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An Epileptic's All-Inclusive Guide to Handling College: Advice and Resources

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Introduction

The goal of this guide is to ensure that epileptic students have the proper tools and guidance when beginning college. Students who do not suffer from brain conditions do not have to go through the same challenges and obstacles that those who suffer from epilepsy do. Therefore, it is the intention of this guide that students who seek information are able to have a reference to go to when they have questions on how to handle certain problems.

Some of the challenges that will be covered in this guide include handling the academics of school, possible legal issues, social life, and more. Many aspects of college that any student will face are covered here. Additionally, those issues that are specific to epileptics are also covered to ensure a comprehensive guide. Not every question can be answered through this guide. However, it is also the goal of this guide to provide the proper tools for epileptic students so that they may make the best judgement for their situation.

Beginning college is a challenging time for any individual. It is also a time that allows you to decide what is best for your body. Take advantage of the opportunity you have to get into healthy habits early on including sleeping sufficiently, maintain friendships, and maintaining your mental health. All of these issues present a new challenge in college, but they also present the best opportunity for epileptics to learn how to handle these scenarios on their own. All of these issues are covered in the guide.

While reading this guide, keep in mind how your particular situation fits into the advice that is given. Evaluate the severity of your seizures, speak with your doctor, and reflect on how you want to live your life and advocate for yourself while reading. Different decisions students make will give them their own unique college experience, and everyone wants students to make decisions that are best for their situation to give them the best quality of life possible.

College will not be easy. With epilepsy, it will be even more difficult. This guide hopes to alleviate some of the burdens that epileptic students carry with them. The advice that should be stressed the most going through school is not to worry about asking for help. Seeking help does not mean that you are weak. It takes strength to admit when a challenge is too much. Accepting others' offer to help is entirely acceptable. They want to help take away a burden or help you through a challenge. Take advantage of the resources that your institution provides.

Through college it is also the prevailing hope that students with epilepsy can gain their independence. Not every case of epilepsy is the same, but students will find advice in this guide for seeking the independence that can become a challenge for epileptics to achieve.

Possible Legal Issues

Reasonable Accommodations

According to the Americans with Disabilities Act of 1990 (ADA), people who suffer from disabilities are allowed “reasonable accommodations.” Most of the possible legal issues that you face will be about reasonable accommodations. What is considered reasonable depends on the severity of your case of epilepsy. For example, if your case of epilepsy is well controlled, then a service animal is not a reasonable accommodation. On the other hand, if you have memory problems or trouble focusing, then you may be entitled to accommodations that include, but are not limited to, quiet rooms during testing, extended test times, and extended due dates. Inquire about accommodations outside the classroom that involve housing and campus to ensure their availability.

In order for you to be considered for such accommodations, a doctor may need to fill out forms that are provided by the institution and then send them in to your school’s disability office or student health organization. It is important that you are aware of what guidelines your college or university requires in order to obtain reasonable accommodations. Contact student health services or the office for students with disabilities, if your school has one, to begin the process of obtaining reasonable accommodations. Contact the office after you are accepted but before the first day of classes.

Being Proactive

It is important to begin the process of obtaining accommodations and informing the appropriate college or university officials about your epilepsy-related needs ahead of time. Do

not wait until the middle of the semester to file for reasonable accommodations. It is best to notify the administration after you are enrolled and before you show up to class. If you are diagnosed after you begin school, notify the institution immediately following your diagnosis.

You should also notify any professors or other class instructors. Professors and instructors you should notify include teacher's assistants and any advisors. They should be notified within the first week that classes begin. If you are ADA certified, the college or university must notify them under law. However, speak with your professors and advisor personally.

It is important that you take control of whom you inform and what you tell them. Informing them yourself will not only guarantee that they are aware, but will also help them gain a greater understanding of what steps need to be taken going forward.

Some cases may involve more effort than others in order to obtain reasonable accommodations. If you find that your school is being difficult, then make every effort to notify the administration and staff of the difficulties you are having. You should notify your school's disability office or student health organization also. All forms that they require should be filled out before you make any complaints.

If, however, you complete the requirements stated by the school, your doctor has recommended accommodations be made, and the school does not grant you reasonable accommodations, then you may want to speak to an outside professional about taking legal action against the college or university. Taking legal action against the institution should only come as a last resort after multiple attempts to communicate with the university or college. A college or university's failure to notify the student of progress in their accommodations case falls under discrimination law. (See Below in 'Discrimination Cases')

Dos and Don'ts When Informing Professors and Advisors:

Dos

When speaking to professors and advisors about your case of epilepsy, it is important to be calm while you are informing them about your case. Not every professor or advisor has dealt with epilepsy before. Do not get angry with them if they do not fully grasp the severity of your case or do not believe you. If this situation arises, it is best to notify the administration, the student health organization, the disabilities office, or any group that will advocate on your behalf as a student with epilepsy.

You should also, whenever possible, engage in possible solutions to solve problems that you have. For example, if you are a student who requires a lab such as chemistry or biology, a possible solution may be to work with a lab partner who is comfortable working with an epileptic. Another example of helping offer a solution is, if you have trouble focusing in class, compare lecture notes with the professor or other students after class or during the professor's office hours.

Don'ts

What you, as a student with epilepsy, should avoid doing includes making unreasonable demands from the instructor. The idea of meeting with them directly is to create a more suitable learning experience that both you and the instructor can accommodate. Avoid asking for large portions of their time. Being brief and direct shows respect and common courtesy. Your goal is to inform, not lecture. The professor or advisor, as a staff member, has other students who may need attention. If they have other concerns about your case, they will ask. Also, when scheduling an appointment, do not be late. Being on time for appointments shows respect for the instructor, and they are more likely to be more understanding and respectful if you are understanding and respectful of their schedule.

Do not overwhelm professors and advisors with personal information that you only share with your doctor and other medical personnel. If professors or advisors ask and you feel

comfortable sharing, then it is permissible to inform them. However, only inform them if they inquire first.

Discrimination Cases

If you feel discriminated against because of your epilepsy, notify the next level of authority. For example, if an instructor refuses to teach you as a student because you have epilepsy, then the disability office or your school's student health organization should be notified. Do not feel bashful about expressing your displeasure. However, do so in a professional manner.

If you feel discriminated against by the school's administration itself, then outside legal counsel may be necessary. The ADA protects you as a disabled person from discrimination in any form. Taking legal action starts by filing a complaint through the Office of Civil Rights in the Department of Education. The complaint form is available at:

<https://www2.ed.gov/about/offices/list/ocr/know.html>

This link offers step by step instructions in order to help guide epileptics who feel discriminated against. The webpage offers a legal action form in 20 languages. Fill out the form in whichever language you are most comfortable. The complaint needs to be filed within 180 days of the last incident of discrimination. Therefore, do not hesitate to file a complaint. Full details on the filing process are available on the above link.

