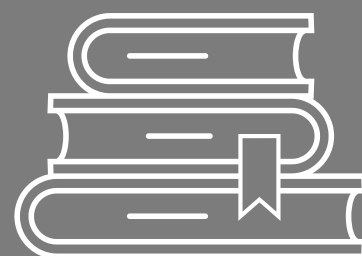


Real Talk: Navigating College with Epilepsy

*A Student Guide to
Seizure Management &
SUDEP Risk Reduction*



Heading off to college is an exciting time full of new opportunities—but it also comes with new responsibilities, especially when you're living with epilepsy.

This guide will walk you through practical steps, essential conversations, and tips to help you stay safe, confident, and connected while managing your health away from home.

**Mental
Health**



SUDEP



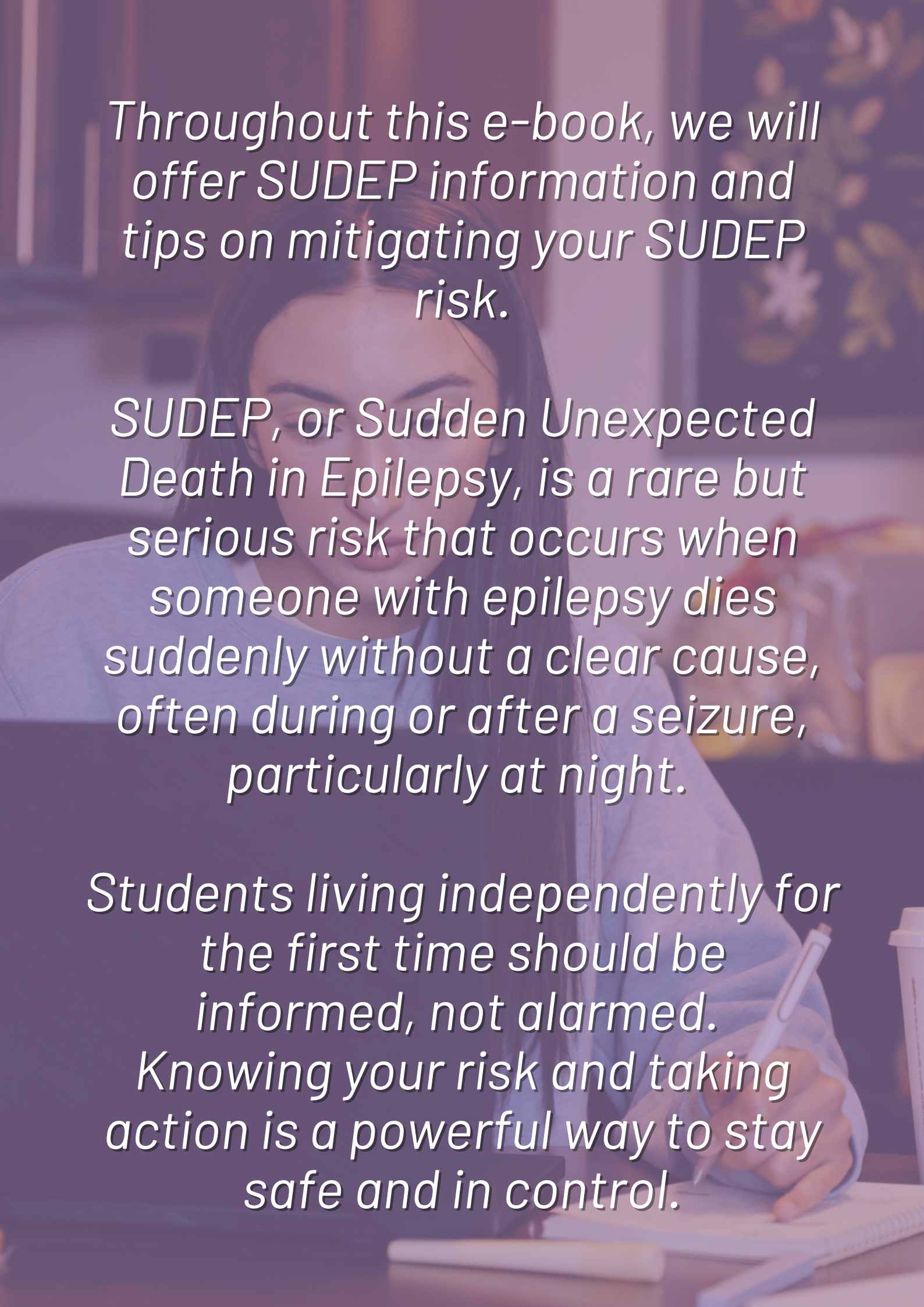
**Dorm
Safety**



**Key
Conversations**



**Risk
Reduction**



Throughout this e-book, we will offer SUDEP information and tips on mitigating your SUDEP risk.

