



International
Transplant Nurses
Society

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MAKING YOUR TRANSPLANT MEDICINES WORK FOR YOU

After Organ Transplantation



Congratulations on your recovery following transplant! One of the most important responsibilities you will have after transplant is taking your medications as prescribed. This brochure provides important information for you and your family about your transplant medications. **Your transplant center's specific guidelines should always be followed.** This information should be used to help you talk about your transplant medicines with your transplant team and should never replace their advice.

What are my transplant medicines?

You are taking medicines to help keep your new organ working well. These medicines, also called immunosuppressants, help prevent your body from rejecting your transplanted organ. We will call them your transplant medicines throughout the rest of this brochure. Although you are taking many different types of medications, this information will cover only your medications used to prevent rejection.

Why is it important for me to take my transplant medicines as ordered?

Getting an organ transplant helps you feel better. When you feel better you can do more things that you enjoy. You will want to take care of yourself so that your new organ lasts as long as possible. Taking your transplant medicines on time, every day, is an important part of taking care of yourself and your new organ. Side effects and other problems should be lower if you take your transplant medicines as ordered.

Every medicine your provider prescribes for you is important for your health and the health of your new organ. Stopping any of your medicines or even skipping a single dose without guidance from your provider could harm your new organ. Taking your medications correctly and following your medication schedule will help you have a healthy, active lifestyle.

Do people with transplants have difficulty taking the right transplant medicines on time every day?

Yes, sometimes they do. Sometimes they are overwhelmed with the number of pills they have to take, and sometimes patients find it difficult to remember the times required to take their medicines. That is why we are giving you this information, to try to make it easier for you to stay on track with taking your medicines.



Why do I need to take transplant immunosuppressant medicines?

Transplant immunosuppressant medicines are needed to protect your transplanted organ from being rejected by your immune system. The immune system protects your body from infection and illness. White blood cells that move through the blood get rid of bacteria and viruses. One job of the immune system is to see what is “you” and what is “non-you” in your body. The immune system cannot tell the difference between “bad” cells, like germs, and “good” cells, such as your transplanted organ. Your immune system will look at your transplanted organ as “non-you” and will attempt to get rid of it, this is called rejection. One of the ways to stop the immune system from harming the transplanted organ is to take medicines that decrease, or suppress, your immune system and prevent it from rejecting your new organ.

Your transplant team has ordered transplant medicines in quantities and doses that are just for you. You may be on higher doses of these medicines right after transplant. Although the amount of medicine you need may decrease over time, you will probably need these medicines for the rest of your life. Transplant immunosuppressant medicines, and taking them correctly, are your lifeline to long-term health!

Why might I need to take more than one transplant immunosuppressant medication?

Each transplant medication works a little differently on your immune system. Taken in combination, the medicines work better together than alone. Think of each medication as a “guard.” Each guard blocks a different part of the immune system giving more protection to the organ. Your transplant team may have you taking more than one transplant medication in order to properly block your immune system.

Why do I need all these other medicines?

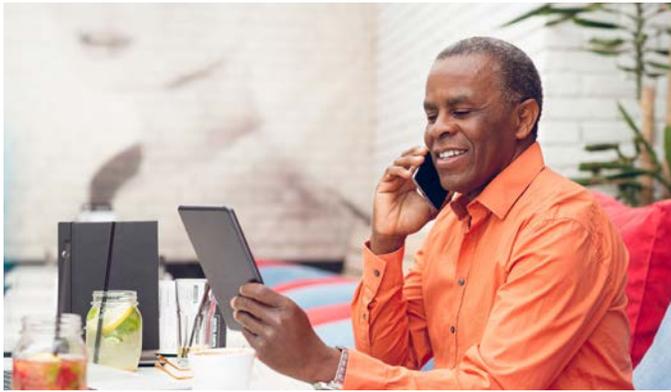
In addition to your transplant immunosuppressant medicines, you may need other medicines to reduce the side effects from the transplant medicines. Some medications can be used to prevent or treat side effects that may include infection, high blood pressure, stomach problems, and high blood sugars. All of the medicines your provider prescribes are necessary to keep you and your organ healthy.

What should I know about my transplant medications?

- The brand name and generic name of the medications prescribed by my provider
- The reason I am taking the medication
- What each medication looks like
- When to take each medication
- How to take each medication
- How long I should take the medication
- The most common side effects of each medication
- Any special instructions for taking the medications
- What to do if I am late, miss a dose, or forget to take a dose
- How to order my refill prescriptions
- The cost of my medications

Why should I talk with my Transplant Team about what “Brand-Name” and “Generic” means with my medicines?

Medications are known by two different names. The brand name is the name given to the medication by the pharmaceutical company that produces it. The generic name is the common, non-branded name of that medication. For example, Prograf® and tacrolimus are the same medication. Prograf® is the brand name and tacrolimus is the generic name. When more than one pharmaceutical company produces the same medication, there can be more than one brand name for that medication.



Please discuss the brand name and generic name of each medication with your transplant team. You should stay on either brand OR generic transplant medicines. Do not switch between brand and generic transplant immunosuppressant medicines without consulting with your transplant team. Generic and brand name medications can be absorbed differently into your blood stream. This can result in different blood levels of the medication. This may put you at risk for rejection or unnecessary side effects.

When you get your prescriptions filled, ask the pharmacist to notify you if the prescription has been filled with a drug made by a different company. These drugs can be absorbed differently.

Why is it important to know why my provider has ordered each of my medications?

You should always know why you are taking each medication because medications often have more than one use and may be prescribed for different reasons. For example, fluconazole is a medication used to treat a fungus infection. Sometimes, though, the transplant team uses it to increase your tacrolimus levels.

Why do I need to know what each medication looks like?

