

EPILEPSY ALLIANCE FLORIDA

SEIZE THE FUTURE

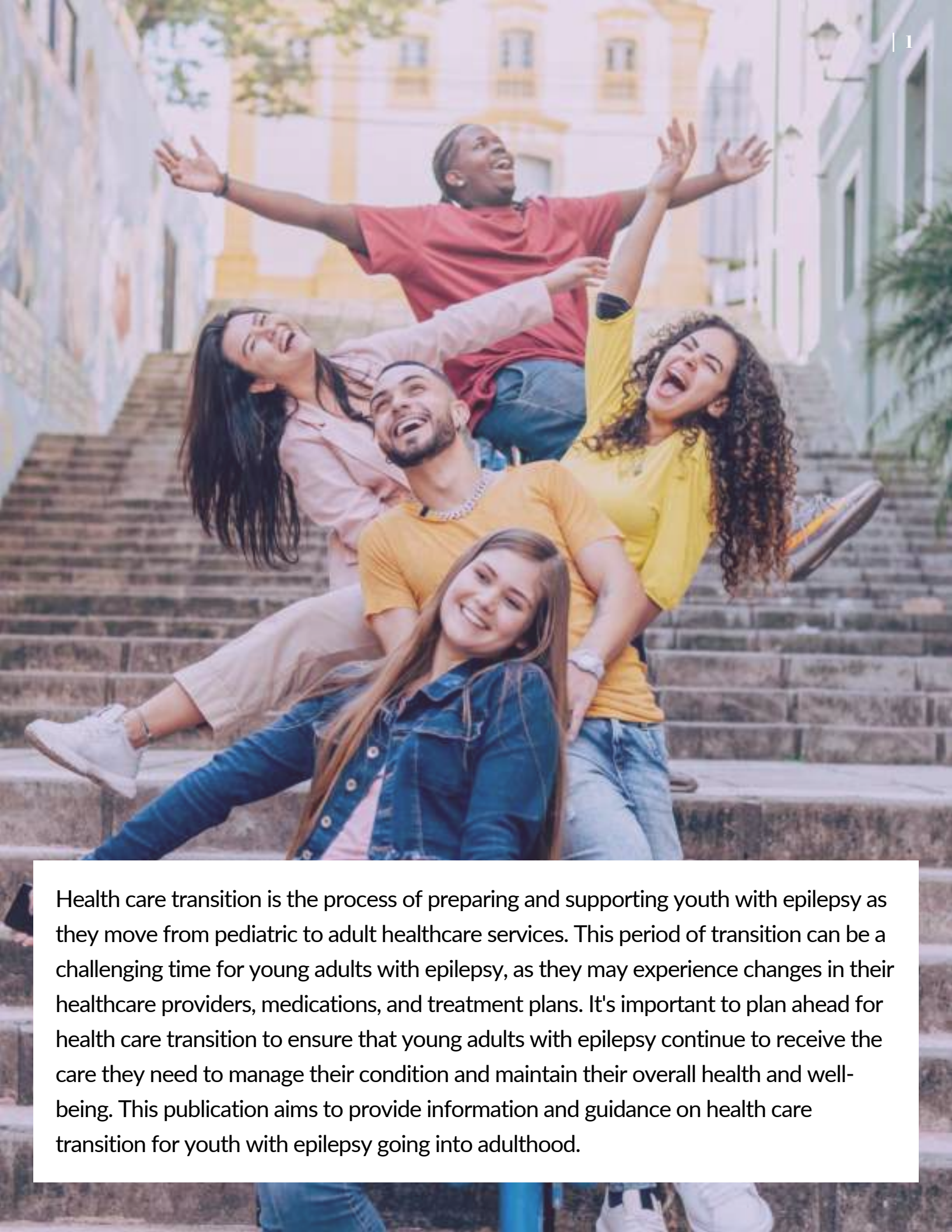
Empowering Youth with Epilepsy in Health Care Transition



**TIPS FOR
MANAGING
EPILEPSY IN
ADULTHOOD**

**WHAT HEALTH CARE TRANSITION
IS AND WHY IT'S IMPORTANT FOR
YOUNG ADULTS WITH EPILEPSY**





Health care transition is the process of preparing and supporting youth with epilepsy as they move from pediatric to adult healthcare services. This period of transition can be a challenging time for young adults with epilepsy, as they may experience changes in their healthcare providers, medications, and treatment plans. It's important to plan ahead for health care transition to ensure that young adults with epilepsy continue to receive the care they need to manage their condition and maintain their overall health and well-being. This publication aims to provide information and guidance on health care transition for youth with epilepsy going into adulthood.

