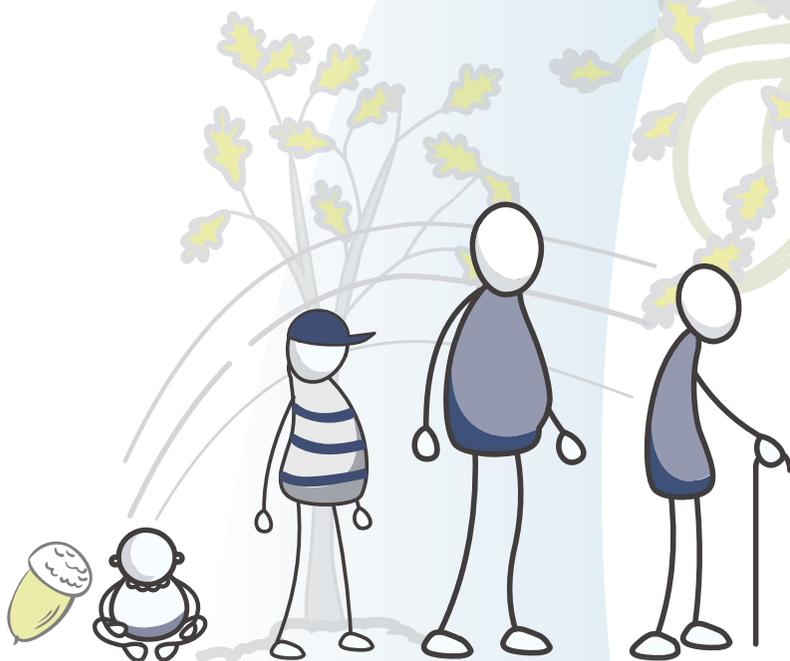


# TRANSITIONS OF CARE IN EPILEPSY

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

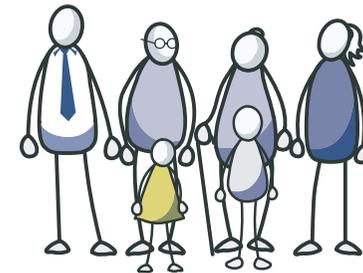


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# TRANSITIONS OF CARE IN EPILEPSY

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



***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.

# 2

## A Patient Guide for Teens & Young Adults: What's Your Plan?



**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 second of 3 modules in the *Transitions of Care in Epilepsy* series

**Module 2** in this educational series discusses the unique needs of the **teen or young adult** living with epilepsy. This booklet highlights a variety of topics including medication adherence; tracking your seizures using a diary; preparing for appointments with your neurologist; and health care-related legal changes after turning 18 years of age. Additionally, topics covered include a review of health insurance concerns; employment; dealing with epilepsy at college; and social issues affected by epilepsy, such as sex, relationships, and driving.

**We hope readers find this educational series  
helpful and informative!**

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## TEENS & YOUNG ADULTS: WHAT'S YOUR PLAN?

Transitioning from childhood to adulthood is an exciting yet challenging time. You may be looking forward to many new events in your life such as graduating high school, going to college, getting your first job, living on your own, or someday starting a family. As a person with epilepsy, it can be intimidating to think about making all these changes in your life in addition to managing your epilepsy; however, with good planning, you can feel prepared and ready for your journey to adulthood.



*Preparation for an effective transition of epilepsy care is the focus of this module.*

## WHAT DOES IT MEAN TO TRANSITION?

### Did You Know?



Transition refers to the process of changing from the care you receive for epilepsy as a child to the care you receive as an adult. Perhaps the biggest transition is changing from a pediatric neurologist to a neurologist who cares for adults.

### The transition process also includes:

- Taking control of your own health care
- Knowing about your epilepsy and your seizure care plan
- Being able to discuss epilepsy and your particular circumstances with others
- Taking responsibility for your social life

This is a process that includes you, your family, and your health care team.

As a child, your family members may have been heavily involved in your care—taking you to your doctor's appointments, filling your prescriptions, reminding you to take your medicines, and calling your doctor. As an adult, you should take charge of your own health care and manage your epilepsy **independently**.



### FAST FACT



Epilepsy self-management includes knowing the names and doses of your medicines, taking your medicines appropriately, being able to discuss the details of your seizures with others, documenting your seizures, considering your degree of seizure control and how to remain safe, sleeping enough, and reducing stress.

Managing your epilepsy is essential because seizures may be adequately controlled in many people, and a single seizure can cause serious injury, negatively affect your mood, and make it difficult to perform certain activities, such as driving and working. Being able to manage your own care is a part of achieving your future goals, whether they include going to college, getting your dream job, or living on your own.

## When should I get started? The sooner the better!



**Did You Know?** You and your doctor can start planning your transition as early as age 12 or 13. If you're older than 13 and you haven't started talking to your doctor, now is a good time to do so.

You, your family, and your doctor will work to develop a plan, and this plan should be reviewed and updated throughout your teenage years. When you're about 18 years old, you should be ready to transition to adult care. The exact timing of your transition will be unique to you and depends on when you, your family, and health care provider feel comfortable.

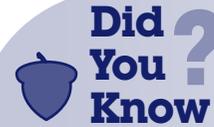
**Between ages 12 and 14 years, start to think about your personal health care needs. Your goal at this age is to know as much as you can about your epilepsy and to understand how you can remain healthy.**

- Think about whether or not you know your specific diagnosis—seizure types and epilepsy syndrome—and the names and timing of your medicines.
- Consider what you can do each day to stay healthy and feel well. Perhaps this includes eating a healthy breakfast or going on a walk.
- Start participating in activities that benefit your health, and think about whether you need help to do them.



**Remember:** Don't be afraid to ask if you need help. Learning who and how to ask for help are important skills, too.

You also can start participating at your doctor's appointments by chiming in to ask questions. During and after your appointments, think about what the plan is for your epilepsy, whether you understand the plan, and whether you agree with it.



**Did You Know?** When you're between 15 and 17 years old, one opportunity to practice caring for your health independently is to spend part of your doctor's appointment alone with your doctor, instead of with your parents or caregiver.

Talking with your doctor alone will help you prepare for seeing the doctor on your own as an adult. You will want to talk with him or her about how you've been feeling, ask any questions you may have, and discuss your treatment plans. These are areas that parents often help with, but you should feel comfortable being alone with your doctor now as a teenager so you're confident seeing the doctor as an adult.

### Before your doctor's appointment, you can:

- Let your parents or caregiver know that you'd like to talk with the doctor alone for a portion of the time. You may want to ask your parents or caregiver to help you prepare.
- Practice speaking to your parents like you'd speak to your doctor. Ask your parents or caregiver to help you think of questions to ask. Write them down before your appointment so that you remember to ask them during your visit. All of this will help you feel more comfortable and less shy about talking with your doctor.
- Consider the opportunity to start managing your prescriptions. For example:
  - You can start contacting your pharmacy and reordering your medicines when needed.
  - If your prescription is about to expire or you don't have any refills, you can call your doctor and ask for a new prescription.



