

# Moving Into Adult Health Care



## ***What Do Parents Need to Know?***

***A guide for parents of young adults with and without disabilities***

***Connecticut Edition, 2012***

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Connecticut Kids As Self Advocates***

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# Introduction

## So Your Child has Become an Adult! Now What?

Turning 18 is a magical moment for most young adults. According to the law, all you have to do to be an adult is become 18 years old. Just like that, you are legally an adult!

That may sound simple, but as any adult knows, turning 18 doesn't mean you just know everything you need to know about being an adult. For parents, the journey to transform their child into an adult is a long one, and requires planning, fortitude and patience. Teaching your young adult to be responsible for their health care is a journey that begins in childhood. This booklet is about the steps parents can take to help their child to lead a healthy, independent adult life. For some parents, whose children have required a lot of assistance and support to meet the challenges of their disability, this vision of independence is not easily attained. This booklet was written for you by young adults with disabilities who have been on this journey with their parents, and who have many ideas about how to make this a smooth and successful process regardless of your child's disability.

This booklet will help you think about the things you need to do to assist your young adult to take care of their own health. It will help you to work with them to think about their own health care needs, organize their information, talk to doctors and other health care providers, and manage their own medications.

**This booklet is about preparing your young adult to be healthy and ready for life!**



## START EARLY!!

It is up to a parent to ensure that a child knows and understands his or her disability. Talk about it; let them meet other children with similar needs. Give them the words to explain their disability to other children they meet. Talk to them lovingly and with hope.

Your child may have questions about why they are different. They can really benefit from straight talk. It is important to give your child's disability the proper name, and explain what that means. This can head off anxieties and better prepare your child to seek appropriate health and support services later in life.

One strategy is to tell the child that everyone is different: some kids wear glasses, some have allergies and can't eat certain things, or sneeze a lot, and some have weak muscles, cannot see, or cannot hear. Everyone learns differently, and some children need special help to learn.



## What is a Medical Home?

A medical home is not a place, but a way of delivering health care that is coordinated, patient and family centered and culturally appropriate. The medical home is also known as an approach to providing primary care that builds partnerships between individual patients, and their health care providers, and when appropriate, the patient's family. When health care is delivered through a medical home, your young adult will have better access to health care, increased satisfaction with care, and improved health.

A key part of the medical home is care coordination. This includes assessing your needs, planning the right services and supports, delivering those services and supports, and measuring how well these services and supports meet the child and family's individual needs. Building a sense of trust between families and the medical home and responding to their needs in a timely and coordinated manner is essential. Care coordination within a practice will:

- Make it easier to access services
- Ensure consistent and coordinated care
- Provide needed support to individuals and families
- Improve health, developmental, educational, vocational, psychosocial and functional outcomes
- Maximize efficient and effective use of resources



## **At the Doctor's Office**

As soon as your child can understand, you should explain to them why they are going to the doctor and what will happen. When appropriate, help them to think of questions they may want to ask when they go to the doctor. If your child needs help organizing their questions, think of other ways to have them ask questions, including working with them to write down their questions and e-mail them to the doctor ahead of time. Encourage the doctor and other health care staff to talk directly with your child when he or she asks a question. You can help explain the answer to your child.

Many young adults don't have the same chance to see the doctor alone, even for part of a visit, and they don't learn how to manage their own health care or talk to the doctor alone. Yet, many young adults who do not have disabilities begin to see their doctor alone for a least part of a visit by the time they are 11 or 12 years of age.

As the parent, one strategy is that you may go into the exam room for some part of the appointment, but not all of it. You will need to prepare both your young adult and the doctor for their time together—communication strategies, etc.

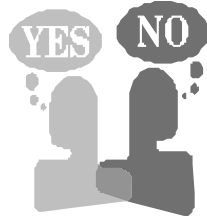
## Help Your Young Adult Learn What To Do If They Don't Agree With Their Doctor

Sometimes your pediatrician or primary care doctor and other health care providers do not agree about your young adult's diagnosis or treatment. This can be a very difficult situation for you and your young adult as you try and make good choices about medical treatment. You have several options:

- **Seek a second opinion.** Ask to see another doctor who may specialize in the treatment of your young adult's symptoms or diagnosis, or another primary care doctor. Explain that you are unsure how to decide about your young adult's health care choices, and need another opinion. Many insurance plans cover second opinions.
- **Seek help from a care coordinator in your medical home.** If your young adult is receiving care in a medical home, you and your young adult should sit with your care coordinator and review the information that all the providers have given. Together, you can decide what to do next, including having a meeting or phone call with the providers to discuss your choices, or getting help in finding a provider for a second opinion. It is important to let people know how difficult it is when your family gets different information and treatment plans from different providers.