If you do not wish to take legal action against the school in the event administration discriminates against you, your options are limited. However, finding another institution that better fits your needs as a student and as an epileptic may be the best option. Finding another school is a common move for students, and it is not out of the realm of possibilities for epileptics. Look carefully into institutions that have well established and reputable disability

offices. <https://www.collegechoice.net/50-best-disability-friendly-colleges-and-universities/> has a list of 45 colleges and universities with the most reputable disability offices. It also details their price range and lists their location.

ADA and Other Disability Laws

For a full list of ADA protections and legal options, please look online at “[ADA.gov/cguide.htm](https://www.ada.gov/cguide.htm).” Here, you will find links that not only include the Americans with Disabilities Act, but also the Rehabilitation Act among other Disability Rights Laws laid out by the United States Department of Justice (DOJ).

Service Pets/Companion Animals

Service pets are protected under the provisions of the ADA. Therefore, if necessary, the school must make accommodations for your service animal if you need one. The law is binding, and, if you find that your school is being difficult with making reasonable accommodations for your service animal, you should speak with the disabilities office at your college or university. If your institution does not have a disabilities office, then seek outside legal counsel. At times, lawsuit possibilities against disabled persons’ protections will force an institution to make changes. Specific training locations for service animals are offered at various locations across the country, and finding a reputable trainer is as close as a google search away. Make sure that your service animal comes from a reputable trainer before designating them a service animal.

Companion animals are different. They are not protected under the ADA if they are not trained to perform specific tasks. For example, if you adopt a dog to counteract depression issues, the dog is not trained. Therefore, the dog is not protected. The institution can still make

reasonable accommodations for the animal, but they are not required to make such accommodations unless the animal is trained.

More details about living with service animals and emotional support animals is covered in the 'Living Situations' portion of this guide. For full revisions to the ADA regarding service animals, please visit the following website: https://www.ada.gov/service_animals_2010.htm

HIPAA

HIPAA, or the Health Insurance Portability and Accountability Act, is a law that provides you with privacy and control over who receives your personal health information. There are strict laws that prevent your health information from being made public. Therefore, you as the patient have full control over who receives information about your health. Not only does HIPAA give you the right to privacy, it also gives you the right to obtain copies of your personal medical records. Furthermore, HIPAA allows you, as the patient, to request possible corrections to your medical records if you feel your care team has made an error.

Often a school will ask for proof that you are epileptic. A college or university asking for proof is part of the standard procedure of obtaining reasonable accommodations. However, the only information that they need to provide is a doctor's signature on your diagnosis. Any additional details are not necessary under the standards set by HIPAA. The same rule applies for any disability.

If you do not wish to seek reasonable accommodations, you do not have to disclose any medical information to the college or university. You have the right to withhold information about medical details if you choose. However, if you are seeking help for epilepsy related issues, you should help the institution understand the reason you are seeking help. Thus, you should, at a minimum, inform them that you suffer from epilepsy.

You also have the right to file a complaint if you feel that your information has been shared without your consent. Keeping your medical records confidential is a serious issue, and you should always feel secure about its privacy. As a patient, you have the right under HIPAA to receive a report about who is accessing your information. HIPAA allows some institutions to see your information without notifying you, but colleges and universities do not fall under this category. For full details about your rights and how to file a complaint, you can visit the webpage provided by the United States Department of Health and Human Services at:

<https://www.hhs.gov/hipaa/for-individuals/guidance-materials-for-consumers/index.html>

Personal Care Team

Disclaimer: The following is advice and counsel as to how to approach one's personal healthcare situation. Any choice that you make as an epileptic is yours. You have full control over whom you choose to trust your healthcare. If at any point in your healthcare journey you feel uncomfortable with the person you are working with, you should find other healthcare options.

Communication

The core of all good healthcare is communication. Do not withhold information from those to whom you trust your care. Information about a wide variety of things, including how that information relates to your stress level, is important for your doctor(s) to know. If your doctor(s)

ask you a question that does not seem to be about your healthcare, or you do not understand why they are asking that specific question, then communicate that concern to them. Withholding any information from your care team can result in misguided care from your team. Information including your comfort level is always relevant when regarding your personal care.

Communication between care teams can be a hassle. It is likely that more than one institution will have your health records. Such institutions include the student health organization on campus, the student disability office (if available), your general practitioner's office (if applicable), and your neurologist's office. These institutions have different information depending on the frequency of visitation, the possible lapses in sharing information between institutions, and the quality of record keeping. As the patient, take the initiative in maintaining a quality line of communication between your care team(s). For example, if you have a seizure, you should inform your neurologist, and you should also inform your student health organization and general practice.

Communication with one's family is also sensitive, but you should seek to maintain the line of communication with your family the most. Your family spent the most time with you prior to leaving for college. Therefore, your family should always be kept in the communication circle when seeking counsel. Ultimately, decisions about one's own health including who to confide information to, what medications to take, and what information is shared is the patient's responsibility. However, seeking counsel from a number of sources including your family is greatly recommended.

Maintaining Your Old Care Team

If you are attending college close to home or you have the ability to maintain a good line of communication with your care team, then you should maintain the relationship with your

current care team. Being a patient is all about trust, and, if you feel that you trust your care team, then do not look elsewhere.

Be advised that communicating with your original care team if you travel away for college may be a very difficult task. If you wish to maintain that relationship, then records will need to be shared with another care team such as your college or university's student health organization or another doctor's office. While it is not an impossible task to keep your original care team, your original care team will not be the only one involved.

If you choose to attend a college that has limited access to quality neurologists, then it is in your best interests to maintain as close a relationship with your original care team as possible. Even if there is a growing physical distance between yourself and your doctor's office, the lack of outside quality care can make it difficult to receive proper treatment. After all, treatment of epilepsy is not all about limiting seizures, it is also about preventing seizures by reducing possible triggers. Your original care team can advise you properly if there is a lack of adequate care closer to your institution.

If you have difficulty controlling your seizures, and you are traveling away for college, then you should find a different care team. You can still maintain your connection with your original doctor, but you should communicate more regularly with a doctor's office that is closer to you. Before leaving, request copies of all your personal medical records in case you wish to add any pertinent information to your future care teams' notes.

Finding A New Care Team

Finding a new care team in your area if you are traveling away to attend college is best begun by seeking recommendations from people you trust. If you trust your original care team, but you must ultimately find different care, then take their recommendations. If you feel

comfortable finding suitable care on your own based on the recommendations from others, then that is your choice. You should seek recommendations from other doctors instead of searching online.

