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

1. Make sure your teen understands all her medical conditions. Help her practice explaining them to others, both in detail and in a three-sentence summary.
   - It's helpful to keep a notebook or binder to organize all of your teen’s medical information. Include the name(s) of her medical conditions, names and phone numbers of doctors, an up-to-date list of medicines and dosages, allergies, discharge instructions from hospital stays, notes from doctor appointments, and the results of labs or medical tests. Your teen should be responsible for updating the binder — with your help — after visits, changes in medications, etc.

2. Make sure your teen knows the names of his medicines, what they do, doses and side effects. Encourage your teen to ask his doctor or pharmacist about what foods or other medicines can affect how well his medication works. Remind your teen about the need to use medications as prescribed, and to never use anyone else’s medications or share his medicine with others. Explain that it is dangerous and illegal to share medications.
   - Make sure your teen knows how to read medication labels for both over-the-counter and prescription medicines. Teach him how to check for side effects and interactions.
   - Allow your teen to be the main person responsible for remembering his medications and taking them. It’s normal for him to make some mistakes so still check on him occasionally to make sure he is doing it correctly. This is especially important for critical medicines and during adolescence when there are a lot of things competing for your teen’s attention.
• Your teen should know which medications he needs to carry with him for immediate use (such as a rescue inhaler for asthma or an EpiPen® for serious allergies) and to know when and how to use them.

• Supervise your teen as he calls in for medication or supply refills, and teach him when to do it based on how much medication is left.

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 any food items, and have a list of safe foods for eating out with friends, in restaurants, at parties, etc.

4. Make sure your teen knows what symptoms are warning signs that he is getting sick or needs to seek help urgently. Review whom to call and what to do. Help him program emergency contact numbers into his cell phone.

5. Help your teen make an emergency card that lists your teen’s medical conditions, medications, allergies, doctors’ names and numbers, and emergency contact numbers. Have her carry the card with her at all times.

6. Make sure your teen knows his health providers’ names, what he sees them for and their contact information. Encourage your teen to start calling and scheduling some of his own appointments. Start with the provider your teen is most comfortable with.

7. Encourage your teen to do most of the talking during healthcare visits and to meet with the healthcare provider alone.

• Providers may discuss private topics with your teen, such as depression, substance abuse (and its effect on medications) and sexuality.

• Teach your teen to prepare questions for the healthcare visit and to write down the information.

• Your teen can start working with you to make decisions about her healthcare. At age 18, healthcare decision-making legally becomes her responsibility. Now is a good time to help her learn to make decisions responsibly.

• 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.

8. Start discussing what happens after high school, with your teen and his healthcare providers. If he is going to college or for further training outside of your local area, you can work together with the team to find healthcare providers in the new location. If your teen will be moving from school to work, talk about what to keep in mind regarding his health conditions.

• If your teen has, or needs, an IEP (individualized education program) and/or a 504 plan (which spells out any modifications and accommodations needed), communicate with the school and the healthcare team to tailor the plan to meet your teen’s needs.

9. 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 and required co-pays with her when she goes to appointments. Work with your teen to get information on health insurance for when she might no longer be covered by your insurance (usually between ages 18 and 23).

10. Make sure your teen knows how to use public transportation, as appropriate, so he can get to appointments independently if necessary.

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11. Encourage your teen to be as independent as possible and participate in all aspects of life (helping with chores, recreational and volunteer activities, etc.). Also, help your teen learn about available community resources — especially those for teens — related to her condition or that may be helpful to her.

12. Encourage healthy eating, especially if your teen has dietary limitations. Help him think creatively about good nutrition and eating appropriate foods outside the home. Encourage him to be involved in food selection and preparation.

13. To prepare for the future, start discussing options for adult healthcare providers for your teen. Ask for recommendations from your teen’s pediatric providers and other patients you know who have already transitioned to adult providers. Check which insurance the adult providers accept, both for when you teen is still covered by your plan and for when she is on her own.

Contact Information

REACH Line
267-426-5569
REACH@email.chop.edu

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.

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