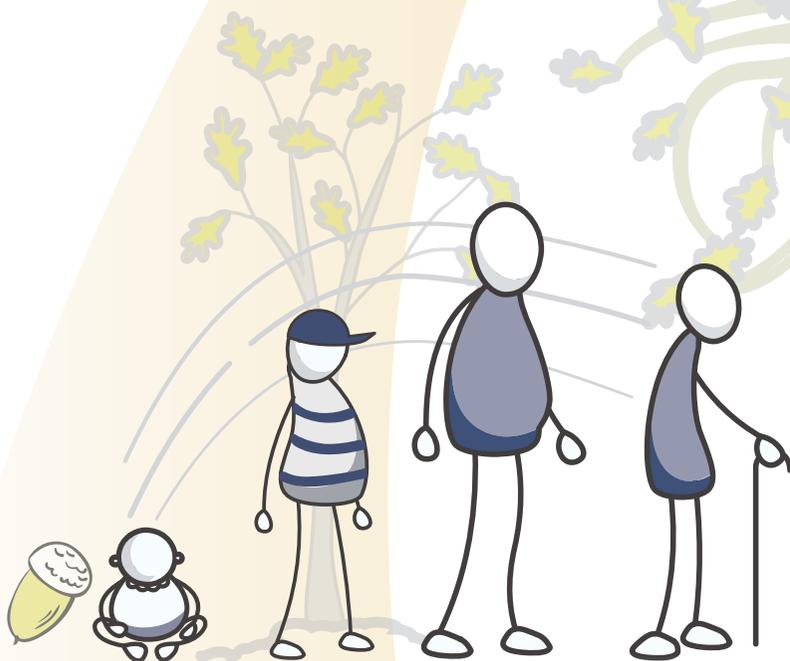


# TRANSITIONS OF CARE IN EPILEPSY

**A Guide for  
Parents & Caregivers**

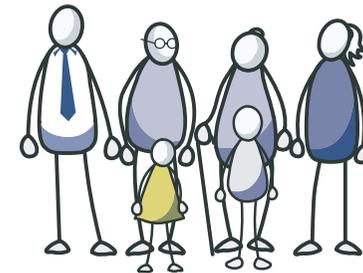


Module 1 in this series is  
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# TRANSITIONS OF CARE IN EPILEPSY

**A Guide for  
Parents & Caregivers**



***The Transitions in Epilepsy series includes***

**Module 1: A Guide for Parents & Caregivers**

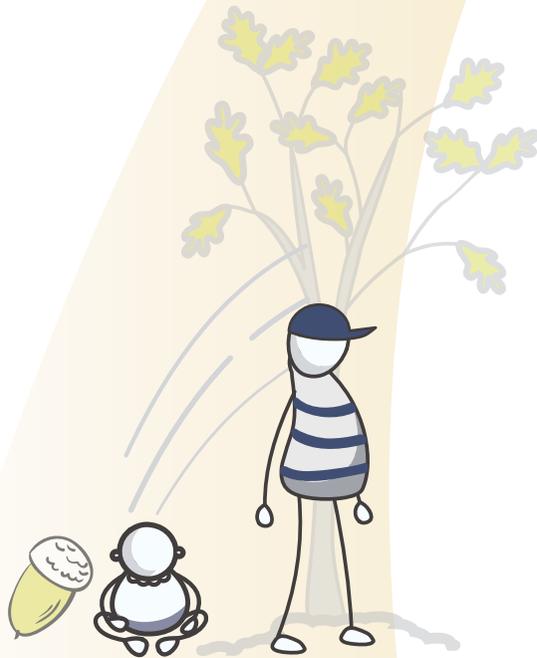
**Module 2: A Patient Guide for Teens & Young Adults:  
*What's Your Plan?***

**Module 3: A Patient Guide for Adults & the Elderly:  
Epilepsy Considerations**

To access all 3 modules in this series, please request copies from your epilepsy health care provider.

# 1

## A Guide for Parents & Caregivers



**Disclaimer:** This educational publication is intended to serve as a detailed, but not all-inclusive, patient-focused summary of selected topics related to epilepsy. The authors have taken care to ensure that the content herein is correct and compatible with AMA style and generally accepted good publishing practices at the time of printing. Nevertheless, as new information becomes available, changes in medical approaches become necessary. This material is for informational purposes only. It does not replace the advice or counsel of a doctor or health care professional. Readers should consult with, and rely only on the advice of, their physician or health care professional. The authors, editors, and Supernus Pharmaceuticals, Inc. disclaim responsibility for any liability, loss, injury, or damage incurred as a consequence, directly or indirectly, of the use and/or application of any content contained herein.

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# Welcome, friends!



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Epilepsy, a seizure disorder, is a common brain condition that affects individuals of all ages. Having a seizure can be a scary experience and learning how to manage epilepsy appropriately may require significant time and effort throughout life. The purpose of our educational series is to describe the changes that people with epilepsy experience throughout the stages of their lives. By addressing medical, psychosocial, educational, and employment needs, this booklet will help individuals successfully manage transitions in epilepsy.

This is the first of 3 modules in the *Transitions of Care in Epilepsy* series

**Module 1** is for the **parent or caregiver** of a child with epilepsy who is moving on to young adulthood. When your child is young, you often handle the majority of the details surrounding his or her epilepsy care. However, as your child gets older, these responsibilities should normally shift away from you to your child. This section helps you and your child work through a purposeful planned process to prevent gaps in epilepsy care as your child becomes a young adult. This process includes discussing when a transition in care should happen; who should be involved in developing the transition plan and what the plan entails; finding an adult neurologist for your child; and how to manage specific challenges such as independence issues, emotional and social changes in young adulthood, and lifestyle factors that impact epilepsy control.

We hope readers find this educational series helpful and informative!

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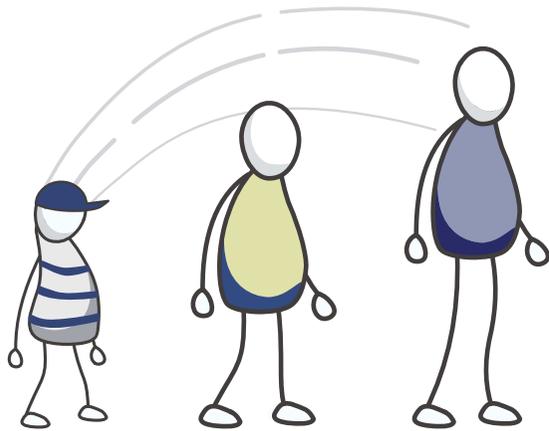
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## CHILDHOOD TO YOUNG ADULTHOOD: WHAT SHOULD CAREGIVERS KNOW?

### Preface

As a parent or caregiver of a child or young adult with epilepsy, you know that living with epilepsy may be frustrating and that management of the condition requires a lot of time and effort. When children are young, you handle most details of their epilepsy care including making and keeping doctor's appointments, refilling medicines, ensuring that medicines are taken at the right time each day, and communicating aspects of care with others involved in your child's life such as school staff, coaches, and childcare providers. As your young child becomes older, these responsibilities may need to shift, or "transition," from you to your child. As appropriate for their age and level of development, children with epilepsy should be encouraged to prepare for adulthood by taking more responsibility for their medical needs. Your goal in this process is to prepare your child to begin to accept the responsibility for his or her care. For children with intellectual or developmental disabilities, you may be able to transition some responsibilities depending on the severity of the disability.



### Did You Know?

Transition is a "purposeful planned process" that addresses the medical, psychosocial, educational, and/or employment needs of young people with chronic physical and medical conditions as they move from child-centered to adult-focused health care systems.

*The effective transition of epilepsy care for you and your child is the focus of this module.*

## SECTION I: TRANSITIONS OVERVIEW

Your child's transition in epilepsy care is not simply about seeing a new doctor. It is about supporting your child's development of self-management skills for handling his or her epilepsy care during the adult years.

Planning should begin when your child is 12 to 14 years old, and the transition should be framed as a positive opportunity for your child as he or she moves closer to independent living. For young adults, including those with epilepsy, the teen years are a period of personal growth. Issues of identity and self-knowledge are explored as part of the process toward adult independence. Many young adults may be discouraged if their epilepsy slows down or prevents this progress toward independence. This discouragement can cause bigger problems with coping.

Young adults with epilepsy have less well-developed coping and problem-solving skills than those without epilepsy.

