

now
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College Survival Guide

With 1 in 26 people developing epilepsy in their lifetime, there are thousands of students entering college experiencing epilepsy and this guide serves to help them thrive.

College should be an exciting time for new experiences and friendships and epilepsy doesn't have to inhibit this!



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1. You are your biggest advocate and have options for accommodations within the College!

There's a major transition from having a parent, guardian, resource team etc. in high school overseeing and (ideally) advocating for your needs to being left to your own devices in an unfamiliar setting.

Accessibility offices exist on campuses and you must transition your 504 or IEP accommodations to a college plan or you may need to start from scratch. If you don't know what an accessibility office is, please ask your resident advisor or dean.

Here is an example of some relevant accommodations you can ask about;

Classes

-  **Recorded Lectures / Shared Notes / Peer Note Taker**
-  **Ability to take notes on a laptop or alternative device**
-  **Modified credit requirement to be considered a full-time student with a lesser course load** (important for loan and scholarship eligibility etc.)
-  **Flexible attendance**
-  **Course schedule:** You can get priority registration for optimal timing. This enables students to get into the later morning classes to protect their sleep, or avoid evening courses (if you are someone who tends to have seizures at night).

Assignments and Exams

-  **Ability to negotiate an extended or flexible deadline for an assignment**
-  **Extended time on exams and/or separate exam space**
-  **No bubble sheets**
-  **Ability to reschedule exams**
-  **Plan to limit number of exams in a single day** (prevents extraneous stress and protects sleep schedule)

Accommodation

-  **Not being placed in a single room:** accessibility staff may recommend not having a roommate to protect your sleep schedule—However, studies show that people living with epilepsy have better outcomes with a roommate.

2. Communication is key to thriving in college and may save your life!

* Speak to your professors

Unlike in high school, it is unlikely all of your professors know and communicate with each other about individual students. While accessibility counselors can help facilitate these conversations, they are unable to oversee your day-to-day experience in the course.

Speak with professors during the first week of class. This may feel awkward the first couple of times, but disclosing your epilepsy tends to result in professors being more willing to make accommodations throughout the semester. Things students may find helpful to include are:

Say: "I have epilepsy, here is how it may affect me in your course..."

- I might miss a class without a pre-approved absence excuse due to a seizure.
- *(If you experience absences seizures)* I experience absence seizures, please do not call on me when my hand is not raised, or please know if I don't answer I am not ignoring you.

Say: "Here is what would help me succeed..."

- I would like access to course notes or presentations for unanticipated absences or "missing time".
- I would like you to understand that I might be absent due to a seizure and unable to contact you to explain in time for class. Can we make a plan in advance on how to address this with you?
- If I have an epilepsy-related reason for missing class time or for requiring a deadline extension, how would you prefer I contact you and how much of an explanation might you need?
- If I am not feeling well or if I think I may have a seizure and need to stay home is there an ideal alternative for participation?

If you have established an accommodation plan, this conversation may feel redundant. However, it tends to help professors understand the legitimacy of your requested accommodations, increase the likelihood of them complying with your plan, and aid in establishing a good relationship with the professor. Accommodation plans typically just outline the accommodations you are requesting without disclosing the reason behind them. If you are uncomfortable disclosing you have epilepsy, just give the professor a heads up that they should be receiving a copy of the plan and that you appreciate their flexibility and understanding!

✳️ **Speak to your resident advisor, roommates and friends**

Having a talk with those you spend a significant amount of time with to make them aware of your epilepsy and educate them about seizure first aid can seem really daunting. But having friends and roommates that know how to help you, or anyone having a seizure, can be a lifesaver. Your peers might be dangerously misinformed about what to do if someone is having a seizure, so communicating with them is very important.

Say: “Hey, just in case this ever happens is it alright if I give you a rundown of what to do?”

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What do I do when someone has a seizure?

DO:

Stay CALM.