Before you meet a new care team, have your previous care team send your full medical records and notes to your new care team's office. Ask for copies to be made for yourself. Keep your personal records for both personal record-keeping reasons and also to add notes in case you have more information to include.

It is important that you establish trust and effective communication with your new care team. This trust and communication leads to a higher quality of care. The process of establishing care can take many forms, and the process depends on the person and the care team. If you begin to establish trust with your doctor by making small talk before any doctor's visit, that is completely acceptable. Jokes, stories, and casual conversation are all examples of ways that trust can quickly be established between you and your care team.

You should find a physician in your care team that you trust not only as a doctor but also as a person. The reason behind trusting them on more than one front is that they need to understand your personal challenges as well as your challenges as an epileptic. Your college life and medical life crossover at every turn, and it is paramount that your care team fully understands that fact. However, there is a fine line between being an understanding person and a friend. Ultimately, your care team needs to be objective professionals at the very core. Bedside manner is important, but the personal relationship between you and your doctor cannot obstruct their objective counsel.

Student Health Organizations

Student Health Organizations are an asset that are at your disposal as a student. Depending on your institution's size, it may have more resources. Larger universities occasionally have hospitals attached to their campus as part of the medical program. For example, the University of Pennsylvania has a reputable hospital at their disposal, and they jointly use hospital facilities as part of their student health organizations. Utilizing hospital resources for student reasons streamlines emergency matters and paperwork.

Smaller colleges or universities may not have the capabilities that larger universities have at their disposal if they have a medical school. Therefore, you need to communicate with your care team that every document that is written about you be shared with the student health organization of your college or university. Doctors will not share your personal information unless asked by you or the institution of your choice on your behalf. Therefore, this line of communication needs to remain open.

Informing the student health organization of your situation is important. The same way that you communicate with doctor about changes in your lifestyle, you should inform student health. The benefit of student health organizations is that there is no cost upfront. Cost of student health operations is tied to student tuition. Therefore, no matter the number of times you meet with student health organizations, you may meet with nurses and doctors from your university's student health office at no out-of-pocket cost. To maintain the highest quality of care possible, you should seek to schedule semiregular meetings to keep all the information as accurate as possible. If you do not wish to maintain regular meetings, then emails about relevant matters are sufficient.

You should only use student health organizations to supplement your healthcare with your neurologist and primary care physician. Unless the student health organization at your school is tied to a practice or hospital, then you should maintain the relationship to your primary doctor first. Student health organizations should only supplement that of your personal care

physician. At smaller universities, doctors are not as readily available. Therefore, nurses make up the bulk of staff. Nurses cannot write prescriptions. The inability to write prescriptions is a key reason to maintain the relationship with your neurologist and primary care physician.

Student Disabilities Offices

Not every college or university will have a Student Disabilities Office. With that being said, if you wish to receive accommodations, get in contact with your Institution's Disabilities Office after admission to the college or university and before classes start. The purpose of a disabilities office is to advocate for the students who have learning disabilities or who may need assistance due to a possible learning disability. Therefore, it is in your best interest, as an epileptic, to establish a relationship with the office. If you are unaware whether or not your school has a disability office, email your advisor or the student health organization for your school.

Communicating your goals as a student to the disabilities office is key to helping them advocate for you. If you have problems on campus due to your disability like discrimination, bullying, or harassment, the disabilities office is the first office you should contact. Their job is to advocate on your behalf. If the office does not advocate for you adequately, voice your concerns to administration. If you are continually dissatisfied with the services you are receiving, consider outside legal action. See 'Possible Legal Issues' for full details.

Some schools have online guides that are specifically oriented to help students with disabilities on their campus. For example, the University of Michigan has a handbook for disabled students that offers specific phone numbers of people whom students may contact in the event of rising concerns. Refer to your college or university's specific guide in order to take advantage of all resources available to you at your institution.

Seasonal Care

It is not uncommon for students to have multiple care teams depending on the location of their college or university. For example, if a student lives in Chicago but attends college in Philadelphia, then having two different care teams is advantageous. You should maintain open channels of communication with both care teams. Every document that is obtained by one care team should be shared with the other. Sharing of information does not always happen automatically. Thus, communicate to your care teams that information should be shared between them.

The idea of sharing information between care teams also applies to student health organizations and any outside doctors. If you are rushed to a hospital in an emergency, you should request copies of any records both for your personal records, but also to send to your care teams in order to keep them informed.

You do not need to have multiple care teams. If you are in a situation where you feel confident in only having one care team, then it is in your best interests to do so. The goal is to be comfortable with the healthcare that you are receiving. If you would like to reach out to other offices then, as the patient, take the initiative to seek different care.

Transportation

Being Prepared

When deciding how you as an epileptic are going to travel, it is important to be prepared. Being prepared includes being prepared mentally and physically. It is important to start by evaluating the severity of your condition. If your case of epilepsy is severe, then certain options are less viable than others. For example, if there is a high likelihood of seizures, then walking may not be the best option. Instead, using a university sponsored shuttle or ride sharing service may be a preferred way of transportation.

You should make yourself aware of all your options before arriving on campus. There are more options for students on urban campuses. Ride sharing options may not be available in all areas. Lack of public transportation may also be limited in rural areas. Therefore, research all of the available transportation options in the surrounding area as well as on campus before arriving on campus. If you would like to live closer to campus, contact your school's disability office or student health organization about establishing accommodations as part of the reasonable accommodations promised by the ADA.

Other preparations also include proper safety equipment when using personal transportation equipment including bikes or skateboards. Always wear a helmet when using personal transportation equipment. For large campuses, look to invest in a bicycle, as licenses are not necessary to ride them. Riding a bike also adds a way to exercise and fight feelings of depression. Walking is the most readily available option, but it takes the most amount of travel time. The extended amount of travel time makes being prepared important, so that you know what safety precautions you need to take. Precautions include avoiding possible areas of high crime and favoring areas that campus personnel and security frequent.

If you are traveling anywhere, invest in wearing a MedicAlert tag, but wearing a tag is not required. MedicAlert bracelets or necklaces provide medical personnel information in the event of an emergency. Medical personnel are trained to look for such tags in the event of a seizure. If you wish to acquire a MedicAlert tag, visit [MedicAlert.Org](https://www.MedicAlert.Org) and fill out the necessary information.

Moving Around Campus

Along with various options including walking, skateboards, and bicycles, there are additional options that include campus shuttles. Not every college or university offers campus shuttles. However, larger campuses often have campus shuttles that offer easy access to dorms, dining halls, and other high traffic areas. In order to research your respective college or university's shuttle situation, look on your institution's website. On the website, you have the ability to see the full route of the shuttle, and, if you have reasonable accommodations as an option, then you may have the option to request a dorm room that is on the shuttle's route.

