Making Your Transplant Medicines Work for You After Organ Transplant

International
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Society

Always follow the recommendations of your Transplant Team. 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. Immunosuppressant medicines are divided into four categories depending on how they act in the body to prevent rejection. We will call them your transplant medicines throughout the rest of this brochure. Later in this brochure, we will talk more specifically about these four types of transplant medicines.

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 doctor 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 doctor could harm your new organ. This brochure will help you understand your transplant medicines and give you some tips to help you take your medicines as ordered.

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. You can think of your new organ as “swimming” in the transplant medicine. When there isn’t enough “water” or transplant medicine in your blood, then the swimming pool is empty and your transplant organ can’t swim properly. To keep your medicine level at the same level all the time, take your medicine on time, every day.

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 Immunosuppressant medicines?

Transplant 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. One of the ways to stop the immune system from destroying 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 take 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. Immunosuppressant medicines, and taking them correctly, are your lifeline to long-term health!

Why do I need all these medicines?

In addition to your transplant medicines, you may need other medicines to reduce the side effects from the transplant medicines. These side effects may include infection, high blood pressure and high blood sugars. All of the medicines are necessary to keep you and your organ healthy.

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 your medicine is used by your body 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.

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 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?

Your Transplant Team will talk to you and examine you when you come to your appointments. They want to know if you are having any troubling side effects from the transplant medicines. If you think that you are having side effects from the medicine, tell your healthcare provider so that, together, you can decide how to reduce the troubling side effects.

Should I talk with my Transplant Team about what "Brand-Name" and "Generic" means with my medicines?

Yes. Please discuss this with your transplant doctor and pharmacist. You should stay on either brand OR generic transplant medicines. Do not switch between brand and generic immunosuppressant medicines without consulting with your Transplant Team.

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. Some of these products interact with your transplant medicines or cause side effects. For example you should never take ibuprofen-containing products with tacrolimus or cyclosporine as it will put extra stress on your kidneys.

Are there any websites to help me with my medicine taking?

Yes, there are quite a few available on the web. There is one that is specific to transplant called MyMedSchedule® at: https://secure.medactionplan.com/mymedschedule/

What if I miss a pill or am feeling sick?

The medicines ordered for you work to keep you and your transplanted organ healthy. Your medicines will help you if you take them on time, every day. If you miss a pill or are feeling ill, here are some helpful tips:

Missed pill

If you miss a dose, do not double the next dose. Contact the Transplant Team for instructions. It is best to stay on schedule with all your medicines.

Even though you may not feel different if you miss a dose of medicine, your transplanted organ may suffer the effect.

Side effects

Know the possible side effects of the medicines you are taking and what you should report to your Transplant Team.

Contact your Transplant Team if you are feeling too ill to take your medicines because of nausea, vomiting or diarrhea.

Going to the hospital

If you are ever readmitted to the hospital, review your discharge medicine plan carefully with your Transplant Team. 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.

Adding a new medicine

If a healthcare provider other than your transplant healthcare 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 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?***
- ***What side effects should I report?***

If you do not fully understand any part of your medicine, just ask! Your Transplant Team welcomes your questions and every question is important. Your Transplant Team is there to help you.

Getting medicines

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. This may serve as a reminder for you so you won't forget.

Most people find that having medicines mailed to their home is the most convenient way to make sure they have their medicine refills.

Paying for my medicines

Work with your Transplant Team to get and keep insurance coverage for your medicines.
If your insurance changes for any reason, contact your Transplant Team to make sure that your new insurance plan covers your medicines.

Drug companies may be able to give you your transplant medicines at little or no cost. Let your Transplant Team know if you are worried about being able to pay for your medicines.

If you are worried that you cannot pay for your transplant medicines, let your Transplant Team know right away. Do not stop taking your medicines because of a lack of money! Notify your transplant office during business hours as soon as you think that you may have problems. Your Transplant Team can help you decide if there are other options to help obtain your medicines. Be ready to provide financial information as well as income tax paperwork. Remember that, 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.

Taking and scheduling your medicines

Always take your medicines as directed on time, every day. Never stop, start or change a dose without discussing this with your Transplant Team.

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.

Some 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, set the alarm to remind you to take your medicines, and have your medicines with you so that you can take them when the alarm sounds. If your watch has an alarm on it, set it to remind you to take your medicines every day.

MyMedSchedule® offers text notification via your cell phone to help remind you to take your medicines.

Keep a list of your current medicines with the times you are taking them. When there are new medicines ordered or there are changes, write down the changes.