Time the seizure.  Move objects that might hurt them or gently guide them away from danger. 

 Cushion their head with something soft and turn them on their side.  Loosen any article of clothing that might make it hard for them to breathe.

Put them in a recovery position after their seizure ends. 

Call 911 if needed.

DON'T:

Don't panic.

Don't restrain them.

Don't put anything in their mouth. 



Don't offer them food, water or medication until they are fully awake.

Don't leave.

sources: The Epilepsy Foundation
The CDC
The Epilepsy Society

For more information visit
www.thecameronboycefoundation.org

Do not immediately call 911 or an ambulance UNLESS:

- The person has never had a seizure before.
- The person has difficulty breathing or waking after the seizure.
- The seizure lasts longer than 5 minutes.
- The person has another seizure soon after the first one.
- The person is hurt during the seizure.
- The seizure happens in water.

[Click here to download](#)

Tell your friends afterwards, that you may be confused or unable to respond, etc. It helps to let your friends know what they may expect to avoid panic.

If you have absence seizures and feel comfortable, explain how to recognize these so they can let you know you are having them. Your friends might then be able to let you know that maybe you shouldn't drive or do other activities that day and can offer to help.

*** It's important that your friends are aware of your epilepsy**



1.

They need to understand that when you say you are uncomfortable with a certain situation (and would prefer to go to an alternative location), someone needs to escort you home or not go out at all.

2.

When you are feeling off and if you don't have a roommate, stay in a friend's room or vice versa or with someone who knows what to do if a seizure did happen. Having friends who are aware and educated about epilepsy can be a lifesaver.

3.

Your friends can advocate for you. For example, if their house/fraternity/sports team is hosting a social event/party they can ask that there be no strobe-lights so that you can be included.

4.

Epilepsy is so common and this knowledge you share might help other people in their lives.

3. Have fun but take steps to stay healthy.

Let's be honest, you are in college, you want to have fun. While we could advocate for getting 8 hours of sleep and avoiding all alcohol and other substances, we understand life happens so you should be best equipped to take care of yourself.

Be aware that certain recreational substances, especially alcohol, can lower seizure threshold so always know what you are drinking.

Consider ordering non alcoholic drinks! Mocktails are taking over so definitely try those out. This can help you fit in and be included without people always asking the annoying questions of why you aren't drinking.

Don't forget there is also risk in using other recreational substances. People with epilepsy have increased adverse reactions to psychedelics, stimulants, and high levels of THC.

Make sure to eat and avoid low blood sugar especially if you plan on going out.



Think about printing out the seizure first aid to give to local bars, dorms, fraternities/sororities, coaches etc.

[Click here to download printout](#)

"All-nighters" may be manageable for your friends, but sleep deprivation puts you at increased risk.

Do not feel guilty for prioritizing your safety and calling it a night...nothing good happens after 2am anyways!

Take a deep breath, manage your stress and use all of the tips above.



4. Maintain your medical care while in college.

Identify a local neurologist or epileptologist through health services if you don't have easy access to your home physician.

Advocating for yourself regarding your health and medications is extremely important.

If you are living away from home *only you* know what side effects you are experiencing or if the medication is a good fit for you. As a young adult your parents may not be attending / or able to sit in on your appointments anymore, so being able to voice your concerns and ask questions is more important than ever.

Be sure to discuss possible medication interactions with alcohol / other substances with your doctor (they won't judge you and there should not be any shame in asking –safety above all). **On that note**, it's important to be honest with your doctor about what your life at college is like (alcohol consumption, etc.) so that they can make the best medication / seizure management strategy recommendations for you.

If you are living on campus, you may be assigned a primary care provider in the health center. If you have been born with female anatomy, they are somewhat notorious for suggesting hormonal birth control, which can interact with some epilepsy medications (making one or both less effective). **If it is something you would like to pursue, be sure to talk to your neurologist about potential interactions with your prescription beforehand.**



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