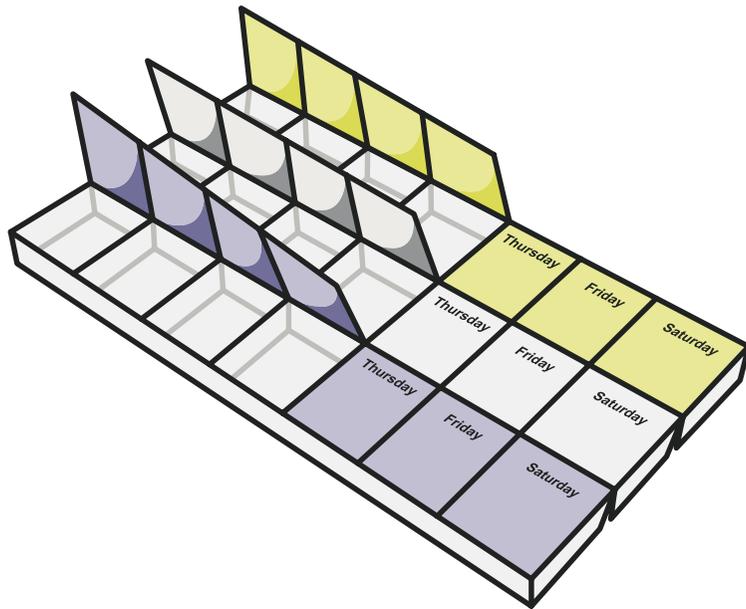
## What else should I do to take charge of my health?



There are other ways you can make sure you're ready to take care of your health.

### Taking medicine as prescribed

One of your most important responsibilities is to take your medicines as prescribed by your doctor. Remembering to take your medicines each day may seem simple, but this task can get overlooked when you're busy or when your routine is different (for example, on weekends, during sleepovers at a friend's house, on trips or vacation).



Missing just 1 dose of your medicine may increase your risk of having a seizure.

### Fortunately, there are ways to help you keep track of your medicines.

- A visual chart may help you remember—these charts can help you keep track of the names and doses of your medicines and when to take them.
- A pill box that gets filled once a week can help, especially when you can't quite remember whether or not you've taken your pills.
- You can set an alarm to go off every day at the time when you are supposed to take your medicine. There are free apps for your smartphone that include medicine reminders.
- Think about your daily routine and pick a specific activity you do that can be associated with taking your medicines each day. Make sure to associate it with something you do at the same time each day, such as eating breakfast, eating dinner, or brushing your teeth.
- If you're not taking your medicines because you're having trouble affording them, you can get help. Contact a **social worker** or **patient assistance program**. Information on patient assistance programs is available in the resources section at the end of this booklet.
- You can contact the manufacturer of your epilepsy medicine to see if it offers a patient assistance program. Ask your doctor or pharmacist to help if you're unsure how to contact the drug manufacturer.

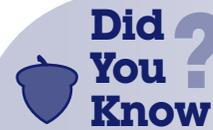


Here is a sample checklist to determine how ready you are for this transition.

### Table G: Sample transition readiness assessment for youth

Respond to each item with "Yes, I know this," "I need to learn," or "Someone needs to do this ... Who?" to gauge your readiness for transition.

- ▲ I know my medical needs.
- ▲ I can explain my medical needs to others.
- ▲ I know my symptoms, including those that may mean that I need to see my doctor quickly.
- ▲ I know what to do if I miss a dose of medicine.
- ▲ I know what to do in case I have a medical emergency.
- ▲ I know what to tell others who are often with me what to do if I were to have a seizure, and if I have several seizure types, what to do for the different ones.
- ▲ I know my own medicines, what they are for, and when I need to take them.
- ▲ I know my allergies to medicines and medicines I should not take.
- ▲ I carry important health information with me every day (for example, insurance card, allergies, medicines, emergency contact information, medical summary).
- ▲ I understand how health care privacy changes at age 18 when I am legally an adult.
- ▲ I can explain to others how my customs and beliefs affect my health care decisions and medical treatment.
- ▲ I know or I can find my doctor's phone number.
- ▲ I make my own doctor's appointments.
- ▲ Before a visit, I think about questions to ask.
- ▲ I have a way to get to my doctor's office.
- ▲ I know to show up 15 minutes before the visit to check in.
- ▲ I know where to go to get medical care when the doctor's office is closed.
- ▲ I have a file at home for my medical information.
- ▲ I have a copy of my current plan of care.
- ▲ I know how to fill out medical forms.
- ▲ I know how to get referrals to other health care providers.
- ▲ I know where my pharmacy is and how to refill my medicines.
- ▲ I know where to get blood work or x-rays if my doctor orders them.
- ▲ I have a plan so I can keep my health insurance after I reach 18 years of age or older.
- ▲ My family and I have discussed my ability to make my own health care decisions at age 18.



If you're not already keeping a seizure diary or calendar, you may want to start. A diary is a helpful way to keep track of your seizures.

You could use your diary to record what happens at your doctor's appointments or any questions you may have for your next appointment.

### Tracking seizures

**You can record when you have a seizure and your activities and feelings before, during, and after the seizure using a seizure diary or calendar.**

- Tracking your seizures can help determine what type of treatment may be best for you and if your current medicines are working.
- You can ask your friends or family who were around you during the seizure to record what they saw as you may not be aware of everything that occurred during the seizure. This can help you and your doctor understand what could be causing your seizures and what you need to be aware of to potentially prevent future seizures.
- Recording information about your seizures can help you recognize patterns and determine common **triggers**. For example, you may realize that you have seizures after getting a bad night's sleep or when you're stressed out over a test.
- You can make a note of any side effects of the medicines you're taking. Your seizure diary can also help you keep track of your moods and feelings related to epilepsy, or you can choose to document these in a separate epilepsy journal.

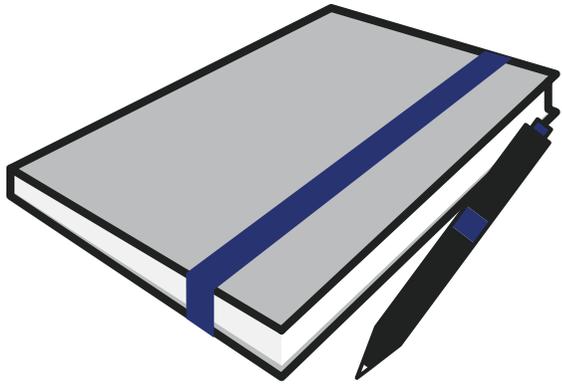
### Tips for tracking seizures

There are many options for seizure diaries or calendars. You can write in a journal or log it on your computer or phone. There are now online and app-based diaries to use on your smartphone or smartwatch if you have one. Refer to the resources section at the end of this booklet for options.

