

About Your Medicines

For lung transplant patients

This handout describes many of the medicines you will take after your lung transplant. You may not take all of these medicines. You might also take other medicines that are not described here.

After your lung transplant, you will be taking a lot of medicines. These medicines are given to help your body:

- Prevent rejection of your new lung
- Prevent *opportunistic* infections (infections that can occur when your immune system is weakened)
- Control your blood pressure
- Keep your bones strong
- Use the nutrients in your food



*Always take your medicines **exactly** as they are prescribed.*

All of these medicines must be taken **exactly** as they are prescribed. If you do not take these medicines as directed, you may become very ill or even lose your transplanted lung(s).

This is not meant to scare you. We just want to stress how important these medicines are. Please be assured, there is plenty of support to help with any problems you may have.

Most of the types of medicines you will take after your lung transplant are described on the next pages. There may be some medicines you will not take. And, you may take other medicines that are not described.

Immunosuppressants

Immunosuppressant medicines are given to prevent your body from rejecting your new lung. But, these medicines make it easier for you to get infections.

This means you will also be taking other medicines to prevent infections. You will learn the signs of infection, and what to do when you have these symptoms.



We will check the levels of tacrolimus in your blood and adjust your doses to lessen side effects.

Tacrolimus (Prograf or FK506)

Tacrolimus keeps cells from attacking your new lung and causing rejection. You will take tacrolimus 2 times a day, 12 hours apart. We will check the levels of tacrolimus in your blood and adjust your dose to lessen side effects.

Side effects of tacrolimus include:

- Kidney damage
- High blood pressure
- Acne
- Tremor
- Magnesium loss
- Potassium retention
- Headache
- High blood sugar

Mycophenolate Mofetil (Cellcept or a generic) and Mycophenolate Sodium (Myfortic)

These medicines reduce the number of white blood cells your body produces that would reject your new lung. Side effects include:

- Nausea
- Diarrhea
- Liver damage (rare and usually can be reversed)
- Headache

Prednisone

Prednisone is a steroid medicine. You will always need to take steroids, either to prevent rejection or to treat acute rejection episodes. But, we will lower your dose over time.

Side effects of prednisone include:

- Weight gain (from increased appetite and water retention)
- Mood changes (especially when high doses are used right after transplant or to treat acute rejection)
- Bone loss (you will take calcium supplements to decrease bone loss)
- Muscle weakness (exercise will lessen muscle weakness)
- Face and shoulders become rounder

- Acne
- High blood sugar (you may need to use insulin to control your blood sugar)
- Thinning of your skin
- *Cataracts* (clouding of the lens of your eye)

Other Immunosuppressants You May Take

Cyclosporine Emulsion (Neoral, Gengraf, Sandimmune)

You may take cyclosporine if you cannot handle tacrolimus. Side effects of cyclosporine include:

- Kidney damage
- High blood pressure
- Tremor
- Magnesium loss
- Potassium retention
- Headache
- High blood sugar
- Excess hair growth
- Changes in lipid levels (cholesterol)

Azathioprine (Imuran)

You may take azathioprine if you cannot handle mycophenolate. Side effects of azathioprine include:

- Nausea
- Decrease in white and/or red blood counts
- Liver damage

Sirolimus (Rapamune)

Sirolimus may be added to your medicines to stop lung rejection in the future if you have many acute rejection episodes. It may also be prescribed if you have kidney problems from taking tacrolimus.

You may take less tacrolimus (to protect your kidneys) if you also take sirolimus. If you take both cyclosporine and sirolimus, you **must** take the sirolimus 4 hours after the cyclosporine. This is because your body cannot fully absorb and use these medicines if you take them at the same time.

Side effects of sirolimus include:

- Higher *triglyceride* and *cholesterol* levels (these are blood fats)
- Fewer white blood cells, red blood cells, and *platelets* (cells that help blood clot)
- Slower wound healing

Anti-infectives and Antifungals

Nystatin Liquid (Nilstat)

Nystatin helps prevent yeast infections in your mouth and throat (*thrush*). Swish the liquid around in your mouth for 60 seconds, then swallow.