You and your child's doctor can help by providing education, advice, and emotional support during this time of transition. By empowering your child, you can help him or her to avoid getting discouraged and to maintain positive feelings about seeking independent living and decision making.

Key steps in the process are outlined below. The overall process should touch on the 8 principles for transition (see Section II), and special considerations for lifestyle aspects are reviewed in Section III.

**Education** is key to helping children become adults who are in control of their epilepsy. When children are encouraged to make and keep doctor's appointments; take their medicine on time and as prescribed; develop good sleep habits; learn to manage stress; avoid all or excess alcohol; and follow other elements of a healthy lifestyle, they gain confidence in their self-management of epilepsy, which will enhance their self-esteem and potentially reduce the chance of a seizure.

For caregivers, taking a leading role in the transition process can be stressful and worrisome. At times, it may feel like helping your child's transition takes more work than having the responsibility yourself. You may feel as if you are forging ahead alone in this process.

However, time and effort invested early in the process will help ensure a better, long-term transition. Planning for and maintaining open lines of communication can guide a smooth and healthy transition process.

Remember, you and your child are not alone in the transition process. Your child's health care providers will be a valuable resource.

## Why is an organized, successful transition so important?



The major goal in the transition from child to adult medical care for epilepsy is to prevent gaps in care or other problems that could increase seizure activity or impair quality of life.

**Without an organized transition process, some young adults cannot find an appropriate adult neurologist or they may have difficulty making and keeping the first appointment with their new doctor.**

- This may lead to a period when your child is without the care of a doctor. For some young adults, this gap in care can be as long as 2 years.

During this time, young adults are at risk of running out of medicine or not having a doctor to help if there is a seizure or other medical emergency.

### FAST FACT

You can help to prevent a gap in care by participating in transition meetings with your child's pediatric neurology provider, learning about adult neurology providers near your home, and asking your health insurance provider for a list of adult epileptologists who participate in your plan. If an epileptologist is not available, find a neurologist with experience treating epilepsy.

Seeking support from health care providers and professional associations, such as the Epilepsy Foundation or the Child Neurology Foundation, can help guide decision making for your child.



## How is the transition to adulthood different for those with epilepsy?

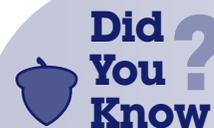
All children go through significant changes as they progress through the teenage years into young adulthood. Along with physical changes, many emotional and social changes occur during young adulthood. Young adults develop identity and self-awareness with strong desires for independence in many areas of life, including health.

Because many aspects of life are affected by epilepsy, the transition that children with this condition take on can be more challenging. The interest in greater independence is a necessary part of transitioning to adult care in epilepsy; however, young adults can easily become frustrated if they do not develop the skills to make a complete transition as quickly as they would like.

**This frustration can translate to conflicts with caregivers, even in normally strong child-adult relationships. More frustration occurs when epilepsy prevents "appropriate" transitions. For example:**

- It may not be safe for a young adult to engage in certain behaviors without adult supervision, such as taking a bath, swimming, going on school field trips, or drinking alcohol.
- Allowing teens with epilepsy to choose their own bedtime may have some expected risks such as tiredness if they go to bed too late. For a teenager with epilepsy, sleep loss can increase the risk for a seizure.

Additional limitations may be related to your child's ability to secure a driver's license or a job (see Section III).



Unlike childhood when family plays a major role, friends often become a bigger influence during adolescence. Your child may feel isolated and socially "abnormal" and may welcome any peer acceptance that is offered, even if the relationship is harmful.

If it feels scary when your child drifts toward peers who may not understand the complex needs of epilepsy care, remember that you are still a major influence and should remain committed to staying as close to your child as you can.



**Talk with your child ahead of time about how alcohol and drugs of abuse can affect seizures so that they know how to make healthy choices with their peers.**

- You also can encourage your child to tell their friends about their epilepsy and answer their questions.

**FAST FACT**

Many high school students are misinformed about epilepsy, adding to the “stigma” associated with the condition. Some areas of confusion include thinking that epilepsy is a mental illness, an exaggerated fear that people with epilepsy often die during seizures, and believing that epilepsy is contagious.

Some young people with epilepsy may have additional concerns that make the transition to adulthood more difficult. For example, children with epilepsy may have physical limitations, learning difficulties, behavioral problems, or mental health issues that children without epilepsy don’t have.

For these reasons, young adults with a disability must receive a sufficient amount of support during the time of transition to adult medical care.



Emotional and relationship problems may be more common in children with both epilepsy and neurologic problems.

## When should I start planning for my child’s transition to adulthood?

The first discussions about the transition to adult care for epilepsy should happen around 12 to 14 years of age. Starting the conversation early gives you and your child plenty of time to move from fully family-focused care to a more independent epilepsy treatment experience. For children with disabilities or other special needs, discussions about transition may begin before the age of 12. Young adults may start seeing an adult neurologist toward late adolescence, around age 16 to 17 years, but this age varies among families and doctors.



The American Academy of Pediatrics suggests that young adults should experience an adult model of medical care after they reach the age of legal adulthood, which is 18 years in most states (19 or 21 years in a few states).

Having some tools may help you and your child make a smooth transition. Ask your child’s neurologist or other members of the neurology team if they have any tools, especially for thinking about and planning for the transition to young adulthood. A checklist of things to do, things to discuss, or questions to ask during the transition may be helpful.

### Table A: Transition Readiness Assessment Questionnaire (TRAQ)

Your child should answer each question using the following scale:

	No, I do not know how	No, but I want to learn	No, but I am learning to do this	Yes, I have started doing this	Yes, I always do this when I need to
Do you fill a prescription if you need to?					
Do you know what to do if you are having a bad reaction to your medicines?					
Do you take medicines correctly and on your own?					
Do you reorder medicines before they run out?					
Do you call the doctor’s office to make an appointment?					
Do you follow up on any referrals for tests, checkups, or labs?					
Do you arrange for your ride to medical appointments?					
Do you call the doctor about unusual changes in your health, such as allergic reactions?					
Do you apply for health insurance if you lose your current coverage?					
Do you know what your health insurance covers?					
Do you manage your money and budget household expenses, such as using a checking/debit card?					

**Table A: Transition Readiness Assessment Questionnaire (TRAQ) (Continued)**

Your child should answer each question using the following scale:

	No, I do not know how	No, but I want to learn	No, but I am learning to do this	Yes, I have started doing this	Yes, I always do this when I need to
Do you fill out the medical history form, including a list of your allergies?					
Do you keep a calendar or list of medical and other appointments?					
Do you make a list of questions before the doctor's visit?					
Do you get financial help with school or work?					
Do you tell the doctor or nurse what you are feeling?					
Do you answer questions that are asked by the doctor, nurse, or clinic staff?					
Do you help plan or prepare meals/food?					
Do you keep home/room clean or clean up after meals?					
Do you use neighborhood stores and services, such as grocery stores and pharmacies?					

Source: East Tennessee State University Department of Pediatrics. <http://www.etsu.edu>.

## Who is involved in the young adult's transition?



Transitions in epilepsy care can involve several individuals including you, your young adult, the pediatric neurology team, and the adult neurology team.

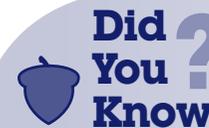
### As your child transitions from a pediatric to an adult neurology team, you and your child can anticipate:

- Feeling sad, nervous, or uncomfortable about leaving the pediatric doctor and team, especially if they were a large support to your child in adjusting to living with epilepsy.
- Needing additional health care providers to manage other health needs that may have been provided by the pediatric team but will not be addressed by the adult neurologist.

When your child sees an adult neurologist, he or she will likely attend appointments without you.

The contact between a young adult and the doctor also may be less frequent.

Consider facilitating a conversation with your child's epileptologist and their planned/proposed adult neurologist.



A recent trend in adult medical care that may help eliminate feelings of disconnect with the doctors is to become part of a "medical home."

A medical home is structured to address your child's general health and his or her epilepsy. The health care provider team in a medical home may include doctors, nurse practitioners, physician assistants, nurses, pharmacists, and care coordinators.

A young adult with epilepsy and other medical and comorbid conditions may benefit from the help of a medical home to coordinate appointments and medicine refills so that nothing is missed when care is provided by several specialists.

Medical homes help support both the medical and nonmedical needs of families.



Medical homes are a doctor's office or clinic that connects all of a patient's health care providers.



## Why is it important to transition to an adult neurologist?

As children grow, higher doses of their medicines may be needed for the same therapeutic effects; however, this may lead to more side effects.

