

MEDICATION ADHERENCE

FOLLOWING GUIDELINES FOR CARE AFTER LIVER TRANSPLANTATION



Introduction

Guidelines are recommendations or instructions that are given for best possible outcome. It could be the care instructions for your new sweater that say to “wash in cold water” or a recipe that calls for 1 cup of milk. If you wash your sweater in warm or hot water, or use water instead of milk in your recipe, you might get an OK result, but not the best.

Of course, following guidelines for care after transplant is much more important and impacts your child’s health. Changing doses, skipping doses, or not giving medications as prescribed will affect the outcome – like washing that wool sweater in hot water. It might be clean, but it may not fit after washing!

Your child’s health care providers prescribe medications very carefully and for specific reasons. The prescribed medication and the dose of that medication is based on your child’s weight, the desired action or outcome of the medication, the possibility of side effects, and interactions with other medications. The dose of a medication may also affect how well other medications work, so skipping a dose will change how another medication works in the body. For example, your child may be prescribed fluconazole for a fungal infection. Fluconazole increases the tacrolimus level so your transplant team will adjust your child’s dose of tacrolimus so that the level is not too high during treatment with fluconazole. The baseline dose of tacrolimus will be resumed when fluconazole treatment is completed. If you miss giving your child any doses of fluconazole, the tacrolimus level will fluctuate, which may increase the risk of rejection.

Your transplant team provides a plan of care with essential medications to help your child achieve the best possible outcome with good liver function after transplant. Following this plan of care every day is the most important thing you can do to help maintain your child’s health. Being adherent, or good adherence, means that you are sticking to the medical plan of care for your child. You are giving your child medications every day as prescribed without missing doses, staying in contact with your transplant coordinator, and getting labs and attending clinic routinely as requested.



This information should not replace medical advice from your doctors or medical team. We encourage our readers to follow their transplant team’s medical advice and reach out to their doctors and medical team for further recommendations.

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Transplant care plans vary by center, but recommendations for care commonly include:

- **Know all your child's medications**
 - You should be able to state why the medication is prescribed, the dose, times given daily and for how long, the most important side effects, and any special instructions for that medication. For example, grapefruit should be avoided because it will increase tacrolimus levels.

- **Give your child's medications daily and on time as prescribed**
 - Most medications are taken one or two times daily, but some may be as often as 4 times a day. Work with your transplant coordinator or advanced practice nurse to organize a schedule that promotes adherence.
 - If you are having trouble adhering to your child's schedule, talk to your transplant team about adjusting the schedule or medications. Arrange a schedule that follows the medication administration guidelines, but also fits into you and your child's daily routine so that taking meds is convenient. If you are having problems giving magnesium three times a day, for example, the dose may be adjusted so that you are giving it twice daily. Most parents find that giving medications twice daily works best, but this is not always possible.
 - If you are having problems giving your child medications daily and on time, contact your transplant coordinator. There is always a way to adjust the schedule and medications to promote adherence.

- **Use adherence strategies to be sure you never miss giving medications**
 - Early on after liver transplant, many parents find it helpful to follow a written schedule or check-off list until they are familiar with the routine. Medications also change frequently in the early months after transplant, so it is important to keep up with all the changes. Your transplant coordinator or advanced practice nurse can help you stay current.
 - Download a medication app on your phone. There are hundreds of medications apps available. Review several and find the one that is most helpful for you. Here are some examples that are used frequently by transplant patients and caregivers.
 - Medisafe Medication Manager
 - Dosecast: My Pill Reminder App
 - Mango Health Medicine Reminder App
 - Walmart Wellness (formally CareZone): A Med List in Your Pocket



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- Pill containers are very helpful in organizing medications. Many of these come with alarms to remind you of dose times. There are many types of pill containers in a wide price range and from basic containers to lots of additional alarms and options. Choose what is best for organizing your child's medications.



- If your child's medications are mostly liquid, you will have to prepare the medications in syringes. Many parents find it helpful to organize their child's liquid medications every evening for the following day. Some parents use portable "caddies" used for craft supplies to hold the syringes until med time.



