





All children develop at different rates and the age range given is intended only as a guideline. You are the best judge of how and when you begin discussions with your child based on their cognitive or developmental abilities.

It may be helpful to keep a notebook with your child's medical information. You can include description(s) of your child's health problem(s), up-to-date list of medicines and dosages, allergies, special equipment, notes from doctor appointments and hospital stays, along with any test results.

Directions: Resources for Your Child's Care, an organizing notebook and a resource guide, can be a useful 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. If you have not already, begin by explaining your child's medical condition to her in simple terms.

- Start small using easy-to-understand descriptions whenever possible. You can get more detailed as your child grows and can understand more.
- Perhaps you might begin by asking your child what she understands about her health condition so you can correct any misconceptions.
- It is important to keep your answers simple answer as directly as possible.
- Explain how all people, whether they have a disability or not, have things that they are good at and things they find harder to do.
- Talk about how it is important for everyone to work on the areas they find difficult, as well as develop their strengths.

2. Teach your child about her medications or special treatments.

- Help her to understand how each of her medications helps her to be healthy. For example, explaining to her that the yellow pill helps to control her seizures.
- She needs to know that she should never use anyone else's medicine or share her medicine with anyone.
- Work with your child on ways to remember when and how to take her medicines.
 - Help her fit them into her daily routine, as you do with brushing teeth.
- A chart, smart phone or alarm clock may be useful reminder tools.

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• Your child should learn where her emergency medications or extra supplies, such as feeding tubes, are kept; and, who to go to if she needs them, such as the school nurse or camp director, when she is away from home.

3. Help your child understand any special nutrition or feeding changes that might be needed for her medical condition. Perhaps your child can go shopping with you or help with special feeding preparations.

4. Make sure your child knows what she is allergic to, and have her practice telling people about her allergies.

- Help her understand what happens when she has an allergy. For example does she get itchy? Is it hard for her to breathe? Does she get a rash?
- Make sure she knows what to do if she is exposed. For example, does she need an EPI pen?
- You may want to role-play an emergency with her to be sure she can get help right away.
- Be sure she knows how to call 911.
- If your child's allergy is a food allergy, make sure she knows exactly what to avoid, like peanut butter or eggs.
- You may want your child to wear an emergency bracelet that lists all her allergies
- You may want your child to keep an emergency card with her at all times.

5. Explain to your child the names of doctors and other health providers, and how each one works to help her feel better.

6. Encourage your child to be as independent as possible and participate in as many activities as possible.

- This includes helping with chores, playing with friends, using a computer, etc.
- You may want to ask your child's healthcare team about developmentally appropriate skills and activities.

7. Try encouraging your child to talk with members of her healthcare team, to ask questions about her condition.

- You might want to work with her to make a list of questions before her appointments.
- You can ask her if she would like to ask the questions or if you should.
- Work with her healthcare team to be sure they make eye contact and speak directly to her, not through you.

8. Teach your child to notice the symptoms that are warning signs that she is sick, and how to let you or other trusted adults (relatives, teachers, and school nurse) know. Help your child to pay attention to her body and to speak up if she notices any changes.

9. Consider purchasing a cell phone for your child with important emergency numbers: you, other trusted adults and 911.

10. Talk with your child's school about her healthcare needs.

- Your child may need special accommodations to be successful in school.
- Your child's school team should work with you to develop a comprehensive Individual Health Care Plan (IHCP) regardless of an IEP or 504 accommodations.
- Work with your healthcare team to see if he may be eligible for an Individualized Education Plan (IEP) or a 504 plan.

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Note: An Individualized Education Plan (IEP) will identify your child's learning style. In addition, the IEP includes the academic areas where your child will need assistance, performance measures, and the setting for each activity.

Note: A 504 plan is an education plan which lists specific assistance your child needs and the changes the school will be responsible for providing, so your child has the same opportunity to learn as her peers. For example, your child may require an elevator to move between floors.