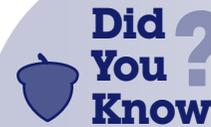
There may be different standards in caring for children and young adults with certain seizure types. For example, to control their seizures, young adults with Lennox-Gastaut syndrome may need a different medicine(s) than the medicine(s) that worked in childhood. When switching medicines is directed by a health care professional, seizures or new side effects may occur around the time of the switch. This can be stressful and can raise doubt about the change in medicine or the entire transition process.

**Table B: Checklist of things to discuss with doctors during transition**

Topic	Specific issues
Your epilepsy	<ul style="list-style-type: none"> <li>▲ Causes, age at first seizure</li> <li>▲ Seizure type</li> <li>▲ Seizure triggers</li> <li>▲ Seizure rescue plan</li> <li>▲ Most recent seizures (eg, timing, duration, treatment changes)</li> </ul>
Other medical conditions	<ul style="list-style-type: none"> <li>▲ Related or unrelated to epilepsy</li> <li>▲ Names of doctors managing these conditions</li> </ul>
Your medicine	<ul style="list-style-type: none"> <li>▲ Antiseizure medicine, seizure rescue medicine, medicine for other conditions</li> <li>▲ Medicine form (eg, pills, liquid)</li> <li>▲ Dose and how you take it (eg, by mouth, stomach tube)</li> <li>▲ Side effects</li> <li>▲ Antiseizure medicine that you have used previously</li> </ul>
Epilepsy tests	<ul style="list-style-type: none"> <li>▲ Dates and results</li> </ul>
Other epilepsy treatments (if applicable)	<ul style="list-style-type: none"> <li>▲ Ketogenic diet, vagus nerve stimulation, surgery</li> </ul>
Personal information	<ul style="list-style-type: none"> <li>▲ Education</li> <li>▲ Living arrangements</li> <li>▲ Employment</li> <li>▲ Sexual history</li> <li>▲ Alcohol, smoking, drug use</li> <li>▲ Driving</li> </ul>

Source: Rajendran S, Iyer A. *Adolesc Health Med Ther*. 2016;7:77-87.

## What is “adherence” and how might it be affected by the transition?



One of the most important ways to help ensure that epilepsy medicine works is called adherence—taking medicines exactly the way a health care provider instructs. Being **nonadherent** means not taking medicine as prescribed, including taking too much or too little, taking it at the wrong times, or forgetting altogether.

Helping your child adhere to their antiseizure medicine is an important part of the transition process. You need to transfer to your child the responsibility for managing his or her own medicine and for developing a system of reminders for taking them at the right time each day. A major part of the transition process will be helping your child take on these medicine management tasks.



About 1 in 3 young adults reported missing at least 1 dose of their antiseizure medicine during the previous month, and 70% of these individuals were nonadherent because they forgot to take the medicine or did not have their pills with them.

You can help your child with medicine adherence by gradually giving them more responsibility for taking their medicine. You could start by making them responsible for 1 dose per day and gradually increase to multiple doses daily.

You also can help your child set up a reminder system, such as electronic reminders on their phone or other device, a pill box organizer, pairing taking their medicine with another activity such as teeth brushing, or making a daily medicine schedule chart.

**As your child takes more control of his or her health care decisions, many situations can lead to adherence issues with epilepsy medicines. These challenges may include:**

- Not making or keeping doctor’s appointments
- Running out of medicine or not requesting refills in a timely manner
- Forgetting to take medicine, skipping a dose; or
- Choosing not to take epilepsy medicine at all

As a caregiver, you understand that your child needs to take his or her medicine correctly and consistently to help reduce the risk of seizures

and that missing even a single dose can lead to a seizure. If a young adult does not understand or believe the need for medicine, he or she may choose not to take it.

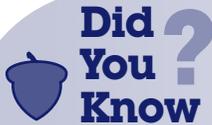


**Having a seizure puts the young adult at risk for complications, which can include injury from uncontrolled body movements during a seizure, falls, injury to the brain after a long-lasting seizure, or even death.**

Even if there is good adherence and antiseizure medicines seem to be working, your child may change medicines during the transition process for many reasons. Older children may be better candidates for certain medicines or forms, such as pills, that are not used in younger children.

Older children may benefit from switching to fewer medicines or a simpler treatment regimen, such as fewer pills per day, as adherence is more challenging in teenagers and young adults.

## What about my child with disabilities?



**Emotional and relationship problems may be more common in children with both epilepsy and neurologic problems.**

**Some young people with epilepsy may have additional concerns that make the transition to adulthood more difficult. Children with epilepsy may have more physical limitations, learning difficulties, behavioral problems, or mental health problems compared with children without epilepsy.**

- Some young adults with epilepsy are more likely to have poor academic performance and unemployment, leading to fewer financial resources and less social support.
- Psychological stress is higher in young adults with epilepsy, especially during the teenage years and the transition to adulthood, and psychiatric problems, such as depression and anxiety, are common, often undiagnosed, and may cause emotional distress.

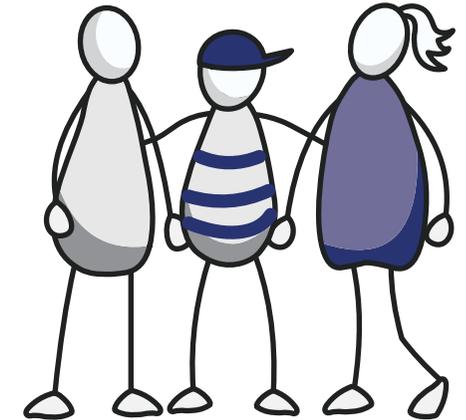
Individuals with intellectual or developmental disabilities have special needs when transitioning to adult epilepsy care.

Many young adults with intellectual disabilities can develop some self-management skills, including making treatment decisions and having the responsibility of taking their medicines.

However, some aspects of the transition process will probably need to be adjusted for children with serious disabilities.

Every young adult's situation is different and the process should be specific to their needs. For example, children who are not expected to live into adulthood may not transition to an adult doctor. Other children may transition to an adult doctor, but the adult doctor may not interact with them as a typical adult until the child's intellectual or behavioral skills have developed more and grown stronger. There also may need to be a larger focus on issues of legal competency, self-advocacy (ie, learning to speak up for one's needs and priorities), guardianship, and living arrangements than when young adults without disabilities are transitioning to adulthood.

**As a caregiver of a young adult with epilepsy and disabilities, you may need to be more involved in the transition process. Your child may have more, or more serious, needs than either the pediatric or adult neurologist's other patients, so more of the responsibility during the transition may fall to you as the person with the most knowledge of both needs and possible solutions.**



- Some young adults with disabilities may benefit from genetic or metabolism testing, as treatments, testing for related conditions, and patient and caregiver support may be different if there is a genetic or metabolic cause of the disability.
- Some treatments for epilepsy may be used more often in adults with disabilities, including vagus nerve stimulation, responsive neurostimulation, or surgery to remove the seizure focus.

You may be the only person aware of some issues that are not directly related to epilepsy, such as those related to digestion or appetite, menstrual cycle or hormones, urination, mood or mental health, teeth or mouth problems, sensory concerns (having a hard time in situations with more noise or things to see), sleep, or preventing falls or other injuries. Your efforts may help ensure that your child does not have unmet needs during the transition process.

**FAST FACT**  


All patients with epilepsy, especially those with tonic-clonic (grand mal) seizures, are at increased risk for sudden unexpected death (SUDEP). Although this is very uncommon, it does occur. Taking medicine as prescribed and following lifestyle recommendations can reduce this devastating consequence of epilepsy.

**Table C: Epilepsy Self-Management Scale**

Your child should answer each question using the following scale:

	Never	Rarely	Some-times	Most of the time	Always
I write down how often I have seizures and when they occur.					
I do things such as relaxation, guided imagery, and self-hypnosis to manage stress.					
I call my doctor when I think I am having side effects from my seizure medicine.					
When my seizure medicine is running out, I spread out the time between doses.					
I keep a record of the types of seizures I have.					
I stay out late at night.					
I keep track of the side effects of my seizure medicine.					
When my seizure medicine is running out, I take less medicine at each time.					
I take my seizure medicine the way my doctor orders it.					
I stay out of situations that might cause a seizure.					
If I am going away from home, I take my seizure medicine with me.					

