



BC Epilepsy Society

The Role for Seizure Alert Devices

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Epilepsy is unpredictable and therefore many people with epilepsy and their caregivers experience constant fear of when a seizure will occur. Overall quality of life is impacted. During a seizure a person is generally unaware and unable to call for help. Many people with epilepsy or their caregivers keep seizure diaries, but there is a difference between recording and detecting seizures.

How could a seizure alert device help?

A seizure alert device may help notify others if a seizure happens and could be of practical benefit for the seizure management. The devices can notify nearby family or caregivers when a seizure occurs through alarms, phone calls or text alerts, depending on the device. A caregiver can then help the person during and after the seizure. For example, they can help reposition the person, making sure they are on their side if they are not conscious. If breathing or other problems occur, they can call for medical help. Additionally, this type of device could alleviate some of the concern and fear associated with the constant risk of recurrent seizures by giving an opportunity for intervention, including first aid and medication administration.

Accidents and injuries are more frequent in people with epilepsy compared with the general population, and the majority of accidents occur at home. Convulsive seizures in particular are a risk factor for both seizure-related injuries and sudden unexplained death in epilepsy (SUDEP). A device to detect seizures, both during sleep and wakefulness, may be able to help reduce the risk of injury and possibly SUDEP. This could also allow the person to be more independent because the parent or caregiver would not need to keep him or her under constant surveillance because of a concern the person may have a seizure.

What types of seizure alert devices are currently available?

The seizure alert devices available at present are motion detection devices. There are currently 3 types of devices readily available:

1. Mattress devices/movement sensors
2. Watch devices/accelerometers
3. Camera/video/infrared devices

In addition,

4. Seizure alert dogs are frequently used to detect seizures

1. Mattress Devices:

How do they work?

Mattress sensors were developed because most cases of SUDEP occur in patients with generalized tonic clonic seizures (GTCs) while unsupervised in bed at night (1-5). Mattress devices consist of a pressure sensor mat placed under the sheet or mattress to detect abnormal movement or absence of movement. They can usually be adjusted to allow for the patient's weight and for normal sleep movements. When seizure-like movements are detected an alarm will sound.

Examples of two products currently available:

1. Medpage™ Model MP5
The MP5 bed seizure monitor detects movement and noise frequency and intensity, with a minimum patient weight of 25 kg.
www.medpage-ltd.com/epilepsy-alarm-bed-seizure-detection-medpage-mp5
2. Emfit
The Emfit monitor detects micro-movements, without a minimum weight.
www.emfit.com

How reliable are Mattress devices?

Most of these devices have the disadvantages of having a weight restriction, detecting only seizures with rhythmic movements, and inability to pick up all seizures. Mattress devices allow for adjustment of the parameters to compensate for individual differences in movement during sleep (3). None of these systems performed as well as video EEG in detecting nocturnal seizures but this is a step in the right direction for a much needed device.

One study showed that the device detected 89% of GTCs (6). But another study detected only 30% of night-time GTCs (5). In a study comparing two seizure movement alarms corroborated by video EEG, one alarm didn't detect any nighttime seizures while the other detected 66% (3). How accurately "true seizures" is questionable. One study, in 64 patients, recorded 269 false positive results (events that were not seizures) (2). While another study noted numerous false alarms and 28 patients had to be excluded from the study due to faulty sensors, false positives and difficulties differentiating seizures from movements associated with getting out of bed (6). In spite of these problems, this type of sensor is currently the first choice for many people, perhaps because it is user friendly and easy to use (7).

2. Watch/Phone/Accelerometers

How do they work?

Watch devices are wristwatches with accelerometers and in some cases GPS. These watch devices can detect repeated movements and alert someone by smartphone text, sound, or email. Some models can also detect the person's location by GPS monitoring.

An accelerometer is a device that measures both motion and changes in velocity in either 2 or 3 dimensions. For example, smart phones have a 3-way axis which detects when they are tilted, rotated, or moved. These are used for motor seizures as it detects changes in velocity and direction (8-10). These usually have a small, rechargeable battery, usually placed on a limb (9-13). The main challenge is to differentiate seizures from normal, daily, repetitive movements (8). Some systems have a cancel button and this gives the opportunity to indicate that a movement was a false alarm, avoiding a false-positive alert to the caregiver (11).

Some options available:

1. SmartWatch™
This is a wrist watch with motion detection and GPS capabilities.
www.smart-monitor.com
2. Embrace:
A phone device uses existing phone accelerometers, GPS and text messaging systems. Embrace, a smart watch based App, has recently been developed to support the self-monitoring of stress and

activity levels with additional claims that it can capture convulsive seizures and alert others via its link to a smartphone.

www.empatica.com/embrace-watch-epilepsy-monitor

3. EpiLert

A phone device uses existing phone accelerometers, GPS and text messaging systems.

bio-lert.com/Epilert

4. Epiwatch

EpiWatch, an app designed for use on an Apple Watch with its paired iPhone. EpiWatch is using Apple's ResearchKit framework to develop a multi-modal seizure detector based on seizure-related movements, heart rate changes, and patient interactions with the app. While participating in research, patients are rewarded with helpful and engaging tools to track their condition. Again research is needed to establish its advantages and disadvantages.