SUDEP, or Sudden Unexpected Death in Epilepsy, is a rare but serious risk that occurs when someone with epilepsy dies suddenly without a clear cause, often during or after a seizure, particularly at night.

Students living independently for the first time should be informed, not alarmed.

Knowing your risk and taking action is a powerful way to stay safe and in control.

Creating a Seizure Safe Dorm

Your dorm room isn't just your study and sleep space – it may also be where a seizure occurs, especially during sleep. Making a few key adjustments to your living space can significantly reduce the risk of injury and support SUDEP prevention.

SLEEP SMART

- Keep a regular sleep schedule (7–9 hours nightly).
- Avoid all-nighters—study earlier in the day.
- Use blackout curtains or a sleep mask.
- Cut back on caffeine and screens before bed.

BED SAFETY

- Sleep on a lower bunk or single bed, especially if you've had tonic-clonic seizures during sleep.
- Use a bed rail or foam bumpers to prevent falls during a seizure.
- Consider an anti-suffocation pillow (medical-grade, breathable foam).

EMERGENCY PREPARATION

- Rescue medication in a clearly labeled, easily accessible location
- Seizure Action Plan posted near your bed or desk (include contact info and medication list)
- QR code that a roommate or RA can scan to access your plan instantly
- Copy of your Seizure Action Plan shared with your roommate, RA, health center, student accessibility office & campus security.



Sleep deprivation is one of the most common seizure triggers, and many SUDEP cases occur during or following sleep.

You may not be able to call for help during a seizure – so build your dorm environment with emergency access in mind.

Keep devices charged and place chargers where they won't be tripped over or knocked loose during a seizure.

If you are prone to seizures at night or your doctor has flagged elevated SUDEP risk, consider requesting a roommate.

Dorm Room Safety Checklist

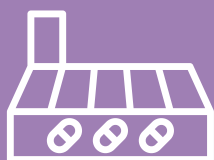
*Creating a safe dorm room is about support, not restriction.
Let your dorm space be a base for safety and self-confidence,
not stress.*



A wearable seizure detection device can alert designated contacts when a seizure is occurring. Seizure detection apps are also available for smart watches. Nighttime seizure monitors are beneficial for those who experience nocturnal seizures.



Keep your Seizure Action Plan (SAP) visible and easy to access—consider displaying it or linking via QR code. Include emergency contacts and clear rescue med instructions. Share it with your inner circle and key campus contacts.



Keep your medications, including rescue medications, organized and stored in temperature controlled environments.



An anti-suffocation pillow can support breathing if a seizure occurs while face-down. Avoid excessive pillows and blankets for sleeping.



Wearing a medical ID or bracelet with a QR code enables first responders to access critical health info in an emergency. QR enabled wallet cards are also available.

Essential Conversations

Key conversations that can help keep you safe, reduce SUDEP risk, and ease the pressure of managing epilepsy alone.

"I'm living with epilepsy, and I'd like to talk about accommodations and emergency planning, including some seizure safety and SUDEP risk considerations."



"I want to let you know that I have epilepsy. I've got it pretty well managed, but in case of a seizure, here's what you should know..."



"I'm a student with epilepsy, and I want to make sure the health center is aware of my condition in case of a seizure or emergency."



"Hey, I want to talk to you about something personal. I have epilepsy. It's important to me that the people I care about know how to support me if I ever have a seizure."

Building a strong support network starts with clear communication.



ROOMMATE(S)

You'll likely spend more time near your roommate than anyone else. If they're calm and prepared, it can make a huge difference in how your seizures are handled—and help reduce your SUDEP risk.

Conversation Focus:

- What your typical seizures look like and if you are prone to nocturnal seizures
- What to do and **not do** during a seizure
- When and how to call for help (911, RA, or campus security)
- Whether you have rescue medication and how to use it
- Any known triggers such as sleep deprivation, stress, flashing lights, etc.
- Share your Seizure Action Plan

RESIDENT ADVISORS

Resident Assistants are often the first line of staff you will interact with in the residence hall and can be a great resource in creating a safe living environment.

Conversation Focus:

- Where to find your seizure action plan or emergency instructions
- Your emergency contact information
- If you use a seizure monitor or night-time safety device
- Dorm preferences such as lower bunk, shared room, etc.