	Never	Rarely	Some-times	Most of the time	Always
I call my doctor if I am having more seizures than usual.					
I make sure I get enough sleep.					
I do things that I enjoy to help manage stress.					
I have a way to remind myself to take my seizure medicine.					
I take my seizure medicine at the same time each day.					
I would go swimming alone.					
I do things such as relaxation, guided imagery, and self-hypnosis to keep myself from having a seizure.					
When the doctor orders blood tests, I have them done.					
I wear or carry information stating that I have epilepsy.					
I have to put off having my seizure medicine refilled because it costs too much money.					
I get enough exercise.					
I use power tools such as electric saws, electric hedge trimmers, or electric knives without an automatic shutoff.					
I miss doctor or clinic appointments.					
If I had side effects from the seizure medicine, I would skip a dose without asking my doctor.					
I take showers instead of baths.					
I plan ahead and have my seizure medicine refilled before I run out.					

**Table C: Epilepsy Self-Management Scale (Continued)**

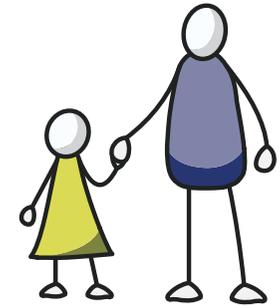
Your child should answer each question using the following scale:

	Never	Rarely	Some-times	Most of the time	Always
I miss doses of my seizure medicine because I do not remember to take it.					
I keep the temperature of the water in my home low enough so I do not get burned.					
I skip doses of my seizure medicine.					
I check with my doctor before taking other medicine.					
I stay away from things that make me have seizures.					
I eat regular meals.					
I climb objects such as high stools, chairs, or ladders.					
I talk with other people who have epilepsy.					
I drink a lot of alcoholic beverages such as beer, wine, and whiskey.					
I participate in a support group for persons with epilepsy.					
I practice what to do during a seizure with my family and friends.					

Source: Managing Epilepsy Well Network. <https://managingepilepsywell.org>.

## What is my role in supporting my child's transition?

Keeping lines of communication open with trusted adults is helpful for children and young adults, especially those with epilepsy. This may be a good time to make special efforts to connect with your child.



Sharing a special meal or activity together can give you both a chance to talk about how the transition is going.

If your child is willing to tell you his or her thoughts and feelings, it might be best to simply listen and share your advice or ideas at another time.

You or your child (or both) might enjoy keeping a written journal of questions, reflections, or artwork related to the transition.

## Ways to support the transition to young adulthood in epilepsy

- ▲ Let your child do part of the doctor's appointment on their own.
- ▲ Encourage your child to make his or her own doctor appointments.
- ▲ Check with your child to see if he or she knows when and how to seek advice and urgent medical treatment should the need arise.
- ▲ Encourage your child to keep an up-to-date seizure diary.
- ▲ Suggest that your child write down questions that come up between doctor appointments.
- ▲ Instill the importance of taking medicine every day and the consequences of suddenly stopping the medicine without medical advice.
- ▲ Show your child how to follow his or her treatment plan and how to refill prescriptions.
- ▲ Discuss the side effects of alcohol, illegal drugs, contraceptives, tiredness, and other issues that may surface with people of this age.

Your child may be interested in hearing about your experiences with adult medical care.

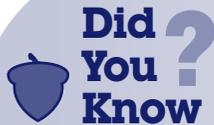
Consider sharing how your doctor's office handles things like paperwork, medicine refills, after-hours communication, making appointments, and communicating with your other doctors.



Telling your child about your feelings when you transitioned to adult care can help reassure him or her that you understand what they are going through.

Your child's transition is an ongoing process. The first appointment with an adult neurologist does not mean that the transition is over. The transition period is the time between starting to talk about change and when the young adult is proficient and feels that managing their own care is "normal."

## How can the stigma of epilepsy affect transition?



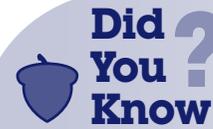
**Stigma** refers to a mark of disgrace or shame felt by people with characteristics considered socially unfavorable. Stigma can come in many forms. Unfortunately, there are people who still believe cruel and untrue myths about epilepsy that make it seem as if the condition is someone's fault or a punishment.

The stigma of epilepsy may limit the success of the transition from child to adult epilepsy care.

The security that comes from a feeling of acceptance is necessary for young adults to progress toward independence with confidence.

Feeling accepted may be more of a challenge for young adults with epilepsy as there is a negative stigma about epilepsy in society.

Rejection from peers, negative social experiences, poor relationships, trouble making, and keeping friends can result from stigma. These effects may cause emotional stress and young adults may not feel enough support to successfully transition to adulthood.



Public stigma about epilepsy has improved with more awareness and education, but children and young adults may still experience stigma from their peers.

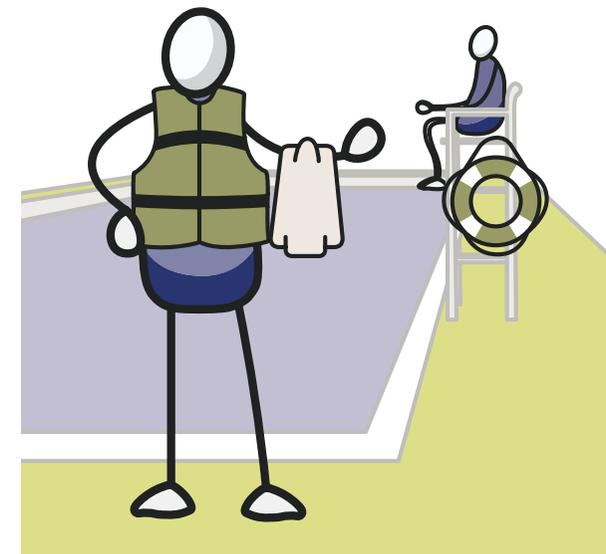
**You can support your child by talking about stigma and helping him or her understand that stigma is about how others respond to epilepsy not how they respond to who your child is as a person.**

- It may help your child to meet other children with epilepsy to share their experiences and feel part of a community.
- The internet and online communities and forums may be useful tools for meeting peers with epilepsy and hearing their stories.

As parents and caregivers, you can help by allowing participation in a wider range of your child's activities and removing unnecessary restrictions.

Your child should not participate in activities that may be unsafe for people with seizures, but you can help them find ways to be involved in those activities. For example, your child may be able to participate in an activity that involves swimming, such as a trip to the beach or pool, as long as they are supervised very closely. In the ocean, this may require a life preserver and having an adult with water safety skills within a few feet of the child.

Friends and other supporters can help your child feel less stigma related to epilepsy and thus more accepted.



## SECTION II: PRINCIPLES OF TRANSITION IN EPILEPSY FROM CHILDHOOD TO YOUNG ADULTHOOD

For children with epilepsy, there is no single, standard path for transition to adulthood. Researchers have studied barriers to a smooth transition and have identified 8 principles that can guide transitions for people with epilepsy and their caregivers. The 8 principles of transition also apply to young adults with disabilities.



**FAST FACT** In 2014, the Child Neurology Foundation developed 8 principles that can be followed by caregivers, medical teams, and young adults in finding the best way forward.

### Child Neurology Foundation's 8 principles of transition

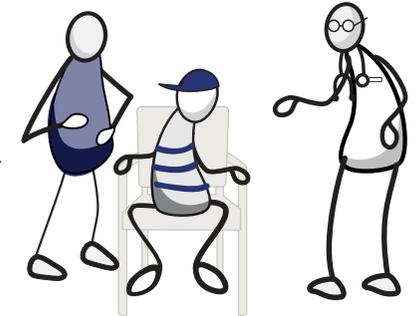
- ▲ **Principle 1:** A formal discussion outlining specifics of the transition plan with you, your child, and your child's neurology team is scheduled around your child's 13th birthday.
- ▲ **Principle 2:** An annual assessment of your child's self-management skills is scheduled with your child's neurology team.
- ▲ **Principle 3:** You, your child, and your child's neurology team have an annual transition-planning meeting.
- ▲ **Principle 4:** A meeting with your child's neurology team is scheduled to discuss your child's legal competency.
- ▲ **Principle 5:** A comprehensive transition plan is outlined by the time your child is 14 years old.
- ▲ **Principle 6:** Your child's neurology team develops and verifies the neurologic component of the transition plan.
- ▲ **Principle 7:** You, your child, and your child's neurology team identify the adult neurologist.
- ▲ **Principle 8:** Your child's neurology team communicates directly with the adult neurologist to ensure that the identified doctor agrees to and accepts the transitioning child and that an appointment is made and kept.