You should be able to recognize each tablet or capsule by color, shape, and size. Many medications have a similar appearance with only slight differences. Look closely at your medications to be sure that you are taking the correct tablet or capsule.

Why is it important for me to take my transplant medicines at the ordered time every day?

When you take your transplant medicine, it stays in your body for a certain amount of time and then it is gone. Your healthcare provider has ordered you to take your medicines at certain times of the day so that the level of the medicine in your blood stays high enough to protect your new organ. To keep your medicine level at the same level all the time, take your medicine on time, every day. Work with your coordinator, pharmacist, or nurse to arrange a medication schedule that is easy for you to follow.

Why is it important for me to know how to take each of my medications?

You probably take most of your medications by swallowing a pill or capsule. Occasionally, particularly for children, a pill may be divided or crushed and mixed with foods or liquids. Some pills should not be crushed because breaking up the pill may decrease how well it works or it could be harmful to non-transplant patients if the medication powder is inhaled or handled without gloves. Discuss how to take each of your medications with your nurse, coordinator, or pharmacist.

Why is it important for me to know how long I should take each medication?

Most patients will take some type of transplant medication for their entire life. However, right after transplant, there may be more than one type that is needed for a short time. Some medications can be discontinued after a complication or side effect has resolved. Likewise, some medications may be stopped if a complication or significant side effect occurs. Taking your medications as ordered by your provider assures the medication will work best for you and that you have less chance of getting unnecessary side effects.

Why is it important for me to know the most common side effects of each medication?

Every medication has side effects, but these are not experienced by everyone. Some side effects can be very mild while others lead to additional complications. You should know the most common side effects that each medication may cause and when to notify your transplant coordinator. For example, mycophenolate mofetil (Cellcept®) can cause diarrhea and stomach upset. Your transplant team can make adjustments to your medicines to help reduce the diarrhea and stomach upset. Report any suspected side effects to your transplant coordinator.

Why is it important to know any special instructions for taking my medications?

Some medications must be taken with food or on an empty stomach. Others must be taken a certain number of hours apart from other medications. Discuss any special instructions for taking and handling your medications with your transplant team.

By following any special instructions, you are assuring the medication works best for you and that you can decrease the risk of unnecessary side effects.



What special handling is required for my medications?

When you are touching and handling your medications, no extra care is needed. Because you swallow your medications, you are already exposed to all of the good and bad effects of the medication.

If caregivers or family members help with your medications, they should wear gloves every time they touch your medication. They should also avoid breathing in any powder from a cut tablet, or an opened capsule.

The National Institute for Occupational Safety and Health (NIOSH) has lists of harmful medications available online. These lists give the name of the medication, what the medication does that is harmful, and how to protect someone who needs to handle the medication. Some common transplant medications are on the NIOSH list (see below). The medications listed may cause cancer in someone who handles them. If a woman who is pregnant, or may become pregnant, handles one of these medications, it may cause birth defects. Gloves should be worn before touching a tablet or capsule. Avoid cutting tablets or opening capsules. Breathing in powder from the cut tablet can be just as harmful as handling the medication.

Immunosuppressant Medications on the NIOSH List:

- Azathioprine (Imuran®)
- Mycophenolate Mofetil (Cellcept®)
- Mycophenolic Acid (Myfortic®)
- Cyclosporine (Sandimmune®, Gengraf®, Neoral®)
- Tacrolimus (Prograf®)
- Everolimus (Zortress®)
- Sirolimus (Rapamune®)

Other Transplant Medications on the NIOSH List:

- Bortezomib (Velcade®)
- Ganciclovir (Cytovene®)
- Valganciclovir (Valcyte®)
- Fluconazole (Diflucan®)
- Entecavir (Baraclude®)
- Leflunomide (Arava®)
- Spironolactone (Aldactone®)
- Colchicine (Colcrys®)
- Finasteride (Proscar®, Propecia®)
- Testosterone
- Voriconazole (Vfend®)

What should I do if I am unable to take my transplant medications as ordered?

Call your transplant coordinator if you are unable to take your medications as ordered for any reason. Some examples of when to call:

- You are nauseated, feeling sick, or vomiting
- Have diarrhea and are worried that your medication is not being absorbed
- Have forgotten to take your medications or missed any doses
- Notice that the directions on the label of the medication container are different from what you were told to take
- Feel you are having an unusual reaction or side effect to a medication

Why is it important for me to know how to order my refill prescriptions?

The number of refills you have for each medication depends on how long you will be taking the medication. Your insurance company may also specify how many refills can be ordered. After the prescription has been given to your pharmacy, you may order online or call for refills/repeat prescriptions. Check with your pharmacy on the best way to order. When calling to refill prescriptions, make sure you have the current prescription number available from the medication bottle. Any new prescriptions and any dose changes in medications you are already taking must be called in or sent to your pharmacy by your provider.

It is very important to monitor the number of pills you have so you can order your refills before you run out of medication. You should always have at least a one-week supply of medications. If you need to call your pharmacy to reorder your medicines each month, try to combine this call with something else that you do at the same time each month, such as paying the water or electric bill. Or set a monthly alarm on your smart phone or watch to remind you. This may serve as a reminder for you so you won't forget. Some people find that having medicines mailed to their home is the most convenient

way to make sure they have their medicine refills. Contact your transplant coordinator if you are having any problems ordering your medications or refills.

Why should I know how much my transplant medications will cost?

It is important to know your financial responsibility for your medications so you can plan ahead. In the United States, some medications may be completely covered by insurance, while others have co-payments where you pay a small part of the total cost of the medication. Often, insurance companies have a certain amount (deductible) you must meet before the insurer pays for the medications. It may be helpful for you or a family member to call your case manager or approved pharmacy provider before your medications are ordered. A toll-free number for "prescriptive authorization" is usually on the back of insurance cards. This contact person should be able to tell you what your cost is for each prescribed medication. Sometimes your transplant coordinator will have to fill out paperwork for a "prior authorization" before you can get your medications. Internationally, medication costs vary by country. You should discuss the possible cost of your medications with your transplant coordinator, social worker, and/or transplant financial counselor.