Most people handle this medicine well. Side effects of nystatin may include:

- Nausea and vomiting
- Diarrhea
- Unpleasant taste
- Dry or irritated mouth

Trimethoprim/Sulfamethoxazole (Bactrim SS, Septra SS)

Trimethoprim/sulfamethoxazole is used to prevent pneumonia caused by *pneumocystis* (PCP), a fungus. If you are allergic to sulfa, your doctor can prescribe other drugs.

Side effects include:

- Rash
- Allergy
- Being more likely to get sunburned
- Liver damage (rare and unlikely)
- Low white blood cell count (rare and unlikely)

Antivirals

Valganciclovir (Valcyte)

Valganciclovir is given to many patients to prevent infections caused by *cytomegalovirus* (CMV) during the first 3 to 6 months after transplant.

Side effects include:

- Nausea
- Producing fewer white blood cells

We may prescribe valganciclovir again after the first 3 to 6 months, if you get a CMV infection.

Acyclovir (Zovirax)

Acyclovir is used to prevent infection with the *herpes simplex virus* (HSV). Side effects are not common but can include:

- Nausea and vomiting
- Headache
- Diarrhea
- Joint pain

This drug is taken for 3 months if neither you nor your donor had ever had a CMV infection in the past.

Supplements and Drugs to Prevent and Treat Bone Loss

Calcium and Vitamin D

- *Calcium carbonate* (in Tums and other products) helps prevent the bone loss that prednisone may cause. Your dose will depend on the amount of calcium in your diet.
- Vitamin D helps your body absorb calcium and prevents bone loss.
- You will also take a multivitamin to support your general health. It also contains some vitamin D.

Alendronate (Fosamax)

If you are at high risk for bone loss, you may need to take *alendronate* (Fosamax) tablets before and after your lung transplant. Side effects include:

- Stomach upset
- Heartburn

If you take this medicine:

- Take it with a full glass of water.
- Do not lie down, eat, or take other medicines for at least 30 minutes after taking it.

Other Medicines You May Take

- **Magnesium oxide** replaces the magnesium that you lose in your urine when you take tacrolimus or diuretics. Side effects include nausea, vomiting, and diarrhea.

- **Metoprolol (Toprol XL, Lopressor)** is often used to lower your blood pressure and slow your heart rate. Side effects include fatigue (feeling very tired) and dizziness.
- **Aspirin** protects your heart and can help keep blood clots from forming. Side effects can include upset stomach or bleeding. Always take aspirin with food to lessen or avoid these side effects.
- **Atorvastatin (Lipitor), pravastatin (Pravachol), and simvastatin (Zocor)** are often used to lower cholesterol. For lung transplant patients, these medicines are used to decrease inflammation of the new lungs. Rare side effects may include muscle pain or liver damage.
- **Omeprazole** or **pantoprazole** are used after transplant to help prevent stomach upset, heartburn, and maybe organ rejection.

Drug-Food Interactions

Other drugs, foods, and herbal and nutritional supplements may affect how your body uses your transplant medicines. Some, such as diltiazem (for high blood pressure) and grapefruit juice, cause high levels of some drugs to build up in your body. Even herbs such as echinacea or St. John's wort may cause problems with your transplant medicines.

Please tell us about **all** medicines and supplements you take. We will tell you which ones are safe to keep taking after your transplant.

Prescriptions

Insurance

Before your lung transplant, be sure that you know what medicines your insurance will and will not cover. If you have financial concerns or need help choosing a prescription drug plan, please talk with your transplant team social worker or financial advisor.



Do not eat grapefruit or drink grapefruit juice when taking drugs that suppress your immune system.

When you come to the hospital for your transplant surgery, please bring:

- ***Your insurance card***
- ***Your pharmacy information***
- ***A list of your current medicines, their doses and how you take them***



You may use the UWMC Outpatient Pharmacy or any pharmacy you like to fill your prescriptions.

Choosing a Pharmacy

You may use the UWMC Outpatient Pharmacy or any pharmacy you like to fill your prescriptions.

UWMC Outpatient Pharmacy

If you want to use the UWMC pharmacy, make sure your insurance prescription plan will work with UWMC's Outpatient Pharmacy. Not all prescription drug plans work with our pharmacy, even if UWMC takes your medical insurance.

Mail-order Pharmacies

Many patients prefer to use a mail-order pharmacy after their transplant surgery. We advise you **NOT** to use a mail-order pharmacy the first month after your lung transplant.