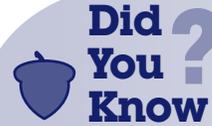
Try to record your seizure right away. If you wait too long to record the details, you may forget. It's a good idea to talk with your doctor or nurse about what would be most helpful to include in your seizure diary.

### Here are some examples of important items to consider including in your diary:

- Record the date, time, and length of the seizure.
- Record what you were doing before the seizure. Did you experience any change in mood before the seizure? Did you experience a warning or **aura**?
- How did you feel during the seizure? Did you experience any changes during the seizure?
  - What were you seeing, tasting, smelling, and thinking about?
  - How were you talking, hearing, and moving?
  - Did you experience any muscle movements or stiffness?
- Did you experience any mood changes, tiredness, or numbness after the seizure?
- What do you think might have triggered the seizure?
  - Did you miss any medicines or take a medicine late?
  - Did you sleep poorly the night before or wake up early?
  - Did you skip meals or eat something that didn't sit well in your stomach?
- If you experienced a seizure during or after exercising, what exercise were you doing?
- Did you drink alcohol or do recreational drugs?
- How was your mood? Were you stressed, happy, excited, or anxious?
- Were you exposed to some sort of sound, a flashing light, or bright sunlight? Were you sick?
- Did you take a new prescription medicine, over-the-counter product, such as a cold or sleep medicine, or herbal product? If you're a young woman, what day is it of your menstruation cycle?



## How do I prepare to find a new doctor?



**Did You Know?** You should plan to spend time looking for an adult doctor. It's a good idea to ask your pediatric doctor at what age he or she stops seeing patients.

Doctors who treat children may stop seeing patients for general care, and management of epilepsy, when they turn 21 years old, but the age may vary based on the doctor's office. You'll want to start thinking about what you want out of a new doctor who treats adults. For example, do you want to go to a small practice where you may see only 1 doctor? Or would you rather go to a large practice where you may have to see more than 1 doctor, but the doctors may see more patients with your condition or have more flexibility in their schedules? You can ask your friends or even look to a local support group for patients with epilepsy for recommendations.

### Table H: Sample list of questions to ask your doctor before and after your transition to adult care

#### Before you leave your pediatric doctor:

- ▲ At what age do I need to change to an adult doctor?
- ▲ When do I start to meet with you on my own for part of the visit?
- ▲ What do I need to do to get ready for adult care? Do you have a checklist?
- ▲ Can I have a copy of my Medical Summary and Emergency Care Plan?
- ▲ When I turn 18, what rights in health care do I need to know about? (If I need help with making my own health care decisions, who can I talk with?)
- ▲ Will you help me move to a new adult doctor?
- ▲ Do you have suggestions of adult doctors, and do you know if they take my insurance?
- ▲ Can you call the new doctor and help me set up my first appointment?
- ▲ Will you send the new doctor my current Medical Summary and Emergency Care Plan?

**Table H: continued****Before you make your first visit to the new adult doctor:**

- ▲ Do you take my insurance?
- ▲ Did you receive my Medical Summary and Emergency Care Plan from my previous doctor?
- ▲ What should I bring to my first visit?
- ▲ Where is the office located? Is there parking or is it near a metro/bus stop?
- ▲ What do I do if I'm sick?
- ▲ What are the office hours and do you have walk-in times?
- ▲ Who and how (by text message or phone call) do I contact my provider during and after office hours?

Once you find someone you like, meet with him or her and feel free to ask questions to determine if it's a good fit. Let the doctor know what your preferences are regarding your treatment, and listen to his or her ideas on treatment. It will take time to feel as comfortable with your new doctor as you are with your pediatrician. To help you prepare, Got Transition has developed a sample list of questions to ask your doctor before and after your transition to adult care (see Table H).



You will want to make sure that the doctor you find participates with your insurance. If the doctor does not, your insurance may not pay for medical costs and you will more than likely be responsible for paying directly for any care you receive.

**There are multiple ways you can find out if your new doctor participates with your insurance plan:**

- You can call the doctor's office and ask if it accepts your insurance.
- You can find out about coverage from your insurance company by:
  - Calling the insurance company and speaking with a representative
  - Looking on the insurance company website
  - Searching your insurance company member handbook

## How should I prepare for appointments with my new doctor?

**As an adult, you will likely see the doctor by yourself instead of with your parents or caregiver.**

- Make sure you know how to get to your doctor's office and take time to plan your visit.
- Arrive to your appointment at least 15 minutes ahead of time.
- Be sure to bring your health insurance card and a form of payment in case you need to pay a fee such as a copayment.

**You also should be prepared to talk about your health.**

- Bring or have available key details of your epilepsy history, such as **magnetic resonance imaging (MRI)** or **electroencephalogram (EEG)** results.
- Bring a list of your medicines, and also know which medicines you were previously on but are no longer taking. Were you previously on an epilepsy drug but stopped taking it due to an allergy or side effect? It's important to keep this information.
- Be prepared to discuss your family's health history. For example, if your mom or dad has a health condition (such as high blood pressure or diabetes), it may put you at higher risk for the same disease so it's important for your doctor to be aware of that so he or she can monitor you for it.

**Remember** : Before your doctor's appointment, write down any questions or concerns you'd like to talk about, so that you don't forget to discuss important topics.

One easy way to do this is to keep a list of questions on your phone that you can update as they come to mind. If you are keeping a seizure diary or calendar, make sure to bring this, too.

If you forget something that happened since your last appointment, you can check in your seizure diary or calendar. If you don't have an epilepsy diary, bring a notebook so you can write down any notes. This way, you don't have to worry about remembering everything that happens.

When it's time to see your doctor or if you have a question about your care, it's important for you to contact your doctor's office. Don't wait for someone else to do it or for your doctor to contact you.



With the transition to adult care, you may go to the doctor's office less often.

## What legal responsibilities should I be aware of after turning 18?

There are important legal changes to be aware of once you turn 18 years old.

**One of the many forms your parents or caregiver may fill out for you at the doctor's office is a medical consent form. If you're not already filling this form out, you'll be responsible for signing it once you turn 18 years old and become an adult.**

- This means you're in charge of making your own health care decisions instead of your parents or caregiver.
- A medical consent form indicates that you understand and agree to the medical plan as discussed with your doctor, which may include tests, procedures, or even surgery.



**Another change that occurs when you turn 18 years old is that your medical information becomes private, meaning it is no longer shared with your parents.**

- Your parents no longer have access to your medical records unless you give them permission.
- Your doctors are not allowed to talk with other people about your health care unless you provide permission.
- If you'd like your parents or caregiver to have access to your medical records, you can sign a form called Authorization for Release of Information, which allows them access.