Take the current list of medicines with you to each healthcare provider appointment.

Planning ahead

Make a plan ahead of time so that when you are out of your routine you will be able to have your medicines. 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. 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.

If you are traveling outside your time zone, be prepared to alter the time you take your medicines. You will want to take doses of the immunosuppressant medicines no more than 12 hours apart.

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. For example, your back-up plan may be to have an extra dose of your medicines at work so that, if instructed, you can then take the dose you missed earlier that morning.

It is important to contact your pharmacy ahead of the time for refills in case the medicine needs to be ordered. Try to form a habit of calling for refills on the same day each month. Keep your Transplant Team and pharmacy contact information with you at all times in your purse or wallet in case you need to call them to get extra medicines.

Medicines that might be prescribed for you

Immunosuppressant medicines are divided into four categories depending on how they act in the body to prevent rejection:

- Calcineurin inhibitors
- Corticosteroids
- Anti-metabolites
- Target of rapamycin inhibitors

You will find detailed information on these medicines on the following pages. Brand names refer to USA-distributed products.

Calcineurin Inhibitors

Tacrolimus (Prograf®)

Purpose:	Tacrolimus is used to prevent and/or treat rejection of the new transplanted organ. You will usually take it in combination with other immunosuppressant medicine. You will likely have to take this medicine for the rest of your life.
How to take:	The pills come as 0.5 milligram (mg) tablets, 1 mg tablets, or 5 mg tablets Tacrolimus is taken **twice daily**. One dose should be taken in the morning and one dose in the evening. The doses should be **12 hours apart.** For example: 8:00 am and 8:00 pm. By taking your medicines 12 hours apart, you will keep medicines at an even level in your blood. This can decrease the chance of rejection (taking doses too far apart in time) and side effects (taking doses too close together in time). Your Transplant Team will decide on the correct dosage for you based on your blood levels, other lab tests and the possible side effects of tacrolimus.
Monitoring:	Your Transplant Team will let you know how often you will need to have lab tests. On the day when your tacrolimus level is to be measured, **do not take your morning dose** until your blood has been drawn. Your blood should be drawn about 12 hours from your last evening dose of tacrolimus. This level is called the trough level.
Precautions:	Tacrolimus may interact with some commonly used medicines as well as over-the-counter medicines. **ALWAYS check with your Transplant Team before starting any new medicines even if it is ordered by another healthcare provider.** Do not take ibuprofen or ibuprofen-containing products (i.e. Motrin®, Advil®). Ibuprofen may add stress to your kidneys. Grapefruit, grapefruit juice and herbal products containing grapefruit extract should not be taken while taking tacrolimus. Grapefruit can affect how your body absorbs tacrolimus. High fat meals prior to lab tests may change blood levels of tacrolimus. Store tacrolimus at room temperature and away from children. It is important to call your Transplant Team if you feel you missed a dose or took too many doses. They will guide you in what to do. Missed or late doses affect your organ even if you do not feel different. Minimize sun exposure on your skin. Wear sun block with sun protection factor of 40 or more when your skin is not covered.
Main Side Effects:	Increased risk of infection Abnormal kidney function Headache, tingling in hands or feet, tremors (hands shaking), seizures Nausea, diarrhea, loss of appetite High blood sugar, high cholesterol Trouble sleeping

Cyclosporine USP Non-Modified (Sandimmune®)
Cyclosporine USP Modified (Neoral®)

Purpose:

Cyclosporine is used to prevent rejection of the transplanted organ. You may take this medicine in combination with other immunosuppressives. You will likely have to take this medicine for the rest of your life.

How to take:

The pills come as soft gelatin capsules in 25 mg tablets, or 100 mg tablets.
It is also available in liquid form usually in a bottle with 100 mg in it. Each millimeter of the liquid has 50 mg of cyclosporine.

There are two types of formulations of cyclosporine:

- Standard oil-based non-modified formulation
- Modified formulation

DO NOT MIX THESE TWO TYPES as this could affect your blood levels. The label on the box of medicine will indicate whether it is a modified version or not.

Cyclosporine is taken **twice a day**. One dose should be taken in the morning and one dose in the evening. The doses should be taken **12 hours apart.** For example: 8:00 am and 8:00 pm. By taking your medicines 12 hours apart, you will keep medicines at an even level in your blood. This can decrease the chance of rejection (taking doses too far apart in time) and side effects (taking doses too close together in time).

Your Transplant Team will decide on the correct dosage for you based on your blood levels, other lab tests and the possible side effects of cyclosporine.

