Disclaimer: I am one person with epilepsy, and I do not have any medical background. I tried to include as many facts in here as possible, but there are likely a lot of subjective things from my own experience as well. I will also be including throughout this my own experiences. If another person with epilepsy does correct you on something you're writing, please listen to them too, as my experiences do not reflect everyone's.

1. LANGUAGE

So, by language in this section, I mean identity-first or person-first language. People with epilepsy are disabled, and when referring to the fact that we are disabled, you should use identity-first language ("disabled character"/"disabled person"). But when it comes to identity-first or person-first language related to epilepsy itself, this gets more complicated. Opinions on this seem to be mixed, most people with epilepsy I've known throughout my life (through real life, Twitter, and TikTok) prefer "person with epilepsy" (though when I made a video on TikTok asking people with epilepsy their opinions many did say that while they prefer "person with epilepsy", they don't mind "epileptic"). I also personally prefer person-first language when it comes to my epilepsy ("person with epilepsy"). However, I have also seen new tags on Tumblr such as "actually epileptic" used by people with epilepsy, showing some do prefer identity-first language.

Personally, I would stay on the safe side of things and use "character with epilepsy" to describe your character (though again, please use "disabled character"). This is also backed up by research, with a February 2017 journal article published in Epilepsy & Behavior showing that 90% of respondents preferred "person with epilepsy." This study, admittedly, did also interview family and friends of people with epilepsy, which slightly skewed the results. However, further down in the study, it is stated that 86.7% of the respondents who did have epilepsy also preferred "person with epilepsy."

Ultimately, I am anticipating this to be the most controversial part of this guide. But it wouldn't be much of a helpful guide if I didn't give any guidance on referring to a character/person. This also sits to clarify the language I will use for the rest of this guide, which is going to be person-first.

2. TYPES OF EPILEPSY/SEIZURES

Please note if you relate to any experiences in the following types of seizures, it may not mean you are having seizures/you have epilepsy. Many of these can also look like several mental health disorders (ex. focal-onset and absence seizures may also look like some dissociative disorders) and also can just look like normal life experiences (ex.

focal-onset and absence seizures can look like totally normal dissociation!). The difference comes in with what the brain is ***actually*** *doing. I do not want to scare anyone into thinking they have seizures/epilepsy by describing these seizures. If you think you may be having seizures/have epilepsy, please seek out a medical professional.*

In writing a character with epilepsy, it would serve you well to recognize that there is more than one kind of seizure. Often, for a person with epilepsy, they predominantly have only one of these types of seizures, though may, on occasion, have others. Therefore, it would also serve you well to pick what kind(s) of seizures your character predominantly has. Much of the actual facts in this section is coming from the Epilepsy Foundation (using this page and then branching off from there). These are broken down into two larger sub-types: generalized onset seizures and focal onset seizures (formerly known as partial seizures). There are technically also unknown onset seizures, but these won't be largely discussed here as these simply mean that it is unknown what onset/kind of seizure someone had, likely due to the fact that they were alone or asleep when the seizure happened.

- Generalized-onset seizures

Generalized-onset seizures involve, basically, your entire brain. I can be bad at explaining, so let's just take the definition straight from the Epilepsy Foundation: "These seizures affect both sides of the brain or groups of cells on both sides of the brain at the same time." If you want an in-depth scientific explanation of what often happens, you can find this on this page from Johns Hopkins Medicine. These include tonic-clonic seizures (formerly known as grand mal seizures), absence seizures, atonic seizures, and myoclonic seizures.

If you've seen a seizure on television or in a movie, or generally pictured to yourself what a seizure looks like, it was likely a tonic-clonic seizure. This is the type of epilepsy that is also the most visible to outsiders. The Epilepsy Foundation does a great job at explaining how these typically present step-by-step but in short: This is the type of seizure where the muscles in one's entire body stiffens, they lose consciousness and fall to the floor, and begin to jerk their body rapidly. For visual learners, here is a video from Epilepsy Toronto showing what a tonic-clonic seizure can look like (and describing what is happening). The time that a tonic-clonic seizure tends to last varies person to person, but it is usually between 1-3 minutes. Since you'll be writing a character with this kind of seizure, here is also a helpful video from the Epilepsy Society that shows it from the point of view of a person having this seizure. This may or may not be repeated in other parts of this section of the guide but many people with epilepsy (including myself) do not go to the hospital after every seizure. But if a seizure lasts longer than 5 minutes, or if there are more than three back-to-back seizures, this does constitute a medical emergency and *that* is when a character should go to the hospital (or, if they are around people, emergency services should be called).

