As Your Child Grows Up

9

9

Transition

Growing up is not always easy for children. It can be hard on parents, too. When your child has special health care needs, growing up may be more complicated.

Still, many parents of children with special needs find it helpful to remember the "bottom line." You want your child to be as independent as possible. Independence in adult life (health care, employment, living, and recreation) takes preparation.

The process of growing up and becoming independent is sometimes called "transition." The term refers to the transition from adolescence to adulthood and is often used when your child is:

- **Learning to be more independent**
- **Learning to manage his or her own health care**
- **Changing from pediatric to adult-oriented medical care**
- **Moving from school to work and other aspects of adult life**

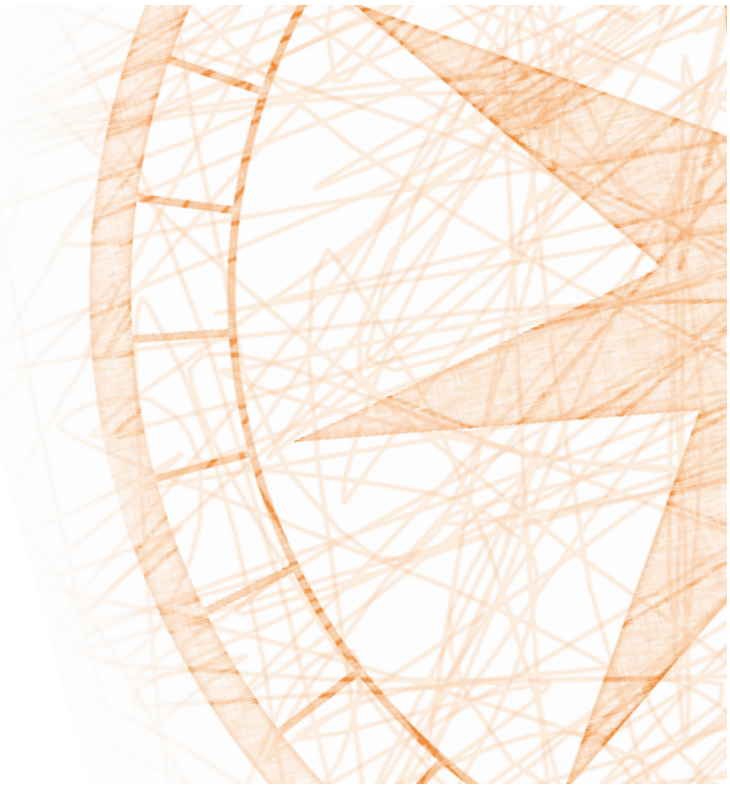
Talking with your child about growing older and being independent can make the transition to becoming a teenager and young adult much easier.

In this chapter you will find tips to help prepare you and your child for the process of transition in health care – when your child is younger, a teenager, and an adult. For information on transition in other areas of your child's life, contact Family TIES at 800-905-TIES or 617-624-5992 (TTY), or the Federation for Children with Special Needs at 800-331-0688.

For more information about transition, see *Transition Planning for Adolescents with Special Health Care Needs and Disabilities: Information for Families and Teens*, a resource guide for parents and teens about growing older and the transition to adulthood. This guide gives information on health care, education, employment, and recreation and is available from the Institute for Community Inclusion. Download this guide from www.communityinclusion.org/transition/familyguide.html.

When Your Child is Younger

- **Talk to your child about his or her condition or disability in words your child can understand. Help your child find a good way to explain it to others.**
- **Teach your child to know when he or she is having an emergency – and to tell you and others.**
- **Teach your child the names of the medicine(s) he or she takes.**
- **Talk to your child about how to stay healthy (for example: getting enough rest and eating well).**
- **Encourage your child to talk directly to health care providers – and to ask questions.**
- **Encourage your child's health care providers to talk directly to your child.**