CAMPUS HEALTH SERVICES

Having an established relationship with campus health services helps ensure that you get timely care and that medical staff are prepared with the right protocols.

Conversation Focus:

- Your seizure history and SUDEP risk (especially if you have tonic-clonic seizures or nocturnal seizures)
- Medication management and prescription refills
- Access to rescue medication
- What to do in a medical emergency involving a seizure
- What is a typical seizure for you and when to call an ambulance.
- Seizure Action Plan and emergency contact information

STUDENT ACCESSIBILITY OFFICE

*This office can give you access to formal protections and can advocate on your behalf across campus systems – housing, academic departments, even food services. **Getting in contact with this office should be your first step in establishing support on campus.***

Conversation Focus:

- Accommodations you might need (e.g., note-taker, extended test time, housing preferences)
- Safety considerations related to SUDEP (e.g., not being placed in a single room if you're high risk)
- Emergency protocol preferences





FACULTY MEMBERS

A conversation can go a long way with your professors when it comes to them supporting your requested accommodations and being flexible with things like attendance, timelines, and testing.

Conversation Focus:

- Only what you are comfortable with: that you may occasionally miss class or need flexibility due to seizures or related appointments
- That you're registered with the student accessibility office and you may need support as documented

FRIENDS & PARTNERS

These are the people who'll notice small changes in your behavior or habits. Their awareness and care can be life-saving.

Conversation Focus:

- What your typical seizures look like and how they can help
- What to expect after a seizure
- Where your rescue meds are, how to use them, and when to call for help
- Whether you're at higher SUDEP risk
- What support looks like to you (emotional, practical, or both)



Talking to Your Care Team About Epilepsy & College Life

Before heading to campus it's essential to have an open, honest conversation about your epilepsy, your goals, and how to stay safe while living independently.

Here's how to make the most of that conversation.

Be prepared to share:

- Your daily routine (class schedule, dorm setup, social life)
- Any concerns about stress, sleep, or medication schedules
- How often you miss doses (no judgment, this helps adjust care)
- Whether you've had seizures during sleep or while alone
- Any side effects from your current medications
- If you're interested in driving, studying abroad, or playing sports
- Questions about alcohol or recreational drug use
- Sex and contraception concerns

Key Questions to Ask Your Neurologist

- "What is my SUDEP risk, and how can I lower it?"
- "What should I do if I miss a dose of medication?"
- "What symptoms or changes should I report right away?"
- "Do I need to adjust my lifestyle or medication while at school?"
- "Can you help me fill out a Seizure Action Plan for school?"
- "When are my rescue meds needed?"



Bonus Tip: Bring Notes

- Jot down questions in your phone or a notebook.
- Bring your seizure log and list of meds.
- Ask for a summary letter or documentation for school if needed.

💡 Remember

Your neurologist wants to help you succeed. Be honest, ask questions, and don't be afraid to speak up, even if something feels minor or uncomfortable.

Mental Health Matters

Your mental well-being is just as important as your seizure control.

Why Mental Health Support Matters

- Living with a chronic condition like epilepsy can increase your risk for depression, anxiety, and social isolation.
- Stress, poor sleep, and emotional overload can all increase the likelihood of seizures.
- Mental health struggles are common but treatable, especially when addressed early.

Common Challenges You Might Face

- Anxiety about having a seizure in public or during class
- Depression due to feeling different or having limited independence
- Difficulty managing stress during exams or transitions
- Concerns about dating or social life
- Fear or uncertainty about the future
- Stress managing your course load and worries about academic performance
- Difficulty being away from home and loved ones



988
SUICIDE
& CRISIS
LIFELINE

People with epilepsy have a significantly higher risk of developing mental health conditions like depression and anxiety compared to the general population.

The National Institutes of Health (NIH) studies on suicide in epilepsy have found a 2 - 5 times higher risk of death from suicide in people with epilepsy than the general population. The risk of suicidal ideation is also higher in people with epilepsy.

Asking for help is a strength, not a weakness. Mental health support can empower you to succeed academically, socially, and personally while living well with epilepsy.



TIPS FOR SUPPORTING YOUR MENTAL HEALTH

Find a Mental Health Provider

Ask your healthcare provider or campus accessibility office for referrals or utilize free services that may be available through your college.

Talk About What You're Feeling

Whether it's with a friend, roommate, RA, or counselor, sharing your emotions can reduce stress and increase your sense of control.

Use Stress-Reduction Tools

Techniques like meditation, breathing exercises, journaling, or a quick walk outdoors can help regulate your mood.

