



Division for Children & Youth with Special Health Needs

Tips for Parents and Caregivers of Children Youth 14-17

Guiding Youth to Take Charge of Their Health



As parents and caregivers, you play an important role in preparing your teen to be responsible for as much of their own health as possible. Within a very short time, your teen will be transitioning to adult health care providers. These tips are intended to help you support your teen to develop the skills they need to make responsible decisions about their health. The age range given is intended only as a guideline; and should be based on their cognitive or developmental abilities. Hopefully, you have been encouraging your teen, with your help if needed, to keep a notebook with important medical information including health conditions, names and phone numbers of doctors, up to-date medicines and dosages, allergies, any discharge instructions from hospital stays, notes from doctor appointments and test results.



Directions: *Resources for Your Child's Care*, an organizing notebook and a resource guide, is a comprehensive tool for organizing health information. Chapter 9 has many useful tools and strategies for your adolescent to increase their self-management skills, www.mass.gov/dph/specialhealthneeds/directions.



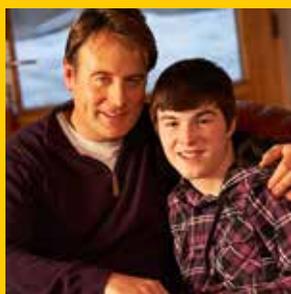
In addition to these tips, the following website has lots of checklists, resources and suggestions to help you as you begin to talk with your child about their health issues, www.mass.gov/dph/youthtransition.



1. Be sure your teen understands all her medical conditions. Help her practice explaining them to others, both in detail and in a three-sentence summary.

2. By now, your teen should know the names of her medications; what they do; doses and side effects.

- Encourage her to ask her doctor or pharmacist about what foods or other medicines can affect how well each medication works. Teach her how to check for side effects and interactions.
- Continue to remind her about the need to use medications as prescribed, and to never use anyone else's medications or share her medicine with others, especially when she may feel pressured by peers.
- Ask how she might respond if she was asked to share or give her meds to someone else.
- Continue to support her to be the main person responsible for remembering when to take her medications. A smart phone app or alarm clock may be helpful reminder tools.
- It is normal for her to make some mistakes, so check on her occasionally to make sure she is doing it correctly. This is especially important for critical medicines during adolescence when there are many things competing for her attention.



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- Your teen should know which medications she needs to carry with her for immediate use, such as a rescue inhaler for asthma or anti-seizure meds, and to know when and how to use them.
 - Supervise her when she calls in for her prescriptions. Be sure she understands to call in before she runs out of meds.
- 3. Your teen should know her allergies, how to avoid them and how to treat reactions to them.**
- For food allergies, your teen should know how to ask questions about food items. You may want to suggest she put together a list of safe foods for when she eats out with friends.
 - Make sure she knows the warning signs that she is getting sick or needs to seek help.
 - Review with her what to do. For example, calling 911.
- 4. Help your teen make an emergency card that lists all her medical conditions, medications, allergies, doctors' names and specialists, along with all other emergency contact numbers. If your child has a smartphone, there are many apps where this information can be stored.**
- 5. Encourage your teen to take the lead and do most of the talking during healthcare visits and to meet with the healthcare provider alone for most or all of the visit, if they wish.**
- Encourage providers to feel free to discuss private topics with your teen, such as sexuality, depression, substance abuse, particularly misusing prescribed medications.
 - Encourage your teen to prepare questions for the healthcare visit and to write down or record the responses during the visit so she will not forget.
 - At age 18, ALL healthcare decisions legally become her responsibility unless you remain involved through guardianship.
 - If your teen will not be able to make healthcare decisions at age 18 because of cognitive or developmental disabilities, talk about it now with your healthcare provider or social worker. You may need to apply for guardianship or a healthcare power of attorney.
 - Encourage your teen to start calling and scheduling some of her own appointments.
- 6. Talk to your teen about what kind of health insurance you have, what your co-pay is, and what the numbers on the card mean.**
- Have her carry a copy of the card along with any required co-pays when she goes to appointments.
 - Begin to work with your teen to get information on healthcare insurance options once they turn 18.
- 7. Discuss with your teen's pediatrician what the practice's transition policy is, if it hasn't already been made clear to you.**
- Ask for recommendations from your teen's providers and others you know who have already transitioned to adult providers.
 - Check which insurance the adult providers accept. This may depend on whether she will remain on your insurance for several years or apply for healthcare coverage based on her disability at age 18.
- 8. This is a good time to begin to develop a healthcare transition plan with your teen and her healthcare providers.**
- If she is going to college or for further training outside of your local area, you want to begin to find healthcare providers in the new location.
 - If your teen will be moving from school to work, you may want to begin discussions about how her health may impact her future employment choices or ability to live independently.

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- If your teen will continue to need an Individualized Education Plan (IEP) through her 22nd birthday, it is important that health self- management goals and skills are included.
- If she will need a 504 plan, which spells out any modifications and accommodations needed, encourage her to communicate with the school and the healthcare providers in the new location. She may ask you to assist in the process.

9. Encourage your teen to be as independent as possible.

- Make sure your teen knows how to use public transportation, as appropriate, so she can get to appointments independently if necessary.
- Explore available community supports, resources and activities, especially groups for teens with similar medical conditions that may be helpful to her.