What should I do if am not able to afford my transplant medications?

As you are aware, taking your transplant medications as ordered is very important to keep you and your transplanted organ healthy. **Do not stop taking your medicines or take less of them because of a lack of money!** If you are worried about paying for your medications, notify your transplant team during business hours as soon as you think that you may have a problem. Your transplant team can help you decide if there are other options to help pay for your medicines. Transplant financial counselors or social workers available on your transplant team know about specific drug assistance programs that may be available to help. Be ready to provide financial information as well as income tax paperwork. If you live in the US, even if you lose your job or are not currently employed, it is important that you still file your federal tax return. Without federal tax paperwork, it is hard to file for drug assistance programs.

What should I do if my insurance coverage is going to change or has changed?

Work with your transplant team to get and keep insurance coverage for your medicines.

Contact your transplant team as soon as you expect ANY changes to your insurance to make sure that you will have coverage for your transplant medications.

Should I use a specialty pharmacy or can I use my local pharmacy?

Each patient may have a different preference on which kind of pharmacy to use. There are advantages and disadvantages to using a specialty pharmacy versus a local pharmacy. Some insurance companies require the use of a certain pharmacy based on your policy type. It is important for you to discuss what pharmacy is best for you with your transplant coordinator, pharmacist, or financial specialist.

How will my transplant team know if I have the right levels of transplant medicine in my body?

The amount of transplant medicine that is in the body at any one time varies from patient to patient. Many things can change how well your body is able to use your transplant medicine, like whether you take it with or without food, and the type of organ transplant you



have. Your transplant team knows if you have the right level of transplant medicine in your body by checking the amount of medicine in your blood. Your transplant team may also do testing to help predict the specific dose that will work best for you.

Why do I need to have my blood checked?

Your transplant team will check your blood regularly at the lab to see how much transplant medicine is in your body. They want to make sure that you have the right amount of transplant medicine in your body to stop rejection and side effects of the medicines.

Your blood will be checked more frequently right after transplant. After you've had your transplant for a while, your blood will be checked less frequently. It is important to take your medicines as directed and to keep your appointments at the lab. Small changes of the level of your transplant medicine can mean a big difference in how your body responds to the medicines!

Why is it important for me to come to all of my scheduled appointments with the transplant team?

Following your transplant plan is critical to your health. Your transplant appointments are your time to ask questions and participate in your care. Your transplant team will talk with you and examine you and your lab results when you come to your appointments. They want to know if you are having any troubling side effects from the transplant medicines or problems following any recommendations.

Can I take over-the-counter medicines or herbal supplements with my transplant medicines?

Do not take any over-the-counter medicines or herbal supplements without first discussing this with your transplant team. Herbal supplements are not regulated for active ingredients or contaminants like prescription



drugs are. Some over-the counter medicines may interact with your transplant medicines or cause unwanted side effects. For example, you should never take ibuprofen-containing products with tacrolimus or cyclosporine as it will put extra stress on your kidneys.

What should I do with my medications when I am in the hospital?

If you are admitted to the hospital for any reason, notify your transplant team as soon as possible. When you are discharged from the hospital, read and review your discharge medicine plan carefully with your transplant team before leaving the hospital. It is likely that your medicine plan will change. Do not assume that your medicines stay the same when you leave the hospital. Make sure to update your medicine list.

What should I do if another provider other than my transplant team starts me on a new medication?

If a healthcare provider other than your transplant provider prescribes a medicine for you, check with your transplant team before taking that medicine.

When any new medicine is given to you, always ask the provider the following questions:

- Why do I need this medicine?
- What will happen if I don't take this medicine?
- When should I take the medicine?

- How long should I take the medicine?
- What side effects should I expect and report?

If you do not fully understand any part of the information about your medicine, just ask! Your transplant team welcomes your questions and every question is important because they want you and your transplanted organ to be healthy!

What have other transplant patients done to help them take their transplant medicines correctly?

Most transplant patients are successful at taking their medications. Here some ideas that other transplant patients have used to help them be successful:

- Plan to take your medicines at times that work best for your lifestyle and routines. If needed, work with your transplant team to determine the best times for your medicines.
- Start your medicine-taking habits as soon after your transplant as possible. Try to form a habit of taking medicines at the same time every day by placing your medicines in plain view with items you use daily. For example, if you brush your teeth every morning and evening, you might want to place your medicines next to your toothbrush as a reminder. If you drink coffee in the morning and evening, you might place your medicines next to the coffee pot.
- Most people find using a pillbox or other medicine dispensers helpful to organize medicines.
- Use alarms to help remind you of when you are due to take your medicines. For example, if you keep your cell phone with you or have a watch, set the alarm to remind you to take the medicine when it is time for a dose.
- There are many smart phone apps that can help you take your medications by sending text reminders as well. Talk with your transplant coordinator or pharmacist about those they are familiar with.
- Always plan to have your medicines with you so that you can take them when it is time.
- Keep a list of your current medicines with the times you are taking them. Write down all changes to your medications as they happen.

- Keep a list of your allergies with your medication list.
- Take the current list of medicines with you to each healthcare provider appointment.
- Keep a personal record of when you take your medications every day and other pertinent information such as blood pressure, weight, blood sugars, etc. (See sample journal in appendix.)
- When you are going to be out of your routine, make a plan ahead of time so that you will be able to take your medicines on time. For example, if you are going to a movie in the evening and you normally take your medicine during that time, take your medicine with you so that you can take it on time.
- If you plan to travel, make sure you have enough medicines to last through the trip. Plan to have a few days extra in case you are delayed for any reason.
- Take your medicines with you when you travel and keep them with you at all times. Keep medicines with you in your carry-on bag when traveling by plane.
- When traveling by plane, be prepared for additional security checks related to your medications. Go to tsacares.org to be prepared for potential security checks. Here are a few ideas from tsacares.org:

- » Medications in pill or other solid form must undergo security screening. It is recommended that medication be clearly labeled to facilitate the screening process. Check with state laws regarding prescription medication labels.