### **Communication is important**

It's a good idea to discuss the changes that will occur when you turn 18. That way, you and your parents or caregiver will be prepared and ready for your entrance into legal adulthood.



**Did You Know?**

Turning 18 does not automatically mean that you should not discuss your medical care with your parents or caregiver anymore. Instead, it means that you're in charge. You should ask questions and consult your parents or caregiver as needed. They can provide good advice and support.

In some cases, your parents or caregiver may decide to submit an application to stay in charge of your health care decisions. This is called **guardianship**. A court will determine whether or not to grant guardianship to your parents or caregiver. You may have family members or friends help with your decisions after you turn 18 years old, although they are not legally your guardians.

## What do I need to know about health insurance?

As a child, your parents or caregiver may take care of your health insurance. As an adult, it is your responsibility to make sure you understand what health insurance is and that you have health insurance coverage. Many insurance companies will not cover children over the age of 26 years and many will not cover you if you have a primary insurance plan from your employer. As a person with epilepsy, it is incredibly important that you plan appropriately so that you continue to have health insurance when you're an adult. This may be daunting considering the complexity of health care. Health insurance can be tricky because there are many options for insurance plans, but there are some basic considerations to keep in mind.



**Did You Know?**

If you do not have health insurance or are going to lose your current coverage and are in search of a new plan, you can visit [healthcare.gov](https://www.healthcare.gov) to see your options.

### **Types of health insurance**

If you're currently enrolled in a government program, such as Medicaid or the Children's Health Insurance Program (CHIP), you may not be eligible for certain government programs once you become an adult. For example, after 19 years of age you may not be eligible for health insurance through CHIP.

If you have Medicaid, you can talk with your Centers for Medicare & Medicaid Services (CMS) nurse care coordinator to determine what changes to expect as you become an adult.

Contact information for CHIP and Medicaid in your state can be found at the following website: <https://www.medicaid.gov/about-us/contact-us/index.html>.

As a person with epilepsy, it's important that you always have health insurance coverage.

**Remember**



According to the Affordable Care Act (ACA), it is illegal for health insurance companies to deny you coverage or charge you higher prices based on epilepsy, which is considered a **pre-existing condition**. However, because the ACA is a hotly debated topic, it's important for you to stay informed about any changes to the law that may occur.

**Table 1: Examples of different types of health insurance providers**

<p><b>Medicaid and CHIP:</b> These are government programs that provide coverage for certain people such as those with low incomes, women who are pregnant, children, the elderly, and people with disabilities.</p>
<p><b>Medicare:</b> This is a government program for people 65 years of age and older, certain people with disabilities, and certain people with kidney disease.</p>
<p><b>Private health insurance through your parent's coverage:</b> Under the ACA, you can receive insurance coverage through your parent's insurance until you are 26 years old.</p>
<p><b>Private health insurance through your work:</b> If your work provides health insurance coverage, this may be an easy way to enroll in a more affordable plan with appropriate coverage.</p>
<p><b>Private health insurance purchased on your own</b></p>
<p><b>College health care plan:</b> If you're a student and your school offers a health insurance plan, you can sign up for it and have coverage.</p>

ACA, Affordable Care Act; CHIP, Children's Health Insurance Program

**When you choose private insurance, there are 4 basic types of plans:**

- **Health maintenance organization (HMO):** With this type of insurance plan, you have a primary care provider who refers you to see specialists, such as a neurologist.
- **Preferred provider organization (PPO):** Under this plan, you can see any doctor who participates in your insurance plan's network without a referral. You can see a doctor out of network as well but you will have to pay an additional cost.
- **Point of service (POS):** With this plan, you usually see 1 doctor who is in your network. You can see a specialist who is not in your network, but it may cost more.
- **Exclusive provider organization (EPO):** This plan is similar to a PPO but has fewer doctors to choose from.

**Health insurance costs**

**There are many different types of costs associated with health insurance. Some of these costs are explained below. It is important for you to understand these costs so you know what you have to pay for out of your own pocket, even with insurance coverage.**

- **Premium:** This is a set amount that you pay each month for your health care plan.
- **Deductible:** This is a set amount that you need to pay before your health insurance starts paying for your medical care. For example, if you have a deductible of \$1,000, you will pay \$1,000 before your insurance pays for any of your medical needs.
- **Copayment or coinsurance:** This is a set amount of money that you pay each time you go to the doctor or seek health services. The amount of copayment or coinsurance may vary considerably between insurance plans.
- **Out-of-pocket maximum:** This cost refers to the limit on the amount you will pay for your medical needs. After you reach your out-of-pocket maximum, your insurance company pays for the rest.

**Consider all these costs when choosing the plan that's best for you.**

- If you go to the doctor often and need regular prescriptions, a plan that has a higher premium but that pays a larger amount of your overall costs may be a good idea.

Although you may be discouraged by the cost of insurance payments, such as monthly premiums and deductibles, keep in mind that these are much less expensive than paying for the cost of an emergency room or hospital visit without health insurance.

## Getting a job

**Getting a part-time job can be a very rewarding experience.**

- Restaurants and retail shops, such as department stores, are great places for you to start looking for a job during your young adult years.
- Your school may have internships, job coaching, or volunteer opportunities that can help you gain experience to get the job you'd like.
- Another way to get initial experience is to look for work during certain seasons, such as a lawn care job during the summer or retail job during the holiday season.



Feel free to be an entrepreneur! You may offer to mow lawns in your neighborhood, help with neighbors' pets, or do something unique, such as making and selling your own jewelry.

Keep in mind that you still need to take care of yourself! Don't let work cause you too much stress or get in the way of sleeping and studying. This may increase your risk for seizures.

If you're starting to think about career options, don't be afraid to contact your guidance counselor and doctor to discuss your career path. If you do start working, you may wonder whether to tell your boss or coworkers about your epilepsy.

**It's completely up to you to decide if and when you feel comfortable disclosing this information.**

- You may want to tell your employer to make sure you're safe and to maintain trust with him or her.
- If you tell your employer and co-workers, they can be better prepared to help you in case of a seizure.

Another reason to consider disclosing this information is that it can allow you to raise concerns if something at work is making your seizures worse. Ultimately, it's your choice when and who you tell.

Having a part-time job is a great step toward independence.

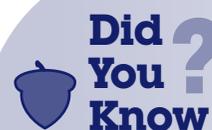
## Going to college

College is often a fun and exciting time, but it is also a huge transition in itself. Leaving your home, parents, and friends can be an intimidating experience, but many people who go to college consider it a rewarding and enjoyable period of their lives.