Be Honest About Alcohol & Drugs

These lifestyle factors directly impact both mental health and seizure control. Be honest with yourself and your care team about the impact of these factors on your life.

Connect With Others

Look for support groups, campus organizations, or online communities for students living with epilepsy.

Know the Warning Signs

*If you feel hopeless, overwhelmed, or like you're withdrawing from people or activities you care about, **reach out for help.***



SUDEP

KEY FACTS

SUDEP most often occurs during or after a seizure, particularly generalized tonic-clonic (convulsive) seizures.

It is believed that SUDEP may result from breathing difficulties, abnormal heart rhythms, or both during or after a seizure.

The exact cause is still being researched, but many cases happen during sleep and when the person is alone.

SUDEP affects approximately 1 in 1,000 people with epilepsy each year. *For people with uncontrolled or frequent tonic-clonic seizures, that risk is higher—up to 1 in 150 per year.*

SUDEP is the leading cause of epilepsy-related death, especially in young adults between 20–40.



National Community • Local Solutions

SUDEP

RISK FACTORS

Frequent generalized tonic-clonic seizures

Poor seizure control or medication adherence

Nocturnal seizures

Living or sleeping alone

Long history of epilepsy

Missed doses, irregular sleep, or use of substances that interfere with medications

Discussing SUDEP openly with your healthcare provider and support system is an important part of epilepsy self-advocacy and safety.



National Community • Local Solutions

Risk Reduction at a Glance

Simple, proactive steps that can help you stay safe, supported, and in control of your epilepsy on campus.

- Take medication consistently
- Prioritize a healthy sleep schedule
- Track your seizures and share patterns with your healthcare provider
- Share your Seizure Action Plan
- Schedule regular check-ins with your care team and talk to them about your personal SUDEP risk
- Set realistic course loads and create a balanced schedule to avoid burnout
- Use a medication reminder system that works for you & your schedule
- Consider using a night time seizure monitoring device
- Prioritize water safety - take showers instead of baths and never swim alone
- Avoid seizure triggers like missed sleep, stress, alcohol, or drug use
- Know your campus-specific emergency numbers
- Register with Campus Health or Accessibility Office



Helpful Tips for Parents & Caregivers

College is a time of transition and new routines for the whole family.

- For family and caregivers, supporting your student may look different now. Be open and discuss how you can best support your student while at college
- Discuss ways to regularly check in and share how things are going
- Once a student is 18, student records and data is protected. Discuss with your student what information should be shared and have them submit a Family Educational Rights and Privacy Act (FERPA) form accordingly.
- Remember your student is an adult now and their college will treat them accordingly. Offices like Student Health and Wellness, the Accessibility Office, and Residence Life will prioritize working with the student, not their families or caregivers. This can often be a difficult adjustment for caregivers to navigate.



Resource Guide

Trusted resources to help you stay informed, prepared, and supported – from managing seizures and accessing support networks to finding scholarships and safety tools.

[Anti-Suffocation Pillow](#)

Specialty pillows that may help reduce suffocation risk during sleep for those with uncontrolled seizures

[Danny Did Foundation](#)

Resources and tools focused on seizure monitoring and SUDEP awareness

[Epilepsy Alliance America Member Organizations](#)

Find an Epilepsy Alliance America member near you

[Epilepsy Alliance America Seizure Recognition & Response Training](#)

Share this free on-demand training with your inner circle

[Epilepsy Alliance America YouTube](#)

Watch educational videos, personal stories, webinars, and more

[My ID Medical Alert](#)

Discount code for customizable medical ID bracelets and accessories

[Partners Against Mortality in Epilepsy](#)

Collaborative initiative focused on understanding and reducing epilepsy-related mortality

[Rescue Medication Videos](#)

How-to videos and information on using rescue medications when needed

[Scholarships for Students with Epilepsy](#)

A list of scholarship opportunities specifically for students living with epilepsy

[Seizure Action Plan Coalition](#)

Resources to help you create and share a personalized seizure action plan with your circle of trust

[Seizure Prepared U](#)

Training to help colleges prepare their campus for seizure safety and inclusivity

[Support Groups](#)

Local or virtual groups to connect with others who understand the epilepsy journey

[TRUST poster](#)

