



Purple Playas Power Pointers

Ages: 12 to Young Adults



WRITTEN BY:

Rochelle Lentini,

EARLY CHILDHOOD/SOCIAL-EMOTIONAL
CONSULTANT AND PARENT

Parker Lentini,

PPF VICE-PRESIDENT
AND YOUNG ADULT WITH CHRONIC ILLNESS







REVIEWED BY


Purple Playas Advisory Team


Releasing the Reins Transitioning Medical Care to Your Teen/Young Adult

Transitioning care to your child may actually be more difficult for you, as the parent, than your child. As parents, we want to protect our kids...no matter how old they are. If your child has a life-long chronic illness, medical self-care begins the day your child is diagnosed. But at some point, we must “release the reins” and allow for our teens/young adults to manage their own medical care. This will be easier on both of you if you pace coaching your teen, so that he/she is ready when reaching adulthood. Of course, we need to keep in mind that medical self-care should align with development and maturity level of your child. As you monitor and promote your teen’s independence, it will build confidence, self-esteem, and resilience.

While your child transitions his medical care, help him understand all components of his/her disease/illness and its care. This includes promoting open communication with each other, therapists, and medical professionals. Involve and monitor his/her decisions and when appropriate allow him to make his own choices. Here are five tips to consider as you guide your teen/young adult in caring for his own medical needs.

-  **Know, manage, and discuss medications.** Teach your child the name, purpose and dosage of each medication. Discuss the importance of each medication and taking them as prescribed. It is also important that he/she knows possible side effects and drug reactions so that he/she doesn’t put himself in harmful situations. As your teen becomes more responsible, have him/her order medication refills. If he/she has questions/concerns about his medications he should talk to the pharmacists.
-  **Track for trends.** Teach your child how to track his own symptoms, concerns, changes, and progress. Tracking trends can help guide conversations with the doctor. There are many apps out there. In addition, these are great resources are:
 -  Got Transition. For a list of resources related to health care transition and organized by topic, visit: <https://www.gottransition.org/resources/index.cfm>
 -  National Resource Center for Patient/Family-Centered Medical Home: Building Your Care Notebook. For free download visit: <https://medicalhomeinfo.aap.org/tools-resources/Pages/For-Families.aspx>
 -  Body Check Journal. To order visit: www.bodycheckjournal.com
-  **Create an “organizational system” that is simple and easy.** Your teen may need some assistance with coming up with an “organizational system” that works for him/her: create a location and schedule for meds (pill cases, mark on calendar, work into daily routine, set alarm on phone, etc.), store records/labs, tests, and keep medical notes/reminders. Some find it helpful to use a binder with tabs, store records in a bin, scan to save electronically, save onto cell phone, or create files in a file drawer.

 **Embed exercise into daily routines.** Some teens/young adults will be involved in activities that incorporate exercise, others will need encouragement. If your child needs help with maintaining exercise routines, try to find fun and/or clever ways to get exercise into each day. For example, stretch/exercise while riding in the car and/or at stop lights, during TV commercials, during play, right before getting out of bed, when getting into bed, in the shower/bath (if needed, with slip guards/hand rails), etc.

 **Medical appointments and management.** Beginning around age 14-18, have your teen/young adult help make appointments and medical calls (insurance company included). Your teen can also check-in and out of the doctor's office. Honor if he/she wants to have a private conversation/examination with the doctor (usually begins around age 12-15). Your child's body is your child's body. Only he/she truly knows how it feels and what is happening with his/her health. Try to get the doctor to talk to your child, not only you. Remember it's your child's body that the doctor is treating.

Some pediatric specialists may see your teen/young adult through college or age 26. Just be aware that there may be rules around this that may impact your health insurance and/or treatment plan. Sometimes there is difficulty with accessing medications that are approved for specific pediatric diagnoses versus adult terminology for the "same disease." Always work with your medical provider for the best course of action and medical care.

Moving from pediatric care to adult care will take some research and recommendations. Try beginning this process of finding an adult doctor at age 17. Communicate with your teen's pediatric doctor, so she can assist in this transition. Some teens find it helpful to start seeing the adult doctor while still seeing the pediatric specialist until they feel that the transition of care will be as smooth as possible. Help your teen understand that it might also take trial and error to find the right match for the best medical care.

*With a little guidance, teens and young adults
can build independence by learning to manage their own medical needs.*

Visit "Purple Playas" on Facebook and let us know what your teens/young adults have found helpful when transitioning from pediatric care to adult medical care?



**Purple Playas
Foundation™**
Hope for kids with chronic illness

www.purpleplayasfoundation.org

You are welcome to share this information. Please site proper attribution credit to Purple Playas Foundation.