Monitoring:

You will have frequent lab tests during the first few months as determined by your transplant center’s protocol.

Your blood level will help the Transplant Team to determine the amount of cyclosporine you need to take to prevent rejection and minimize side effects from the medicine.

On the day when your cyclosporine level is to be measured, **do not take your morning dose until your blood has been drawn.** This should be approximately twelve hours from your last evening dose of cyclosporine. This level is called the trough level.

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Calcineurin Inhibitors (cont.)

Cyclosporine USP Non-Modified (Sandimmune®)
Cyclosporine USP Modified (Neoral®)

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Precautions:

Cyclosporine may interact with some commonly used medicines as well as over-the-counter medicines. **ALWAYS check with your Transplant Team before starting any new medicine even if it is ordered by another physician.**

Do not take ibuprofen or ibuprofen-containing products (i.e. Motrin®, Advil®). Ibuprofen may add stress to your kidneys.

Grapefruit, grapefruit juice and herbal products containing grapefruit extract should not be taken while taking cyclosporine. Grapefruit can affect how your body absorbs cyclosporine.

Store cyclosporine at room temperature and away from children.

It is important to call your Transplant Team if you feel you missed a dose or took too many doses. They will guide you in what to do. Missed or late doses affect your organ even if you do not feel different.

Minimize sun exposure on your skin. Wear sun block with sun protection of 40 or more when your skin is not covered.

Main Side Effects:

Increased risk of infections
Headache, tremor (shaking of hands), seizures
Abnormal kidney function
High blood pressure
High blood sugar, high blood cholesterol, high blood triglycerides
Trouble sleeping
Swelling
Increased hair growth (note: for females, they may have hair growth on their upper lip and unwanted areas), darkening and thickening of hair
Overgrowth of your gums
Gout
Increased risk of infection.

Corticosteroids

Prednisone (Deltasone®)
Prednisolone (SoluMedrol®, Medrol®)

Purpose:	Prednisone helps prevent and treat rejection of the transplanted organ. You may be weaned from this medicine or you may have to take this for the rest of your life. This will vary from person to person and will be decided by your Transplant Team.
How to take:	The pills come as 1 mg, 2.5 mg, 5 mg, 10 mg, or 20 mg tablets It is best to take prednisone with food to decrease the risk of stomach upset. Your doctor may order your prednisone to be taken once a day or twice a day. If you take prednisone once a day, you should take it in the morning. If you are ordered to take it twice a day, try to take your evening dose a while before you go to sleep so that it doesn't interfere with your sleep.
Monitoring:	Prednisone is not measured by a single blood level. Your Transplant Team will determine the dosage.
Precautions:	**NEVER STOP** taking prednisone abruptly. This medicine needs to be gradually decreased over time. Always discuss this with your Transplant Team. **Take with food** as prednisone can be irritating to your stomach lining. You may require medicine for acid reflux during this period. Report any stomach pain or dark colored stools to your physician. Prednisone can **affect your mood**; you may feel energetic or you may feel low; you may feel very happy or you might feel angry and irritable. It is important to be aware of this possibility so that you and your family can be prepared. Discuss any concerns with your Transplant Team. Minimize sun exposure on your skin. Wear sun block with sun protection factor of 40 or more when your skin is not covered.
Main Side Effects:	Increased risk of infection Increased weight gain due to fluid retention and increased appetite Muscle weakness High cholesterol, increased blood glucose (steroid-induced diabetes) Stomach ulcers Difficulty with wound healing Acne, oily skin Mood swings, anxiety Increased hair growth Change in appearance: your face may become more round (moon-face) and you may develop a fat pad between your shoulder blades Bone loss Cataracts, glaucoma.

Anti-Metabolites

Mycophenolate Mofetil (Cellcept®) (MMF)
Enteric-Coated Mycophenolic Acid (Myfortic®) (EC-MPA)