### Scholarships

When you're applying to college, keep in mind that there are national and local scholarships specifically meant for people with epilepsy. You can find more information on scholarships on the Epilepsy Foundation website at <http://www.epilepsy.com/learn/age-groups/youth/work-and-college/scholarships>. Your local Epilepsy Foundation should have information on scholarships available where you live. Another website to check for scholarships for students with epilepsy is [www.collegescholarships.org](http://www.collegescholarships.org).



Throughout most college campuses you will find security alarms marked by blue lights. Keep in mind that you can use these alarms if you feel you're about to experience a seizure. It may be a good idea to talk to campus security beforehand about what to do if you experience a seizure.

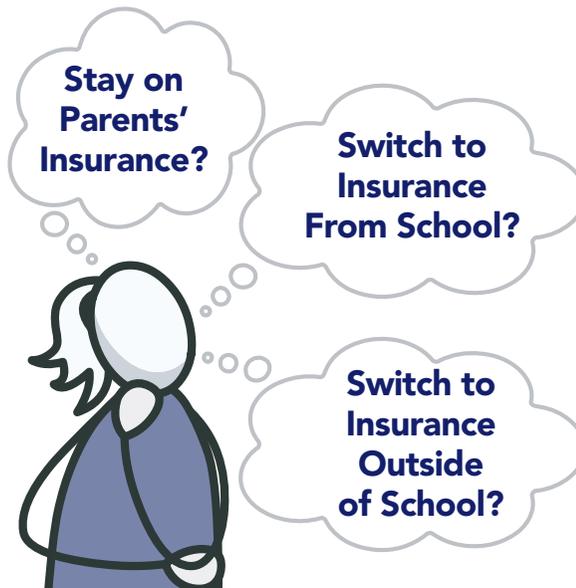
## Disclosing your epilepsy while at college

It's up to you who you tell and how much you decide to share about your epilepsy. People you may want to tell are your roommate(s) and the resident assistant (RA) assigned to your dormitory.

- Your RA may be contacted if you have a seizure, so it's best for him or her to know the plan in case this happens.
- If you tell others about your epilepsy, it may be a good idea to describe your seizures. You should describe any aura or typical **symptoms** you may experience before a seizure, and also what they can do for you if you experience one. For example, let them know when they should call your doctor, family, or 911.
- If you feel comfortable, you can also leave contact information for your doctor and family in a visible place, such as the dormitory fridge, with specific instructions for when to contact them and when to dial 911. You can write down the plan in case there is an emergency and give it to your RA and/or roommate(s), making sure to include all the medicines you take. Your doctor can give you a seizure action plan that can help others know what to do in case you have a seizure.

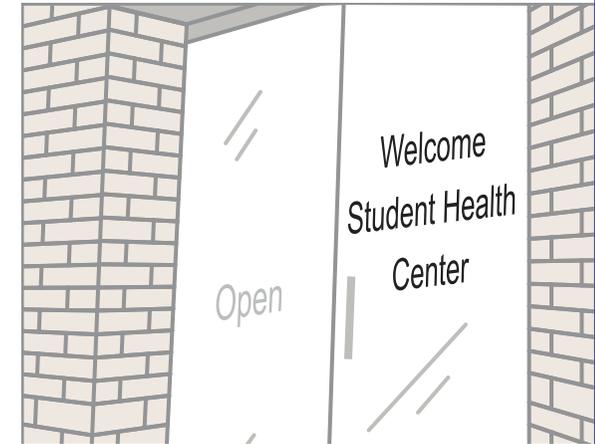
### On-campus health care considerations

You'll also want to think about your health insurance. When you go to college are you going to: (1) stay on your parents' insurance; (2) switch to the health insurance provided by your school; or (3) get your own insurance outside of your school? If you switch to your school's insurance plan, it's important to know where you will go to see the doctor. Many college health centers provide basic medical needs, such as for a cold; however, they may not be as comfortable caring for someone with epilepsy.



**If you decide to use your college's health services, be sure to check their hours, especially during breaks and holidays.**

- It's a good idea to call the health center before you arrive to determine whether or not they'll have doctors who are experts on epilepsy.
- You can make an initial appointment to meet the doctor so you can get to know each other.
- The doctor you find at school may want to talk with your doctor at home. You'll want to make sure whoever is taking care of you has all your important health care information.



- It would be a good idea to find a neurologist near campus before arriving at school. You will want to start your search as soon as possible to make sure you're ready when you arrive on campus.
- You should talk to your insurance company to make sure that if you plan to see 2 doctors (1 while you're home and 1 while you're at school), both are covered.
- Another issue to consider is where will you go to pick up your prescriptions.
- If there's no pharmacy on campus that's easy for you to get to, you can consider using a **mail order pharmacy**. These pharmacies can mail your prescription medicines directly to your door.
- You should ask your insurance company or pharmacist if your insurance allows you to receive 3-month supplies of your medicines, which can cut down on the amount of times you need to refill your prescriptions during the year.
- Whichever pharmacy you use, make sure to give them plenty of time (at least 1 week) to have your prescription ready, just in case something comes up.

**Contact your campus health services before arriving on campus so you're prepared.**

### Transportation on campus

Another aspect of college life to consider is how you will get around campus, especially if you are not able to drive because of your epilepsy. Many smaller campuses are walkable or easy to bike, whereas larger campuses may have a shuttle bus. Asking current students about transportation options before choosing a college can help make sure that you're prepared.



### Disability services on campus

Be sure to contact the Disability Services Office at your new school before or when you first arrive on campus.

#### **FAST FACT**



Your school is required to offer certain "appropriate academic adjustments" that may include registering for classes first or changing classes, accessing people or using recording devices to take notes, extra time for tests, and use of school computers that can read the screen or recognize your voice. Let your school know which of these adjustments you require or if you require a different type of adjustment.

Your academic advisor can discuss any concerns you have related to your epilepsy, college classes, and college life. Remember, it is advisable for you to initiate contact with the Disability Services Office right away so that you can have any accommodations you need.



## Additional lifestyle considerations

### Alcohol and drugs

At some point during your adolescence and young adulthood, you may be tempted to drink alcohol underage or use illegal drugs. In addition to the many legal and health risks involved in using alcohol and recreational drugs, as a person with epilepsy, these actions may increase your risk for seizures or side effects from your medicines.