The benefit of using the shuttle includes remaining in a controlled setting. Using other forms of transportation leaves you in the open. In a shuttle, you remain in a seated position, and, if a seizure occurs, then the likelihood of head injuries is significantly reduced. Further, the driver can then escort you to the student health office, disability office, or your residence.

You should plan your route to and from classes before school begins. Planning your routes to class ahead of time will make your trips between classes much less stressful. It will also help you understand where assistance is if it is required. Doing such reconnaissance includes knowing where administration buildings, security stations, and any medical facilities are located. You should always walk in populated areas so that help can be called in the event of an emergency.

Public Transportation

"We don't receive any [first aid] training at all. They showed us how to use a defibrillator, but that was only after a guy had a heart attack."

- Anonymous SEPTA bus driver

Fully use the public transportation options that are available to you. But, take caution when using public transportation. There are plenty of issues that can arise when using public transportation. For example, when waiting for subways and trains, stay more than six feet away from the edge of the rail. Also, remain seated both when waiting for the transportation to arrive and when on route with whichever form of transportation you choose. Staying seated reduces the risk of injury if you fall during a seizure. Furthermore, use the most direct route to your destination possible. That means that, if you can arrive to your location in one trip, then do your best to carry out that option.

There are both benefits and drawbacks to using public transportation. Depending on the location of your college or university, your experience with public transportation will vary.

Benefits

- Very cost effective - The cost for using public transportation is often very low. For example, in Philadelphia, the fare for using a city bus one way is \$2.50 for as far as the line goes. The low cost makes public transportation highly affordable on almost any budget.
- Wide variety of options - The major forms of public transportation are subways, buses, and elevated trains. However, there are other options that include trolleys or specially requested busing that is designed for health-compromised individuals.
- Highly used - The frequent use by other individuals means a higher likelihood of an individual knowing how to handle an emergency if the occasion arises. There is no guarantee that a person who is medically trained will be on the bus, but the likelihood is higher.
- You are seated - The seating availability reduces injury during falls.

- Regular schedules - Even with delays, the schedules for transportation systems are widely published and make it easy to schedule trips ahead of time.

Drawbacks

- Untrained personnel - drivers and operators are often not trained to handle emergencies, and routes do not always drive past hospitals.
- Indirect routes - the routes are dictated by the respective transit authority. They are not open to taking requests. If you require timely arrival at hospitals or medical facilities, Public Transportation is not your best option.
- Inefficient schedules - If a city has an underfunded transit system, then schedules are more susceptible to delays and schedule errors.
- Long travel times - Since buses and trains make numerous stops during their routes, they are indirect and can take a long period of time to travel between your pickup location and your destination.

Ride Sharing

Ride sharing is another option that you have as an epileptic to get around. Ride Sharing is much more direct and timelier for in-the-moment needs. But ride sharing prices can become rather steep. Students should take the cost into consideration before using it frequently.

Students should also know that even though ride sharing services can be fast, direct, and cheaper than ambulances during emergencies, that does not mean that they should be used to deliver patients who have had medical emergencies to hospitals or other medical facilities. Using ride sharing services to deliver patients to nearby hospitals would be ineffective anyway, as seizures typically do not last more than a couple minutes.

The drivers in ride sharing programs are normal people providing this service to supplement income. They are not trained medical personnel. They also are not likely to have encountered those with a seizure disorder. Therefore, you should avoid using them frequently. If you do, you should then politely notify the driver that you have a seizure disorder and that they should drive to the nearest hospital if an emergency arises.

The following is a list of benefits and drawbacks to ride sharing services:

Benefits

- Direct routes - as opposed to public transportation, ride sharing can deliver you directly to a specified address.
- High comfort - the comfort level is much higher than that of any bus or train. The seats are more comfortable, and many drivers will also ask if they can make any adjustments to the air conditioning or music for your comfort needs.
- Quality service - Ride sharing has a much higher level of service because of the direct control the consumer has on tipping. Direct service also plays a role that adds to the high quality of service offered with ride sharing.
- Fast trips - Ride sharing trips often take a fraction of the time that public transportation may take.

Drawbacks

- Expensive - for what a person receives in direct routes and faster travel times, they pay for up front. Using ride sharing frequently can become an unnecessary strain on your budget.
- Untrained personnel - similar to the issues with public transportation, the people who work as ride sharing drivers are not medically trained. They are not trained to handle emergency situations.

- Limited availability - ride sharing is only available in highly populated locations like cities and some surrounding suburbs. They may not exist at all in rural areas.

Driving

Overall, do not drive or operate any heavy machinery if you experience any seizure activity. Seizure activity, in this case, includes both generalized tonic clonic seizures and absence seizures. Either type of seizure can result in serious injury to both you and to others in the event of an accident that result from having a seizure while operating machinery. Do not drive without consulting your care team.

Legally speaking, those who suffer from a generalized tonic clonic seizure cannot drive or operate machinery on the roads in the United States for six months following a seizure. The patient's license is suspended. After that time, they are then free to drive. You should remain honest with yourself and your care team about the frequency of your seizures and what kind of seizures from which you are suffering.

Speaking with your care team and being completely honest about your capabilities is paramount for both the epileptic's and the public's safety. Therefore, you need to be entirely honest with both your care team and yourself about the timing and the severity of any seizures. Tests such as electroencephalographs (EEGs) can be done in order to determine the frequency and severity of seizures over a short period of time.

If there are any complicating side effects from epilepsy medication including sedation or lack of focus, then you need to either refrain from driving or limit yourself to driving short distances if they are cleared by your doctor to drive. Refraining from driving long distances reduces the chance of having a seizure while driving. If there are any doubts about the state of

your driving capabilities, then do not drive. If you are able to find a person who is not suffering from a seizure disorder to drive, then politely ask that person to drive instead.

If there is the occasion where you feel that a seizure may occur while on the road, pull over to the side of the road and turn the car off. Turning the car off prevents any jerk movements that occur from forcing your car to move. Immediately after turning the car off, dial emergency services. At the very minimum, even if you are not able to communicate, emergency services are within their authority to find you by the GPS on your phone. If you have enough time, lock the doors. Locking the doors prevents unwanted personnel from entering the vehicle while you are vulnerable. Emergency services will have the tools necessary to enter your vehicle if they find that it is necessary.

It is understood that driving offers a great deal of freedom, but it also entails a great deal of responsibility. Being honest with yourself is of the utmost importance, and reporting every seizure to your healthcare team, while difficult, is necessary. In doing so, you keep an accurate record of your health and progress. Keeping an accurate record of your progress will offer the basic tools necessary to make the best decision for yourself.

