Next Steps to Help Children Understand Their Health

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 her medical condition, increase her comfort around healthcare providers and prepare her to make decisions about her health.

1. Explain your child’s medical condition(s) to him in simple terms. You can get more detailed as your child grows and can understand more. Ask your child life specialist or a member or your healthcare team for information on how to explain medical conditions in a way your child can understand.
   • 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.

2. Teach your child the names of her medicines, what they do and how they help her.
   • Remind your child to use medicine correctly, to check with a trusted adult (parent, caregiver, teacher) before she takes medication, and to never use anyone else’s medicine or share her medicine with anyone.
   • Start teaching your child how to read medication labels for both over-the-counter and prescription medicines.
   • Work with your child on best ways to remember to take her medicines, and help her fit them into her daily routine, like you do with brushing teeth. Start having your child be the main person to remember her meds, with you checking on her and helping her to take or inject the medicine. A chart or alarm clock may be helpful as a reminder.
   • Teach your child where her emergency medications are kept and whom to go to if she needs them (school nurse, camp director, etc.) when she is away from home.

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3. 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 and help with food preparation — especially if his diet is limited.

4. Make sure your child knows what she is allergic to, and have her practice telling people about her allergies. Explain what happens to her if she has a reaction and what she should do. 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.

5. Teach your child the names of his doctors and other health providers and tell him why he sees them.

6. Encourage your child to be as independent as possible and participate in all parts of life (helping with chores, playing with friends, participating in sports, etc.). Discuss age-appropriate skills and activities with your child’s healthcare team.

7. Encourage your child to talk with members of her healthcare team, to ask questions or talk about her medications or whatever topics she brings up. Work with her to make a list of questions before appointments. This will allow her to be comfortable talking about her medical condition, help you and the team be aware of what she does and does not understand, and allow her to be relaxed and confident talking to healthcare providers. Allow your child to talk with the healthcare provider alone if she would like or if the healthcare provider suggests it.

8. Teach your child to notice the symptoms that are warning signs that he is 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.).

9. Consider purchasing a cell phone for your child and program in her emergency numbers — to call you, other trusted adults and the doctor’s office.

10. Communicate with your child’s school about his healthcare needs. Your child may need special accommodations to be successful in school. Find out from your healthcare team if he may be eligible for an IEP (individualized education program) or a 504 plan (which lists specific assistance your child needs and the changes the school will provide so your child has the same opportunity to learn as his peers). If your child already has an IEP or a 504 plan, work with the school to keep it updated.

Contact Information

REACH Line
267-426-5569
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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.