Talk Teach
ENCOURAGE

When Your Child Becomes a Teenager

- Learn more about the process of transition in health care. Ask your teen's primary care provider (PCP) and specialty providers about how they handle transition from pediatric to adult-oriented medical care.
- Talk to your teen about his or her condition in words your child can understand. Help your teen find a good way to explain it to others. Look up information together about your teen's condition (at the local library or on the Internet). You can also read through this book together with your teen.
- Talk about what it means to grow up with a disability or chronic condition. Even though you haven't got all the answers, it may help to have the conversation.
- Teach your teen what to do in case of an emergency (see *Chapter 4*).
- If it is safe to do so, teach your teen to take his or her own medications. Review the names and dosages of medications often.
- Teach your teen the names of all health care providers and how to contact them.
- As your teen gets older, encourage him or her to talk directly to health care providers – and to ask questions. As the parent, this may be hard at first. So, try staying in the waiting room for part of the office visit while your child sees the provider alone. You can always talk to the provider at the end of the visit or by phone afterwards. (See **Teen Tips** on page 95.)

Tip:

Ask your teen about his or her relationships with health care providers. Your teen may want to keep on seeing his or her pediatric providers. Or, your teen may want to see another provider who specializes in adolescent and young adult health. Sometimes a teenager wants a change so he or she can have a more independent relationship with a health care provider.

When Your Child Becomes a Teenager

- Think about whether your teen might have trouble making independent financial and medical decisions when he or she turns 18. If yes, learn about legal guardianship, conservatorship, and health care proxy. These are legal processes that give a parent or legal guardian the right to control property and make medical decisions. Talk to your teen's primary care providor (PCP) about these issues **before** he or she turns 18. (See **Guardianship**, **Conservatorship**, and **Health Care Proxy** in the ***Glossary***.)

- Call a Member Services Representative at your teen's health plan to ask about what happens when he or she turns 18. Your teen may need to meet certain qualifications to stay on the plan.

- Talk to your teen about other health issues that come up at this time, such as:

  Healthy eating and body image
  Relationships and sexuality
  Smoking, alcohol, and drug use

  Ask your teen's primary care provider (PCP) for advice on how to speak to your teen about these issues.

- Encourage your teen to take more responsibility for his or her health. For example, have your teen fill out the checklist on the next page. It asks about important tasks that your teen should do to help keep track of his or her health care. Talk about the answers together. If your teen answers "no" to any of these questions, help your teen to start doing these tasks. If needed, ask your teen's PCP for help.

- Encourage your teen to attend educational "team" meetings at school. Include health care skills in your teen's Individualized Education Program (IEP) as goals, if applicable. Also, ask the educational "team" to help with transition planning. Remember that special education services end for everyone at age 22.

Tip:

For more resources on Adolescence and Transition, visit www.bostonleah.org.
See links to *Resources for Families* and *Resources for Youth.*

For Teens: Keeping Track of My Own Health Care

Fill out the checklist. Talk about your answers with your parent/guardian and your primary care provider (PCP). If you answered NO to any of the questions, start learning and doing these new tasks (with help from others if needed).

How well do I manage my own health care?	**Please circle Yes or No**	
1. I know my height, weight, birth date, and social security number.	**Yes**	**No**
2. I know the name of my condition and can explain my special health care needs.	**Yes**	**No**
3. I know who to call in the case of an emergency.	**Yes**	**No**
4. I ask questions during my medical appointments.	**Yes**	**No**
5. I respond to questions from my health care providers.	**Yes**	**No**
6. I know what kind of medical insurance I have.	**Yes**	**No**
7. I know the names of my medications and what they do.	**Yes**	**No**
8. I know how to get my prescriptions refilled.	**Yes**	**No**
9. I know where to find my medical records.	**Yes**	**No**
10. I know how the use of tobacco, alcohol, and drugs will affect my health and my ability to make decisions.	**Yes**	**No**
11. I know how to get birth control and protection from sexually transmitted diseases if I need it.	**Yes**	**No**
12. I know how to schedule a medical appointment.	**Yes**	**No**
13. I keep a schedule of my medical appointments on a calendar.	**Yes**	**No**
14. I can get myself to my medical appointments.	**Yes**	**No**

Adapted from the Children's Hospital Boston, Massachusetts Initiative for Youth with Disabilities Project, a Healthy and Ready to Work project of the Massachusetts Department of Public Health. Available at www.bostonleah.org/transitions.html.