Health care transition is important for youth with epilepsy going into adulthood because it can have a significant impact on their overall health and well-being. During the transition process, young adults with epilepsy may experience changes in their healthcare providers, medications, and treatment plans. These changes can be challenging to navigate, and without proper support and guidance, they may struggle to manage their epilepsy effectively.

WHAT YOU'LL LEARN:

- What health care transition is and why it's important for young adults with epilepsy
- Tips for preparing for health care transition, including how to talk to healthcare providers and identify support resources
- What to expect during the transition process, including changes in healthcare providers and healthcare plans
- Strategies for managing epilepsy in adulthood, including medication management, stress reduction, and maintaining a healthy lifestyle
- The importance of self-advocacy and knowing your rights as a person with epilepsy
- Resources for finding support and connecting with others who have epilepsy



TABLE OF CONTENTS

UNDERSTANDING EPILEPSY	4
GENERALIZED SEIZURES	5
FOCAL SEIZURES	6
COMMON SYMPTOMS OF EPILEPSY AND HOW THEY CAN IMPACT DAILY LIFE	7
HEALTH CARE TRANSITION	8



TIPS FOR PREPARING FOR HEALTH CARE TRANSITION	9
WHAT TO EXPECT DURING THE HEALTH CARE TRANSITION PROCESS	10
MANAGING EPILEPSY IN ADULTHOOD	12
SELF-ADVOCACY	14
RESOURCES	15

UNDERSTANDING EPILEPSY

Epilepsy is a neurological condition that affects the brain and causes seizures. Seizures happen when there is abnormal electrical activity in the brain. There are different types of seizures, and they can look different for different people.

Some people may have seizures where they stare into space and don't respond to their surroundings. Others may have seizures where they lose consciousness and convulse or shake uncontrollably. Some people may have seizures that involve unusual sensations, such as tingling or numbness, or changes in their sense of smell, taste, or hearing.

Epilepsy can be caused by a variety of factors, including genetic factors, brain injuries, infections, or other medical conditions. However, in many cases, the cause is unknown.

While epilepsy can be a challenging condition to manage, there are effective treatments available, including medications, surgery, and other therapies. With proper management, many people with epilepsy are able to live full and active lives.

It's important for young adults with epilepsy to work closely with their healthcare providers to develop a management plan that meets their individual needs and helps them to stay healthy and manage their seizures effectively. This may include taking medications as prescribed, managing stress, getting enough sleep, and avoiding triggers that can bring on seizures.



GENERALIZED SEIZURES

GENERALIZED TONIC-CLONIC SEIZURES (FORMERLY KNOWN AS GRAND MAL)

Tonic-Clonic seizures are the most visible and recognized type of seizure. They involve uncontrolled convulsions and other muscle movements that usually last no more than a few minutes.

MYOCLONIC SEIZURES

Myoclonic seizures are characterized by brief, jerking spasms of a muscle or muscle group. There may be rapid muscle contractions on both sides of the body.

ABSENCE SEIZURES

This type of seizure is more common in children and is characterized by brief periods of staring with a loss of awareness. The person may appear to be daydreaming or “zoned out” during an absence seizure.

ATONIC SEIZURES

Atonic seizures have an abrupt onset and are characterized by a sudden collapse causing the person to fall. After 10 seconds or a minute, he/she recovers, regains consciousness, and can stand and walk again.