Absence seizures are incredibly common in children, not as much as adults but they still can happen in adults. This, quite literally, just looks to an outsider as if you are staring off into space/having a staring spell, especially in typical absence seizures, which only last around 10 seconds or less. When it comes to atypical absence seizures (which can last up to 45 seconds), it is common that some kind of muscle movements will start to happen, but even these are likely not identifiable by many outsiders as a seizure. These movements tend to be repeated blinking/fluttering of the eyelids, chewing movements, and/or rubbing fingers together/other motions with hands. Unfortunately, these often are mistaken by others as just not paying attention (especially true as, while not visible, you do lose some type of consciousness during these seizures – meaning that you are not aware of what happened during the period of time in which you were seizing). For visual learners, here is a video from Epilepsy Toronto showing what an absence seizure can look like (and describing what is happening). Since you'll be writing a character with this kind of seizure, here is also a helpful video from the Epilepsy Society that shows it from the point of view of a person having this seizure.

If a tonic-clonic seizure first causes every muscle in one's body to stiffen, which is known as the tonic phase, an atonic seizure does quite the opposite. An atonic seizure involves your body's muscles going entirely limp (though this does not have to be the entire body, this can be only part of the body such as the arms). To just take it straight from the Epilepsy Foundation: "The eyelids may droop, the head may nod or drop forward, and the person may drop things. If standing, the person often falls to the ground." As a result, atonic seizures may sometimes also be referred to as "drop seizures"/"drop attacks." These typically last only 15 seconds or less. For visual learners, here is a video from Epilepsy Action showing what an atonic seizure can look like. Since you'll be writing a character with this kind of seizure, here is also a helpful video from the Epilepsy Society that shows it from the point of view of a person having this seizure. *It is possible for atonic seizures to only impact one half of the body, but it is more rare and is rather known as a focal motor atonic seizure (a type of focal seizures).*

The final kind of generalized-onset seizure (that at least I will be discussing in this guide) is myoclonic seizures. These involve very brief, shock-like jerking movements of a muscle or group of muscles. Many people will likely have experienced myoclonus before, in a completely normal, healthy way. Hiccups, for example, are a form of myoclonus. If you've ever been almost asleep then suddenly felt like you were falling and then your body jerked itself fully awake, that's also a form of myoclonus. So, if you choose to write your character as having myoclonic seizures, hopefully you can really relate. But ultimately these are indeed seizures and go beyond those normal motions and jerks. Often, these involve jerks in the neck, shoulders, and arms. These seizures often last only a few seconds, and are most common within the first few hours since someone has woken up for the day. For visual learners, here is a video from Epilepsy Action showing what a myoclonic seizure can look like. Since you'll be writing a character with this kind of seizure, here is also a helpful video from the Epilepsy Society that shows it from the point of view of a person having this seizure.

● Focal-onset seizures

It's me! This is the type of seizures mine fall into. Focal-onset seizures (formerly known as partial seizures), to quote the Epilepsy Foundation, "start in one area or group of cells in one side of the brain." *Focal-onset seizures are more common than generalized-onset seizures.* As for which area of the brain, this will be discussed more with the types. Focal-onset seizures include focal onset awareness seizures (formerly known as simple partial seizures) and focal onset impaired awareness seizures (formerly known as complex partial seizures).

For focal onset awareness seizures, the person is completely awake, alert, and aware of what is going on around them, leading to them being able to then recall the events that happened while they were having their seizure (hence the "awareness" part). But unable to do anything or respond to anyone/anything during the seizure. I was unable to find online what area of the brain these seizures typically start in (and I know less about them, as I have focal onset impaired awareness seizures), but like all focal-onset seizures, they happen on only one side of the brain. Focal onset awareness seizures typically last around 2 minutes. For visual learners, I could not find a video of what focal onset awareness seizures look like from an outsider's perspective. But since you'll be writing a character with this kind of seizure, here is a helpful video from the Epilepsy Society that shows it from the point of view of a person having this seizure.