#### **Alcohol may increase your risk for seizures in different ways. For example:**

- If you have more than 2 alcoholic beverages, you may undergo a withdrawal reaction, known as a hangover, 6 to 48 hours after you stop drinking.
- Alcohol can interfere with your sleep quality, resulting in seizures.
- If you're drinking, you may miss your medicines or, after a night of drinking, you may sleep through your usual wakeup time and miss your medicines in the morning.
- Alcohol may decrease how well certain epilepsy drugs work.
  - Additionally, alcohol combined with your seizure medicines may cause a dangerous sedative effect and certain epilepsy drugs may make it easier for you to get "drunk" from alcohol.
- Recreational drugs may cause you to have seizures.
  - Cocaine may cause a seizure even in people without epilepsy.
  - Other drugs such as heroin, LSD ("acid"), or "ecstasy" may increase your risk for seizures. Although it is not known exactly how, seizures may result from the way these drugs work on your brain or from missing medicine doses or losing sleep while taking these drugs.
- Regular, excessive alcohol consumption can lead to seizures when someone stops drinking.
- The effects of smoking marijuana on people who have epilepsy are not clear. It may be something to discuss with your epileptologist.



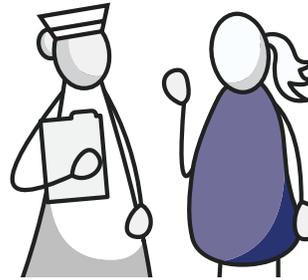
Unlike high school, your college won't contact you regarding accommodations. You must start the discussion with them.

Although your friends might be doing it, think about whether drug or alcohol use is actually a good choice for you and your health. Keep in mind that due to your diagnosis of epilepsy, you have different and very important choices surrounding these issues; make smart choices. If you are of legal drinking age and choose to drink alcohol, limit your consumption to 1 to 2 drinks. Avoid punches or mixed drinks because it is hard to know how much alcohol is in them. In general, 6 ounces of wine, 12 ounces of beer, or 1.5 ounces of 80-proof liquor equal 1 drink.

### Sexual relationships and contraception

**Talking with your doctor about sex is important. If you plan to have sex, it's essential that you practice safe sex. This is especially true if you're a woman with epilepsy in order to prevent an unintended pregnancy.**

- Many epilepsy drugs can cause birth defects in unborn babies.
- Some epilepsy drugs (but not all) may reduce how well certain types of contraception work, such as birth control pills.



There are many types of contraception, so talk with your doctor about whether your epilepsy medicine affects contraception and which types of contraception will work best for you:

- Birth control pills
- Barrier methods such as condoms or diaphragms
- Intrauterine devices (IUDs), which may or may not have hormones released locally
- Long-acting contraceptives such as hormone injections or implants

**Together, you and your doctor can find what works best for you.**

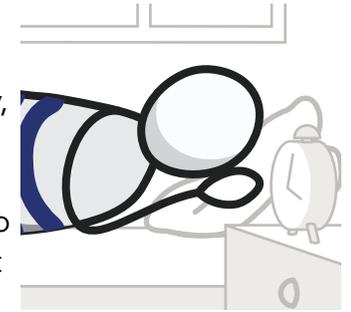
### FAST FACT

If you do become pregnant, don't panic. Do not stop taking your epilepsy medicines because this could cause you to have seizures. Uncontrolled seizures may put you and your unborn baby at risk. Instead, talk with your health care provider right away.

Talking with your doctor about sex can seem intimidating, but it can help you stay healthy.

### Sleep

Getting a good night's sleep is one of the most important things you can do to help have less seizures! As someone with epilepsy, sleep is very important for staying healthy. In fact, if you don't sleep enough, it increases your risk for having seizures. You should try to maintain good sleep hygiene so that you get at least 7 to 8 hours of sleep per night.



### Did You Know?

Sleep hygiene consists of a variety of different practices and habits that are necessary to have good sleep quality at night and full daytime alertness.

There are some simple steps you can follow to help improve your sleep quality listed in Table J.

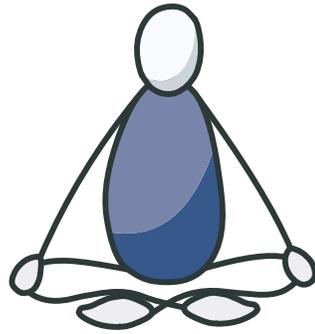
### Table J: Tips for improving your sleep quality

- ▲ If your medicines make you drowsy and you have trouble sleeping, talk with your doctor or nurse about possibly taking them at nighttime to help you sleep.
- ▲ Try to keep consistent timing of sleep each night. Go to sleep at around the same time every night and wake up around the same time every morning.
- ▲ Have a consistent bedtime routine each night that includes relaxing activities, such as taking a bath, reading, or stretching.
- ▲ Avoid napping too much and too close to your bedtime.
- ▲ Keep naps to 30 minutes or less at a time.
- ▲ Keep your bedroom quiet and dark.
- ▲ Avoid using your bed for activities unrelated to sleep, such as working or studying.
- ▲ Avoid exercising too late in the day. Exercising earlier in the day can improve the quality of your sleep.
- ▲ Because alcohol can disrupt sleep, and stimulants such as caffeine, chocolate, and nicotine can keep you up, avoid these close to bedtime.

**If you're lying in bed unable to sleep after 30 minutes, get up and perform a quiet activity instead of just staring at the clock. After 20 to 30 minutes, try again.**

## Managing stress

As you get older, there may be many different stressors in your life, such as work, school, relationships, and your epilepsy. Managing your level of stress is another important part of taking care of your health because stress is a common trigger for seizures. It's important that you learn to manage your stress.

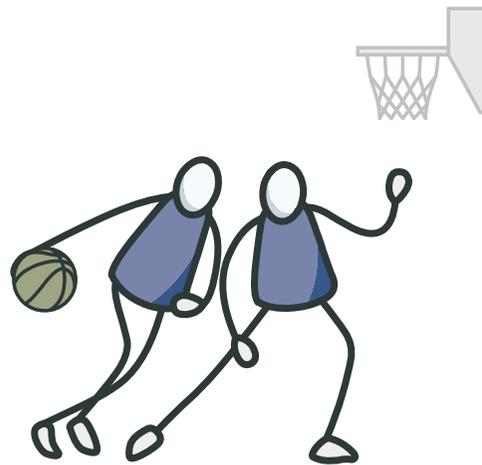


### Here are some practical and useful ways to manage stress:

- Get a good night's sleep and exercise on a regular basis.
- Keep a diary in which you can write down your thoughts and feelings so you're not bottling them inside.
- If you're in a stressful situation, take a moment to reevaluate how you're approaching the situation, and think about whether you can approach it differently.
- Try a relaxation technique! There are many different types of relaxation techniques that can help you cope with stress and stay healthy, including deep breathing exercises, yoga, tai chi, a massage, or even short naps.
- Don't be afraid to talk with someone about things that may increase your stress. You can reach out to your doctor or nurse or you may even consider looking for an epilepsy support group.