Academic Issues and Adjustments

Seeking Accommodations

As an epileptic college student, take advantage of the legal options at your disposal. Legal options include academic accommodations that allow you, as a disabled person, to keep up with necessary schoolwork despite medical setbacks. It is common for disabled students to

request accommodations in order to maintain a sustainable grade point average. Certain commonly sought accommodations include longer testing times, the use of quiet rooms during examinations, and extended due dates. Discuss with your school's administration, disabilities office, and student health organization the exact accommodations you wish to seek.

When seeking accommodations, you may also go directly to professors in order to reduce confusion. If you qualify for ADA accommodations, the institution is required to inform your professors. You should meet with your professors yourself to establish any additional necessary accommodations if possible. These additional accommodations include the use of a note taker because of a shortened attention span or the recording of lectures. Informing the professor personally also builds a personal understanding of the exact nature of your disability. This process should be done before classes begin.

It is paramount that you take the proper college or university channels when seeking accommodations. Fill out every form required in a timely manner, and do not request that accommodations be made in the middle of the semester. Fill out every necessary form provided by the school in its entirety after you are enrolled in the institution and before you begin classes. Failure to follow the proper procedures laid out by your institution can lead to an immediate dismissal of your request for accommodations.

Getting Sleep

Epileptic students should sleep six to eight hours each night in order to maintain proper mental and physical health. Avoid all night study sessions under any circumstances. Staying up all night causes a significantly increased risk of seizures. Depending on your field of study, gaining a full night's sleep may be more difficult to achieve than other majors. Break down projects, papers, and other assignments that take extended periods of time to complete into smaller pieces that can be completed in manageable amounts of time. Practicing this style of

study requires discipline. You should make a list of small tasks that need to be completed in order to promote completion of the larger project.

Maintaining a regular sleep schedule also requires discipline. In order to promote the most regular sleep times possible, set alarms on your phone or other device that can alert you for when it is time to go to sleep. Calculate ahead of time the amount of sleep that is recommended (6-8 hours) and set an alarm earlier in the day. Do not set it close to the scheduled time you fall asleep, as the constant need to sleep will have the opposite effect and will cause your mind to continually think about other worries.

If you require sleep aids such as melatonin or other medications, talk to your neurologist or health care team before taking any new medications. Do not self-medicate under any circumstances. Self-medicating can be dangerous, as there may be side effects that are caused from reactions with your regular medications. Researching online sources is not sufficient when deciding what medications to take. Talk to your care team about the best medication options if needed.

If there are days where you do not receive the proper amount of sleep, do not hesitate to prioritize sleep over class attendance. If there comes a time you need the day to sleep properly, inform your professor of the reason for your absence. Notify them immediately, before class, if attendance is a portion of your grade. Also, reach out to a classmate about receiving the notes from class.

Talking to Professors

When talking to professors throughout the semester about your disability and the possible difficult situations that may arise, it is always best to inform them ahead of time when possible. Do not expect professors to be trained in first aid or emergency preparedness. They

are most likely not equipped to handle a seizure. When approaching them before classes, ask politely if they would like to know what to do if a seizure happens. If they would like to be informed, oblige them. If they do not wish to be informed, then do not press the issue. Politely inform them who to call if a seizure occurs. Sometimes, emergency services are not needed, and informing them of who to inform causes less stress on both you and the professor.

If emergencies arise outside the classroom that affect class attendance and assignments, inform your professors as soon as possible. Even if the administration is aware of the situation, do not expect the administration to notify professors about individual emergencies. It is more direct and convenient to take care of the matter yourself. Notifying professors directly also reduces confusion and the possibility of miscommunication.

During the semester, it is also highly advised that you take advantage of the accommodations allotted to you as an epileptic. When doing so, you should inform the professor before the assignment or examination. If you do not speak with your professor or instructor beforehand, the instructor may become upset. Informing the professor politely before the assignment also allows them to adjust any lesson plans if necessary.

Coming to Terms with Limitations

During your collegiate career, you need to take time to reflect on what your limitations are as an epileptic. Facing the fact that you have limitations can take time. Do not force the issue, but also, do not wait until you are struggling in school to ask for help. Different epileptics have different severities of epilepsy. Therefore, it is important to be proactive for your health and advocacy. If you feel as if you are having trouble in a certain area, be proactive and seek help early.

Accept your limitations at your own pace. It may take some time, and everyone comes to terms with their body's limitations at their own pace. However, if you need to see a counselor or medical professional to help with the acceptance process, do not hesitate to do so. The idea of coming to terms with one's limitations is to make the best decisions for your health. Therefore, you should ask for professional help whenever you need it.

Seeking Help

Do not be afraid to seek help from others about your school problems. Just like talking frequently with your doctor, students who have problems should never hesitate to seek help. The sooner you seek help for your problems, the easier your college experience will be. Seeking additional help includes seeking help for depression and anxiety.

Academic help is the most readily available tool for students at any college or university. Academic help can come in the form of tutoring, study workshops, and office hours with professors. It is absolutely vital that any student take full advantage of the resources that are available to them. Talking to professors and administrators and staff is a good first step, but students should go further and seek additional tools to help ease the academic burden.

Seeking medical help is also an issue that you should not stigmatize. Outside of your preferred care team, talking to the disabilities office (if your institution has one) and your institution's student health organization can help with more immediate needs including first response to emergencies. Informing them of your preferred care during emergencies can help cause less confusion and can help keep you calm knowing that those who may respond to your emergency first know how to conduct themselves properly.

Asking for help with the side effects of your medication and the residual effects of being an epileptic is also an issue that you should destigmatize. Prioritizing your mental health should

be a normal part of your healthcare plan. Talking to your doctor regularly about these issues should become common practice. Seeking help from a professional counselor should also become part of your healthcare. Seeking help at times comes in the form of a psychologist who is provided by your college or university. Prioritize your mental health.

Social Life

Common Challenges

Depending on the severity of your epilepsy, there will be differing challenges you will face as a student. However, common issues involve social ostracization, difficulty studying, informing others of your medical issues, and fear from loved ones and strangers alike about the possibility of a seizure. Dealing with these issues is common, and it is often difficult to face. However, know that no student faces challenges alone. Your care team, family, friends, and the school faculty are there to help you succeed as a student.

Many students face challenges such as the ones listed above despite not being epileptic. Therefore, realize that you are not alone just because of your epilepsy. While it may play a factor in how you talk to people or who you trust with certain information, it should not frighten anyone away from having an enriching collegiate experience.

You should face the challenges you encounter head on and without hesitation. The temptation to shy away from the problem and ignore the fact that you are epileptic will be ever present. This temptation is especially present if your type of epilepsy is well managed or you have been seizure free for a substantial amount of time. However, the idea should always be to face problems, no matter how difficult, with confidence. Epilepsy should not hold you back from

achieving your goals, and advocating for yourself by taking full control of the problems at hand is the best first step.