For focal onset impaired awareness seizures (which is the type of seizures I have), awareness is well … impaired. We often have no memory of what happened during the seizure event, and while we seem like we are conscious (often awake, can even be making sounds and movements (including walking, hand movements, chewing movements, lip smacking, etc.) while having the seizure. But, for the sounds, these will likely be nonsensical, it will not be like carrying on a conversation, they are grunting sounds or basically just a bunch of random little sounds, not even usually making a word out of it. *Personal anecdote: In undergraduate, I was in choir (love to sing) and I had a seizure during rehearsal of Carol of the Bells, and fair to say it was really thrown* *off (and my choir director was aware of my epilepsy, she released us from practice early that day then pulled me aside before I left saying she thinks I had a seizure … I did).* But movements and sounds don't need to happen, often in turn, they look like absent seizures do, where it's just staring off into space (and this is more common for me as well). Like in all seizures, you will not be able to respond to what is happening during the seizure, and if someone is calling your name or even clapping their hands right in front of you, you will remain in the daze. These often start in the temporal lobe or frontal lobe. These often last around 3 minutes. For visual learners, here is a video from Epilepsy Toronto showing what a focus onset impaired awareness seizure can look like (and describing what is happening). Since you'll be writing a character with this kind of seizure, here is a helpful video from the Epilepsy Society that shows it from the point of view of a person having this seizure.

What is worrying about all focal seizures (but especially focal onset impaired awareness seizures), is that the seizure can spread to both sides of the brain and become a generalized seizure. When it does do this, it is most often a tonic-clonic seizure. This is not extremely common, however.

- ## Breakthrough seizures

This is not actually a type or onset of seizures in the ways the other two are. In this, the person would then have one of those kinds of seizures. But I thought it was important to include this, and that this is still the best place for this. As described in a 2008 journal article published in Neurology (yes, this is the real name of a peer-reviewed medical journal), a breakthrough seizure is "When an epilepsy patient experiences a sustained period of freedom from seizures (seizure control), then suddenly experiences a seizure, such an event is commonly referred to as a breakthrough seizure."

You may notice that that article largely blames non-adherence to taking anti-epileptic medication as the cause of breakthrough seizures, but ultimately there is no known cause. It just something that happens sometimes. As described by the Epilepsy Foundation of Greater Chicago, breakthrough seizures also often happen when someone is ill, especially if a fever becomes involved. And they happen outside of those two things too!! Epilepsy is a truly complex disorder, the brain is a complex organ. There is never any telling what can happen. But it is important to recognize breakthrough seizures, especially as the next section will be dedicated to ways to treat epilepsy.

- ## Final notes on types of epilepsy/seizures

There are such things as non-epileptic seizures, and they are interesting in their own right. But since this guide is dedicated to writing a character with epilepsy, these will not be gone over in this guide.

Also, it is important to always note that just because your character predominantly has one type of seizure, that doesn't mean they will only ever have that type of seizure. I've had at least one focal onset awareness seizure that I remember, and from my medical records, I've had at least three tonic-clonic seizures. It is just very important to choose and recognize what type (or even types!) of seizures your character predominantly has, and stick to describing those in your writing (if you choose to describe them having a seizure).

3. WAYS TO TREAT EPILEPSY

There were truly some inhumane ways of treating epilepsy in the past (ex. lobotomies), but today the most common ways of treating epilepsy are anticonvulsant/anti-epileptic medications and service animals.

I probably cannot name off all of the anticonvulsant/anti-epileptic medications out there, even if I tried (especially as I know some are used off-label). Here is a list of the most common ones from the NHS, but here is a more in-depth list from the Epilepsy Foundation, where you can also filter the results you get by which kind of seizures they can treat! I've personally been on Tegretol (carbamazepine) and Lamictal (lamotrigine). I stopped taking Tegretol around the age of 12, and have been on Lamictal ever since. I had a lot of seizures while I was on Tegretol, but since I've been on Lamictal my epilepsy has mostly been under control! To speak on medications and breakthrough seizures from a personal perspective: I have a lot of breakthrough seizures when I get generic, so I need brand-only. That is just my experience, but it is also a shared experience with others, and the Epilepsy Foundation has lobbied since the 1990s to prevent pharmacists from substituting name-brand medications with generic as a result of reports from several people with epilepsy of this exact issue. Also, as a random note, you may notice that many anticonvulsant/anti-epileptic medications are also mood stabilizers (including Tegretol and Lamictal, my cousin has Bipolar Disorder and actually takes the same dosage of Lamictal as I do for my epilepsy). Yeah, not much to say on that, but personally it has led me to have frustrating conversations with therapists after they learn I take Lamictal, having to explain to them that it is also an anticonvulsant/anti-epileptic medication.