## Exercise

Exercising regularly can help your overall health and well-being. However, exercise can sometimes trigger a seizure. This is very rare, and exercise is recommended for most people with epilepsy. Depending on the severity of your seizures, you may need to modify your exercise. When exercising, wear a medical device bracelet or necklace and keep a medic alert card on you. In particular, water sports and swimming may



pose a safety risk to people with epilepsy. If you participate in water sports, always wear a life vest and swim with a buddy or coach who knows about your seizures and how to administer basic life support. You can determine how closely you need to be monitored based on how well controlled your seizures are and the setting (a pool is safer than a lake or the ocean). People with epilepsy should never swim alone. Baths can be dangerous for those whose seizures are not fully controlled. Contact sports such as soccer and basketball are generally considered safe for patients with epilepsy, but always talk with your doctor about what specific exercise and sporting activities are best for you.

## Can I get a driver's license?

### Driving with an epilepsy diagnosis

**As a teenager/young adult, one of your main concerns may be getting a driver's license. Each state has different requirements for obtaining a license.**

- In most states, you'll be able to get your license if your seizures are controlled, although each state has its own exact rules.
- One of the main requirements for getting your license is that you must be free from seizures that impair awareness or motor control for a specified period of time. This time period varies depending on your state of residence.

If you currently have a license and have recently been experiencing seizures, make sure to tell your health care provider. He or she will work with you so that your medicines can be adjusted to avoid having a seizure while driving. It's more important that you drive safely, even if that means you lose your license for a period of time, so that you avoid having an accident that could hurt or even kill you or another person. If you lose your license because of uncontrolled seizures, you can apply to get it back once you are seizure free.



## Final tips

Refer to the Resources section found at the end of this booklet for some select websites and resources to help with your transition.

**Here are some basic steps you can take to start your transition:**

**Take your medicines every day at the scheduled time.**

**Schedule your own doctor's appointments.**

**Start to spend time with your doctor on your own without your parents or caregiver.**

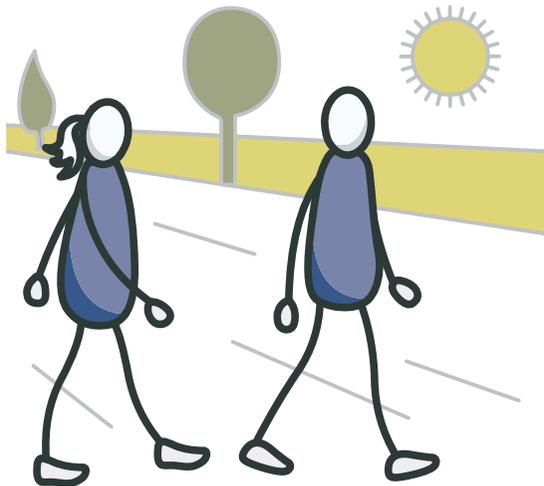
**Practice ordering your prescription refills and following your treatment plan on your own.**

**Keep your seizure diary up-to-date and record any side effects you may experience from your medicine.**

**Keep a list of questions you want to discuss with your doctor or nurse between appointments.**

**If you are planning to attend college, review the considerations in the "Going to college" section starting on page 23.**

**These simple tips will help you and all those around you manage your epilepsy more easily and get you off to a good start on the road to independence and achieving your future goals.**

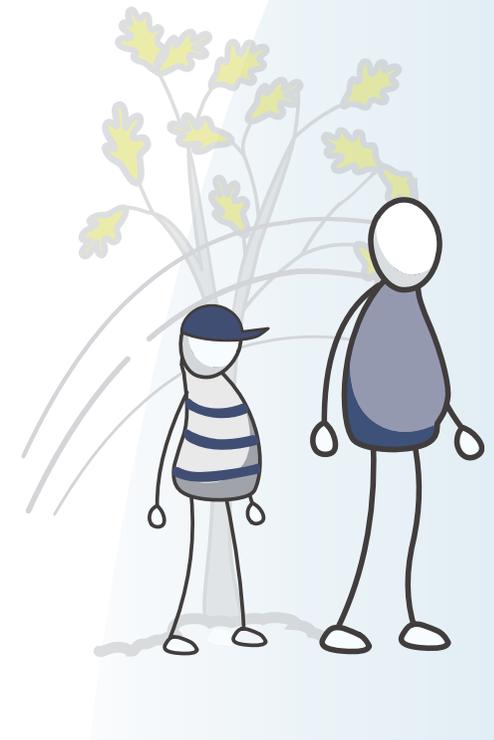


## CONCLUSION

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. Additional information and resources can be accessed by consulting the following final 3 sections in this publication. 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

## LIST OF TERMS

**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

**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

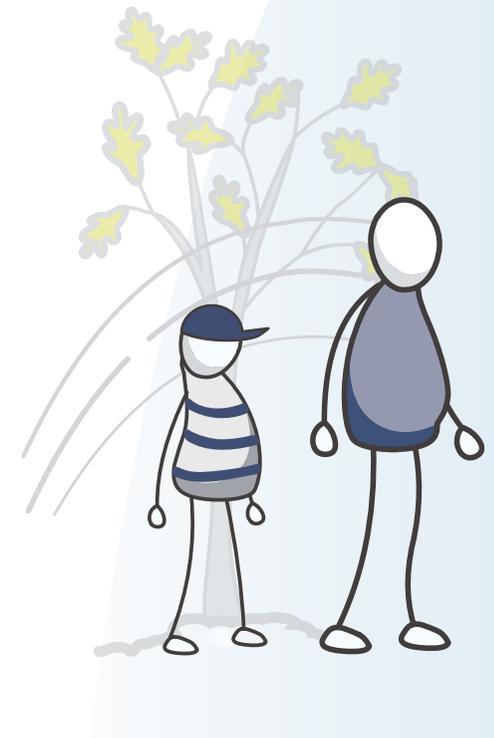
**Triggers:** refers to situations that bring on a seizure

**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>

## Epilepsy Foundation

Information for youth

<http://www.epilepsy.com/learn/age-groups/youth>

Medication and communication tools

<http://www.epilepsy.com/get-help/toolbox/medication-and-communication-tools>

Epilepsy and seizures 24/7 helpline

<http://www.epilepsy.com/helpline>

Scholarships

<http://www.epilepsy.com/learn/age-groups/youth/work-and-college/scholarships>

Tips for seizure observation and recording

[http://www.epilepsy.com/sites/core/files/atoms/files/tips\\_seizure\\_observation\\_recording.pdf](http://www.epilepsy.com/sites/core/files/atoms/files/tips_seizure_observation_recording.pdf)

## Epilepsy Foundation – Eastern Pennsylvania

Epilepsy Disclosure Chart (blank)

<https://www.efepa.org/wp-content/uploads/2014/01/Diclosure-Chart-blank.pdf>

Epilepsy Disclosure Chart (completed)

<https://www.efepa.org/wp-content/uploads/2014/01/Diclosure-Chart.pdf>

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>

## Kids as Self Advocates

<http://www.fvkasa.org>

## Resources for seizures monitoring

Seizure tracker

<https://www.seizuretracker.com/>

Seizure diary

<https://www.depakote.com/Content/Pdf/Seizure-Diary.pdf> (seizure diary)

