

Timestamp	1. Have you ever experienced a seizure or taken care of another person experiencing a seizure? Please elaborate if you are comfortable sharing.	2. What were the signs that you or the other person were experiencing a seizure?	3. Have you ever experienced or taken care of another person experiencing a seizure while they were asleep? What is different about it compared to during the day while awake or any other considerations?	4. If there were a device to detect seizures, what features would you want it to have?	5. What are your usual next steps/response after detecting the seizure?	6. Do you have any additional comments or anything you want to let us know?
10/2/2024 15:55:38	yes, I have witnessed several seizures	s/s can range from mild tremors to full convulsions with loss of consciousness	no	an alarm would be beneficial so the person could get to a safe position	Keeping the person safe during the seizure, getting help if possible, helping to get person follow up if needed.	N/A
10/2/2024 16:22:02	yes	the characteristic shaking	no	i would like the device to be able to provide data on heartbeat to make sure the person's heart is still beating	you turn the person on their side and wait for their seizure to end or for them to stop breathing to take action	i'm an emt
10/2/2024 16:27:41	Yes	Prodrome of anxiety and feeling unwell, tonic clonic spastic movements, jaw clenching, oral trauma such as tongue biting or cheek biting, urinary incontinence, post-ictal confusion and retrograde amnesia	Yes, this can be more difficult to detect if no nearby witnesses. If on monitor low oxygen level is often noted. Similar tonic clonic spastic movements.	Ability to notify emergency contact and/or EMS with location. Blood glucose reading.	Protect airway, ensure adequate ventilation.	best of luck
10/2/2024 17:06:26	Yes my mother in law developed epilepsy after her massive stroke. I was with her during her whole seizure. She had no history of seizures before her stroke	After her stroke my mother can't really talk apart from yes and no and the other half. She was smiling and laughing at me one minute then started shaking and sounded like she was choking.	No	I have epilepsy myself I have drop seizures no warning. I would love to have some way of given me a warning	Unable to answer as I have blanks in my memory.	My epilepsy and my mother in law's epilepsy is different. But when me and my husband looked after her for 3 years I had to tell people what to do. But I think all care companies should be trained on what to do
10/2/2024 17:24:02	Yes	I was scared, couldn't talk, walk, hearing went muffled, stared to the side, was drooling, it lasted about 30 seconds, but afterwards I was very confused and needed to lay and sleep for hours. It can be very difficult to think straight for the next week or 2	Yes, while in my sleep I'm never aware of it, my husband tells me I will wake up, sit up, raise one of my arms, look around, it'll last about 30 seconds to a min, might try to speak some, but once it's over I lay down and fall back to sleep. I'll wake up the next morning very, very confused, might have a headache, muscles a little achy, and still very tired.	I'm sorry, I don't understand. I also had 2 seizures at the end of last week, so goes to show I'm still having a problem putting things together.	I need sleep. Trying to take things easy, but sometimes that can only go so far. With epilepsy.	I have what're called Aura's. A little feeling before a seizure to let me know one 'might be coming'. My heart starts to beat very fast, my hearing goes away, I get hot very fast, my stomach starts to turn, mine usually last about 20 seconds or so before I have my seizure. About 90% of the time they will turn in to a seizure, other's it'll just go away. They are very scary, but I'm thankful I have that warning. Some people who have them hate them, which I understand, but I've always been ok with them.
