Healthcare Transition: What Families Need to Know

Parents of children with special health care needs and disabilities need to plan, connect, advocate and find information on behalf of their child. Planning is very important and makes a difference. There are important things to consider as you prepare your adolescent to become more independent in adulthood. Young adults need increased responsibility for their own health care. This means that it is important for families to plan for transferring health care from a pediatrician to adult health care providers.

Here are some tips to consider:

- Begin by age 14 because at 18 your child is an adult.
- Make a plan that is specific to your adolescent and his/her special health care needs.
- Ask the provider how and when age-appropriate information will be shared with your adolescent about: his/her disability or chronic illness, sexuality, genetic counseling, vocational awareness, work opportunities and leisure time.
- Suggest to the provider that he/she meet privately with your adolescent to discuss topics such as physical, emotional and sexual development, relationships and friendships, sexuality, alcohol, drug and tobacco use, and family issues.
- Ask the provider who can assist you in care coordination
- Talk to your adolescent about his/her condition and or disability in a way that he/she can understand.
  - If your adolescent has development disabilities, work with his/her primary care provider to choose the key points and figure out how to make them clear.
- Help you adolescent understand the importance of the medication he/she takes.
- Encourage your adolescent to participate in making his/her health care appointments.
- Encourage your adolescent to prepare for doctor visits by asking questions in advance. Young adults should learn how to keep their own health notes and records if appropriate.
- Begin teaching your adolescent about his/her insurance coverage.
- You will need to talk the Pediatrician when you will need to transition your child’s care to an adult provider.
  - That usually happen between the ages of 18-21.

If your adolescent has a special health care need or disability significant enough to interfere with his/her ability to make financial, educational, and medical decisions, you will need to decide what kind of supported decision making you will have with your child.

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Supported decision making can be through a formal process of a guardianship or a less formal power of attorney. You have choices.

If you need help understanding what healthcare transition looks like and what options you and your child will have, please call Parents Reaching Out and ask for the Healthcare Family Liaison.

Here are some resources that may be helpful as you and your child plan for what adulthood.

[https://www.gottransition.org/youthfamilies/index.cfm](https://www.gottransition.org/youthfamilies/index.cfm)
[https://nm.medicalhomeportal.org/?homeRedirect=true](https://nm.medicalhomeportal.org/?homeRedirect=true)

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