Pharmacists at mail-order pharmacies are used to dealing with the major insurance companies, and many insurance plans charge lower copays for patients who use these pharmacies.

Know Your Medicines

It is important that you know what medicines you are taking.

- Update your list when your medicines or doses change.
- Keep a list of your medicines with you. Put your list in your wallet or purse, or something else you always have with you.
- Give all your healthcare providers a list of all the medicines you take. Include any vitamins, supplements, or medicines you bought without a prescription. Call Post Lung Transplant Services at 206.598.5668 **before you start or stop any of your medicines.**

Lung Transplant Medicine Sample Table

Most lung transplant patients take the medicines listed in the table on pages 8 and 9. Use this table to check what drugs your insurance will pay for and which ones you may have to pay for. This list does not include all the medicines you may take.

Before your transplant, we will review all the medicines you are taking and tell you which to keep taking.

Note: OTC stands for “over the counter.” It means you can buy this product at your local drugstore without a prescription. Most insurance plans do not pay for OTC medicines.

Drug Name	How Many to Take	Breakfast	Lunch	Dinner	Bedtime	Purpose/Cautions
Tacrolimus (Prograf) <i>Generic</i>	As directed	9 a.m. _____mg			9 p.m. _____mg	Prevents rejection. Caution: No grapefruit, pomegranate, or starfruit. No ibuprofen (Advil, Motrin) or naproxen (Aleve, Naprosyn). Dose changes based on blood levels.
Mycophenolate 1,000mg (Cellcept) <i>Generic</i>	2 (2 x 500 mg)	✓		✓		Prevents rejection. Caution: Always take the same way – either with food or without food (not with food sometimes, and without food other times).
Prednisone <i>per taper*</i> (Deltasone) <i>Generic</i>	<i>Per taper:</i> 35 mg (3.5 x 10 mg)	✓				Prevents rejection. At higher dose, also used to treat rejection. Caution: Take with food <i>* Dose is decreased every 2 weeks until you are taking 10 mg a day.</i>
Nystatin liquid (Nilstat) <i>Generic</i>	5 mL	✓	✓	✓	✓	Prevents fungal infection. (Used for 3 to 6 months.) Swish for 60 seconds. then swallow. Take after meals and then do not drink or eat anything for 15 to 30 minutes.
Trimethoprim/Sulfa 80 mg/400 mg (Bactrim, Septra) <i>Generic</i>	1				✓	Prevents pneumocystis lung infections (used long-term) Take with a full glass of water Caution: Wear sunscreen
Valganciclovir 900 mg (Valcyte) <i>OR</i> Acyclovir 400 mg (Zovirax) <i>Generic</i>	2 (2 x 450 mg) <i>OR</i> 1	✓ ✓		✓		Prevents infection from herpes simplex or cytomegalovirus. (Taken for 3 to 6 months.) <i>OR</i> Prevents infection from herpes simplex (taken for 3 months)
Calcium Carbonate (Tums) 1,000 mg <i>Generic, OTC</i>	2 (2 x 500 mg)	✓		✓		Calcium supplement. Protects bones.
Cholecalciferol (vitamin D ₃) 2,000 units <i>OTC</i>	1	✓				Helps bones absorb calcium.

Drug Name	How Many to Take	Breakfast	Lunch	Dinner	Bedtime	Purpose/Cautions
Multivitamin (such as Centrum) <i>Generic, OTC</i>	1	✓				Vitamin supplement for general health.
Magnesium oxide 400 mg (MagOx) <i>Generic, OTC</i>	1	✓		✓		Electrolyte replacement.
Metoprolol 25 mg (Lopressor) <i>Generic</i>	1	✓			✓	Lowers heart rate and blood pressure.
Aspirin , enteric-coated 81 mg (Ecotrin) <i>Generic, OTC</i>	1	✓				Prevents blood clots. Caution: Take with food.

Atorvastatin 10 mg (Lipitor) <i>Generic</i> OR Pravastatin 10 mg (Pravachol) <i>Generic</i>	1			✓	
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Pre-Transplant Planning: Medicare

Medicare Part A

- Pays for your hospital stay.