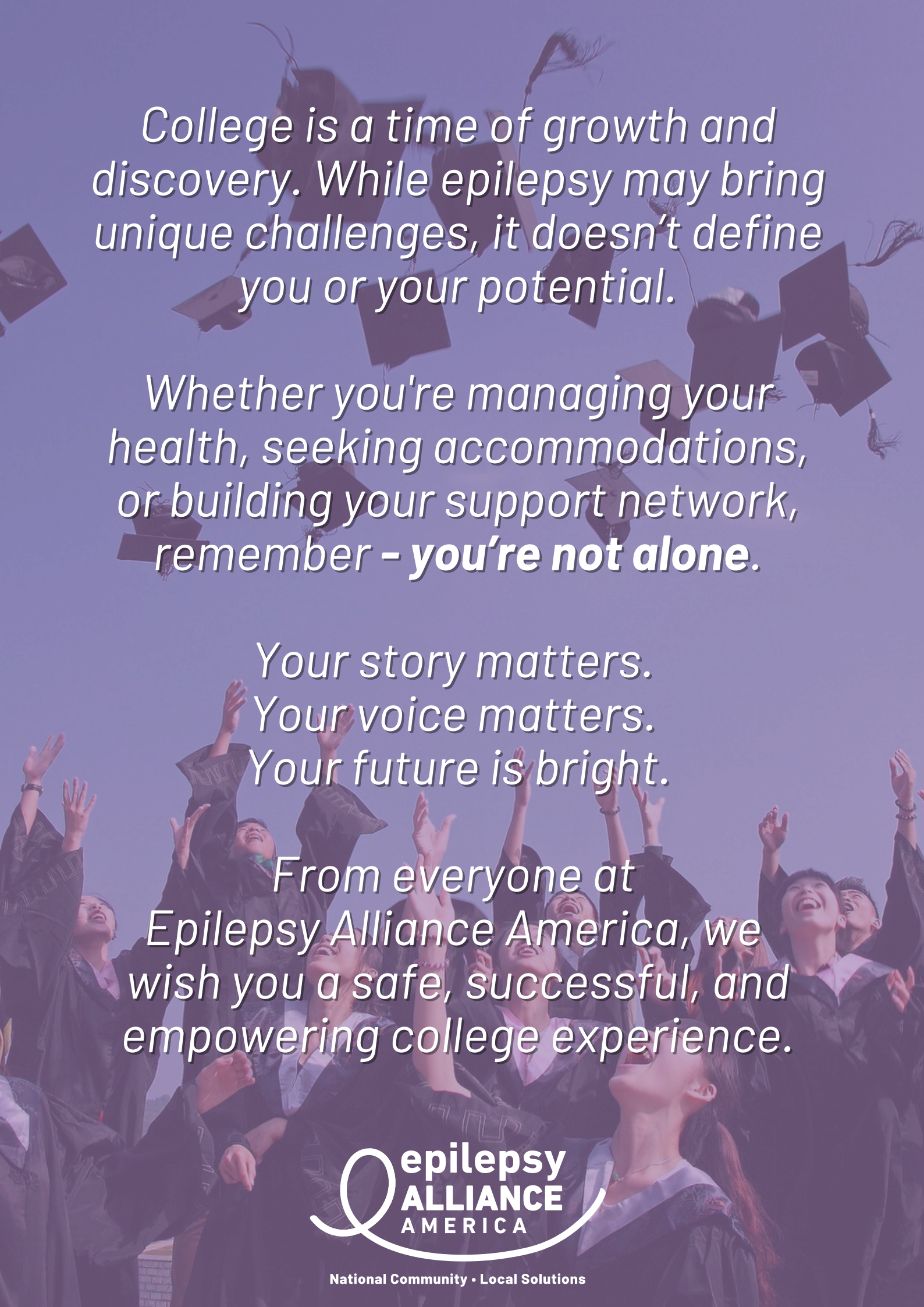
A simple visual guide to seizure first aid

[Young Adults With Epilepsy](#)

A peer-focused support community for navigating life transitions with epilepsy



**Scan For More
College Resources**

A background image showing a large group of graduates in black gowns and caps, with many caps being tossed into the air. The scene is set against a clear blue sky, and the graduates are looking upwards with expressions of joy and accomplishment. The text is overlaid on this image in a white, sans-serif font with a subtle drop shadow.

College is a time of growth and discovery. While epilepsy may bring unique challenges, it doesn't define you or your potential.

Whether you're managing your health, seeking accommodations, or building your support network, remember – **you're not alone.**

Your story matters.
Your voice matters.
Your future is bright.

From everyone at Epilepsy Alliance America, we wish you a safe, successful, and empowering college experience.



National Community • Local Solutions

*This guide was developed in
collaboration with
Paul's Purple Warriors and the
Seizure Prepared U college
program - two initiatives
dedicated to equipping campus
personnel with the tools to
create safer, more inclusive
environments for students
with epilepsy.*