You are responsible for displaying, handling, and repacking the medication when screening is required. Medication can undergo a visual or X-ray screening and may be tested for traces of explosives.

» **Inform the TSA Officer**

Inform the TSA officer that you have medically necessary liquids and/or medications and separate them from other belongings before screening begins. Also declare accessories associated with your liquid medication such as freezer packs, IV bags, pumps and syringes. Labeling these items can help facilitate the screening process.

» **3-1-1 Liquids Rule Exemption**

You may bring medically necessary liquids, medications, and creams in excess of 3.4 ounces or 100 milliliters in your carry-on bag. Remove them from your carry-on bag to be screened separately from the rest of your belongings. You are not required to place your liquid medication in a plastic zip-top bag. If a liquid, gel, or aerosol declared as medically-necessary alarms, then it may require additional screening and may not be allowed.

» **Accessories**

Ice packs, freezer packs, gel packs, and other accessories may be presented at the screening checkpoint in a frozen or partially-frozen state to keep medically necessary items cool. All items, including supplies associated with medically necessary liquids such as IV bags, pumps, and syringes must be screened before they will be permitted into the secure area of the airport.

» **Screening**

TSA officers may test liquids, gels, or aerosols for explosives or concealed prohibited items. If officers are unable to use X-ray to clear these items, they may ask to open the container and transfer the content to a separate empty container or dispose of a small quantity of the content, if feasible.

- Inform the TSA officer if you do not want your liquid medication to be screened by X-ray or opened. Additional steps will be taken to clear the liquid and you will undergo additional screening procedures to include a pat-down and screening of other carry-on property.

- If you are traveling outside your time zone, be prepared to alter the time you take your medicines. Your transplant coordinator or pharmacist can help you plan for this.
- Have a back-up plan for missed or late medicines. Sometimes, there is a one-hour window in which you can take your missed dose. Again, contact your transplant team for instruction before acting.
- You may want to consider wearing a Medi-Alert to assure any providers that do not know you that you are taking special medications for your transplant.

Transplant Medicines that might be prescribed for you

There are many different transplant medications to prevent rejection that your provider may order for you. You will find detailed information on these medicines on the following pages. Brand names refer to USA-distributed products only.

Tacrolimus (Prograf®)



Tacrolimus is used to prevent or treat rejection after transplant. It prevents rejection by inhibiting or suppressing the immune system so that the immune system does not attack the cells of the transplanted organ, causing rejection. Tacrolimus may be used by itself or in combination with other transplant medications (immunosuppressants) to prevent rejection.

Dosage:

Tacrolimus is available in 0.5 mg, 1 mg, and 5 mg capsules. Several generic forms of tacrolimus are also now available so it is important to know which one you are taking and try to stay consistent. Patients are usually asked to take a dose in the morning and in the evening, about 12 hours apart. For example, you can take your doses at 8 AM and 8 PM. It is important to take tacrolimus at the same time every day and exactly as directed to maintain a steady level of immunosuppression so that the transplanted organ is protected from rejection. Most transplant centers advise that patients take their tacrolimus no more than one hour earlier or one hour later than it is scheduled.

Side effects:

The side effects of tacrolimus vary and are often related to the blood level of the drug. Side effects are more commonly seen when levels are high, particularly in the early weeks after transplant and during treatment for rejection. The most common side effects include:

Nervous system side effects (referred to as neurotoxicities)

Side effects may include headache, insomnia (trouble sleeping), numbness and tingling of the hands and feet,

hand tremors, or an increased sensitivity to bright or blinking lights. These side effects are more commonly seen with high tacrolimus levels. Difficulty speaking and seizures are very rare side effects, but have occurred. Nervous system side effects usually improve or resolve as the tacrolimus level decreases.

Kidney dysfunction (referred to as nephrotoxicity)

Tacrolimus can cause the blood vessels that carry oxygen-containing blood in the kidneys to get smaller or constrict. When these tiny vessels constrict, the flow of oxygenated blood into the kidney is decreased. Because of this effect on the kidneys, some patients may have high blood pressure, high blood levels of potassium, low blood levels of magnesium, and/or abnormal kidney function tests (an elevated blood urea nitrogen [BUN] and creatinine). Your provider will maintain the lowest tacrolimus level that is safe for you. Long term problems with kidney function can occur in some patients.

Increased risk of infection

If you are taking tacrolimus, your immune system is suppressed. Because your body's natural ability to fight infections is decreased, you may be more likely to develop infections. You are at greatest risk for developing infections when your tacrolimus level is high, usually during the first three months after transplant. You are also at risk for infection if you are being treated for rejection and receiving higher doses of tacrolimus and other anti-rejection medications.

Other side effects that may be experienced with tacrolimus are nausea, diarrhea, high blood sugar, and mild hair loss.

Additional information:

- Do not change the dose of tacrolimus or take it more or less often than prescribed for you by your transplant provider.
- Tacrolimus levels are monitored through blood tests. Levels are monitored daily in the early period after transplant, then less frequently over time. Most patients have a tacrolimus level checked monthly by the time they are several months post-transplant. Although management of immunosuppression varies

by transplant center, levels are higher during the first 3 months after transplant or during treatment for rejection. Levels are usually lowered slowly over time and may continue to decrease after one to two years if there is no rejection.