As always with writing that your character takes medication, it is important to research interactions and pay attention to those/take those into account in your writing. For example, many anticonvulsant/anti-epileptic medications interact very negatively with grapefruit and with alcohol.

I do not have much knowledge on the use of service animals for treating epilepsy, as I do not have a service animal. But this is a common treatment, especially if the seizures are not well under control. But reading up on it, service dogs can alert (by barking or otherwise finding trained ways of alerting, such as ringing an alarm) family members/other people that someone is having a seizure, service dogs can lie down next to someone having a seizure to prevent injury (even learning to put their body in between the floor and the person having the seizure so to break the fall/reduce the risk of a head injury), and more, all of this taken from the Epilepsy Foundation. But it is worth noting that there is currently no evidence to prove that a service dog can alert the individual to an oncoming seizure (though I have seen some people who do report anecdotal evidence that their service dog can do so).

Three less common forms of treatment are Vagus Nerve Stimulation (VNS), the ketogenic diet ("keto"), and medical marijuana.

Vagus Nerve Stimulation (VNS) has **only** been approved by the FDA for treatment of focal-onset seizures, it has **not** been approved for generalized-onset seizures, and it is **only** approved in the case that anticonvulsant/anti-epileptic medications have failed to work (drug-resistant epilepsy) (taken from the Epilepsy Foundation). To quote the Mayo Clinic, for this treatment to work, "a device is surgically implanted under the skin on your chest, and a wire is threaded under your skin connecting the device to the left vagus nerve." This device then sends "regular, mild pulses of electrical energy to the brain via the vagus nerve." According to the Epilepsy Foundation, usually a person is not aware when the device is sending these pulses, and an added benefit is that: "If a person is aware of when a seizure happens, they can swipe a magnet over the generator in the left chest area to send an extra burst of stimulation to the brain. For some people this may help stop seizures." But again, this treatment has only been approved for a select portion of people with epilepsy. (I apologize for the amount of quotes in this section, I know absolutely nothing about Vagus Nerve Stimulation.)

I'm not going to write out a lot about the ketogenic ("keto") diet, there is plenty of information online about it. But yes, there have been medically proven benefits in reducing seizure activity with people with epilepsy, in fact, when studied in children, 40% to 50% of those studies had 50% or more less seizures after starting the diet than before they started it, and even 10% to 20% had 90% or more less seizures after starting the diet than before they started it (taken from the Cleveland Clinic). In undergraduate, I also knew a fellow person with epilepsy who did treat her epilepsy with following the ketogenic diet and it worked super well for her. Important to note though that it is currently **only** recommended though in the case that anticonvulsant/anti-epileptic medications have failed to work (drug-resistant epilepsy) (taken from the Epilepsy Foundation).

- This is not me endorsing the diet when it comes to typical “diet culture,” just as knowledge that this is a treatment for epilepsy.

I personally feel that most people reading this guide will know what marijuana is, and what medical marijuana means, so I won’t be going over that too much either. For American characters, this is largely going to depend on the state of which they reside. Not all states allow medical marijuana, and even in states that do, epilepsy isn’t always on the list of approved conditions for medical marijuana. For characters outside of the US, this is going to depend on the country. Not all countries allow medical marijuana, and even in countries that do, epilepsy isn’t always on the list of approved conditions for medical marijuana. But the bottom line is that laboratory studies, anecdotal reports, and small clinical studies have proven that cannabis does have at least some effect in reducing the amount of seizures someone has. Therefore, it has helped people in treating their epilepsy.

It is important to figure out how your character manages their epilepsy, or if they even do a combination of different things (ex. most people with service animals do also take medication). Pick something, and commit to it when writing your character.

