmacists (try to choose one pharmacy to use for all your medicines)

**Tell your transplant coordinator if other doctors make medicine changes before taking them.

Resources

Important Phone Numbers:

- UW Mail Order Pharmacy: (866)
 UWH-DRUG or (866) 894-3784
- UW Outpatient Pharmacy: (608) 263-1280
- Transplant Pharmacy B4/6: (608) 263-7229
- Transplant Unit B4/6: (608) 263-8737
- Transplant Pharmacy B4/5: (608) 263-5531
- Transplant Unit B4/5: (608) 263-8720

Transplant Pharmacists

- The transplant pharmacists are available by phone (see numbers above) from:
 - o 7:00 AM 4:00 PM (Monday Friday)
 - 8:00 AM 3:30 PM (Saturday – Sunday)
- You may also call the B4/6 or B4/5 unit and have the pharmacist paged at other times.
- Pharmacists are also available in the transplant clinic for questions.

Medicines List

Every patient should have an **up-to-date** medicine list that has:

- Names and doses of medicines you take
- How often you take them
- Why you take them
- Name of your doctor
- Allergies and reactions to any medicines
- Health history

Bring this list to **all** appointments/hospital visits and keep it in your wallet/purse.

Medicine Box

Medicine boxes organize your medicines and make them easier to take.

UW Mail Service Pharmacy

If you would like to use the UW Hospital's prescription mail order program, please ask your transplant pharmacist or coordinator for more information.

Local Pharmacy

Some pharmacies fill medicine boxes for you or offer automatic refill reminders. Call your local pharmacy to see what services they offer.

Medicine Refills

- If you are on your last refill of a medicine, call the transplant clinic.
- Your primary doctor should **not** refill your transplant medicines but should refill your other medicines.
- Medicine refills should be requested at least 7 days before running out of medicine. This might need to be longer around holidays.

Transplant Medicines

Transplant patients will be sent home with these medicines.

• Anti-Rejection Medicines

- o Tacrolimus or alternative
- Mycophenolate or alternative
- Prednisone

Anti-Infective Medicines

- o Antibiotic
- o Anti-fungal
- o Anti-viral
- Supplements
- Other medicines

Anti-Rejection Medicines

These medicines:

- Lower your body's immune system against illness and your new organ.
- When your body's immune system fights your organ, it is known as rejection.
- These medicines stop your body from rejecting your new organ.
- Each anti-rejection medicine works differently to lower your immune system.
- The medicines you receive depend on the type of new organ and your medical history.
- Anti-rejection medicines are never stopped unless directed to by your transplant doctor.

Prednisone

Side Effects	High blood pressure, cholesterol and blood sugar, thinning skin, easier bruising, swelling, hyperactivity, mood changes, lower bone mass, stomach upset, stomach ulcers, trouble sleeping, bigger appetite, and cataracts	
Food	Take with food to prevent upset stomach and ulcers	
Special Tips	 If you have high blood sugar or diabetes, your dose may be twice a day. If you take it once a day, you should take it in the morning so it is easier to sleep. Have an eye exam once a year for cataract prevention. 	

Tacrolimus (Prograf/Hecoria)

Side Effects	Tremor, headache, kidney injury, hair loss, diarrhea, nausea/vomiting, trouble sleeping, and high cholesterol,		
Side Effects	blood sugar and blood pressure		
Food	Take with or without food, but be consistent in what you choose		
Interactions	Avoid grapefruit or pomegranate and their juice, since they increase tacrolimus levels.		
	Tacrolimus blood levels are drawn to make sure you are getting the right amount of the medicine.		
Monitoring	• Blood is drawn right before your morning dose and approximately 12 hours after your evening dose to measure the amount of drug in your body when it is lowest (a trough).		
	 DO NOT take your morning dose until AFTER your blood is drawn. 		
	Goal levels are based on your history and time from transplant		
	• Call your transplant coordinator if:		
Special Tips	o tremor or headache worsen		
	o you notice burning in your fingers		
	 the shape and/or color of your medicine changes. 		
	Changing manufacturers may need lab monitoring.		

Mycophenolate Sodium ECT (Myfortic) or Mycophenolate Mofetil (Cellcept)

Side Effects	Diarrhea, nausea/vomiting, headache, and low white blood cell and hematocrit
Food	Take with food to help prevent stomach upset and diarrhea
	Do not crush, chew or cut mycophenolate tablets.
Special Tips	Pregnant women should not handle the tablets or capsules due to risk of fetal harm.
	All female patients of reproductive age who take mycophenolate must use birth control.

Anti-Infective Medicines

Why do I need anti-infective medicines?