- Tacrolimus levels should be drawn before taking a dose and about 12 hours after the previous dose. This is called a **trough level** and is the lowest level of tacrolimus that is present in the blood. Check with your transplant center for the timing of the trough. For example, if your transplant center wants you to have the trough drawn at 12 hours, and you take tacrolimus at 8:00 AM and 8:00 PM, then have your trough level drawn at 8:00 AM prior to taking that dose.
- On days when you are having blood work, be sure to have your labs drawn before taking tacrolimus so that an accurate trough level is obtained. Bring a dose with you to take after your labs have been drawn so you will not be late taking your dose.
- Your dose of tacrolimus may be increased if you are experiencing rejection. The dose may be decreased if you have an infection or if you have complaints or complications due to side effects of the medication.
- Take your tacrolimus dose in the same way and at the same time every day to maintain a stable level.
- Food may affect the tacrolimus level. Some transplant centers prefer that patients not eat an hour before or an hour after taking tacrolimus. It is best to take tacrolimus in a consistent manner to decrease the variability of absorption. Please check with your coordinator or transplant pharmacist for your center's guidelines.
- You should not eat grapefruit or pomegranate or drink grapefruit juice while taking tacrolimus. Chemicals in these fruits can interfere with the enzymes that break down tacrolimus and can increase tacrolimus levels. An increased tacrolimus level increases your risk of infection and serious side effects.
- Some medications should not be taken at the same time as tacrolimus. Consult with your transplant coordinator or pharmacist for full information about your medication regimen.

Tacrolimus interacts with some other medications, causing higher or lower levels. Always check with your transplant coordinator before starting any new medications to be sure that it does not interfere with tacrolimus.

- If you miss a dose of tacrolimus, take it as soon as you remember. If it is near the time for the next dose, skip the missed dose and resume your regular dosing schedule. Do not double the next dose. Contact your transplant coordinator if you have missed a dose as your levels may need to be monitored more frequently.
- Store tacrolimus capsules at room temperature and away from the reach of children and pets.
- If you are planning to become pregnant, discuss the use of tacrolimus with your transplant provider and obstetrician/gynecologist.

Cyclosporine (Sandimmune[®], Neoral[®], Gengraf[®])



Cyclosporine is used to prevent or treat rejection after an organ transplant. Cyclosporine prevents rejection by inhibiting or suppressing the immune system so that the immune system does not attack the cells of the transplanted organ, causing rejection. Cyclosporine may be used by itself or in combination with other anti-rejection medications (immunosuppressants) to prevent rejection.

Cyclosporine is available in two products (formulations), but these products are not equal. They are cyclosporine (Sandimmune[®]) and cyclosporine-modified (Neoral[®] and Gengraf[®], and come in Oral Capsule, Liquid Filled: 25 MG, 50 MG, 100 MG, and Oral Solution: 100 MG/1 ML. Cyclosporine is made by several pharmaceutical companies. Your body absorbs these cyclosporine formulations in different ways. Because of this difference in absorption, be sure that your pharmacist always gives you the brand of cyclosporine that has been prescribed for you.

Both types of cyclosporine are available as capsules. The cyclosporine-modified products (Neoral® and Gengraf®) are also available as liquids. You may find that the liquid form of cyclosporine tastes better if diluted with milk, chocolate milk, or orange juice. Mix cyclosporine and a room temperature liquid in a glass or cup and stir the mixture with a metal spoon. Styrofoam or soft plastic cups should not be used since the medication may cling to the foam container or plastic. Hard plastic containers are acceptable for safety reasons with small children.

Cyclosporine is prescribed to be taken once a day or twice daily. It should be taken at the same time each day to ensure a steady level of immunosuppression. Most transplant centers advise that patients not take their cyclosporine more than one hour earlier or one hour later than it is scheduled.

Side effects:

The side effects of cyclosporine vary and are usually related to the blood level of the drug. Side effects are more commonly seen when levels are high, particularly in the early weeks after transplant and during treatment for rejection. The most common side effects are:

Nervous system side effect (referred to as neurotoxicities)

Side effects may include headache, hand tremors, trouble sleeping (insomnia), and numbness and tingling of the hands and feet. These side effects are more commonly seen with a high level and usually improve or resolve as the level is lowered.

Kidney dysfunction (referred to as nephrotoxicity)

Cyclosporine can cause the blood vessels that carry oxygen-containing blood in the kidneys to get smaller or constrict. When these tiny vessels constrict, the flow of oxygenated blood into the kidney is decreased. Because of this, some patients may have high blood pressure, high blood levels of potassium, low blood levels of magnesium, and/or abnormal kidney function tests (an elevated blood urea nitrogen [BUN] and creatinine). Your provider will maintain the lowest cyclosporine level that is safe for you. Long term problems with kidney function can occur in some patients.

Infection:

Cyclosporine suppresses the immune system. Because your body's natural ability to fight infections is decreased, you may be more likely to get infections. You are at the greatest risk of developing infections when your cyclosporine level is high, particularly during the first three months after transplant. You are also at risk for infection if you are being treated for rejection with increased immunosuppression.

Cosmetic side effects:

Cyclosporine can cause some changes in your appearance. Excessive hair growth can occur. Patients may also develop bleeding and tenderness of the gums. The gums can swell and become overgrown. This gum enlargement is also known as gingival hyperplasia. Acne may develop or worsen in adolescents or younger adults taking cyclosporine.

Additional information:

- Do not change the dose of cyclosporine or take it more or less often than prescribed for you by your transplant provider.
- Cyclosporine levels are monitored through blood tests. Levels are monitored daily in the early period after transplant, then less often over time. Most patients have a cyclosporine level checked monthly by the time they are several months post-transplant. Although management of immunosuppression varies by transplant center, levels are usually higher in the early period after transplant or during treatment for rejection. Levels may be decreased and maintained at a lower level after one to two years if there have been no episodes of rejection.
- Cyclosporine levels are usually drawn before taking a dose and about 12 hours after the previous dose. This is called a trough level and is the lowest level of cyclosporine that is present in the blood. Check with your transplant center for the timing of the trough. For example, if your transplant center wants you to have the trough drawn at 12 hours, and you take cyclosporine at 8:00 AM and 8:00 PM, then have your trough level drawn at 8:00 AM prior to taking that dose.