10/2/2024 20:22:27	Yes I have been diagnosed with generalized tonic clonic seizures 44yrs ago and have increased to complex partial seizures and atonic drop seizures over the years.	I usually get an aura that comes on just before a seizure occurs	Not to my knowledge	I use the Embrace watch, from the empathica company. It has electro-dermal sensors, gyroscope, accelerometer sensors. It's FDA approved wrist worn seizure detection device.	If I catch the aura quickly enough I use a nasal inhaler nazylam	I hope that this helps you, and I don't mind my answers being made public. I just want to help people out
10/2/2024 21:21:24	Yes, I have regular seizures. All seizure types are different, mine sometimes I am fully conscious but my body goes into full violent convulsions. Definitely not fun!	Depends on the seizure, most of the time it's full body convulsions but I also have absent seizures where I will zone out and be entirely unresponsive until I come back too	I have most of my seizures during my sleep. I only know because my husband alerts me too them. The biggest difference is you don't usually know you have them while asleep	Just that, for it to detect a seizure. That info is huge to report to your neuro. Especially if it can connect with an Apple Watch	Lay down. Biggest thing is to get somewhere safe	
10/2/2024 22:40:24	Yes. My son started having seizures at 2 years old. He is now 4.	Depends. He has had many different types of seizures. The most common has been a focal seizure. His arms go up in front of him like a C and stiffen. He just falls over. He does not have convulsing with these which makes seizure detection devices useless. These could be from 5 seconds to 20 minutes.	Yes. They are pretty much the same as when awake only he doesn't fall. My son's started out small after about 2 years they became more aggressive during the night to the point that he would wake up screaming and loose bladder function.	Alert to wake parent. Something to check pulse and oxygen levels would be a plus. Me personally I am so forced on him being ok and counting to see how long before rescue is needed. I guess that adds a timer. Nearby panic button to alert 911.	Protect him from being injured , keep time of how long that it has lasted, watch his color to endure that he is breathing, then helping him get back to baseline .	Night time is the scariest. I cannot tell you how many times I slept with my son because I was afraid he would seize and die in his sleep. Not all seizure consist of strong convulsing. Having one that requires a phone or a huge watch is not the best idea for a small kid. affordable because insurance most likely isn't going to cover it.
10/2/2024 22:45:23	I have experienced my first ones on August 18th, 2024 and ER doctors came up with the dx of epilepsy for me. I'm going through extensive tests to see if there is a cause. I had 4 that day.	Unknown, happened all the sudden. I'm thinking genetic triggered it bit idk why it triggered in my mid 20s (I'm 24yrs old). You think I would have seen it earlier.	I haven't had one in my sleep before and I hope that doesn't happen but I have an epimonitor watch to tell me if I do. I hope not.	I have the epimonitor which is fda approved but it's very expensive. I wish it was more affordable and stopped disconnecting. It's a fairly new device and insurance didn't cover it. It has features of contacting people on your emergency list, tracts mainly tonic clonic seizures and can tract during your sleep. I wish it wasn't white though. Seems boring to wear. I hadn't had a seizure since I was dx because I'm on keppra.	I'm not sure as this is relatively new for my but my mom called 911 when it did happened. I just know basic training if I do see another person seize.	Nope
10/3/2024 2:14:50	Yes, I have had about 10. The first two I was sleeping and my husband woke up. One was in the bath tub and my dog was downstairs and alerted my husband because she could sense it was happening.	Shaking or a blank stare of it was a partial seizure.	No	Track history, heart rate, sugar	I have epilepsy so after about a half hour you are fully present but usually sore and very tired.	
10/3/2024 3:58:43	My son has been having seizures since 4m old, now 14m old.	Unresponsive, arms and legs shaking, struggling to breathe	He sleeps next to my bed in his cot, but still I worry that I won't hear him having a seizure. I won't put him into his own room for this reason.	An alert to me. A lot of devices can give false alerts or stat machines come off his body as he moves around in his sleep. A fixed stat machine would be useful.	We observe for 5 minutes making sure he is safe, if it doesn't stop then administer buccolam and call for an ambulance.	The fear of your child having another seizure is impossible to describe. He is on 3 medications and still has seizures. For adults there are watches and apps available but for kids there is barely anything.
10/3/2024 5:37:20	Yes, I have and so have observed someone going through it.	Aurae and headaches. Head twisting sideways. Extreme strong jerks and shaking in the body that lasted for upto 5 mins.	Both. Always it is the safety first protocol. Still I have hurt myself during sleep and even while being awake.	My brother built a fall detector. I will prefer a prefall detector like aurae detector through your optical interface.	Finding an opimal spot to limit physical damage.	Thankyou for this survey. I did completed my PhD even having epilepsy since I am 5 years old. Do make sure to keep the Epileptics motivated. If you need more details and insight from my end, you can reachout at drsfalam@gmail.com. I will be glad to be resourceful.