Medicare Part B

- Pays for outpatient visits and equipment (such as wheelchairs, walkers, etc.), dialysis, diabetes supplies, and drugs you are given in a clinic.
- Also helps pay for 80% of immunosuppressant drug prescriptions if Medicare is your primary insurance at the time of your transplant. You would pay 20% as your copay.
- Benefits last for at least 3 years.
- If you are enrolled in Medicare Part B, your pharmacy is required to bill Part B for your drugs.
- You must confirm that your pharmacy can bill Medicare Part B for you.

Medicare Part D

- Prescription drug plans that are managed by private insurance companies.
- Part D will not pay for immunosuppressant drug prescriptions if you are enrolled in Part B.
- May not have to pay the 20% copay after Part B is billed for immunosuppressive drugs.
- Each year, you must pay a *deductible* for the Part D program. A deductible is what you pay before Part D starts paying. For 2021, this amount is \$445.
- For 2021, after your and your insurance plan's total drug costs for the year reach \$4,130, there is a gap of \$2,420 that Medicare Part D will not pay. During this period, you must pay 25% of drug costs. This gap in coverage is called the "donut hole." You will leave the coverage gap when your total out-of-pocket cost on covered drugs

(not including premiums) reaches \$6,550. Find your out-of-pocket cost by adding together all of these amounts:

- Yearly deductible, coinsurance, and copayments from the entire plan year
- What you paid for drugs in the coverage gap (including the discounted amounts you didn't pay in that stage).

To Learn More

To learn more about Medicare, visit the Medicare Plan Finder website at www.medicare.gov/find-a-plan/questions/home.aspx.

This website shows detailed monthly cost information for drugs. It may help you understand your drug coverage and out-of-pocket costs more fully, including costs while you are in the “donut hole.”

Mail-order Pharmacies

First Month After Transplant

We advise you NOT to use a mail-order pharmacy the first month after your lung transplant.

For 1 month after your transplant, your prescriptions should be filled at the hospital outpatient pharmacy or a local pharmacy. This will help ensure that you get your medicines when you need them.

After 1 Month

After the first month, check with your insurance provider to find out if your insurance plan has a list of preferred mail-order services that can provide your medicines at lower cost to you. You may also be able to get a larger supply of your prescription medicines through mail order.

Mail-order pharmacies are often most useful for prescriptions that you need on a regular basis when you are at stable doses. But, if you receive a new prescription that you need right away (such as a prescription for a **new** immunosuppressant medicine, pain medicine, or antibiotic) you should have your prescription filled at your local pharmacy.

Mail-order pharmacies may be very helpful if you live in a rural area, or if you save a lot of money by using them. Services that are usually offered by mail order include:

- Prescription and non-prescription medicine fills and refills
- Medical equipment such as blood pressure cuffs, thermometers, and blood glucose meters

Prescriptions may be phoned in or faxed by your doctor, or mailed. Automatic refill service may also be offered.

Mail-order pharmacies usually accept direct payment from your insurance company. Medicare may also be billed directly, but you may still have to pay for the 20% that Medicare does not pay for immunosuppressant drugs. Some companies may accept state Medicaid programs.

With mail order, you must pay any copays or insurance deductibles. You will be billed for these costs. Processing and delivery of new or refilled prescriptions is made directly to your home by express mail companies.

Websites for Financial Aid

These online resources provide help for people who cannot afford their transplant medicines. Some charge a small copay.

- Medicare: www.medicare.gov
- NeedyMeds: www.needymeds.org
- The Medicine Program: www.themedicineprogram.com
- Medicine Assistance Tool: <https://medicineassistancetool.org>
- RxHope: www.rxhope.com
- RxAssist: www.rxassist.org

Manufacturer Patient Assistance Programs

Some drug companies have programs to help patients be able to afford their medicines. These are toll-free numbers you can call to learn more about these programs. The company name is in parentheses.

Prograf (Astellas)	800.477.6472
Cellcept, Valcyte (Genentech).....	888.754.7651
Rapamune (Pfizer)	888.327.7787
Neoral, Sandimmune, Myfortic (Novartis).....	800.277.2254

Patient Assistance at the UWMC Outpatient Pharmacy may also be able to help. You can reach this resource at 206.598.3958.

Questions?

Your questions are important. Call your doctor or healthcare provider if you have questions or concerns.

Post Lung Transplant
Services: 206.598.5668