- On days when you are having blood work, be sure to have your labs drawn before taking cyclosporine so that the trough level is accurate. Bring a dose with you to take after your labs have been drawn so you will not be late taking that dose.
- Your dose of cyclosporine may be increased during an episode of rejection or to prevent rejection if your level is low. The dose may be decreased if you have an infection or if you have complications due to side effects of the medication.
- Take your cyclosporine in the same way and at the same time every day to maintain a stable level.
- You should not eat grapefruit or pomegranate or drink grapefruit juice while taking cyclosporine. Chemicals in these fruits can interfere with enzymes that break down cyclosporine and can increase cyclosporine blood levels. An increased cyclosporine level increases your risk of infection and serious side effects.
- Some medications should not be taken at the same time as cyclosporine. Always check with your transplant team before starting any new medication.
- If you miss a dose, take it as soon as you remember. If it is near the time for the next dose, skip the missed dose and resume your regular dosing schedule. Do not double the next dose. Contact your transplant coordinator if you have missed a dose. Levels may need to be monitored more frequently.
- Cyclosporine capsules and liquid should be stored at room temperature and away from direct sunlight. Cyclosporine capsules are packaged in individual blister packs. Do not open the blister pack until you are ready to take the medication because air and light will damage the medication. An opened bottle of cyclosporine liquid may be used for up to two months.
- Be sure to keep cyclosporine and all medications out of the reach of children and pets.
- If you are planning to become pregnant, discuss the use of cyclosporine with your transplant provider and obstetrician/gynecologist.

Prednisone (Deltasone®), Prednicot) or Prednisolone (Orapred®)



Prednisone is a steroid used to help prevent or treat rejection in organ transplantation. It prevents rejection by suppressing the cells in the immune system that cause rejection. Prednisone is usually given with tacrolimus or cyclosporine. Although some patients require prednisone for life, many transplant recipients are weaned from steroids within weeks to a few months after transplant. Some centers do not use prednisone unless it is needed to treat rejection.

Dosage:

Prednisone is available in several strengths including 1 mg, 2.5 mg, 5 mg, 10 mg, 20 mg, and 50 mg tablets. It is also available in a liquid form called prednisolone which comes in Oral Solution: 5 MG/5 ML. Prednisone is usually prescribed once daily and should be taken in the morning. If taken at night, it can affect sleep. If prednisone is prescribed twice daily, you can take a dose in the morning and the second dose in the afternoon or with dinner.

Side effects:

Prednisone may cause side effects, but these vary depending on the dose, frequency, and duration of your treatment. The most common side effects include high blood sugar, increased appetite, weight gain, stomach irritation and/or stomach ulcers, mood changes, irritability, anxiety, and acne. You may also retain fluids which can make your face, hands, and ankles look "puffy." Side effects that can occur with higher doses over a longer period of time include bruising, high blood pressure, high cholesterol levels in the blood, high blood sugar, muscle weakness, night sweats, delayed wound healing, vision problems due to cataracts and glaucoma, and growth delay in children. Patients are encouraged to take calcium with vitamin D supplements in order to minimize bone loss. As always, first discuss adding any new medications or supplements with your transplant provider.

Additional information:

- Be sure that you know your correct dose of prednisone and that you have the correct strength of tablets. Because prednisone is available in several strengths, it is easy to get confused.
- Do not change the dose of prednisone or take it more or less often than prescribed.
- If prescribed once a day, prednisone should be taken in the morning so that you do not have trouble sleeping.
- If prednisone is to be stopped, the dose should be decreased slowly over several weeks. If prednisone is stopped suddenly, serious complications may occur.
- Prednisone should be taken with food because this medication can cause stomach upset.
- If you miss a dose, take it as soon as you remember. Do not double the next dose. Call your transplant coordinator if you have missed a dose.
- If you are taking prednisone, examine your skin routinely for bruising. If you have any wounds that don't seem to be healing well, notify your transplant coordinator or other provider. Maintain good care of your skin.
- Your provider may advise you to avoid concentrated sweets, like candy bars and soda, while taking prednisone. High blood sugar can occur with higher doses of prednisone. Patients who already have diabetes may find it more difficult to control their blood sugar when they are taking prednisone.
- If you are taking prednisone, you may need to take an antacid or an acid blocker so that you do not get a stomach ulcer. If you develop a stomach ulcer from prednisone, you may have an upset stomach or abdominal pain. Call your transplant coordinator with any of these symptoms so medications and treatment can be prescribed promptly.

Sirolimus (Rapamune®)



Sirolimus is used to prevent rejection in organ transplant recipients. It prevents rejection by inhibiting the cells in the immune system that cause rejection. Sirolimus may be the only transplant medicine (immunosuppressant) that is prescribed for you, but sometimes providers prescribe it to be taken with tacrolimus, cyclosporine, or prednisone.

Dosage:

Sirolimus is available in 0.5 mg, 1 mg, and 2 mg tablets. It is also available in a liquid. Sirolimus is usually taken once or twice daily and should be taken on time to maintain a stable level of immunosuppression, just like tacrolimus and cyclosporine. The liquid form of sirolimus should be mixed with two ounces of water or orange juice in a glass or plastic cup. Do not use a Styrofoam or paper cup because sirolimus may cling to the container. Sirolimus should not be taken with apple or grapefruit juice. The tablet should be swallowed whole and never crushed or broken.