## Perspectives on the principles of transition

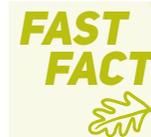
### Principle 1: Formal discussion of the transition plan

The first step in the transition process will likely be a meeting with you, your child, and your child's doctor to talk about the plan for your child's transition to adult medical care. This meeting will usually happen around the age of 13 years.

Some of the steps in the years after the first meeting include having your child learn more about their epilepsy condition, learning how to manage their epilepsy and advocate for their care needs, working through the effect of normal physical and emotional changes on epilepsy during the teen years, and learning about and choosing a new neurologist.



The first transition meeting may have a lot of information to take in all at once. You may find it helpful to take notes or your child's doctor may give you some handouts or other written information about the issues discussed.



**FAST FACT** Many doctors have formal policies that talk about how they handle this transition. You should ask your child's doctor if he or she has a transition policy and request a copy of it or check if it is available on the doctor's website.

### Principle 2: Annual assessment of your child's self-management skills

**Starting at the age of 12 years and every year after that, your child's doctor will assess your child's skills in managing their epilepsy.**

**Your child will need:**

- Self-management skills before successfully transitioning to adult care.
- To understand their condition and limitations, know and take responsibility for their medical care needs and decisions, and know how to advocate for their care needs.

Children whose seizures started very early in life may have never received an age-appropriate description of their seizures, the overall disease of epilepsy, the purpose of their medicine, or how their medicine works.

Your child will need to fully understand this information to independently manage their condition.

Your child's doctor may use a checklist or other tool to assess your child's skills. A checklist can allow you and/or your child to rate the strength of your child's skills in several areas.

**Table D: Sample checklist to assess your child's self-management skills**

**Items rated on a scale from *never does this to always does this***

- ▲ My child can describe his or her condition and explain any special health needs to others.
- ▲ My child is in charge of preparing and taking his or her medicines and/or treatments on his or her own.
- ▲ My child takes part in medical discussions about him or her.
- ▲ My child plans how to take care of his or her own health needs.
- ▲ My child organizes and keeps track of his or her own health information, including appointments, medicine, and test results.
- ▲ My child uses people outside of the family, such as friends, or community members, to support him or her in managing his or her condition.
- ▲ My child can get him or herself to medical appointments.
- ▲ My child spends time alone with his or her doctor at each visit.
- ▲ My child talks with health care providers about the impact of his or her condition on his or her sexual functioning and health (for example, sexually transmitted infections, protection).
- ▲ My child talks with the doctor about how his or her condition is affected by the use of tobacco, alcohol, and drugs.
- ▲ My child speaks up for him or herself and tells others what he or she needs during medical visits.
- ▲ My child talks with health care providers about ways to manage stress.
- ▲ My child talks with health care providers about how his or her health condition affects his or her life.

Source: The Hospital for Sick Children. <http://www.sickkids.ca>.

**Table E: Additional sample checklist**

**Items rated on a scale of *does not know about this to knows all about this*.**

- ▲ My child knows the names of his or her medicines and/or treatments.
- ▲ My child knows what his or her medicines and/or treatments are for.
- ▲ My child knows how his or her medicines and/or treatments are paid for.
- ▲ My child knows what his or her health condition may bring in the future.
- ▲ My child knows he or she has the right to get information about his or her health.
- ▲ My child knows the kind of health care providers he or she will need to see as an adult.
- ▲ My child understands how his or her condition will affect the way he or she develops through puberty.
- ▲ When my child gets sick he or she knows how to get the help he or she needs.
- ▲ My child knows how to schedule a medical appointment.

Source: The Hospital for Sick Children. <http://www.sickkids.ca>.

**Principle 3: Annual transition-planning meeting**

After the first meeting, you and your child should continue meeting with your child's doctor at least once a year to talk about the transition process.

These meetings strengthen communication about and planning for all transition issues. Some topics that may be discussed include your child's epilepsy symptoms and disease control; medicine side effects; reproductive issues (including genetic counseling); concerns related to puberty and sexuality; driving; alcohol; substance use; and emotional or psychological concerns.

If your transitioning child is female, it may be important for her to take folic acid and she should have information on possible issues as she gets older and wants to start a family of her own.

These meetings also allow you to ask questions about your child's transition and medical needs and to hear the doctor's advice about how to help your child take more responsibility for his or her health.

Your child's doctor may have you or your child complete a self-management assessment checklist during these meetings.

Yearly transition meetings should ideally happen separately from regular care visits. This allows enough time to fully address all of the potential issues around the transition process. If separate meetings are not possible, try to discuss transition issues during routine appointments rather than at urgent appointments.



One thing that may be talked about during the transition is understanding your child's diagnosis. Many children are diagnosed with epilepsy years before they transition to adult care. At the time of transition, better tests may be available and it may be possible to learn more about some aspects of your child's seizures, such as causes, triggers, or the specific type of seizures. Results from new tests, including imaging tests such as magnetic resonance imaging (MRI) or genetic tests, may help your child's adult doctor to better understand and treat your child's epilepsy.



Pictures of your child's brain from an MRI, as well as updated electroencephalogram (EEG) readings of brain signals, may help your child's neurologist to better understand your child's epilepsy.

**Principle 4: A discussion of your child's legal competency**

By the time your child is 14 years old, you and your child's doctor should discuss your child's legal competency.

Being legally competent means that your child is able to make independent decisions.

Your child's legal competency may need to be assessed each year for several years before a final decision about his or her decision-making abilities can be made.



If the doctor does not think that your child will be legally competent when he or she reaches adulthood, there may be actions to help increase your child's decision-making abilities or a need for legal documents such as a guardianship, a health care proxy, or a power of attorney.

**FAST FACT**

The process for these legal documents can take up to 2 years, so start early.

**Legal options for young adults with limited legal competency**

<b>Guardianship</b>	<b>Gives the right to make legal decisions about an adult (someone older than age 18 years in most states) to another trusted individual when the adult is not capable of making decisions on their own.</b>
<b>Power of attorney</b>	<b>Another way of giving a person's right to legal decision making to another person.</b>
<b>Health care proxy</b>	<b>An adult with the authority to provide health information or make health care decisions for another adult if the adult is not able to speak for themselves.</b>

**Principle 5: Comprehensive transition plan is developed**

After these initial meetings and assessments, you and your child's doctor may need to talk to other individuals about your child's transition to adult medical care and adulthood in general.

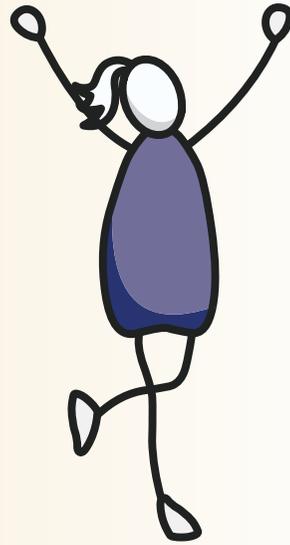
These may include other caregivers, other health care providers, school staff, career or vocation advisors, legal services, or social workers.



Your child's legal competency is an important issue in the transition to adulthood.

The information gained from these discussions may allow you and your child's doctor to develop a more cohesive and final transition plan for your child. Ideally, the final transition plan should be ready when your child is 14 years old.

The final transition plan should not focus entirely on medical concerns. Rather, the transition plan should describe how your child's complete range of needs will be met during the transition process, including health insurance/access to health care, legal concerns, primary medical care from a general doctor, care from medical specialists, and other health care services such as physical therapy, nutrition, education, employment, housing, and community services. The plan should include specific activities for your child to grow in their self-management skills. Since needs and services change over time, the plan should be reviewed every year.



**You may wonder who is responsible for implementing your child's transition plan. According to the Child Neurology Foundation, your child's doctor should:**

- Include you and your child in the process of developing the full transition plan and make sure that other professionals (for example, legal) are included in the process.
- Determine the person on your child's health care team who will primarily oversee and update the plan, such as a nurse or transition coordinator (if not the neurologist).
- Update the medical and neurologic parts of the plan at least once a year.

### **Principle 6: Neurologic concerns are addressed**

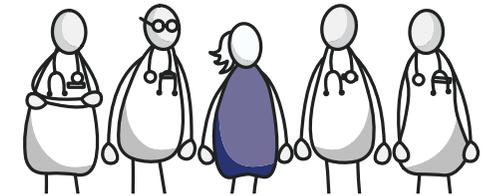
The medical part of the plan that will be prepared by your child's doctor has the most specific information about your child's epilepsy condition. This part of the plan may be called the "transfer packet" because the information will be given to the child's adult doctor(s) to tell them about your child's epilepsy condition and needs. You and your child may read the transition packet to better understand your child's medical condition and needs.