- Because your immune system is lowered, you are at a greater risk for becoming sick.
- Anti-infective medicines help prevent infections after your transplant.
- If you experience any signs of infection, call your transplant coordinator:
 - o **Fever:** any temperature 100.5°F or greater
 - Bladder infection: painful urination, frequent urination
 - Pneumonia: Severe cough, coughing up colored or bloody mucous
 - o Wounds that won't heal: increased redness, pain or drainage from your wound

Vaccines

- **Do not** get vaccines within the first 6 months after transplant unless approved by your transplant coordinator or transplant doctor.
- Avoid live vaccines, including shingles, chicken pox, and the influenza nasal spray.
- People living with you should get the influenza vaccine. They can receive the live vaccine.
- Call your transplant coordinator if you have been around someone who has chicken pox.
- The major vaccines you need include:
 - o **Influenza** yearly (shot only, not nasal spray)
 - **Pneumonia** 1 shot plus 2 booster shots five years apart if less than 65 or 1 booster shot if you are over 65 years
 - o **Tetanus** Every 5 to 10 years

Preventing General Infections and Pneumonia

Trimethoprim/sulfamethoxazole (Bactrim DS or Septra DS) or TMP/Sulfa

Duration	1	Take for one year after transplant. You may need to take for life if you or your donor had indicators of prior infection for toxoplasmosis.
Side Effe	ects	Sun sensitivity, nausea/vomiting, diarrhea, rash, high potassium, low white blood cell count

Atovaquone - ALTERNATIVE to TMP/Sulfa

Duration	Take for six months after transplant
Side Effects	Headache, insomnia, rash, nausea, change in taste

Preventing Viral Infections (Cytomegalovirus – CMV)

- CMV is a virus that may hide out in the body.
- This virus is normally harmless but is dangerous when your immune system is lowered.
- The antiviral medicine you receive depends on whether you or your donor have had CMV.

Valganciclovir (Valcyte)

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Duration	Take for three to six months after transplant
Side Effects	Decreased white blood cell count

Acvelovir (Zovirax)

Duration	Take for three months after transplant
Side Effects	Headache, upset stomach

Preventing Fungal Infections (Aspergillus)

- Common fungus found indoors and outdoors. Exposure to this infection can cause illness when your immune system is weak.
- Most aspergillus infections occur in the lungs, but this fungus can be found in other parts of the body.

Posaconazole (Noxafil)

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Duration	Take for 3 months after transplant
Side Effects	Increases tacrolimus absorption. You will need dose changes and close monitoring of tacrolimus after stopping Posaconazole. Do not stop unless told to do so by your transplant team.

Supplements/ Over-the-Counter Medicines

Avoid other prescription, over-the-counter, herbal, homeopathic, or dietary supplements unless recommended by your doctor and approved by your transplant coordinator.

The supplements/medicines listed below are available without a prescription (over-the-counter or OTC). If you need these medicines they will be listed on your discharge medicine list. You will need to buy these at a store or pharmacy after discharge:

Supplement/ Medicine	Purpose	Side Effects	Tips and Comments
Calcium (carbonate or citrate)	Prevents bone loss	Constipation or diarrhea	Look at the "Supplement Facts" on the back of the bottle to see how much elemental calcium is in each tablet.
Vitamin D (cholecalciferol)	Helps your body use calcium	None	You can purchase a combination of calcium and vitamin D.
Multivitamin	General health	Stomach upset	Choose any multivitamin appropriate for your age group.
Pantoprazole (Protonix) or Omeprazole (Prilosec) or Lansoprazole (Prevacid)	Prevents stomach ulcers	Headache	This may be given as a prescription depending on your insurance
Aspirin 81 mg	For heart health	Higher risk of bleeding	If you were on aspirin before transplant, you may need to resume your home dose

Pain Medicines to Avoid and Limit

Medicine	Avoid or Limit?		
Extra Aspirin	Do not take extra aspirin on top of your low dose aspirin (81 mg) without discussing with your coordinator.		
NSAIDs (ibuprofen (Advil/Motrin), naproxen (Aleve), Celebrex, diclofenac)	Do not take these without permission from your transplant coordinator. Use Tylenol for pain or fever.		
Acetaminophen (Tylenol)	 Do not take more than 4,000 mg in 24 hours (no more than 12 regular strength or 8 extra strength tablets). Liver Transplant: Do not take more than 2,000 mg in 24 hours (no more than 6 regular strength or 4 extra strength tablets). 		