As Your Teen Becomes an Adult

- Talk with your teen about making the change from pediatric to adult-oriented health care providers. Include your teen in the process. Do the planning together.

- Talk with your teen's primary care provider (PCP) and specialty providers about making the transition to adult-oriented care. Some providers, like a family doctor or specialist, may care for a person throughout their lifespan. Other providers, like pediatricians, care for children and adolescents only. Depending on your teen's medical team, transition could mean changing providers and/or health care settings.

- If your teen will need to change providers, think about when would be a good time to make the change. Try not to do this in the middle of other big changes in your teen's life or your own. Also, it may be easier to change your teen's providers one at a time, rather than all at once.

- Contact your teen's health insurance plan and ask about changing health care providers.

- Get recommendations for **new** PCP and specialty providers from **current** PCP and specialty providers if needed. You and your teen should meet with **new** providers before you say goodbye to the pediatric team.

- Make a special request to your teen's **current** health care providers to contact the **new** providers to discuss your teen's special health care needs.

- Continue to encourage your teen to take more responsibility for his or her health and health care. Talk to your child about other health issues that come up at this time, such as:

  Healthy eating and body image
  Relationships and sexuality
  Smoking, alcohol, and drug use

Tip:

When setting up the first appointment to meet with a new health care provider, ask for a "consultation" appointment. This will allow you to meet and learn more about the new provider. Remember to tell the receptionist to schedule extra time for the appointment. Bring this book and a list of questions.

Teen Tips: Communicating with Health Care Providers

Talking to health care providers can be difficult, overwhelming and, at times, scary. Here are some tips to help you communicate with health care providers.

- Make sure to **ask for a long enough appointment**. Sometimes appointments are very rushed. If you know that you will have a lot to talk about with your provider, ask for an extended appointment so you don't run out of time.
- **Tell your provider everything you can about yourself, what you do, and how you feel**. The more information the provider has, the more helpful he or she can be.
- **Say what you think** – and be honest.
- **Be assertive**. Be nice, but persistent.
- **Bring a list of questions and concerns**. It's easy to forget things when you're sitting there, in the provider's office. A written list of questions, concerns, or other things you want to make sure to tell the provider will help you remember everything that's been on your mind.
- Tell the provider to be honest and to tell you everything. **You're entitled to know all** about your condition, your treatment, and any options that might be available to you.
- **Ask questions**. Remember – there's no such thing as a stupid question. If you don't understand an answer to a question, ask the provider to explain it again until you do understand it.
- **Write down what the provider says**. That will help you remember later on.

Teen Tips: Communicating with Health Care Providers

- **Bring someone with you**, if you'd like. Sometimes it helps to have someone else there for support, to hear what the provider has to say, or to ask questions that you might not think of.

- Ask your parents to wait outside the exam room so you **have some time alone to talk to the provider, if you'd like**. Sometimes that helps the provider focus on you and what you have to say. Your parents can come back in after you've had a chance to talk to the provider yourself. Then they can ask their questions.

- **If you need help, ask for it.**

- When visiting a new provider, **ask the provider about his or her background and experience.**

- Even if you've seen your provider for a long time, **it's ok to ask about the provider's background** and what his or her experience has been.

- Call back if you have any questions after the appointment. Sometimes questions come up after you get home, or you forget something the provider said. **It's ok to call and follow up with more questions**.

- **Learn about your insurance coverage**. What services are covered and what procedures do you have to follow to get those services?

Adapted from Transition Planning for Adolescents with Special Health Care Needs and Disabilities Institute for Community Inclusion, 2000. Available from www.communityinclusion.org/transition/familyguide.html.