*The most important thing to remember is that your young adult has to make an informed decision about their care. Encourage them to tell their doctor if they are confused or do not agree. Then they have to make a choice about what to do next. This means getting as much information as they can before they choose the right treatment plan for them.*





## Let Your Young Adult Take Charge

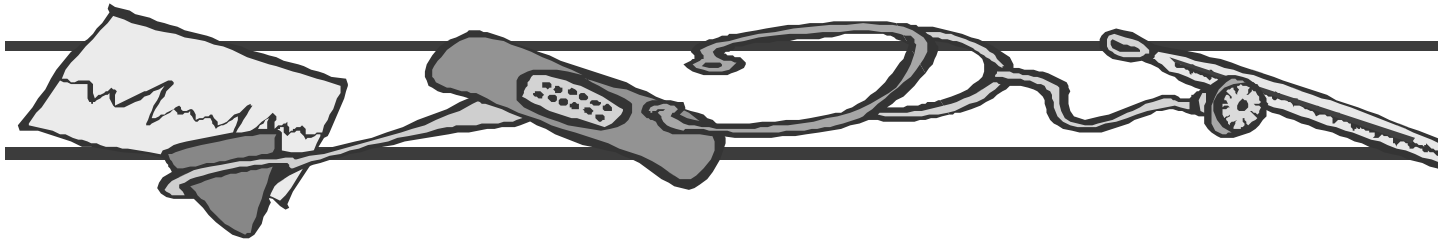
By the time your young adult is 16 or 17, help them call the doctor to make their own appointments. If your young adult has difficulty speaking on the phone, help them find an alternate way to schedule appointments. It is important that they know the date, time and location of all medical appointments, and the reason for each appointment. You can use a calendar with them to write down appointments. You can also mark on a calendar when they need to order or refill medications and other information.

**Encourage your young adult to keep their doctor's number and insurance information with them at all times.** This is information they will need to know as an adult. They need to be aware of how bills are paid, what they have as a co-pay, and how all payments are made. Help them understand the type of coverage they have, and the limits to their coverage.

Encourage your young adult to be prepared for emergencies! Assist them in completing an emergency information form, with your names, and the names of others to contact in case of emergency. Don't forget to teach them ICE (In Case of Emergency). ICE is the contact that all emergency responders will look for in a cell phone. If your young adult carries a cell phone, help them program in the emergency contact number under ICE.

## Partnering With Your Young Adult's Primary Care Physician

Discuss your plan to help your young adult take charge of their health care, and ask the doctor and office staff to assist you. This can begin with letting your young adult register at the desk when he or she arrives, presenting the insurance cards, going into the exam room alone, scheduling appointments with the staff and making the co-pays. It includes encouraging your young adult to ask their own questions, and encouraging staff to talk directly with your young adult.



## Finding A Doctor to Treat Your Young Adult With A Disability

As your young adult approaches age 18, ask their doctor for input on the age to transfer care to an adult health care provider. You may need help in finding another doctor who understands the unique health needs of your young adult. Talk with your young adult's doctor and care coordinator about choices. Some families choose to have their young adult receive medical care from the physicians who treat the parents. This may work well for some families. Some families ask for referrals from their pediatrician. Others dialogue with other adults with disabilities to learn where they receive their care.

There are many things for you and your young adult to consider-accessibility of the office, knowledge of the disability, other young adults with disabilities treated by this physician, and whether or not they will accept your young adult's insurance.

In most cases, there will need to be an initial discussion of special health care needs in addition to the transfer of records that will routinely occur.



## What Is My Role in Managing My Young Adult's Health Care?

You may always need to be available to answer questions and assist your young adult according to their abilities. But it is critical that your young adult develop the skills, confidence and strategies to navigate the adult health care system in advance of turning 18. And after that, there is no magic date when your young adult won't need to ask you questions.

**The difference is-it is now their responsibility to know when they need help and seek your assistance. If you do your job when they are young, this can be a smooth and easy process that allows your young adult the independence to manage their own health care!!**



## Quick Links to Health Care Transition Resources

### Connecticut Department of Public Health Youth with Special Health Care Needs

- <http://www.ct.gov/dph/cwp/view.asp?a=3138&q=432684>

### Connecticut Kids As Self Advocates (CT KASA)

- <http://www.ctkasa.org>

### Got Transition? National Health Care Transition Center

- <http://www.gottransition.org/>

### Health Care Transitions: The Institute for Child Health Policy at the University of Florida

- <http://hctransitions.ichp.ufl.edu/hct-promo/>

### Healthy and Ready to Work National Resource Center

- <http://www.syntiro.org/hrtw/>

### National Center for Medical Home Implementation - Transitions

- [http://www.medicalhomeinfo.org/how/care\\_delivery/transitions.aspx](http://www.medicalhomeinfo.org/how/care_delivery/transitions.aspx)

### United Way of Connecticut 2-1-1 Infoline

- <http://infoline.org>

# NOTES

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