Other Medicines

Blood Pressure Medicines (Goal blood pressure: less than 120/80 mmHg)

- Many transplant patients have high blood pressure or develop high blood pressure as a result anti-rejection medicines.
- Some patients resume their home blood pressure medicines, some patients may need them added, or some patients may be able to stop taking them.
- It is important to own a blood pressure cuff and monitor your blood pressure at home.
- You should keep a logbook of your blood pressure and bring it with you to appointments.
- Blood pressure can also be controlled through:
 - Diet and exercise (loose excess weight)
 - Avoiding high-salt foods (DASH diet)
 - Quitting smoking

Medicines for High Blood Sugar (Diabetes)

- Prednisone and tacrolimus can cause you to have high blood sugar (diabetes).
- You may be started on insulin to lower your blood sugar.
- You may be asked to test your blood sugar up to four times a day.

Medicines to Lower Cholesterol

- Your medicines, diet, or family history may cause you to have increased cholesterol. Medicine may be used to help lower your cholesterol level.
- Some of these medicines (statins) may help reduce your risk of coronary allograft vasculopathy (CAV).

Antibiotics

- Transplant patients may need antibiotics to prevent infections prior to procedures.
- It is advised that heart transplant patients take an antibiotic for general teeth cleaning and other dental procedures

Top 10 Medicine Tips for Transplant Patients

- 1. Take all the medicines prescribed by your transplant doctor at the dose prescribed. Your transplant will not last if you do not take them.
- 2. Keep a list of your current medicines. Bring this list to all hospital and clinic visits along with your medicine box.
- 3. Do not take ibuprofen, naproxen, or ketoprofen. Talk with your doctor about taking more than 81 mg of aspirin a day. These NSAIDS can harm your kidney when mixed with other transplant drugs.
- Store all of your medicines in a bedside stand or pantry. They cannot be near any heat source. Keep all medicine out of sight and reach of children and pets.
- 5. If you miss a dose, take it as soon as you remember. If you take it twice per day, and if you are more than 6 hours late, skip the missed dose and take your it at your normal time.

- 6. If you or your local doctor feels that you need a new medicine check with your transplant coordinator first.
- 7. Be careful not to run out. Refill your prescriptions before they are too low. Make sure you have enough between clinic visits and over weekends, holidays, or vacation.
- 8. When you pick it up from the pharmacy, make sure the name and dose match what the doctor or transplant coordinator told you. If a refill looks different, be sure to tell your pharmacist.
- 9. If you become pregnant or plan to become pregnant, contact your doctor right away.
- 10. Your doctor will want to check the way your body responds to your medicine. Be sure to keep all your scheduled check-ups and blood tests.

Managing Side Effects

Use the table below to help manage your medicine side effects. If your side effects are serious or bothersome, call your transplant coordinator.

Side Effect	How to Manage		
Acne	Treat with prescription or over-the-counter medicines, such as benzoyl peroxide		
	Keep your skin clean by washing your face two times per day		
	Avoid moisturizing soaps and lotions with oils (try oil free)		
	Do not pick at pimples since it can increase your risk of infection		
Hair Loss	Use a conditioner after shampooing		
	Avoid perms, dyes, or bleaching		
	• Limit your exposure to chlorine (swimming pools) and the sun		
Swelling	 Treat with diuretics (water pills) as prescribed by your doctor Weigh yourself daily 		
	• Call your transplant coordinator if you gain more than 3 pounds/day or more than 5 pounds/week		
	Avoid salt		
	Increase physical exercise		
Headaches	Call your transplant coordinator if you have severe headaches		
	Avoid caffeine, bright light, stress, and loud noises		
	Try 1 or 2 regular strength Tylenol tablets to relieve a mild headache		
Hair Growth	Hair may be removed by bleaching, trimming, shaving or with hair removal products		
High	Take your cholesterol medicines as directed by your doctor		
Cholesterol	Exercise regularly		
	• Eat a diet low in fat and cholesterol, and high in fiber		
Infection	Wash your hands often with antibacterial soap		
	Avoid contact with sick people		
	Use gloves if pet waste must be handled		
	• Clean cuts with soap and water and apply a triple antibiotic ointment and cover		
Bone Loss	Take calcium and vitamin D daily		
	Quit smoking		
	Do not use alcohol		
	Walk and lift weights to keep bones strong		
Tremors	Call your transplant coordinator if you have tremors:		
	Stretching exercises may help relieve mild tremors		

Your health care team may have given you this information as part of your care. If so, please use it and call if you have any questions. If this information was not given to you as part of your care, please check with your doctor. This is not medical advice. This is not to be used for diagnosis or treatment of any medical condition. Because each person's health needs are different, you should talk with your doctor or others on your health care team when using this information. If you have an emergency, please call 911. Copyright © 4/2021 University of Wisconsin Hospitals and Clinics Authority. All rights reserved. Produced by the Department of Nursing HF#8193.