Division for



Children & Youth with Special Health Needs

Tips for Parents and Caregivers of Children Ages 11-13















As parents and caregivers, you play an important role in preparing your child to be responsible for as much of their own health as possible. Within a few years' time, your child may be ready to transition to adult care providers. These tips are intended to support you as you encourage your child's independence and work with him on the skills he needs to make good decisions about his health. Hopefully, you have been keeping a notebook with your child's important medical information including health problems, names and phone numbers of doctors, up-to-date list of medicines and dosages, allergies, discharge instructions from hospital stays, notes from doctor appointments, labs or medical tests. You and your child can update it together after appointments.

Directions: Resources for Your Child's Care, an organizing notebook and a resource guide, is a comprehensive tool for organizing your child's information and can be found at 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. Continue to talk with your child about his medical conditions. Your child has probably developed a good understanding of his body and health needs by this time.

- Ask what his concerns are now and for the future.
- Help him to decide what health information is important to share about his condition(s) with others. For example, what may happen if he has a seizure and what they should do.
- Help him to become comfortable sharing the information; you might suggest role-playing different settings.

2. Your child should know the names of his medicines; what they do; and how they help him.

- Remind your child to use medicine correctly, to check with a trusted adult such as a parent, caregiver or school nurse, if he needs help taking his medications.
- He needs to know never to use anyone else's medicine or share his medicine with anyone.
- Let your child know that it is dangerous and illegal to share medicines.

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3. Support your child to be the main person responsible for taking his medications. You may want to start by observing him and then gradually increasing responsibility.

- Perhaps, start with the least important meds, and then move to more important ones as your child shows ability and responsibility.
- Work with your child on the best ways to remember to take his medicines by helping him fit them into his daily routine.
- A chart or smart phone app may be helpful reminder tools.
- Make sure your child knows how to read medication labels, for both over-the-counter and prescription medicines.
- Show your child how to call for medicine or supply refills before they run out.
- Consider taking your child to the pharmacy with you. Introduce him to the pharmacist, explaining the pharmacist's job and how the pharmacist can help him.
- Be sure your child knows where his emergency medications are kept and whom he should go to if he needs them, such as the school nurse or camp director, when he is away from home.

4. Your child should know his allergies and how to avoid them.

- Teach him the importance of asking about things he is allergic to in other settings. For instance, if he is allergic to latex, asking the healthcare provider if the gloves are latex.
- He should know what steps to take if he is exposed and how to contact 911.
- Be sure your child wears an emergency bracelet that lists all their allergies and that he carries an emergency contact card at all times.
- 5. By this time, your child has most likely experienced some form of medical emergency, review with him how well it was handled. Ask him for suggestions for improving any emergencies in the future. Consider purchasing a cell phone for your child to program in his emergency numbers, specialty providers and contact information.

6. Encourage your child to do most of the talking during healthcare visits.

- Encourage him to meet alone with the healthcare providers, for all or part of each appointment.
- Encourage him to prepare a list of questions for the doctor before visits.
- Be sure that you and his healthcare team involve him in all decisions about his healthcare.

7. Encourage your child to be as independent as possible by participating in social activities.

- Work with your child to identify available resources, social activities and peer support groups to increase healthcare skills.
- You may want to ask his healthcare team for suggestions.

8. Work with your child to understand how healthy eating is important, particularly if he has specific nutritional restrictions.

9. This may be a good time for your child to learn about how to use public transportation so when he is older, he can get to his appointments independently.

10. Be sure your child understands his health insurance including:

• What is health insurance and why is it important.

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- The type and name of the insurance company.
- 11. Begin to talk with your child about what he would like to do in the future.
- 12. Talk with your child's school about changes in his healthcare needs.
- As your child grows, any special accommodations he has been receiving may need to be adapted.
- This may also require changes to his Individual Health Care Plan.
- 13. If your child has an Individualized Education Plan (IEP) or a 504 plan, it should be reviewed annually.

Note: An IEP will identify your child's learning style. In addition, the IEP includes the academic areas where your child will need assistance and includes how his progress will be measured.

Note: A 504 plan is an accommodation plan that lists the specific assistance your child needs so your child has the same opportunity to learn as his peers. For example, your child may require an elevator to move between floors.

Note: Both your child's Individual Education Plan (IEP) and/or 504 accommodations plan, should include goals for increased health self-management skills, as cognitively and developmentally appropriate.