Lack of Understanding

Interviewer: Do you feel, as a professional, that there is a widespread lack of knowledge about epilepsy?

Dr. Bethany Thomas, University of Pennsylvania: Yes

Despite affecting 3.4 million Americans, the general population is found to have many misconceptions about epilepsy. As an epileptic, it is likely that you have dealt with unintentional ignorance or misinformation multiple times throughout your life. The amount of ignorance you encounter is not likely to change as you enter college. The healthcare workers in the disability office or student health office are well informed on the issues that epileptics face on a daily basis.

The Epilepsy Foundation estimates that epilepsy causes a \$19.4 billion burden on the United States each year. However, the same foundation also reported that they only requested \$11.5 million from the Center for Disease Control (CDC) between 2020 and 2021 in order to train and educate students, teachers, and first responders about epilepsy. The massive underfunding of epilepsy-related causes is a serious reason for this lack of understanding. The link to the Epilepsy Foundation's funding requests and letters to Congress can be found here:

<https://advocacy.epilepsy.com/federal-funding-for-epilepsy>

Despite the advocacy of groups including the Epilepsy Foundation, the majority of people whom you encounter during your studies will have little experience or knowledge about

epilepsy. Administrators, professors, and students will all know very little when you first meet them. Advocating for yourself is the most effective way to guarantee understanding and reduce fear in those you encounter.

Informing Others

If you wish to advocate for both yourself and others, there are numerous ways that you can effect positive change at your institution. The following steps can help you begin to start the process of increasing understanding and reducing fear in your institution's community:

1. Speak with those immediately around you –People you most commonly encounter includes professors, friends, family, and your care team. Gaining support can give you a confidence boost before facing any difficult task that can be mentally draining.
2. Contact your Disability Office and Student Health Office - Both school offices are designed to advocate on your behalf. These offices often create pamphlets or host gatherings designed to inform students on basic first aid and how to handle basic emergencies including seizures.
3. Identify whom you want to inform - Depending on whom you will inform, there will be different procedures on how to approach different audiences. Students are easier to gather in large numbers, and it is important to keep your audience's schedule in mind to reach the widest audience possible.
4. Identify the proper approach to inform your audience - To speak to students from the entire university, a university sponsored workshop may be best. For speaking to administrators and staff, speaking directly to department heads and trusting that they pass on information may be best.

5. Carry out your approach and receive feedback - It is always important to inform others when advocating for a cause. And receiving feedback will help you in the future if you wish to continue advocating in the future.

Being honest and open with others helps reduce fear about epilepsy, and it can lead to friendships and professional relationships that can help you throughout your college career and life after college. Furthermore, advocacy leads to a more open community as a whole, and it may lead others to speak up about the issues they face. In all, the best advocate for epilepsy is the epileptic.

Use the steps listed above if you wish to speak to a wider audience in one attempt. If you wish to approach a smaller audience then the approach changes slightly. If you wish to speak to a small audience like one or two individuals, then use the following steps:

6. If they do not know, then calmly inform them that you are an epileptic. It is not always best to let them know upon the first encounter. However, if the topic comes up naturally in conversation, then do continue to inform them.
7. Ask if the person you are talking to has any questions. Often times others have assumptions about epilepsy that have been perpetuated by media or movies. Take this opportunity to dispell those myths.
8. Answer their questions to the best of your ability. Do not answer questions that you are uncomfortable answering. Furthermore, if you are unsure about any answer, then let them know that you are unsure. Then, try and direct them to another resource for more information.
9. If the person you are talking to shows either fear or ignorance about the matter, try to reassure them. If at any point they make you feel uncomfortable, you are under no obligation to finish the conversation. You are free to walk away at any point.

You do not have to speak to anyone about your struggles or inform other people who have incorrect information about epilepsy. If you wish to keep that fact more personal, that is your choice. Do know that if you would like to inform others and advocate for yourself and others, then the approach outlined above will help.

Social Clubs and Sports

There should be no problems joining academic clubs while in college. Colleges and universities offer a wide variety of clubs to join. Any club that is academic does not pose an immediate issue to your epilepsy. Some social clubs or organizations may cause you to stay up late. Maintain your sleep schedule as well as possible. Also continue to take your medication at the times worked out between you and your care team.

You should make sure at least one other person in the group knows about your condition. Furthermore, at least one person present at each group event should know how to handle a seizure if the situation arises. If no one present is comfortable handling a seizure, be sure they know who to contact. This precaution guarantees that they notify proper medical personnel.

Sports are a different matter because of the amount of contact in various sports. Different schools have different rules about epileptics' involvement in various sports. According to the ADA, the institution cannot officially ban you from participating in the sport of your choosing. However, roadblocks and challenges may be put in your way including additional forms from your doctor. This approach is legal.

From a medical perspective, avoid contact sports in order to protect your brain from possible injury. Such contact sports include football, rugby, volleyball, soccer, field hockey, and other sports that involve direct contact to the head. Basketball is also ill advised depending on

whether or not you have seizures that are triggered by hyperventilation. Many schools and doctors do not recommend sports that involve swimming or water. Sports involving water include swimming, diving, crew, and water polo. While doctors may not recommend sports that involve water, they are possible as long as others who have proper training are always present. Speak candidly with your care team about which sports options are available to you.

Non-contact sports that are more open to epileptics from a medical perspective include baseball, ultimate frisbee, golf, softball, flag football, track and field events, and other sports or activities that do not involve direct contact to the head. The list provided may expand or be narrowed depending on the severity of your epilepsy. Speak to your doctor about specific activities that interest you. Regardless of which activity you choose to participate in, always have proper medical staff available.

Parties and Social Gatherings

Going to parties and other social gatherings does not have to be an activity that epileptics avoid entirely. The perception is often that drinking and drugs are always present. That perception is false. Do not ingest alcohol and drugs such as cocaine, MDMA, or other prescription drugs without consulting with your doctor. Your care team should inform you before starting college of the dangers of participating in drinking and doing drugs. Colleges and universities also speak to students themselves during freshman orientation or on dorm bulletin boards. Also, do not feel pressured to take part in such activities. If you feel uncomfortable in an environment where you are being pressured to do drugs or alcohol, leave the environment as soon as possible.

When attending parties, it is recommended that students attend parties with a person whom they trust in order to avoid running into situations where they may feel pressured to do

drugs or alcohol. Attending parties with a friend or trusted person can also provide epileptics with someone whom they trust in the event of a seizure or other medical emergency.

Do not be afraid to refuse drugs and alcohol. With the unique situation that epileptics face, they may have not only to refuse drugs or alcohol, but they may also have to inform some people as to why they are refusing drugs and alcohol. If that occasion arises, remember to remain calm when informing individuals, because they are most likely meeting a vocal epileptic for the first time. If others continue to pressure you, then leave the environment or find more supportive friends.