Side effects:

The side effects of sirolimus vary and are often related to the level of the drug. The most common side effects are an increased risk of infection, nausea, diarrhea, a low red blood cell count (anemia), high cholesterol and/or triglyceride levels in the blood, a low white blood cell count, headache, acne, mouth sores, arthritis, swelling of the hands and feet, muscle cramping, and delayed wound healing. Side effects usually resolve or lessen as the dose is decreased.

Additional information:

- Do not change the dose of sirolimus or take it more or less often than prescribed for you by your transplant provider.
- Check with your transplant coordinator or pharmacist about the correct time to take your dose of sirolimus. If you miss a dose, do not double the next dose. Contact your transplant coordinator for instructions.
- Sirolimus is usually not started immediately after transplant like other anti-rejection medications

because it can affect wound healing. Patients may be prescribed cyclosporine or tacrolimus for the first six to eight weeks after transplant, then changed to sirolimus.

- Due to the effects of sirolimus on wound healing, always notify your transplant team prior to having any surgery.
- Sirolimus levels are monitored through blood tests. Levels are monitored one to two times weekly in the early period after transplant, then less frequently over time. Most patients have a sirolimus level checked monthly by the time they are several months post-transplant. Your ideal sirolimus level depends on whether it is the only transplant medicine (immunosuppressant) you are taking or if you are taking it with tacrolimus or cyclosporine. The level also depends on your transplant center's management of immunosuppression.
- Sirolimus levels should be drawn one to four hours before taking a dose or 20 to 24 hours after the previous dose if it is taken once a day. This is called a trough level and is the lowest level of sirolimus that is present in the blood. Your coordinator will tell you what time of day to have your level drawn.
- On days when you are having blood work, be sure to have your labs drawn before taking sirolimus so that an accurate trough level can be obtained. Bring a dose with you to take after your labs have been drawn so you will not be late taking your dose.
- Sirolimus tablets should be swallowed whole without crushing or breaking. The medication is coated on the outside of the pill, so breaking or crushing can result in losing some of the drug.
- If you take the liquid form of sirolimus, mix your dose in one to two ounces of orange juice or water in a glass or cup. Discard the syringe used to measure the liquid sirolimus after each use. Do not use a Styrofoam or paper cup because sirolimus may cling to the container. Rinse the container with another ounce of water or orange juice and swallow that amount as well. You should also rinse your mouth with more water or orange juice after swallowing the medicine. Some patients have developed mouth ulcers from the liquid form. These ulcers usually get better over time or resolve if the dose is decreased.
- Store sirolimus tablets at room temperature and out of the reach of children. The liquid form of sirolimus

must be refrigerated before and after the bottle is opened. The bottle of medicine will be good for one month after opening.

- If you are planning to become pregnant, discuss the use of sirolimus with your transplant provider and obstetrician/gynecologist.

Azathioprine (Imuran®)



Azathioprine is used to help prevent or treat rejection in organ transplant recipients. Azathioprine is a “helper” transplant medicine (immunosuppressant) and may be given with tacrolimus, cyclosporine, and/or prednisone.

Dosage:

Azathioprine is available as a tablet. It is usually prescribed once daily and should be given at about the same time each day.

Side effects:

Azathioprine may lower the number of white blood cells in your body, the cells that fight infection. It may also lower platelets, which are cells that help your blood clot. Other side effects may include nausea, vomiting, and rash. Azathioprine may also be harmful to the liver resulting in an increase in the liver function tests (LFTs). It can cause an inflammation of the pancreas (pancreatitis).

Additional information:

- Do not change the dose of azathioprine or give it more or less often than prescribed.
- The dose of azathioprine may be decreased by your transplant team if you have an infection or if you have complaints or complications due to side effects of the medication. The dose may be increased during an episode of rejection or to prevent rejection.
- Azathioprine interacts with a medication called allopurinol, a drug used to treat gout. Call your transplant coordinator if you are diagnosed with gout or if a provider has prescribed this medication for you. Azathioprine and allopurinol are usually not ordered together.
- If you are taking azathioprine and considering becoming pregnant, consult your transplant provider and obstetrician/gynecologist.

Mycophenolate mofetil (Cellcept®) **Mycophenolate sodium (Myfortic®)**

Mycophenolate is used to help prevent or treat rejection in organ transplant recipients. It is usually given with tacrolimus, cyclosporine, and/or prednisone.

Dosage:

Mycophenolate is available in two formulations: Cellcept® and Myfortic®. Mycophenolate mofetil (Cellcept) is available in 250 mg capsules and 500 mg tablets. It can be prescribed up to four times a day but is generally taken twice daily. Mycophenolate sodium (Myfortic®) is available in 180 mg and 360 mg tablets. Myfortic® is enteric-coated to help decrease stomach upset and other gastrointestinal (GI) side effects. Typically, it is dosed twice daily. Both forms of the drug should be taken at about the same times each day.

Side effects:

Mycophenolate may lower the number of white blood cells in your body, the cells that fight infection. It may also lower the number of platelets which help your blood clot. Other side effects may include nausea, stomach irritation, vomiting, and diarrhea. Side effects may decrease over time or resolve with a lower dose of mycophenolate. The enteric-coated form of mycophenolate helps decrease GI side effects in some patients.

Additional information:

- Do not change the dose of mycophenolate or take it more or less often than prescribed.
- The dose of mycophenolate may be increased during an episode of rejection or to prevent rejection. The dose may be decreased if you have an infection or if you have complaints or complications due to side effects of the medication.
- Mycophenolate capsules should be swallowed whole and should not be opened. The powder inside the capsule may be harmful if inhaled. Mycophenolate tablets should not be broken or crushed.
- On days when you are having blood work and your transplant team monitors mycophenolate blood

levels, be sure to have your labs drawn before taking mycophenolate so that an accurate trough level can be obtained. Bring a dose with you to take after your labs have been drawn so you will not be late taking your dose.

