



Division for
Children & Youth with Special Health Needs
Tips for Parents and Caregivers of Young Adults
Ages 18 & Up
Transitioning Young Adults from Pediatric to Adult Healthcare



As parents and caregivers, you play an important role in preparing your young adult to be responsible for as much of their own health as possible. Around this time, your adult child will continue to transition from pediatric to adult care providers. In most cases, the transfer will occur by age 18, but may occur anytime up until age 26.

These tips are intended to help you partner with your adult child, supporting her ability to make responsible health care decisions. Hopefully, you have been encouraging your young adult with your help if needed, to keep a notebook with important medical information including health conditions, names and phone numbers of doctors, up to-date medicines and dosages, allergies, any discharge instructions from hospital stays, notes from doctor appointments and test results.

Directions: Resources for Your Child's Care, an organizing notebook and a resource guide, is a comprehensive tool for organizing your child's information and can be found at www.mass.gov/dph/specialhealthneeds/directions.

In addition to these tips, the following website has lots of checklists, resources and suggestions to help you as you begin to talk with your child about their health issues, www.mass.gov/dph/youthtransition

1. Make sure your adult child understands all her medical conditions. Make sure she can explain them to others, both in detail and in a three-sentence summary.

- Share with her any additional information that she may not remember.
- Encourage her to update her health information in her binder, on her flash drive or smartphone after visits, changes in medications, etc.
- Be sure she has all her health information in an easily accessible place. Include diagnoses, medications and dosages, allergies, names and phone numbers of doctors, and emergency contact information. Have her keep it with her at all times.
- Make sure she knows the warning signs that indicate she needs to seek help immediately, as well as whom to call or what to do for these symptoms.
- Make sure she knows where emergency medicines, such as an Epi-pen or a rescue inhaler are; and how to use them.

2. Your adult child is now the legal decision-maker, and legally the only one who has a right to her medical information. Ideally, you and your adult child will work together as a team, but she is now the team leader.

- Unless your adult child has agreed in writing to your continued involvement in her healthcare, or you have obtained guardianship, all her visits and communication will be confidential.

continued on next page

Tips for Parents and Caregivers of Young Adults Ages 18 & Up Transitioning Young Adults from Pediatric to Adult Healthcare

- You are now in a coaching and backup role only; be available if she has questions.
- Your adult child can choose to sign a HIPAA (Health Insurance Portability and Accountability Act) form that will permit the healthcare team to discuss issues with you or with another support person your child chooses.
- As your adult child considers where to attend college, live or work, encourage her to talk with her healthcare providers about any health concerns that will need to be addressed.
- You, your adult child, and her current health team should work together to find appropriate providers if she is relocating.
- Ask if she would like assistance interviewing new adult providers either in person or by phone.
- Your adult child is now the person discussing her medical conditions at healthcare visits.

3. Check that your adult child knows the names of her medications, what they do, their doses and side effects - this includes:

- Knowing how to read medication labels for both over-the-counter and prescription medications.
- Asking the doctor or pharmacist about how other medications or foods might affect how the medication works.
- Understanding she should only use her own medications and use them as prescribed. It's dangerous and illegal to share medications.
- Remembering her medications and taking them at the right times; using a smart phone app, alarm or other reminder tool. Be available to troubleshoot if needed.
- Calling in prescriptions and supply refills. Let her know you are available to help, in case she has problems.

4. Your adult child should know the severity of her allergies; how to avoid them; and what to do in an emergency.

5. Your adult child should be responsible for calling and scheduling most or all of her own appointments.

- Be available to help if she has trouble contacting the office, or if her school or work schedule makes it difficult to call during office hours.
- Suggest that she make her next appointment while still at the doctor's office. She can ask the receptionist for a reminder card so she does not forget.

6. Help your adult child understand what kind of health insurance she has.

- She should always carry the card with her; and present it during medical visits; know if there is co-pay, and, if there is, be able to pay it.
- If your adult child is no longer covered under your insurance, help her find the best options based on her disability and financial need. You can ask a social worker or case manager for help.

7. Make sure your adult child can use public transportation, arrange a ride or drive by herself, so she can get to appointments independently.

8. Make sure your adult child knows about available community resources and organizations related to her condition and situation that may be helpful. Encourage your adult child to contact them and use the support they provide.

9. Encourage your adult child to be as independent as possible and participate in all other areas of her life,

continued on next page

Tips for Parents and Caregivers of Young Adults Ages 18 & Up Transitioning Young Adults from Pediatric to Adult Healthcare

including:

- Household tasks
- Self-care
- Transportation
- Work life or school
- Financial management
- Scheduling respite or other care workers
- Recreational activities
- Volunteer work
- Social activities

10. Continue the process of helping your adult child transition from pediatric to adult healthcare providers.

- Your young adult should prepare a one or two page summary that describes her: likes, dislikes, learning and communication style, and any other information she thinks is important.
- She should bring this with her when she consults with potential new adult providers.
- It may be important to know if her current provider is available to consult with the potential new provider if needed. She should work with her pediatric team to make sure her healthcare record is up-to-date.
- Once your adult child has chosen new providers, she will sign papers to transfer her health records to the new doctor's office.
- The new adult practitioner will be better prepared to care for the adult child's medical needs if they get a one- or two-page medical summary from the pediatric doctors, in addition to the detailed records.
- In certain cases, based on your adult child's condition, she may continue to see her pediatric specialists.