Personal Relationships

Epilepsy affects friendships at times. Your friends should be made aware of your condition only when you are comfortable telling them. Do not feel pressured to inform them upon a first meeting. You should know that you are not defined by your epilepsy. You do not need to inform others about what you do not want them to know. It may take time to feel a level of trust before informing friends about your epilepsy. Taking time before informing others is normal. Do not feel the need to rush to tell those whom you do not trust.

The amount of time that it takes to tell friends and those whom you trust will differ depending on the individual. However, do not wait too long to inform your friends. On the other hand, if you feel comfortable informing people as soon as you meet them, that is also fine. It differs between individuals, but what matters is how comfortable you feel.

Ultimately, the information that a friend should know includes the basics that a parent or guardian would know. Basic information includes the medications that the epileptic takes, basic first aid in the event of a seizure, and the person who should be contacted in the event of a seizure. They do not need to know every detail of the patient's medical history. They do not also

need to escort you to medical appointments. However, it is advised that epileptics disclose the most important information to someone they trust to tell medical personnel if the occasion arises.

Dating

Intimate relationships are another area that requires a delicate approach to revealing information. You should not begin informing a possible partner about health issues on the first date. Instead, you should simply let conversation progress naturally. Do not force topics that do not feel natural. If you do not feel comfortable sharing a piece of information, including your health, then there is no need to bring it up. However, if you feel comfortable bringing up your health with a person, then it is appropriate to do so.

If you wish to pursue a relationship with an individual, then you should hold off on having sex until after the information regarding your health is revealed. Different individuals will have different reactions. Therefore, you should withhold sexual relations in order to give your partner a chance to properly digest the information without feeling committed or used.

Informing partners about your medical history and the handling of emergencies will take time, and most of the information that you have including contact information of your doctor and the prescriptions that you take are not necessary for them to know until they decide they wish to become a more important part of your life. Once they decide that they would like to be a larger part of your life, then it is important to inform your partner appropriately. Overwhelming a partner can scare them and make them less open to learning more about you. Overwhelming them can then cause other communication issues in a relationship.

Once you decide to reveal information to them, begin by asking if they have any questions. Answer any questions that they have in order to make them feel comfortable. If they

do not, then inform them about the most important information first. The most important information includes basic first aid and your triggers. The medication that you take and your doctor's contact information is information you should address in a conversation after informing them about the basics.

Keep in mind that a person is within their right to leave at any time that they feel uncomfortable. It is, therefore, best to inform any possible partner before physical contact or any further intimate emotions develop. They may not react in the way that you wish, but that is their choice. For some people, a medical disorder such as epilepsy is not a major issue. For others, it is a responsibility that they cannot handle. If they feel as though they cannot handle possible emergencies that may arise, it may be within your best interest as an epileptic not to have that individual as an intimate partner.

Additional Resources

A variety of links have been provided throughout the guide. Additional resources are available with brief descriptions of what material they hold:

<https://www.mayoclinic.org/diseases-conditions/grand-mal-seizure/diagnosis-treatment/drc-20364165>

Mayo Clinic breaks down what epilepsy is, how it can be diagnosed, and how it can be treated. Treatments that it offers includes medications, dietary therapy, and medical device possibilities alongside other possible treatments. The Mayo Clinic also

offers advice specifically geared towards women offering advice on pregnancy and contraceptives. Tips are also offered on this webpage.

https://www.cdc.gov/epilepsy/toolkit/resource_guide.htm

The CDC provides a guide of their own that addresses issues related to epilepsy throughout teenage years. The CDC also offers links to nationally recognized organizations that address epilepsy. Furthermore, they offer support for family of epileptics and additional resources of their own.

<https://www.naec-epilepsy.org/for-patients/patient-resources/>

The National Association of Epilepsy Centers offers a comprehensive list of organizations that are dedicated to advocating for epileptics and their caregivers. On their page, they offer links to a plethora of organizations they sponsor as well as tools to find an epilepsy center near you.

<https://www.epilepsy.com/living-epilepsy/toolbox>

The Epilepsy Foundation is one of the most reputable epilepsy advocacy organizations in the country. On this link you will find a list of frequently asked questions as well as links that answer those questions in detail. The Epilepsy Foundation also offers a seizure hotline that are available 24/7 that is available in case any questions need to be answered about epilepsy. Online outreach groups and social media pages also have links on the Foundation's page.

“Epilepsy - A Medical Dictionary, Bibliography, and Annotated Research Guide to Internet References” published by ICON Health Publications

The book offers extensive medical terminology and studies, and the book guides users on updating their knowledge using the internet. The book is written as a medical textbook. Therefore, it is heavy in research and can become draining. However, it is a comprehensive tool that can be the all-encompassing research guide for epileptics who wish to gain an in-depth knowledge about epilepsy.

<https://www.medicalnewstoday.com/articles/317922#Causes-of-epilepsy>

The article written by Medical News Today offers a brief description of alternative options to antiepileptic drugs. Considering that antiseizure medications do not work for every patient, the article offers a variety of options that do not include the use of traditional medications. The article is a good starting point for alternative medicine research. However, speak with your care team before beginning any alternative medicine treatment.

<https://www.myepilepsyteam.com>

This website is entirely dedicated to offering support and help for epileptics. MyEpilepsyTeam.com not only has a community of people that are willing to listen to your story, but it also has articles that are designed to help guide others in dealing with the condition.

<https://www.facebook.com/EpilepsyFoundationofAmerica>

The Epilepsy Foundation has a Facebook page that frequently posts articles, others' testimonies, and information relating to their charitable causes. The page is not dedicated to any specific age group and is open to anyone that looks to advocate for those with epilepsy. Their address and telephone number is provided on their Facebook page.

Epilepsy Memes and Support – @epilepsy.seizure.memes (Instagram)

If you are looking for a laugh, memes may be the answer. The page not only posts relatable memes for epileptics, but it also posts pertinent information relating to epilepsy. If humor is your coping mechanism of choice, then this Instagram page offers the perfect remedy.

Important Dates Related to Epilepsy:

- All November – November is National Epilepsy Awareness Month in the United States, and the month is often sponsored by various epilepsy advocacy groups and foundations. The month is also full of gatherings and charitable events designed to raise awareness about epilepsy.
- March 26 – in the United States, Epilepsy Awareness Day, also known as “Purple Day” is celebrated on March 26 each year and is celebrated by increasing awareness about epilepsy. Purple is the color that represents epilepsy in the medical community.
- Second Tuesday in February – International Epilepsy Day is recognized on the second Tuesday of February each year. It changes each year, but it is recognized in 120 countries around the world.