4. SEIZURE TRIGGERS

You are probably the most familiar with photosensitive epilepsy, where flashing lights trigger a seizure, but would it surprise you that only 3% to 5% of those with epilepsy actually experience photosensitive epilepsy? This number jumps to 90% for those who experience myoclonic seizures, so if your character experiences those then having flashing lights as a trigger would be very accurate, but ultimately when we are talking about everyone with epilepsy, only 3% to 5% are triggered by flashing lights.

This is not me saying that you can’t make your character triggered by flashing lights, ultimately when it comes to specific triggers, 3% to 5% for simply one trigger is **very high**. But it isn’t the only trigger that is out there. Additionally, many with photosensitive epilepsy aren’t just triggered by flashing lights, but also by extremely bright lights.

Personal mention time: If you look at my gif packs, if there are flashing lights, I will put a TW for flashing lights. But I, as someone with epilepsy, was able to make those gifs!! This is because I am not extremely photosensitive. When it comes to absolute strobe lights, that can trigger me, but it needs to be pretty severe before it does! I get triggered more by smells that overwhelm my system, specifically I have found the smell of lavender and the smell of marijuana are large triggers for me (so medical marijuana is completely out of the question for me lol).

Triggers often have to do with your senses in some way: sight, smell, touch, hearing, and taste. Really sour or really spicy tastes have been known to trigger some people, extremely loud noises (especially such as that at a concert) have been known to trigger people, obviously there's photosensitive epilepsy which has to do with sight, and so on and so forth. If I were to list every single trigger I've seen people have or that there has been reported having, this guide would be over 100 pages long. There's even been a mention in a study of one person who had to use specific toothpastes, as the mint taste in many toothpastes were a trigger.

Some top known seizure triggers, that haven't been previously mentioned in this section (flashing lights have already been mentioned), according to the Epilepsy Foundation and Penn Medicine are: specific times of day, sleep deprivation, illness (especially with fever, but even without fever), alcohol, illicit drug use (not including marijuana), stress, menstrual cycle (this wasn't mentioned in the above section, but birth control is sometimes used to treat epilepsy for some people as a result of this), dehydration, lack of food, low blood sugar, vitamin and mineral deficiencies, caffeine, and not taking medication on a regular basis.

It is not only important to know what your character gets triggered by, but start to take that into consideration when deciding what your character can and cannot do or engage in. If your muse is triggered by extremely loud noises (such as that at concerts), sorry, but they shouldn't attend a concert. If your muse is triggered by alcohol, sorry, they shouldn't drink alcohol. If they're triggered by their menstrual cycle, they should take birth control.

If they have photosensitive epilepsy, this may make things even more difficult for them. There has been a push in the epilepsy community in the US for the FCC to start regulating the use of flashing lights in movies and tv, and at the very least make it so that there needs to be a clear warning of these, but that's ultimately not something that has happened yet. Your character will need to be careful when picking movies and shows to watch. They likely will avoid the first night of a movie, and possibly even avoid watching tv shows on the night they air, as they want to look the next day online to make sure no flashing lights were featured. This character may also have problems attending concerts, as many artists use flashing lights, and may avoid those. This character will also need to avoid certain plays and musical productions, as they involve flashing lights.

Triggers are also not always going to be able to be avoided. My neighbors' teenage kids do smoke weed, and I smell it sometimes, and it triggers seizures. And there is frankly nothing I can do about preventing it.

Or maybe, your character doesn't care sometimes! I would be lying to you if I said that all people with epilepsy do indeed put in every effort to avoid their triggers, especially if their epilepsy is well under control. It's up to you, but if they are purposely not caring and not putting in the effort, you should make that clear.

Edit 12/27 8:08 pm EST: Thanks to haikyuupaladin on tumblr for pointing it out: "not everyone is entirely sure of what their triggers are and so they may avoid a lot of common triggers to be on the safe side." This is important too when considering seizure triggers! This is even fairly true to my own experiences, as while I know of the smell triggers mentioned earlier, there have been times I've had seizures where those aren't present so I'm unsure of all of my triggers! So it is an important note that not everyone knows their triggers, or even if they know some they may not know all! Thanks for pointing it out!

5. HOW DOES EPILEPSY FORM

Idk if this makes sense to be this low in the guide, but whatever. Anyways, the answer is … there's no one right answer! Personally, I was born with epilepsy, and this is relatively common. This often results from some type of issues that happened in utero or during birth. Many genetic disorders have high comorbidities with epilepsy, showing genetic and hereditary connections sometimes with epilepsy. Many people (50% to 60%) with myoclonic seizures also have at least one other family member that also experiences myoclonic seizures.

