## MEDICATION ADHERENCE

STARZL NETWORK

for Excellence in Pediatric Transplantation

INFORMATION FOR TEFNS

Younger children rely on their caregivers and family for their care, but as you become older, it is important that you learn about your transplant care and take on more responsibility. Developing independence is an important goal in being a teen – you want to become more self-sufficient not only with your transplant care, but also with school, your activities, and maybe getting that first job. Gradually taking on more responsibility and learning more about your care will take some time, but your caregivers and your transplant team are there to help you with this transition. Start with small steps, like watching your parent fill your medication container, then doing it with their help, then eventually doing it by yourself. As you do more, your parents can check in to be sure you are doing OK, then eventually as you are doing more on your own, you can let them know whenever you need some help. The goal is for you to become the manager and owner of your transplant care!

Here are some things you can to do get started to be on your own:



Listen while your parent calls your pharmacy or watch them when they go to the pharmacy website to order refills. Then, you try to do it on your own. Your parents can be nearby to help you.



Download an app on your phone and set alarms to take your meds or to remember lab appointments. You can remind your parent when you need to go for labs!



Think about what reminders will work best for you. This could be an alarm on your phone, an app, or even a sticky note on your bathroom mirror.



What's the best schedule for you to take your meds? This might need to be adjusted for your school routine or after school activities.



Talk to your parent and transplant team about how you feel taking on more responsibility. Slow and steady progress is the best! There are lots of ways to start taking small steps towards being independent – and adherent – with your transplant care.



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INFORMATION FOR TEENS

Many teens have problems with taking their medications, getting labs as requested and attending appointments.

- Sometimes this is because they are very busy with school, activities, and work. Teens often say they don't miss their meds on purpose, but that they "forget" because they were busy or didn't take their meds with them when they went out, or maybe they just fell asleep watching a movie and missed the evening dose.
- Some teens may be concerned about side effects from medications. If you have any side
  effects of medications that bother you (maybe feeling like your face is puffy because of your
  prednisone dose or your hands are shaky because your tacrolimus level is a little high), be sure
  to talk to your transplant coordinator or physician. Sometimes doses can be changed, or
  medications adjusted so that any side effects you may have are less of a problem.
- Maybe you miss your meds when you are out with friends and don't want to take them when you are having fun at a football game or at a movie or in front of your friends. You can talk to your parents or your transplant team about the best way to be sure to take your meds when you are out. Sometimes, just being with one friend who understands will really help.

If you are having problems with your self-care, talk to your parents about some ideas that might help. You can also talk to your transplant coordinator, advanced practice nurse and other members of the transplant team. They are there to help you and they want you to succeed! It can also help to talk to other teens who have had transplants to share ideas about how to stay on top of your care. Some transplant centers have special events and activities for teens such as camps, interactive web sites, and support groups. Maybe your peers will have the best suggestions to help you take your meds on time!

Having a transplant and being worried about your care and how to get everything done every day can be very emotional for some teens. If you are feeling overwhelmed and like you are the only one having problems after transplant, there is always someone to help. Your transplant team, particularly your social worker and transplant psychologist, can help you. You can contact your transplant coordinator to arrange an appointment with them.