Purpose:	Mycophenolate mofetil (MMF) is given with other medicines to help prevent rejection of the newly-transplanted organ. <u>You may have to take it for the rest of your life.</u>
How to take:	The MMF pills come as 250 mg tablets and 500 mg tablets. Liquid is available. The Enteric-Coated Mycophenolic (Acid EC-MPA) pills come as 180 mg tablets. MMF is usually taken two times each day but may be taken 3-4 times per day to reduce any stomach side effects. Taking MMF with food can decrease its ability to work for you.
Monitoring:	Blood levels for Enteric-Coated Mycophenolic Acid can be drawn. Other lab work may include: Complete blood count (CBC): gives your Transplant Team information about your white blood cells and platelets, which can be affected by MMF, and show a need to change the dose. Kidney function tests and liver enzymes: gives your transplant doctor information on how MMF is working on the kidney and liver.
Precautions:	It is important to report to your Transplant Team if you are experiencing nausea, vomiting and/or diarrhea. This may be a side effect of MMF and can alter all your medicine levels. MMF may lower the amounts of certain blood cells called platelets. You should report any unusual bruising or bleeding to the Transplant Team. Report to the Transplant Team if you notice any blood in your stool as this medicine can cause **gastrointestinal bleeding**. Minimize sun exposure on your skin. Wear sun block with sun protection factor of 40 or more when your skin is not covered. May decrease the effectiveness of birth control medicines. Always use back-up methods when you are taking MMF. MMF may cause damage to an unborn baby. Let your Transplant Team know if you are planning to become pregnant. MMF should not be opened or crushed. If the contents of the pill come in contact with your skin, wash with soap and water. If eye contact occurs, rinse eyes with plain water.
Main Side Effects:	Nausea, vomiting, diarrhea Gastrointestinal bleeding Decreased white blood cells and platelets which may increase your potential for infection and bleeding

Anti-Metabolites

Azathioprine (Imuran®)

Purpose:	Azathioprine is given with other medicines to help prevent rejection of the transplanted organ. You may have to take it for the rest of your life.
How to Take:	Pills come in 50 mg tablets. Usually taken once per day. May take with food to reduce stomach upset.
Monitoring:	Your Transplant Team may order other lab tests to monitor your response to the medicine. Complete blood count (CBC): gives your Transplant Team information about your white blood cells and platelets, which can be affected by azathioprine, and show a need to change the dose. Kidney function tests and liver enzymes: gives your transplant doctor information on how azathioprine is affecting these organs.
Precautions:	**Do not take with Allopurinol,** which is used for long-term treatment of gout. Report any bruising or bleeding to your Transplant Team. Minimize sun exposure on your skin. Wear sun block with sun protection factor of 40 or more when your skin is not covered.
Main Side Effects:	Nausea, vomiting Decreased white blood cells and platelets which may increase your risk for infection and bleeding

Target of Rapamycin Inhibitors

Sirolimus (Rapamune®)

Purpose:	Sirolimus may be given to you with other drugs to prevent rejection of the transplanted organ. This medicine is usually not prescribed immediately after transplant surgery due to the risk of slow wound healing near the incision. You may have to take this medicine for the rest of your life.
How to Take:	The pills come in 1 mg, 2 mg tablets. Liquid form is available for children and when a small dose is needed. Sirolimus may be taken once or twice daily. Sirolimus should be taken four hours apart from other immunosuppressant medicine.
Monitoring:	Blood levels may be drawn to determine sirolimus levels in your blood. Your Transplant Team may order other lab tests to monitor your response to the medicine. Complete blood count (CBC): gives your Transplant Team information about your red blood cells and platelets, which can be affected by sirolimus. Kidney function tests and liver enzymes: gives your transplant doctor information on how sirolimus is affecting these organs.
Precautions:	Report to your Transplant Team any fever, rash, diarrhea, chills, sore throat and/or other signs of infection. If you are diagnosed with a cancer, you must report this to your Transplant Team immediately. Minimize sun exposure to your skin. Wear sun block with sun protection factor of 40 or more when your skin is not covered. Report to your Transplant Team if your urine turns dark, your skin has a yellow color, and/or your stools are light-colored. This may indicate liver problems. Sirolimus may cause wounds to heal slowly. If you have any surgeries after your transplant, it is very important to coordinate this with your Transplant Team as they may need to change the dose.
Main Side Effects:	Delayed wound healing High blood pressure High cholesterol and triglycerides Rash, acne Swelling of the legs, weight gain Anemia Diarrhea Muscle aches Increased risk of infection and malignancies

Your Medicine Diary

Allergies ______________________________

Drug Intolerance ______________________________

Date: ________ Day: ________				Date: ________ Day: ________				Date: ________ Day: ________				Date: ________ Day: ________				Date: ________ Day: ________			

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	AM	AM	AM	AM	AM	AM	AM	AM
Blood Pressure	PM	PM	PM	PM	PM	PM	PM	PM	PM
Temperature									
Fluid Intake									
Daily Activity	minutes	minutes	minutes	minutes	minutes	minutes	minutes	minutes	minutes

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