But epilepsy isn't necessarily something that needs to form this way. Many people develop epilepsy later in life (including in childhood). This can be from an illness, traumatic brain injuries (including mild traumatic brain injuries such as a concussion), a stroke, a brain tumor, drug and alcohol abuse (even after someone has been in recovery and no longer actively using), and more.

I am unsure if you really ever need to state how a character’s epilepsy formed or developed, but it could possibly be something that comes up. And if it’s something that did form later in life, it could be something that is mentioned as a result!

6. MEDICAL THINGS TO KNOW

Besides just seizures, there are things your character is going to go through as they live their life with epilepsy. They will need a neurologist, and specifically one who specializes in epilepsy (these are specifically called *epileptologists*, but honestly if I didn’t do any research I wouldn’t have known that because I’ve always just called mine my neurologist). How often your character sees them is likely going to be dependent on how well controlled their epilepsy is. I currently see mine once a year, but I am to schedule an “emergency appointment” when I have breakthrough seizures. When I was younger, I used to see my previous neurologist (as she was in pediatrics) every 6 months, and when I was super younger, every 3 months. It all depends on how well under control your character’s epilepsy is, but ultimately your character will have a doctor they see, probably at least once a year.

Epilepsy cannot be detected using blood work (only an EEG, which will be discussed next), but it is not uncommon to get blood work done as a result of epilepsy. Blood work can detect the levels in blood of anticonvulsant medication (make sure the dosage is at an appropriate therapeutic level) and CBC and chemistry panels to look at just overall health things are common too. After all, as discussed in the triggers section, having something else “off” (illness, low blood sugar, vitamin and mineral deficiencies, etc.) can end up triggering a seizure.

EEGs (electroencephalograms) are pretty much the unifying annoyance for those of us with epilepsy. They are very much necessary, don’t get me wrong, but it is long to attach the electrodes and take them off, not to mention getting the glue and marker out of your hair, and, depending on what kind of EEG you need to get, it can present further annoyances (ex. if it involves an overnight stay in the hospital).

In essence, an EEG is able to evaluate the electrical activity of your brain. This will show epileptic seizures, hence it being used to diagnose epilepsy, and it is important in the evaluation of how well under control someone’s epilepsy is. During an EEG, the examiner (? there’s probably a correct term for this but this is page 11 and I am getting tired) will purposely try to trigger a seizure. This involves putting a strobe light right in front of your face (and trust me, the light part is extremely bright), taking a deep breath and then having you blow a lot of oxygen out (to move a small windmill), rapidly blinking, and some more tests. Sometimes, an entire EEG is done inside an office for just a few hours, but in that they will also ask that you try to rest/sleep so they can evaluate that part too. Most often, at least for me, there are at least 24 hour EEGs. This can involve staying in the hospital, as I often did while a pediatric patient, or going on home with it yourself (this is very new to me). Especially when first evaluating for epilepsy, they are even longer. I have had a few 72-hour EEGs in the past (while in pediatrics), and that was even after I was diagnosed! Now, I have at most 24-hour EEGs, and I only have them once every two years unless I experience a seizure.

MRIs and CTs are also occasionally done, if they feel the need to evaluate if there is any brain damage.

This is it, I think? Again, much of this is based on my own experiences! I took mostly just my own experiences into this section!

7. BEFORE AND AFTER A SEIZURE

Starting to feel like the order of things doesn't make sense in this guide, but it’s because these things are coming to me as I go. Anyways! Especially for focal onset impaired awareness seizures and for tonic-clonic seizures, but occasionally for other seizures as well, many people have reported experiencing an “aura.” This, itself, is most likely actually a focal onset awareness seizure. These have been experienced in many different ways, but some common ones according to the Epilepsy Society are: a ‘rising’ feeling in the stomach or déjà vu; getting an unusual smell or taste; a sudden intense feeling of fear or joy; a strange feeling like a ‘wave’ going through the head; stiffness or twitching in part of the body (such as an arm or hand); a feeling of numbness or tingling; a sensation that an arm or leg feels bigger or smaller than it actually is; visual disturbances such as colored or flashing lights or hallucinations. Some have also reported significant spikes in feelings of anxiety as an aura. I frankly have not been able to identify an aura myself, but anxiety is something I sometimes feel before a seizure, so I do wonder if that is an aura for myself.