**Here are some issues that should be included in your child's transition packet:**

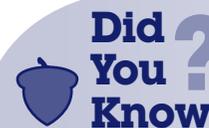
- Summary of all medical issues – for epilepsy, this includes seizure history, causes, medicines tried, current medicines, and previous test results
- Summary of your child's goals and preferences for adult medical care
- Planned timing of transition to adult medical care
- Any testing that is needed before transferring to the adult neurologist
- Current assessment of your child's understanding of the condition and treatment
- Plans for emergency care
- Advanced care directives (for example, power of attorney, living will, do not resuscitate orders)
- Plans for guardianship (for children with a serious intellectual disability)

### **Principle 7: Finding your child's adult neurologist**

As a caregiver, you have had a long-term relationship with your child's epilepsy doctor, and finding a new adult-focused doctor can be a challenging part of the



transition process. Establishing care with an adult doctor is an essential part of the transition, critical to maximizing your child's seizure control. You may not know how to find a new doctor and this task may seem daunting, but this task is shared among you, your child, and your child's doctor. Your child's doctor will probably take the lead in this process given his or her knowledge of your child's epilepsy care and other medical needs, and will help you find the best doctor for those needs.



Management of adult epilepsy is increasingly provided by multidisciplinary teams that can include epileptologists, neurologists, nurse practitioners (NP), or physician assistants (PA).

A major difference between child and adult medical care is that pediatric doctors often care for a full range of medical concerns. In contrast, adult doctors often only care for medical concerns in their specialty.

When transitioning to adult care, your child will likely have several doctors: a primary doctor for general concerns, a neurologist, and other specialized doctors if your child has other specific medical conditions or needs.

Finding an adult neurologist may be challenging, especially if your child has a rare form of epilepsy, intellectual or behavioral problems, or limited health insurance coverage.

The adult neurologist may be more confident about caring for your child if the pediatric neurologist is available for ongoing discussion.

Not all young adults have a neurologist and some continue to see only a general doctor even with poor seizure control. Although it may seem bothersome to have many doctors, children and adolescents with epilepsy should see an adult neurologist when they become adults. A neurologist can best treat your child's epilepsy.

Adult doctors may spend less time with you and your child during appointments. Rather than seeing this as a lack of care for your child, it may help if you understand that adult doctors tend to have busier practices. Having realistic expectations may help to prevent feelings of disappointment or resentment.

It may help everyone involved if your child's adult neurologist is chosen well before the actual care transition, even as early as 1 to 2 years beforehand.

This will allow enough time for you and your child to learn about the new doctor and for the new doctor to learn about your child's type of epilepsy and other medical needs.

Any tests that the adult neurologist will need before your child's first appointment can be performed during this time as well.

It may help to have an initial meeting with your child's new neurologist, giving you and your child an opportunity to see their



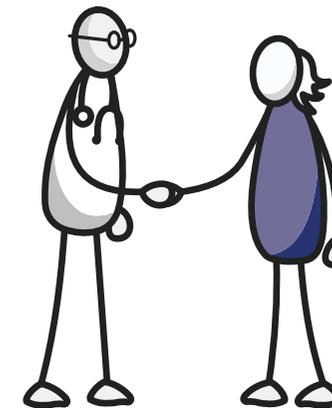
office, and get to know them before the actual transition and the first care appointment. Your child's pediatric neurologist may help you set up this type of meeting or help you coordinate the initial contact with the new neurologist.

### **Principle 8: Your child's doctor communicates with the adult neurologist and your child has his or her first appointment**

After several years of talking about your child's transition, the final step happens when your child makes and keeps the first care appointment with his or her new neurologist.

This will likely happen around 18 years of age, but could happen earlier or as late as age 21 years.

You and your child may not be fully comfortable with the new doctor for a while, but your child's doctor will consider the transition process complete after the first kept appointment with the adult neurologist.



In some cases, if it is taking a long time to get comfortable with the adult neurologist, parents and caregivers may wonder if they can "bounce back" to their pediatric neurologist. In general, this will not be possible due to age limits of the pediatric neurologist's practice and your child's changing medical needs as he or she grows and develops. Health insurance providers may not allow individuals over the age of 18 years to see pediatric providers. A bigger concern, however, is that bouncing back to childhood doctors would be a step backward in the transition process. Unless you are concerned that the adult neurologist is not caring for your child's epilepsy properly (in which case you should consider another neurologist), it is best to stick with the adult neurologist.

## SECTION III: LIFESTYLE CONSIDERATIONS FOR TRANSITION IN EPILEPSY

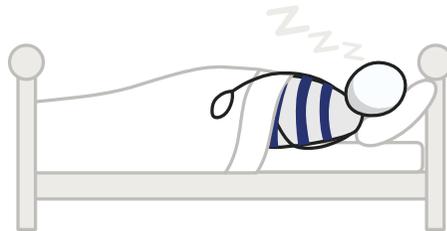
### Sleep

Not getting enough sleep is a common cause of seizures in people of all ages, including young adults.



**In a survey of people with epilepsy, lack of sleep was the most commonly identified seizure trigger.**

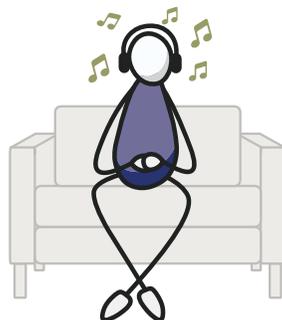
Unlike younger children with stricter bedtimes, older children and young adults may set their own bedtimes and may be more likely to go to sleep too late. In contrast, getting enough sleep may improve seizure control in some people. Young adults with epilepsy need to understand the importance of getting enough sleep and the risk for seizures if they choose not to get enough sleep. You can help your child by letting them know if you have any concerns about their sleep patterns and help them find ways to get more sleep, such as setting bedtime alarms or using curtains to keep their bedroom as dark as possible.



Talk to your child about getting enough sleep as a way to prevent seizures.

### Stress

Stress can increase the chances of a breakthrough seizure. Along with seizures caused by the body's response to stress itself, stress can increase seizures if stressful situations lead to barriers to taking medicine on time or other adherence problems. Stress also can cause insomnia.



Normal social and emotional changes during the transition years may increase your child's stress and lead to seizures even if there is no concern about adherence to medicine. If you think that your child is experiencing more stress than usual or is often "anxious or stressed," try to find ways to help them reduce stress. Some people manage stress by increasing physical activity or time spent on creative hobbies (for example, painting, knitting), whereas others enjoy relaxing activities (for example, listening to calm music). Your child may be skeptical, but steps to deal with stress are worth trying if they can prevent seizures. In some cases, cognitive-behavioral therapy or medicines can help treat the anxiety disorders that can be seen with epilepsy.

### Special diets

Ketogenic diets are used mainly in children to control certain seizure types. Many children receive a ketogenic diet for only a short period of time (up to 2 years) but others need to continue the diet longer.

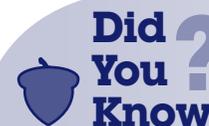
If your child receives a ketogenic diet, it may be more difficult to transition because fewer adult neurologists are familiar with ketogenic diets.



You will also need to find a doctor who can manage the diet during the unique metabolic and growth period of the teenage years.

Finding a doctor and dietitian who can help you and your child manage a ketogenic diet is also important because there can be some safety concerns when the diet is used long-term.

Some possible long-term side effects are kidney stones, decreased bone density (increases risk for fracture), and increased cholesterol, but overall these concerns seem to be minimal or the long-term effects are not well established (such as an increase in the risk for heart disease due to high cholesterol). For example, kidney stones can be prevented by taking an extra medicine to change urine chemistry, drinking extra fluids, or both.



**One concerning long-term side effect of the ketogenic diet is that your child may grow more slowly while on the diet.**

The modified Atkins diet is a less-restrictive and often more palatable option for young adults. You can work with your child’s doctor to choose the best diet for your child.