My Seizure Diary (free online tool to help manage your seizures)

<https://diary.epilepsy.com/login>

## Resources for patient assistance programs

Epilepsy Foundation

<http://www.epilepsy.com/get-help/services-and-support/patient-assistance>

[http://www.epilepsy.com/sites/core/files/atoms/files/Patient%20Assistance%20Programs%20%20353PMA\\_Rev1-2016.pdf](http://www.epilepsy.com/sites/core/files/atoms/files/Patient%20Assistance%20Programs%20%20353PMA_Rev1-2016.pdf)

## Needy Meds.org

<http://www.needy meds.org>

## Partnership for Prescription Assistance

<https://www.pparx.org>

## PatientAssistance.com

<https://www.patientassistance.com>

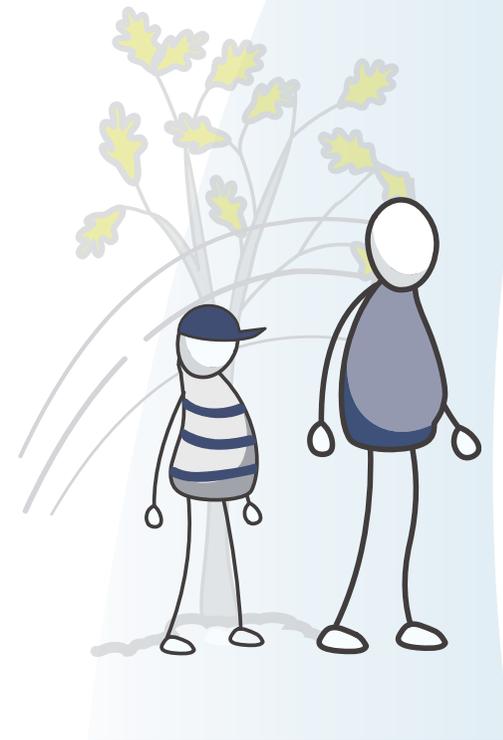
## RxAssist

<http://www.rxassist.org>





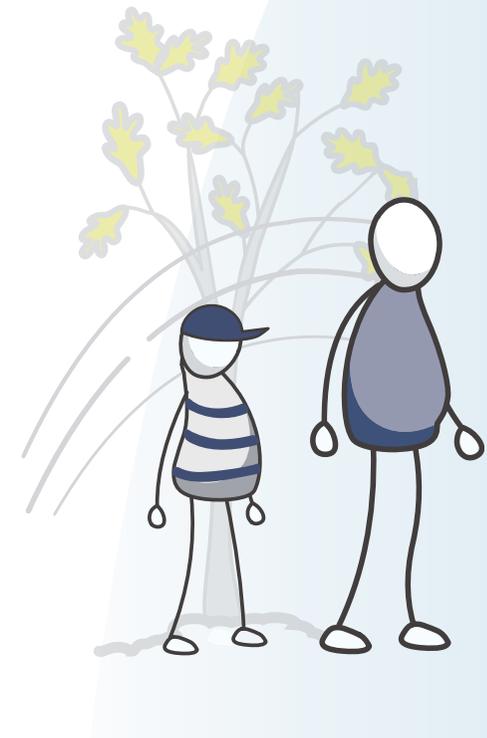
## **REFERENCES CONSULTED DURING THE DEVELOPMENT OF THIS MODULE**



## REFERENCES CONSULTED

- Bautista RED. Understanding the self-management skills of persons with epilepsy. *Epilepsy Behav.* 2017;69:7-11.
- Camfield P, Camfield C, Pohlmann-Eden B. Transition from pediatric to adult epilepsy care: a difficult process marked by medical and social crisis. *Epilepsy Curr.* 2012;12(suppl 3):13-21.
- Centers for Medicare & Medicaid Services. <https://www.medicare.gov>.
- College Scholarships.org. Epilepsy Scholarships. <http://www.collegescholarships.org/health/epileptic-students.htm>.
- Cooley WC, Sagerman PJ, et al; American Academy of Pediatrics; American Academy of Family Physicians; American College of Physicians; Transitions Clinical Report Authoring Group. Clinical report—Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics.* 2011;128(1):182-200.
- Epilepsy Action. Contraception and epilepsy. <https://www.epilepsy.org.uk/info/contraception>.
- Epilepsy Foundation. <http://www.epilepsy.com>.
- Epilepsy Foundation Eastern Pennsylvania. Teen and young adult resources. <https://www.efepa.org/living-with-epilepsy/young-adults/>.
- Epilepsy Foundation Michigan. Managing seizures. <http://www.epilepsymichigan.org/page.php?id=360>.
- Epilepsy Ontario. Alcohol and seizures. <http://epilepsyontario.org/living-with-epilepsy/alcohol-and-seizures>.
- Epilepsy Society. Alcohol, drugs, and epilepsy. <https://www.epilepsysociety.org.uk/>.
- Florida Department of Health. Envisioning my future: a young person's guide to health care transition. [http://hscj.ufl.edu/jaxhats/docs/envisioning\\_my\\_future\\_gray.pdf](http://hscj.ufl.edu/jaxhats/docs/envisioning_my_future_gray.pdf). Published 2005.
- Got Transition. <http://www.gottransition.org>.
- Haigh K. Tips on preparing for a doctor's appointment. Kids as self advocates. <http://fvkasa.org/resources/files/health-preparing.php>.
- Herzog AG, Mandle HB, Cahill KE, Fowler KM, Hauser WA, Davis AR. Contraceptive practices of women with epilepsy: findings of the epilepsy birth control registry. *Epilepsia.* 2016;57(4):630-637.
- Krumholz A, Hopp JL, Sanchez AM. Counseling epilepsy patients on driving and employment. *Neurol Clin.* 2016;34(2):427-442, ix.
- National Institute on Alcohol Abuse and Alcoholism. What is a standard drink? <https://www.niaaa.nih.gov/alcohol-health/overview-alcohol-consumption/what-standard-drink>.
- National Sleep Foundation. Sleep hygiene. <https://sleepfoundation.org/sleep-topics/sleep-hygiene>.
- Rajendran S, Iyer A. Epilepsy: addressing the transition from pediatric to adult care. *Adolesc Health Med Ther.* 2016;7:77-87.
- Teens Health from Nemours. <http://m.kidshealth.org>.
- U.S. Centers for Medicare and Medicaid Services. <https://www.healthcare.gov>.
- U.S. Centers for Medicare and Medicaid Services. <https://www.medicare.gov>.
- U.S. Department of Health and Human Services. <https://www.hhs.gov>.

## THINGS TO REMEMBER







Provided as an educational service by



**Epilepsy** & You



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