- If you miss a dose, take it as soon as you remember. Do not double the next dose. Contact your transplant coordinator if you have missed a dose.
- If you are planning to become pregnant, it is important to discuss the use of this medication with your transplant provider and obstetrician/gynecologist. Women of childbearing age should use contraception while on this medication. If mycophenolate is discontinued, contraception should be continued for an additional six weeks to ensure that the drug is eliminated from the body before becoming pregnant. New laws now require your healthcare provider to give you, "Mycophenolate REMS Overview & Your Birth Control Options" booklet. You will sign a form stating that you received this booklet and that this information was discussed with you. There is a higher risk of losing the pregnancy (miscarriage) in the first 3 months and a higher risk that the baby will have birth defects. If of childbearing age, pregnancy tests will be performed before starting and during mycophenolate treatment. If pregnancy does occur while on this medication, notify your healthcare providers (transplant and obstetrician/gynecologist) immediately. If this does occur, your healthcare provider is required to report any pregnancies to the Mycophenolate Pregnancy Registry at www.mycophenolaterems.com/PregnancyRegistry.aspx

Antithymocyte globulin: ATG **(Thymoglobulin®, Atgam®)**

Antithymocyte globulin (ATG) is a transplant medicine (immunosuppressant) given in some transplant centers as a "pre-conditioning" agent immediately before transplant surgery. One dose of ATG is given before or during transplant surgery to reduce the body's immune response and possibly reduce the risk of rejection. Some transplant centers also use ATG to treat rejection that does not resolve with steroids.

ATG is available only as an intravenous (IV) solution and is administered in the hospital.

Side effects:

During the ATG infusion, patients may have fever, chills, rash, low blood pressure, increased heart rate, or difficulty breathing. To minimize this “infusion reaction,” patients are usually treated with methylprednisolone (Solumedrol®), acetaminophen (Tylenol®)/paracetamol, and diphenhydramine (Benadryl®) before and during the infusion. The infusion may also be slowed down to decrease side effects. Patients are closely monitored to watch for any of these side effects.

Other side effects that can occur later, after the infusion, include a low white blood cell count, a low platelet count, pain, headache, fever, abdominal pain, diarrhea, high blood pressure, nausea, swelling of the hands and feet, and an increased level of potassium in the blood.

Because ATG can increase the risk of viral infections, patients may receive medications to prevent these viruses.

Everolimus (Certican®, Afinitor, Zortress & Afinitor Disperz [US Brand])

Everolimus is used to prevent rejection in organ transplant recipients. It prevents rejection by inhibiting the cells of the immune system that cause rejection. Everolimus may be the only transplant medicine (immunosuppressant) that is prescribed for you, or it may be prescribed to be taken with tacrolimus, cyclosporine, or prednisone.

Dosage:

Everolimus is available in tablets. Afinitor Oral Tablet: 2.5 MG, 5 MG, 7.5 MG, 10 MG; Afinitor Disperz Oral Tablet for Suspension: 2 MG, 3 MG, 5 MG; Zortress Oral Tablet: 0.25 MG, 0.5 MG, 0.75 MG

Everolimus is also available as a dispersible tablet that breaks apart or disperses in water. Everolimus is usually prescribed twice daily. Doses should be taken 12 hours apart. It is important to take everolimus on time every day to have a stable level of immunosuppression. Most transplant centers advise that patients not take their everolimus more than one hour earlier or one hour later than it is scheduled.

Side effects:

The side effects of everolimus vary and are often related to the level of the drug. The most common side effects are an increased risk of infection, high cholesterol and/or triglyceride levels in the blood, a low white blood cell count, anemia, acne, nausea, diarrhea, and headache. Side effects usually resolve as the dose is decreased.

Additional information:

- Do not change the dose of everolimus or take it more or less often than prescribed for you by your transplant provider.
- Everolimus is usually not started immediately after transplant like other anti-rejections medications. It is usually prescribed at six to eight weeks after transplant.
- The dispersible tablet should be placed in a plastic cup with 25 ml (about one ounce) of water. Wait for about two minutes so the tablet can break up in the water. Then swallow the entire solution. Rinse the cup with another 25 ml (one ounce) of water and swallow that amount of water as well. The maximum dose of the dispersible tablet that can be dissolved in 25 ml of water is 1.25 mg. If your dose is greater than 1.25 mg, you will need more water to mix with the medication. Be sure to discuss how to prepare this medication with your transplant coordinator or pharmacist.
- Your dose of everolimus may be increased during an episode of rejection. The dose may be decreased if you have an infection or if you have problems with side effects of the drug.
- Everolimus tablets should be swallowed whole without crushing or breaking. The medication is coated on the outside of the pill, so breaking or crushing can result in losing some of the drug.
- Store everolimus tablets at room temperature.
- If you are planning to become pregnant, discuss the use of everolimus with your transplant provider and obstetrician/gynecologist.

Although taking your transplant medicines can seem overwhelming, you can be successful. It takes asking lots of questions, planning ahead, and creating a routine. We wish you all the best!

Daily Home Recording Sheet

Use this sheet to keep track of how you are doing each day. You may also bring this sheet to your appointments to discuss with your transplant team.

Date									
Pulse									
Blood Sugar									
Weight									
Blood Pressure	AM								
Blood Pressure	PM								
Temperature									
Fluid Intake									
Daily Activity	minutes								

ITNS is the first professional nursing organization to focus on the professional growth and development of the transplant clinician. ITNS offers nurses a forum for learning about the latest advances in transplantation and transplant patient care. To access more transplant education materials for patients and healthcare workers, please visit the International Transplant Nurses website at itns.org.

For a list of selected references please contact ITNS at info@itns.org

ITNS would like to thank Astellas for their generous contribution to this educational endeavor.

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