**Table F: Ketogenic and modified Atkins diets for epilepsy**

Ketogenic diet	Modified Atkins diet
Prescribed by a doctor and may require seeing a nutritionist or dietitian	Less doctor involvement, but a doctor should approve the use of the diet and monitor its effects
Requires strict tracking of calories, fluids, and proteins	You may need to see a nutritionist or dietitian
High-fat, low-carbohydrate diet	Less strict than the ketogenic diet
Fat is the body’s main energy source	No restrictions or limits on fluids, calories, or protein Fats are encouraged but not measured or tracked
Fats come from butter, heavy whipping cream, mayonnaise, and oils	Carbohydrates are counted and monitored
Other carbohydrates must be avoided, including those in medicine	Fat food choices include bacon, eggs, mayonnaise, butter, meats, heavy whipping cream, and oils
Going off the diet for even one meal can decrease its effect	Other common foods are certain fruits, vegetables, nuts, avocados, olives, and cheeses
Vitamin and mineral supplements, such as calcium, vitamin D, iron, and folic acid, may be needed	

## Driving

Learning to drive and getting a driver’s license are major milestones between childhood and adulthood. Part of this transition for your child with epilepsy includes learning about seizure-related driving laws.



The Epilepsy Foundation website lists seizure-related driving laws by state, including how long people have to be seizure-free before applying for a driver’s license or starting to drive after a seizure (see the Resources section at the end of this booklet).

Young adults may have more concerns about being independent, wanting to keep up with their friends, being able to transport themselves, and whether they can get a job that requires driving than about issues of safety related to driving and epilepsy.



Together, you can learn about driving laws in your state and encourage your child to talk to their doctor about driving.

Learning about epilepsy driving laws in your state can help your child learn about safe driving.

## Jobs and employment



Along with driving, many young adults want to begin working and earning money during the teenage years. However, working can be more complicated for people with epilepsy. Unemployment rates in people with epilepsy are much higher than in the general population, and lower rates of employment may start in the teenage years.

Young people with epilepsy may not be sure if they should tell their employer about their epilepsy or may be afraid of losing their job or job advancement opportunities if they have a seizure at work.

You can help your child work through these issues and find jobs that are safe for them to perform. They may not realize that telling an employer about their epilepsy may allow the employer to modify high-risk jobs so that they are less risky or to evaluate work performance in a more realistic way.

Long-term jobs and careers should be considered early. Your child may consider college or work-training programs during their medical transition to adult care. You can suggest that they talk with their doctor about how their epilepsy could fit with jobs or careers that interest them.

Having a general idea of jobs that would be unsafe or challenging for someone with ongoing seizures that impair awareness, such as working with heavy machinery or driving, can help your child make the best work and training choices.

Your child may benefit from academic support services or college scholarships that are only for young adults with epilepsy or disabilities.

## Exercise



**Both young and older people with epilepsy may be less physically active and may have higher rates of obesity than people without epilepsy, which means that they may need to make more of an effort to exercise regularly.**

You should be aware that physical exercise itself generally does not increase the risk for having a seizure, but there have been rare cases of seizures related to exercise. A bigger concern with exercise is safety.

Before your child engages in physical activity, you should consider whether there would be any risk for injury if he or she has a seizure during the activity. For example, swimming and other water sports carry a risk for drowning among people with epilepsy if a seizure occurs unexpectedly, regardless of age.

As your child gets older, he or she becomes physically able to engage in more intense activities and sports, but with higher intensity there may also be increased risk.

Young adults can stay safe by wearing appropriate safety gear for the activity and staying near other people who can get help quickly if a seizure occurs.

Safe exercises can help your child maintain a healthy weight.

### **Risk levels for various activities**

Low risk	Moderate risk	High risk
Baseball	Basketball	Boxing
Bowling	Biking	Downhill skiing
Cross-country skiing	Boating or sailing	Gymnastics (equipment with height)
Golf	Football	Hang gliding
Table tennis	Gymnastics (floor)	Hockey
Track	Horseback riding	Motor sports
Walking	Karate	Rock climbing
Weight training (machines)	Skateboarding	Scuba diving
Yoga	Soccer	Swimming (in open water)
	Swimming	
	Waterskiing	

## Bone health

Bone health needs to be considered during the young adult years as children and young people with epilepsy are more likely to have weaker bones. Some bone issues may be caused by certain antiseizure medicines, but can result from immobility that accompanies many comorbid disorders such as cerebral palsy.

Your child's bone growth generally ends around the last part of the teenage years, so his or her epilepsy transition occurs during a time of bone growth.

Your child's doctor may check your child's vitamin D level or bone mineral density, and may suggest a vitamin D supplement to maintain your child's bone health.

You can also help your child by ensuring that they have plenty of calcium-rich options in their diet, such as milk, yogurt, and cheese.

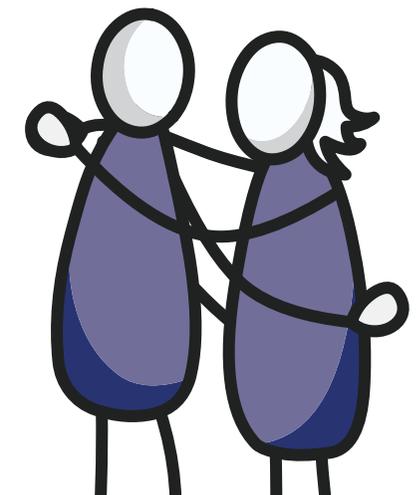


## Sexuality

Sexual identity and expression are a part of life for all teenagers. Young adults with epilepsy should know that sexual activity does not make it more likely that they will have a seizure. This means that young adults with epilepsy can engage in the same sexual activities as their peers. But sex can cause problems for people with epilepsy due to sexually transmitted diseases or unwanted pregnancies.

Birth control pills and some other types of hormonal birth control, such as the patch or vaginal ring, can prevent pregnancy and are easy to use, but they can cause problems with some antiseizure medicines.

When taken together, some antiseizure medicines may not work as well and there may be a higher risk for seizures. There is a chance that hormonal birth



control, including the “morning after” pill, may not work as well and there may be a higher risk for getting pregnant.

Condoms are safe for people with epilepsy and can prevent sexually transmitted infections, but they do not prevent pregnancy as well as hormonal forms of birth control.

Other forms of hormonal birth control, such as the injection, under-the-skin implant, or intrauterine device, may be better options for young women taking antiseizure drugs.

Folate vitamin supplements (at least 0.4 mg) in women with epilepsy who are having a period are recommended as they may reduce the chances of a birth defect if an accidental pregnancy were to occur.



Some parents are not comfortable talking about sexuality with their children, but this is an important topic to discuss with young adults with epilepsy, especially young women, so that both seizures and pregnancy can be safely prevented. Whether or not you are comfortable having this conversation with your child, you should give your child and his or her doctor time to discuss sex and birth control questions or concerns in private.

## Taking care of YOU

Although you may be focused on supporting your child, caregivers may need more support during times of transition as well. Taking care of yourself may help reduce the stress and increase your ability to support your child.

Keeping up with hobbies and activities you enjoy, maintaining a healthy lifestyle that includes physical activity, and having time to connect with friends and other supporters or support groups can go a long way in helping you so that you can help your child.

You probably already know that epilepsy affects the entire family, and the usual stress and coping problems that caregivers experience may be more likely during times of transition.



**Studies have shown that young adults with parents and families who have better coping skills have an easier time adjusting to having epilepsy.**

You may already have strong skills in coping with stress since you have been caring for a child with epilepsy for many years—these skills will be helpful during your child’s transition.



## CONCLUSION

Transitioning through various stages of adulthood is challenging for most adults and even more so for people with epilepsy. The goal of this publication is to provide people with epilepsy at any stage, and their families and caregivers, with a valuable resource that can be consulted time and again. Having tools and resources at your disposal can help you and your caregivers with your transitions of care in epilepsy.