FOCAL SEIZURES

FOCAL AWARE SEIZURES (FORMERLY KNOWN AS SIMPLE PARTIAL)

This type of seizure begins in a specific area of the brain and can affect different parts of the body depending on where the seizure originates. Fully aware of what is going on, the person may experience seizures that involve tingling, numbness, or weakness in one part of the body, or they may experience seizures that involve changes in their sensory perception or emotion.

FOCAL IMPAIRED AWARENESS SEIZURES (FORMERLY KNOWN AS COMPLEX PARTIAL)

This type of seizure usually starts in one area or group of brain cells, in the temporal lobe or frontal lobe of the brain. They can start in other areas as well. Symptoms can include involuntary movements called automatisms like rubbing of the hands, lip-smacking, and chewing movements. The person may lose awareness and stare blankly as if he is daydreaming.



COMMON SYMPTOMS OF EPILEPSY AND HOW THEY CAN IMPACT DAILY LIFE



Epilepsy can cause a variety of symptoms that can impact daily life for young adults in different ways. Here are some of the most common symptoms of epilepsy and how they can affect young adults:

Seizures: Seizures are the primary symptom of epilepsy, and they can be unpredictable and disruptive to daily life. Young adults with epilepsy may need to take precautions to avoid injury during a seizure, such as avoiding activities like swimming or driving that could be dangerous during a seizure.

Memory problems: Epilepsy can cause memory problems, which can impact academic or work performance. Young adults with epilepsy may need to take extra steps to manage their memory problems, such as using tools like calendars or reminder apps.

Mood changes: Epilepsy can cause changes in mood, such as anxiety, depression, or irritability. These mood changes can impact relationships, social activities, and overall quality of life for young adults with epilepsy.

Fatigue: Epilepsy can cause fatigue or sleepiness, which can impact energy levels, motivation, and overall productivity. Young adults with epilepsy may need to make adjustments to their daily routine, such as getting enough rest or taking breaks when needed, to manage their fatigue.



Cognitive problems: Epilepsy can cause cognitive problems, such as difficulty with attention or problem-solving skills. These cognitive problems can impact academic or work performance and may require accommodations or extra support.

It's important for young adults with epilepsy to work closely with their healthcare providers to manage their symptoms and develop a management plan that meets their individual needs. With proper management, many young adults with epilepsy are able to achieve their goals and live full and active lives.

HEALTH CARE TRANSITION

Health care transition is the process of preparing and supporting youth with epilepsy as they move from pediatric to adult healthcare services. This period of transition can be a challenging time for young adults with epilepsy, as they may experience changes in their healthcare providers, medications, and treatment plans. It's important to plan ahead for health care transition to ensure that young adults with epilepsy continue to receive the care they need to manage their condition and maintain their overall health and well-being.

Health care transition is particularly important for youth with epilepsy for several reasons:

Changes in healthcare providers: Young adults with epilepsy may need to transition from pediatric healthcare providers to adult healthcare providers. This can be a challenging and stressful process, as they may need to establish new relationships with healthcare providers and adjust to new treatment plans.

Changes in medications: Young adults with epilepsy may need to transition to different medications or adjust their dosages as they enter adulthood. This can be a complex process that requires careful monitoring and adjustment to minimize the risk of seizures or side effects.

Increased responsibility for self-care: As young adults with epilepsy enter adulthood, they will need to take on more responsibility for managing their condition, including managing their medications, scheduling appointments, and monitoring their symptoms. Health care transition can help prepare them for this increased responsibility and provide them with the tools and resources they need to manage their epilepsy effectively.





PLANNING AHEAD

TIPS FOR PREPARING FOR HEALTH CARE TRANSITION

By planning ahead for health care transition and working closely with healthcare providers, young adults with epilepsy can ensure that they continue to receive the care they need to manage their epilepsy and maintain their overall health and well-being as they enter adulthood.

Preparing for health care transition can be overwhelming for young adults with epilepsy, but there are steps they can take to make the process smoother. Here are some tips for young adults preparing for health care transition:

Start early: It's never too early to start thinking about health care transition. Young adults with epilepsy should begin planning for the transition to adult healthcare services at least one year before they turn 18, or earlier if possible.