10/3/2024 10:06:14	Yes, my daughter has epilepsy, has had multiple types of seizures, day and night, over 20,000 seizures in the last 3 years.	Uncontrolled repetitive body movements, sometimes stopped breathing, sometimes she is upset after, sometimes vomits after	For her, they are the same, uncontrolled repetitive body movements	Motion sensing, video, heart rate, blood oxygen level	Monitoring, taking video, counting time, seeing if she needs help breathing, seeing how long it lasts and if we need to give a rescue medication.	
10/3/2024 10:52:47	Yes, my son has them daily	Staring off, limb/body stiffening, loss of consciousness, rhythmic shaking/twitching, apnea episodes	Yes, unless you're bed sharing it can be hard to tell, harder to keep them safe.	Rhythmic movement, heart rate, oxygen	Monitoring HR, oxygen level, keeping child safe by turning to side if necessary, rescue meds if needed.	

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10/3/2024 10:56:07	Yes, my 3yo has drug-resistant epilepsy and experiences both tonic-clonic and atypical absence seizures.	Tonic clonics have the typical rhythmic jerking; atypical absences have "zoning out" with mild rhythmic jerking in eyes, hands, toes, or head.	My child's vitals are stable during a tonic clonic and he is quiet so it's near impossible to detect during sleep unless we're actively watching him.	The SAMI video alert monitor is piss poor because it doesn't try to detect specific types of motion, or repeated/rhythmic motion. If you were doing the macarena it would start alarming. There is ripe opportunity for using more nuanced computer vision techniques (not DIFFICULT or ADVANCED, just making smarter choices in creating an algorithm) to detect specific types of motion and repeated motion. In addition, recognizing clusters (where the patient returns to baseline in-between) is currently not supported but requires rescue medication and intervention just like a long seizure does.	Timing the seizure and administering rescue medication if needed.	Feel free to reach out - olivia@cami.health. I have a background in web development and also have a computer engineering degree and took a class in computer vision. Haven't used that knowledge in a while but I'd be happy to help however I can. I also think there's opportunity for an actual at-home EEG monitor where the level of accuracy in detecting seizure location in the brain is not important, but just knowing there IS a seizure is helpful. So that would be a cool avenue as well, especially since not all seizures are movement-based.
10/3/2024 10:57:51	Yes - I myself have epilepsy and I care for a child with epilepsy	I have distinct auras. My child desats, has tachycardia, stares into space and is unresponsive, clenches fist, sometimes shakes	Yes my child. It is much harder to tell unless you are closely watching and/or has a pulse ox device on to alarm for any desats	Something that both a child and an adult could use (so different sizes). Being able to customize alarms. For kids something like a ring for the toe since watches would be tough for them to stay on. Something Bluetooth or WiFi enabled so no wires for people that move a lot when sleeping. Ability to detect movement but need to be careful with this since people may move in sleep and it is not a seizure.	Time the seizure. Make sure in safe position.	Love that you are doing this for such an under researched area!
10/3/2024 11:15:13	Many seizures over 52 years but never scared of even severer one. Always knew I'd be fine.	Strange out of body deja vu feeling. Emotions overwhelming so just need to let pass. My kids as adults say just can tell	Few night ones but easy to shake off. When awake during but unable to speak move think emotions riled by seizures can be scary Just remind self will pass then all returns to normal. Give self time for things to settle down if needed. Once mind knows this no reason to get upset after 52 years just glad its over so can shrug off too.	I see no reason to alert self if seizure on the way. Will still occur so why live in fear of? Few have serious non stop seizures that require ER or 911	Simply relax let it pass keep in mind it will. Worse was loss of bladder control so dashed to nearest bath, new panty like have eliminated. If in public put hand up till speech returns many concerned. We know why that meds will control clear mind of fears to avoid getting upset.	I know how epilepsy seems to be linked to depression far too much. Bright side of epilepsy needs more attention to avoid this. All should realize we live in 1st century to explain seizures with meds to help. Clear mind of fears with real medical advice.
10/3/2024 12:54:53	Yes I have. I have had to take care of my son when he had a seizure. It was disconcerting and scary as it was my first time seeing anyone with a seizure, let alone my own son.	Fits - grand mal seizure - uncontrollable jerks.	No.	Seizure alert. But also be able to pause it when they are playing sports so no false alarms.	Sit with him and stay calm.	