Facebook has a plethora of epilepsy support pages that are full of other people who suffer from epilepsy. Overall, it provides the best base of communities for epileptics who are looking for support. Simply search, “epilepsy support” to find a list of support groups to choose from. All are welcoming to anyone who supports those with epilepsy and is willing to learn more about it.

The Epilepsy Foundation also has Facebook, Instagram and Twitter pages in order to increase outreach to those who wish to seek help and information. To reach their pages, either visit the links provided on the Epilepsy Foundation website, or search, “Epilepsy Foundation” in the social media platform search bar.

Appendix

To Students

To those who deal with epilepsy every day, I have been in your shoes. I attended a school that was underprepared for the challenges I faced. In some cases, they made it even more difficult than my situation already was. I was told multiple times that I should go home, that I should choose a different major, and that I shouldn't participate in certain activities. In every case, I chose to endure.

I know just how hard things can be when your epilepsy feels out of control or if others are making it more difficult for you to thrive. The best advice I can give you is to endure. At the end of the day, schools are often looking to do best by themselves. Rarely do they do what is

best for the students, and my epilepsy showed that to me. You should do your very best to endure in spite of all the challenges that you will face. In no way will it be easy, but in no way will you be alone in your endeavor. I wrote this guide so that no student who reads this will ever be alone. The online resources at a student's disposal are endless, and there are support groups that can help you through even the toughest challenges.

I have done my best to advocate for epileptics, and it is my hope that others will do the same. Despite affecting 3.4 million individuals in the United States, there is still a massive problem with a lack of funding, training, and understanding. I have had to inform hundreds of people that my type of epilepsy is nothing that they should fear. I learned about how my body reacts, and I take care of myself accordingly. Please, advocate for yourself. At the end of the day, you know your epilepsy and how it affects you more than anyone else.

Do not be afraid of having a seizure. Do not hide who you are. You may be an epileptic, but epilepsy does not define who you are. It does not take full control of your life. I made the choice not to live my life in fear, and I live my life everyday as I always would. I had to make certain decisions to ensure my health, but I do not regret the decisions I have made about my health. I do not regret not driving. I do not regret biking to work. I do not regret being outwardly open about my affliction.

The best people will help you. They will look to be there for you, and they are not afraid of your epilepsy. They see through the disorder and see the unique person underneath. Sometimes, the wrong people will approach you first, and that can be difficult. Sometimes, the university will employ the wrong people, and you will have additional challenges. However, there are always good people who will help you through hard times. Whether that is through a bout of depression or helping take you to doctor's appointments, good people will always be willing to help you.

I wrote this guide so that any student may find answers to questions they may have. If they cannot, then I did my best to provide them resources to know where they should look in order to find the answers they seek. If you have any questions that you need answered, I will always be willing to answer them to the best of my ability. I will advocate on your behalf in the best way I can, and I wish you the best in your college experience. Do not be afraid of the challenges you will face. You will be stronger for it. Trust me. I've been there.

To Parents

I can remember many difficult conversations that I had with my parents about living as an epileptic. I cannot imagine how difficult it is living in a state of constant worry about your child that you have done your best to protect from many hardships. However, with that being said, you have done your part. It is time for your child to learn how to take care of themselves. I had to learn the hard way in many instances, but I do not regret any of it. That does not mean that you should sever contact with them entirely. Doing so is never recommended, but it is recommended that you give them space to let you grow as an adult.

I remember when my freshman year became especially difficult. My mom visited me when I did not even ask her to come. I am beyond grateful for her efforts, and even though I was always stubborn, she played a huge role in my success in college. I also cannot say that I would be where I am without my father. He was the first person I called when I faced serious depression, and without his support I may not be here writing this to you right now. I will be forever grateful for what my parents have done, and even if your kids do not always say so, they are also.

I know you as parents are probably going to want to call your kids everyday and ask a thousand questions about their health. That is totally normal. But I implore you to instead talk about school or other things that don't involve their epilepsy. Your child is already having to

inform dozens of new people about their affliction and inform them as if they are experts themselves. The last thing they want is for the people who know them as who they truly are to keep asking about their health.

Asking about how their dorm looks or if they have made any friends is much more refreshing than answering questions about whether or not they took their medicine. I can personally tell you that I would rather tell my parents about the mundane details about school over the details about my epilepsy any day. Be there for them, but do not be looking over their shoulder. I know that it may be difficult at times, but in order for them to grow, they must be allowed to struggle at times.

To Faculty and Staff

I remember both many good and bad experiences with faculty members. Some faculty made me question my motivation for being a college student at times. I was asked to go home. I was asked to change majors. I was asked why I was so far from home. Instead of nurturing and enriching my college experience, I received so much negative feedback at just 18 years old. At the same time, I received great compassion from many professors who were very empathetic. To those who looked out for me from a distance or always asked if I was feeling well, I have the greatest respect.

I am writing this to you, faculty and staff, so that you may understand that students who suffer from epilepsy already have an enormous amount of stress to deal with. Not only that, but they also have the constant drag of trying to become independent when even members of their own family are trying to tell them that they should remain under someone else's care. In short, it's harder than normal for many epileptics, and the fact that their condition is not often recognized makes the experience of becoming independent that much more difficult. Please be

calm and empathetic towards any epileptics you encounter. From personal experience, I know that you have the potential to make a world of difference in an epileptic student's life.

Not every student who suffers from epilepsy will ask for help. I remember that despite having reasonable accommodations, I rarely used any assignment extensions. The constant drive to be "normal" often pushed me to not ask for help. It would have made a real difference if more professors occasionally asked if I needed help or needed to take time off because of medical issues. I understand that you may have hundreds of students to attend to, but all too often epileptics are treated as a statistic. Our condition often goes unnoticed, so nobody asks how we are doing. If you can, take that small step and ask how that student is doing.

If there comes a time where you need to have a difficult discussion with an epileptic, be calm about it. I remember that when I was told that I needed to change majors, the department chair was very cold and direct. It never occurred to her that my issues were out of my control. My grades were not where they should have been, but in my freshman year I had suffered two extended hospital trips, over 30 seizures, and a broken jaw. None of that mattered. I implore you to not follow her example. Ask about the student's problems outside class. More than likely, the issues are a result of struggling with medication and seizures. They cannot control that aspect of their life. Please be patient and understanding with them.

Finally, as members of a college or university, I ask that you seek to educate your school about epilepsy. Millions of individuals suffer from it, but it is severely underfunded, and most people do not understand anything about epilepsy. Misinformation and myths are constantly put out in media, and epileptics rarely are given the opportunity to educate large numbers of people and dispel those myths. I ask that you begin by educating yourselves, and then continue by looking to educate others. I have had to carry the burden of informing almost everyone I meet about how epilepsy works. The more educated people are, the less of a burden others must carry.