Identify your needs and concerns: Young adults with epilepsy should think about their specific needs and concerns related to their epilepsy management, such as medication management, seizure control, or emotional well-being. Identifying these needs and concerns can help guide discussions with healthcare providers.

Communicate with your healthcare providers: Young adults with epilepsy should talk openly and honestly with their healthcare providers about their needs and concerns. They should ask questions and seek clarification to ensure that they understand their treatment plan and how to manage their epilepsy effectively.

Seek out support resources: There are many resources available to help young adults with epilepsy navigate health care transition, such as advocacy organizations, support groups, and transition coordinators. Young adults with epilepsy should take advantage of these resources to ensure that they receive the support they need.

Take ownership of your healthcare: As young adults with epilepsy enter adulthood, they will need to take on more responsibility for their healthcare. Being a part of the shared-decision making process is an integral component to successful health care transition

By following these tips, young adults with epilepsy can prepare for health care transition and ensure that they receive the care they need to manage their epilepsy effectively as they enter adulthood.



WHAT TO EXPECT DURING THE HEALTH CARE TRANSITION PROCESS

Health care transition can involve many changes for young adults with epilepsy. Here's what to expect:

Changes in healthcare providers: Young adults with epilepsy may need to transition from pediatric healthcare providers to adult healthcare providers. This can involve establishing new relationships with healthcare providers and adjusting to new treatment plans.

Changes in healthcare plans: Young adults with epilepsy may need to transition to new healthcare plans as they enter adulthood. This can involve changes in coverage, copayments, and other aspects of healthcare that can impact their access to care.





Adjustments to medication and treatment plans: As young adults with epilepsy enter adulthood, they may need to make adjustments to their medication and treatment plans to ensure that they continue to receive the care they need to manage their epilepsy effectively.

Changes in support systems: Young adults with epilepsy may need to adjust to new support systems as they enter adulthood. This can involve connecting with new support groups, advocacy organizations, and other resources to help them manage their epilepsy effectively.

By being aware of these potential changes, young adults with epilepsy can prepare for health care transition and ensure that they receive the care they need to manage their epilepsy effectively as they enter adulthood. Working closely with healthcare providers and support resources can help ensure a smooth transition process.

MANAGING EPILEPSY IN ADULTHOOD



Managing epilepsy in adulthood can be challenging, but there are steps that individuals can take to help manage their condition effectively. Here are some tips for managing epilepsy in adulthood:

Stay on top of medication schedules: Taking medications as prescribed is essential for managing epilepsy effectively. Individuals should work with their healthcare providers to develop a medication schedule that works for them and set reminders to ensure that they take their medications on time.

Manage stress: Stress can be a trigger for seizures in some people with epilepsy. To manage stress, individuals can practice relaxation techniques, such as deep breathing, meditation, or yoga. Regular exercise can also help reduce stress levels.

Maintain a healthy lifestyle: Eating a healthy diet, getting enough sleep, and staying physically active can all help

manage epilepsy. It's important to avoid alcohol and drugs, which can interfere with medications and trigger seizures.

Avoid triggers: Everyone's epilepsy is unique, and certain triggers, such as flashing lights or lack of sleep, can trigger seizures in some people. Individuals should work with their healthcare providers to identify their specific triggers and take steps to avoid them.

Seek support: Living with epilepsy can be challenging, and it's important to have a strong support system in place. Individuals can connect with support groups, advocacy organizations, and other resources to help them manage their epilepsy and maintain their overall well-being.

By following these tips and working closely with healthcare providers, individuals with epilepsy can manage their condition effectively and maintain their overall health and well-being in adulthood.



SELF-ADVOCACY

Self-advocacy and knowing your rights as a person with epilepsy are essential for managing your condition effectively and ensuring that you receive the care and support you need. Here's why self-advocacy and knowing your rights are important:

Empowerment: Knowing your rights as a person with epilepsy and advocating for yourself can help you feel more empowered and in control of your healthcare. By speaking up for yourself, you can ensure that your needs and concerns are addressed and that you receive the care you need.