10/3/2024 12:56:48	yes - I have had them since 1997	sometimes I get a wave of nausea or de ja vu	no	an alarm	there hasn't been enough time to react	
10/3/2024 17:47:56	I have seizures. I would have a lot of dejavu growing up and began to have seizures when I fall and lose consciousness about 4 years ago. I had meningitis and brain surgery when I was a 7month baby.	My sisters say I stay paused or begin to shake.	The stringest seizures I've had have been when I am already sleeping. My sisters notice because I fall from the bed; I also wake up with body aches, weak/no energy and bitten tongue.	Have it notify family memebers as well as keep a record to show doctor.	I feel tired and usually lay down and sleep	
10/3/2024 20:25:32	Yes, my son's (10 yo) seizures mostly happen in bed when waking up in the morning or middle of the night and when he is falling back asleep. The one he felt coming on he got out of bed and I had to lay him on the floor. I turn him on his side and make sure nothing is around that can harm him.	Starts with twitching on one side. The one that he felt coming on, he was scared and ran up and hugged me. He lost control of his face and body on one side. He makes a guttural noise with the twitching and loses consciousness and the seizure progresses to tonic clonic seizure.	He does not remember the seizures that happened after he closed his eyes to fall asleep. He only remembers one that came on right before he was falling back asleep. He says he gets a weird taste in his mouth.	Early detection to allow time to be prepared. Maybe a feature to time the seizure or monitor the physical symptoms and seizure type	We normally do not have any warning, but I make sure the area is cleared and he can't get hurt	My son has dyslexia and a language disorder as well and I am wondering if it is related to the epilepsy since the focal idiopathic epilepsy originates on the side of his brain that controls language and speech. I would be happy to share any information if it helps advance epilepsy treatment.
10/3/2024 21:24:21	Yes!	I had been having Deja vu, vivid dreams, and mental confusion	Yes. I was asleep when mine happened. I woke up in an ambulance and was more confused.	Heart rate, motion detection, call for help, ability to hear loved one talking you through it	Waiting	
10/6/2024 17:58:54	I have experienced many seizures.	In the Tonic-Clonic Seizures, I passed out but had very heavy convulsing and shortness of breath. I always bite my tongue. Unfortunately, I always pee in my pants. I get the most intense migraine after them. I can't handle those migraines. They hurt so much. Usually I'll fall asleep after a while too. Then I'm completely knocked out for at least 5-6 hours. In my Focal Aware Seizures, I get a strong deja-vu and an extreme sense of doom; I truly feel like I'm about to be attacked. I feel like I'm about to die. It scares me very much. I get so shaky. In my Focal Unaware Seizures, I completely blank out. I'll stare for quite a while, around 2-3 minutes, without moving or blinking at all. I'm completely silent. When I come out of them, I'm in "baby mode." I talk and slightly act like a toddler, but I have no idea that I'm doing that. After 30 minutes or so, I just slowly go back to normal.	I've had them in my sleep but I can't remember what my husband has told me that I do when I'm asleep.	How soon that seizure is coming. How strong that seizure would be.	Sleep as long as I can. Drink a lot of water.	Everybody needs support with their Epilepsy. It's hard and different for everyone.
10/8/2024 9:09:55	I have experienced 5 generalized tonic-clonic seizures, all as an adult	Loss of consciousness/responsiveness, muscle spasms, shaking, impaired mental status after resolution of seizure activity	No	Display identifying information (name, DOB) and an explanation of what's happening and basic seizure first aid (don't hold me down, don't put anything in my mouth, etc) so that bystanders can help (or at least not cause harm)	I don't need to go to the ER unless I get injured in the seizure or don't recover as expected after, so usually I take acetaminophen for headache and ondansetron for nausea and have someone hang out with me for a while. I also call out of work for the next day because I know that I'll be SORE from the muscle contractions.	I would be hesitant to use a device that detects seizures at night without knowing how it works and that it's not going to give a false positive. Having a seizure is a HUGE inconvenience for me because I cannot drive for 6 months after one, so I would want to be absolutely certain that I actually had a seizure if the device reports one.
10/8/2024 10:24:26	Yes-I have taken care of patients having seizures in a medical setting	muscle spasms, loss of consciousness, confusion.	no	Measure duration of seizure activity	call 911, monitor breathing and airway, reassure the patient as they regain consciousness	