Ultimately, there is no way to stop the seizure from happening. If someone experiences an aura, that can be great as, if they are able to move or alert someone during the aura then they can be in a safer position when having the seizure, limiting the risk for injury. But the aura is simply going to be a warning. There is no way to stop the seizure from happening.

We’ve discussed when talking about tonic-clonic seizures about what constitutes an emergency and a trip to the hospital, and what does not. But there is a lot that may happen after a seizure. More than 70% of people with epilepsy have expressed that they feel different after coming out of a seizure, myself included! A feeling of confusion and disorientation is common in almost all seizure types, as you could see in almost all of the videos from the Epilepsy Society on what a seizure looks like from the person who is having it’s point of view. Headaches are also extremely common, even if the type of seizure doesn’t involve hitting the ground in any way. After all, think about what is happening in the brain during a seizure (if you don’t know: “the normal electrical pattern is disrupted by sudden and synchronized bursts of electrical energy”). I personally experience headaches after pretty much any seizure, even though my type is focal onset impaired awareness seizures. Feelings of intense anxiety are common as an aura, but it is also common after coming out of a seizure. Embarrassment is also extremely common. People have also reported emotional changes (suddenly getting very emotional), behavioral changes, and extreme exhaustion after a seizure. I personally experience extreme exhaustion as well. I can be out like a light after a seizure. The Epilepsy Foundation says it can take hours to recover, but some feel they experience it for days. Personally, I’d say it probably takes about a day to recover.

Having epilepsy is scary! Having a seizure is scary! Even if it’s experienced often, it doesn’t change that. Hence some of the feelings after.

When 70% of people report experiencing this, I feel that it is important to recognize this somewhat in your character. How do they feel after a seizure? Are they part of the lucky 30% to recover immediately? If so, make that clear. But I would love to see more characters with epilepsy who do take time to recover. Because that is more realistic.

8. FINAL NOTES

I’m sure I missed something, but I'm going to try to hit on as many things I may have missed in this final notes section.

Epilepsy can be an isolating condition. Think about the triggers, and think about how many things your character may need to avoid. It can be difficult to explain that to others, and even more difficult to find people who properly understand. But epilepsy isn’t all bad, and I would really love to see more epilepsy representation.

Do I think your chosen fc needs to have epilepsy for you to use them for a character with epilepsy? Personally, no. I wish it was possible for that, but there’s not many celebrities I know with epilepsy, and none have resources. Unfortunately, many times we even only learn that celebrities have epilepsy after their death. You also can't tell someone has epilepsy just by looking at them, so yeah! You can go ahead and use a fc who doesn't have epilepsy for a character with epilepsy, in my opinion.

- BTW: SUDEP (Sudden Unexpected Death in Epilepsy) is extremely rare. Mentioning this as I know I mentioned that many times we even only learn that celebrities have epilepsy after their death, and this death is often associated with SUDEP. But SUDEP is extremely rare. Though it is frightening, and I would appreciate not really reading about it! Lets focus on epilepsy representation as something positive!

I know a lot of this is just … facts about epilepsy. But the reason for that is so that you can make an informed decision on things when writing your character. You can pick a seizure type, pick triggers, pick a way to treat, etc., and write based on the knowledge of that. I hope this purpose makes sense!

If I missed something/didn't touch on something and I should have, I will just continue to add to this section. If you know of something I missed/didn't touch on, and want me to add it, please let me know! I am like … fairly certain I missed something.

Edit 12/27 4:42 pm EST: Already remembered something I forgot! As an American, I am unsure how this works in other countries (so please check laws in each country) but in the United States, there are restrictions put on people with epilepsy when it comes to driving. Typically you have to be 6 months or a year seizure free before you can get your driver's license (I do believe some states are longer). Some states also require you to submit information from your doctor proving that your epilepsy is well-controlled enough that you can drive (this also means that some doctors may not actually issue this information until longer). Therefore, especially if the epilepsy is not well controlled, your character may be unable to drive. The Epilepsy Foundation provides information by state on this matter here.