- Always keep a copy of your child's medication schedule with you. This can be a hard copy, a picture of the schedule on your phone, or a list within a medication app. This should always be easily accessible. If your child has an appointment in transplant clinic or another provider's office or is seen in an emergency room, it will help to have a current list of meds available.

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- **Manage your child's medications to improve adherence**
 - Make sure you always have an adequate supply of your child's medications, especially anti-rejection medications. Having extra doses on hand whenever you leave the house can be helpful. In case you are delayed and need to give your child a medication you will have it with you. It's important to plan ahead!
 - Make sure you always have an adequate amount of each medication.
 - Contact your pharmacy when you need refills of your medications or set up an automatic refill or delivery. Working with your pharmacy is another way to improve or maintain good adherence.



Talk to your pharmacist about how they can help you refill your medications on time. Many pharmacies offer refills by automated messaging, texts or through websites. Some pharmacies will deliver or ship medications to your home.

- Contact your transplant coordinator when you have 1 refill remaining so updated refills can be sent to the pharmacy. Be sure to do this when you have a 7-10 day supply remaining. Calling at the last minute for refills increases the risk of missing one or more doses.
- **Schedule appointments**
 - Routine and follow-up appointments should be scheduled as needed with your transplant team and other health care providers. Your child will be seen more frequently in the first six months after liver transplant. In the long term, most patients are seen annually or every 6 months for a comprehensive clinic appointment. It is important to stay on schedule with these appointments so that if your child is having any complications, any changes can be detected early.

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- **Obtain labs as requested by your team**

- Lab results may be needed as often as every week, but if your child is several years post-transplant, it could be every month or every 2 months. If your child is being monitored after treatment for rejection, labs may be more frequent for a while. Use a lab that is most convenient for you and your child. Many labs now schedule appointments online, so it is easy to find an open time that works for you. You can also arrange for a standing appointment, like the first Monday of every month at 8:00 AM.

Schedule Appointment

✓ REASON FOR VISIT

TESTING LOCATION

SCHEDULE

2.0 mi
1. Quest Diagnostics
1011 Care Way Suite 101
Inside of Mary Washington
Tests at this location
All Other Tests
Glucose Tolerance
Urine Drug Electronic
T-SPOT.TB test
Urine Drug Paper
Urine Drug DOT - Electronic
Urine Drug DOT - Paper
Health & Wellness Screen

Sun Closed
Mon 8:00 AM-4:30 PM
Tue 8:00 AM-4:30 PM
Wed 8:00 AM-4:30 PM
Thu 8:00 AM-4:30 PM
Fri 8:00 AM-4:30 PM
Sat 8:00 AM-12:00 PM

Handicap, Lot MJR

GET DIRECTIONS

WALK IN NOW
Location currently closed

SCHEDULE APPOINTMENT

- **Be aware of your financial responsibility for medications**

- Know the cost of your child's medications so that you can plan ahead. Some medications may be completely covered by insurance, while others have co-pays that can range from a few dollars to being quite expensive. Often, insurance companies have a deductible you must meet until coverage begins. 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 will be able to advise you.
- If you are having financial difficulties related to medications, please discuss this with your transplant coordinator or social worker. There are some programs to help defray costs. Your transplant team will work with you to be sure you are able to get all your child's medications.

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- **Obtain medical procedures or tests as requested**
 - Procedures and tests are often needed, particularly in the early months after liver transplant to monitor your child's liver function and health. For example, your team may request an X-ray, liver ultrasound, liver biopsy, or a cholangiogram to assess your child's health status.
- **Keep track of your child's transplant health**
 - This may seem challenging at first because there is so much going on, but it becomes easier over time. Ask for help on how to get started. Your transplant center may have a website or app with a record of your labs and test result.
- **Maintain routine care with your child's primary care physician**
 - Your child's local pediatrician is an important partner in your child's transplant care and will work collaboratively with your transplant team to monitor your child's health. Your child will need to see the pediatrician for routine illnesses, immunizations, and if your child ever has an emergency medical need or is hospitalized in your local area. Your transplant team will work with your local pediatrician for any labs, testing or procedures that may be needed.



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