As parents and caregivers, you play an important role in preparing your children to be responsible for as much of their own health as possible. When the time is right, you will help them transition to adult care providers. These guidelines will help you teach your child about his medical condition, increase his comfort around healthcare providers and prepare him to make decisions about his health.

1. Explain your child’s medical conditions to her with words she can understand. You can get more detailed as your child’s understanding of her body improves. Practice with her on how to talk about her condition(s) with others, such as the school nurse, coaches, etc.

• It’s helpful to keep a notebook or binder that keeps all of your child’s important medical information organized. You should include the name(s) of the health problems, names and phone numbers of the 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.

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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 (parent, caregiver, school nurse) if he needs help taking his medication, and to never use anyone else’s medicine or share his medicine with anyone. Let your child know that it’s dangerous and illegal to share medicines.

- Allow your child to be the main person responsible for remembering his medications and taking them. You should observe him at first and gradually allow him to be more independent as he is able. Start with least important meds and move to more important ones as your child shows ability and responsibility.

- Work with your child on best ways to remember to take his medicines, and help him fit them into his daily routine. A chart or alarm clock may be helpful as a reminder.

- Show your child how to call in for medicine or supply refills, and teach him when to do it based on how much is left.

- Make sure your child knows how to read medication labels, for both over-the-counter and prescription medicines.

- Take your child to the pharmacy with you and introduce him to the pharmacist, explaining the pharmacist’s job and how the pharmacist can help him.

- Teach your child where his emergency medications are kept and whom to go to if he needs them (school nurse, camp director, etc.) when he is away from home.

3. Your child should know her allergies and how to avoid them. Teach her how and when to ask about allergies (for instance, if the gloves are latex or if she is allergic to the food). If your child’s allergy is a food allergy, make sure she knows exactly what to avoid and how to read labels to see if foods contain those ingredients. She should know what steps to take if she is exposed.

4. Teach your child to notice the symptoms that are warning signs that he is getting sick, and to let you or other trusted adults (relatives, teachers) know. Help your child pay attention to his body and to speak up if he notices any changes. Review with your child what to do if he doesn’t feel well and you are not with him (such as tell a trusted adult, like a neighbor, teacher, school nurse, etc.).

5. Help your child make an emergency card that lists your child’s medical conditions, medications, allergies, doctors’ names and numbers, and emergency contact numbers. Have her carry it in her wallet. Consider purchasing a cell phone for your child, and program in her emergency numbers.

6. Teach your child the names of his doctors and other health providers, why he sees them, and how to find their phone numbers.

7. Encourage your child do most of the talking during healthcare visits, and let her meet alone with the healthcare providers for part of the appointment. Teach her how to prepare a list of questions for the doctor before visits. Involve your child in decisions about her healthcare.

8. Encourage your child to be as independent as possible and participate in all aspects of life (helping with chores, recreational activities, etc.). Teach your child about available community resources. Start looking for teen resources and peer support related to the condition. Ask the healthcare team for ideas.

9. Teach your child about healthy eating and any dietary changes that might be needed for his medical condition. Have your child go shopping with you, help pick appropriate foods and join in food preparation — especially if he has a limited diet.

10. Help your child learn about using public transportation as appropriate, so when she is older, she can get to appointments independently.

11. Talk to your child about your health insurance: what insurance is, the name of the insurance your family has, the need to take care of the insurance card, and who in the family is the “subscriber.”

12. Communicate with your child and his school regarding appropriate career, employment or education options for after high school. Make sure an IEP (individualized education program) and/or a 504 plan (which spells out modifications and accommodations needed for your child to have an opportunity to learn as his peers) are in place, if appropriate.
REACH

Rapport, Empowerment, Advocacy, through Connections and Health is a program for teens and young adults ages 12 – 24 with special healthcare needs and their families, created by teens and young adults with special healthcare needs.

Contact Information

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