Improved healthcare outcomes: Self-advocacy and knowing your rights can help improve healthcare outcomes by ensuring that you receive the appropriate care and support. This can help reduce the frequency and severity of seizures, improve overall health and well-being, and enhance quality of life.

Increased access to resources: Self-advocacy can help you access resources and support services that can help you manage your epilepsy effectively. By connecting with advocacy organizations, support groups, and other resources, you can access information, education, and support that can help you manage your epilepsy more effectively.

Protection from discrimination: Knowing your rights as a person with epilepsy can help protect you from discrimination in the workplace, school, or other areas of life. This can include protections against discrimination in hiring, promotion, and other employment decisions, as well as protections against discrimination in education, housing, and public accommodations.

By practicing self-advocacy and knowing your rights as a person with epilepsy, you can take an active role in managing your condition and ensuring that you receive the care and support you need to live a full and active life.



RESOURCES

College Resources

Scholarships

- College Resources for Students with Disabilities the Ultimate Guide
- Disability Scholarships

Nationwide Scholarship programs

American Association On Health And Disability

“Frederick J. Krause Scholarship on Health and Disability” is awarded annually to deserving college students with a disability who are pursuing undergraduate/graduate studies related to health and disability.

www.aahd.us/initiatives/scholarship-program

Federal Student Aid Information Center

Apply for federal financial aid for college or graduate school.

Washington, DC Tel: 1-800-433-3243

www.fafsa.ed.gov

FACES (Finding A Cure For Epilepsy And Seizures)

A program of NYU Langone Health, FACES provides partial financial support for the education of incoming freshmen or currently enrolled college students affected by epilepsy and seizure disorders.

faces.med.nyu.edu/events-programs/college-scholarship-program

HEALTH Resource Center

Managed by The George Washington University, this center provides information on post-secondary education for students with disabilities, including information on financial aid resources. Write or telephone:

2121 K Street, N.W. Suite 220

Washington, DC 20037

www.heath.gwu.edu

Patient Advocate Foundation

“Scholarship for Survivors” program to honor these individuals by offering educational scholarships to individuals who have suffered (or are suffering) a life-threatening disease or chronic condition.

patientadvocate.org/connect-with-services/apply-for-a-scholarship

UCB Family Epilepsy Scholarship Program™

The program offers educational scholarships to people living with epilepsy, family members and caregivers to help them fulfill their dreams.

Ucbepilepsyscholarship.com

Employment Resources

Jobs and Education for People with Disabilities
Epilepsy in the Workplace and the ADA | US Equal Employment Opportunity Commission

RESOURCES

Call **911** if you or someone you know is in immediate danger or go to your nearest emergency room.

Epilepsy Alliance Florida

Call the toll-free helpline 1-877-553-7453
Visit our website www.epilepsyalliancefl.org

National Suicide Prevention Lifeline

Call 1-800-273-TALK (8255);
En español 1-888-628-9454

Disaster Distress Hotline

Call or text 1-800-985-5990
The disaster distress helpline provides immediate crisis counseling for people who are experiencing emotional distress related to any natural or human-caused disaster. The helpline is free, multilingual, confidential, and available 24 hours a day, seven days a Week.

Federal Resources:

Some federal agencies offer resources for identifying health care providers and help in finding low-cost health services. These include:

- **Substance Abuse and Mental Health Services Administration (SAMHSA):**

For general information on mental health and to locate treatment services in your area, call the SAMHSA Treatment Referral Helpline at 1-800-662-HELP (4357). SAMHSA also has a Behavioral Health Treatment Locator on its website that can be searched by location.

- **Health Resources and Services Administration (HRSA):**

HRSA works to improve access to health care. The HRSA website has information on finding affordable healthcare, including health centers that offer care on a sliding fee scale.

Watch our Seize The Future Video



Visit our website to know more!



THE POWER OF LOCAL



info@eafla.org



@epilepsyafila



epilepsyalliancefla.org

Our mission is dedicated to supporting those impacted by epilepsy by confronting the spectrum of challenges created by seizures.

This publication is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) as part of a financial assistance award funded by HRSA and HHS. The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by HRSA and HHS, or the U.S. Government