## LIST OF TERMS USED THROUGHOUT THIS EDUCATIONAL SERIES



# LIST OF TERMS

**Adherence:** taking medicines exactly as instructed by a health care provider

**Americans with Disabilities Act (ADA):** passed in 1990, this act protects people against discrimination based on a disability, such as epilepsy, when looking for a job at a company or organization that employs at least 15 people; these companies are required to make arrangements for people with disabilities to complete job tasks

**Antidepressant:** medicine used to treat major depressive disorder

**Antipsychotic medicine:** medicine used in schizophrenia

**Asset protection:** protecting your wealth and home from lawsuits

**Aura:** a perceptual disturbance experienced by a person with epilepsy

**Bone mineral density:** a test that measures the amount of calcium in a person's bones using x-rays

**Copayment or coinsurance:** set amounts of money that a person must pay each time he or she sees a doctor or seeks health services

**Deductible:** a set amount of the fees for service that a person must pay before the health insurance company starts paying for medical care

**Electroencephalogram (EEG):** is a test that measures and records the electrical activity of your brain

**Epilepsy:** a seizure disorder that affects individuals of all ages

**Equal Employment Opportunity Commission (EEOC):** an organization that provides support to people with epilepsy in the workplace and ensures that companies and organizations follow the law and do not discriminate against a job applicant or employee based on a disability such as epilepsy

**Exclusive provider organization (EPO):** an insurance plan that allows a person to select 1 doctor from a smaller network and charges additional fees when seeing a specialist out of network

**Focal impaired awareness seizure:** also known as complex partial seizure this is considered the most common form of epilepsy in adults, it involves abnormal regional discharges of electrical activity in the brain

**Generalized epilepsy:** types of epilepsy characterized by seizures affecting both sides of the brain that can result in a loss of consciousness

**Guardianship:** a legal option that gives the right to make legal decisions about an adult (someone older than age 18 years in most states) to another trusted individual when the adult is not capable of making decisions on their own

**Health care proxy:** an adult with the authority to provide health information or make health care decisions for another adult if the adult is not able to speak for him or herself

**Health maintenance organization (HMO):** an insurance plan in which the primary care provider refers a person to see specialists, such as a neurologist

**Hormone replacement therapy:** medical treatment used to relieve discomfort caused by the lack of estrogen and progesterone hormones in menopausal women

**Intrauterine devices (IUDs):** a small plastic T-shaped device inserted in the uterus to prevent pregnancy

**Ketogenic diet:** prescribed by a doctor, this high-fat, low-carbohydrate diet requires strict tracking of calories, fluids, and proteins

**Legal competency:** being able to make independent decisions

**Living will:** a document that explains a person's health care wishes in situations when he or she is alive but unable to provide consent for medical care

**Magnetic resonance imaging (MRI):** is a test that uses a magnetic field and pulses of radio wave energy to make pictures of organs and structures inside the body

**Mail order pharmacy:** pharmacies that can mail prescription medicines directly to a person's home

**Medical home:** refers to a doctor's office or clinic that connects all of a patient's health care providers

**Menopause:** the absence of menstrual periods for 12 consecutive months

**Modified Atkins diet:** a diet with no restrictions or limits on fluids, calories, or protein but requires carbohydrates to be counted and monitored; usually requires less doctor involvement

**Neurologist:** a specialist who treats diseases related to the nervous system, including epilepsy

**Nonadherence:** not taking medicine as prescribed, including taking too much or too little, taking it at the wrong times, or forgetting altogether

**Nurse Practitioner (NP)/Advanced Practice Nurse:** a registered nurse with advanced training who usually works with a pediatrician, neurologist, or epileptologist

**Out-of-pocket maximum:** the limit on the amount a person will pay for his or her medical needs before the insurance company pays for the rest

**Paratransit services:** transportation services available for people with disabilities who are unable to access mass transit

**Physician Assistant (PA):** a health care professional who is trained to practice medicine as part of a team with a physician

**Point of service (POS):** an insurance plan that allows a person to see a doctor who is in the network, but charges additional fees when seeing a specialist out of network

**Power of attorney:** a legal option that gives a person's right to legal decision making to another person

**Preferred provider organization (PPO):** an insurance plan that allows a person to see any doctor who participates in the insurance plan's network without a referral, but charges additional fees when seeing doctors out of the network

## LIST OF TERMS

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**Premium:** a set amount that a person pays each month for a health care plan

**Stigma:** a mark of disgrace or shame felt by people with characteristics considered socially unfavorable

**Symptoms:** a physical or mental feature or sensation indicating a condition of disease

**Transition:** a "purposeful planned process" that addresses the medical, psychosocial, educational, and/or employment needs of young people with chronic physical and medical conditions as they move from child-centered to adult-focused health care systems

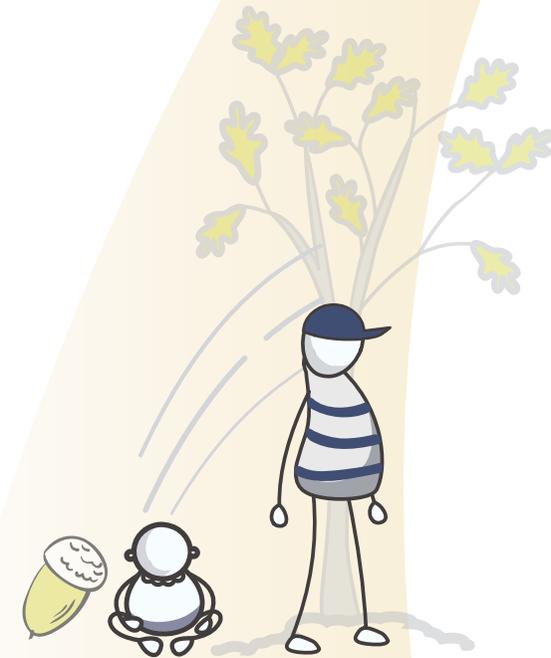
**Triggers:** refers to situations that bring on a seizure

**Umbrella coverage:** maximum personal excess liability insurance coverage

**Vagus nerve stimulation:** a medical treatment in which electrical impulses are sent to the vagus nerve



## ADDITIONAL TOOLS AND RESOURCES FOR FURTHER READING



# ADDITIONAL TOOLS AND RESOURCES

## Got Transition

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

Sample transition readiness assessment for youth  
<http://www.gottransition.org/resourceGet.cfm?id=224>

Sample transition readiness assessment for parents/caregivers  
<http://www.gottransition.org/resourceGet.cfm?id=225>

## Epilepsy Foundation

Epilepsy & My Child Toolkit

[https://www.epilepsy.com/sites/core/files/atoms/files/English\\_Toolkit\\_updated%202014.pdf](https://www.epilepsy.com/sites/core/files/atoms/files/English_Toolkit_updated%202014.pdf)

## Driving laws database

<http://www.epilepsy.com/driving-laws>

## TalkAboutIt.org

Encouraging children and parents to talk about epilepsy

<http://www.talkaboutit.org/>

## Epilepsy Foundation – Eastern Pennsylvania

Keys to Independence Checklists

Medical management – <https://www.efepa.org/wp-content/uploads/2013/10/Keys-Medical-Checklist-Letterhead.pdf>

Personal and social - <https://www.efepa.org/wp-content/uploads/2013/10/Keys-Social-Checklist-Letterhead.pdf>

Vocational and educational - <https://www.efepa.org/wp-content/uploads/2013/10/Keys-Vocational-Checklist-Letterhead.pdf>

## Child Neurology Foundation

Community Conversations: Transition into Adulthood (webinar)

<https://www.youtube.com/watch?v=NlcX5Ppr1uc>

The Arc

<http://www.thearc.org/>

## National Center for Medical Home Implementation videos

How does a medical home support transitioning from pediatric to adult care?

<https://www.youtube.com/watch?v=6JfCsxpLfo>

Why should providers prepare patients/families to transition to adult care?

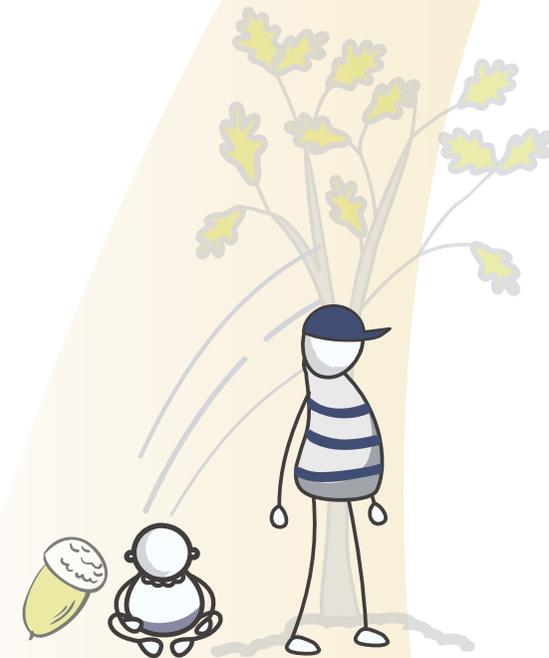
<https://www.youtube.com/watch?v=ECao63W84I&feature=youtu.be>

## National Collaborative on Workforce and Disability

A Young Person's Guide to Health Care Transition

<http://www.ncwd-youth.info/sites/default/files/Young-Persons-Guide-to-Health-Care-Transition.pdf>

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