<http://www.hopkinsmedicine.org/epiwatch#.WHfIHtIrKUK>

5. Pebble Seizure Detector

This is free for anyone with a Pebble watch plus an apple or android phone.

<https://github.com/PebbleSeizureDetect/PebbleSeizureDetect>

How reliable are Accelerometers?

Wearing small accelerometers on the limbs are “user friendly” and able to provide long term monitoring of GTCs. The ability to detect seizures ranges between 16 and 100%. It had a false alarm rate of 0.2 per day (9-13, 15-16). Seizures were detected 9–60 s after seizure onset (11,13). The same accuracy for night time and daytime seizures was achieved (8, 9, 11).

One study validated the system in a home environment detecting 78.5% of the seizures reported by parents, with 0.6 false alarms per night (16). The accuracy of an accelerometer is dependent on the associated settings that are used to analyse the rate, amplitude, intensity, duration and rhythm of the motor component of the seizure. It has been suggested that a minimum of two accelerometers are needed to reliably detect nocturnal convulsive seizures (17).

3. Camera/video/infrared devices:

How do they work?

Camera devices record audio and video information from a remote infrared video camera.

Information is sent to a smart phone and an app records and analyzes the video for seizure like activity. When an unusual event is detected, an alarm is sounded, followed by live sound and video from the camera.

Automatic video detection systems use velocity, area, duration, rotation, oscillation, angular speed, and/or displacement (motion trajectory) to detect seizures (18-21). The underlying concept is to detect complex motor patterns by automatic interpretation of video data (18). The systems have been classified as marker-based or marker-free, depending on whether the cameras track detectable markers placed in relevant places (18).

Seizure types that can be captured by video include focal, hypermotor, myoclonic, and clonic (18-20). Reference markers could be placed on the head, body and limbs to assess for movement when evaluated with infrared light by a video system. This was achieved by monitoring frontal and temporal lobe seizures to evaluate head turning during a seizure (22-23).

One option available:

1. SAMi monitor.

A sleep activity monitor with video and audio to detect unusual motion disrupting sleep setting off an alerting alarm

www.samialert.com

How reliable are camera/video/infrared devices?

The overall accuracy varies from 75 to 100%. True seizures are detected 53–93% (18-21). Marker-based devices present with the shortcoming that sensors can be uncomfortable or dislocate over time (19). Marker-free systems detect only seizures with a motor component, and they are more limited to the area covered by video: the patient must be visible and properly placed (18). Seizure detection based on video is feasible, but it recognizes mainly seizures with large movements.

One study concluded that video monitoring for seizure detection is feasible but needs further development (n = 5) (24). A study of video surveillance specifically looked at the detection of nocturnal myoclonic jerks in 8 subjects and found 75% were picked up, but this was not confirmed with EEG (20). Shankar et al. found that movements correlate well with carer reports of seizures (n = 5) (25,26).

4. Seizure alert dogs (SAD)

How do they work?

Seizure-alert dogs are those that display some attention-getting behavior prior to human appreciation of an impending seizure event (27-29). While the trigger to which these animals respond is not completely understood, it is believed that they alert to subtle human behavioral changes. They may be responding to changes in human respiratory or heart rate or even olfactory phenomena. They are able to alert from 30 s to 45 min before seizure onset (29-31). For example seizure dogs may be able to:

- Get help by finding a person or activating a medical alert.
- Pull potentially dangerous objects away a person's body.
- Help keep a person safe, for example keep them from walking into dangerous areas.
- Try to arouse an unconscious person during or after a seizure.
- Carry emergency medication and information regarding the handler's medical condition.

How reliable are seizure alert dogs?

A study of an untrained pet dog observed that the dog was able to detect seizures with 100% accuracy and no false positives (32). This was corroborated by EEG. One study reported a detection rate of 80% and that all events picked up were “true seizures” (29). Another study found a 43% reduction in seizure frequency with the use of seizure-alert dogs, possibly due to diminished stress (31).

Seizure-alert dogs have been reported to detect atonic, focal dyscognitive, and GTC seizures (27, 30, 33). One of the few seizures detected by a seizure-alert dog with concomitant video EEG monitoring was focal dyscognitive (33).

See also: www.bcepilepsy.com/get-help/staying-safe/seizure-dogs

Other options?

There are other seizure alert devices available, including heart rate detectors, electromyography (detect muscle activity), portable EEG devices with a few leads, devices that measure blood oxygen levels in the brain and devices that measure changes in sweat during seizures. There is also research into devices that are implanted in the brain to predict seizures (Implanted advisory systems) and programmed to detect a patient's typical seizures. Some of these still require ongoing research to make them more “user friendly” and to study the accuracy of the devices. Please refer to:

Table 1: provides a comparison of commonly used devices and also less commonly used devices.

Other Questions/Concerns:

Can seizure alert devices prevent SUDEP?

It is not known why SUDEP is more often unwitnessed than witnessed. Better monitoring of especially night time seizures with automatic seizure detectors would give caregivers the opportunity to intervene, and this might be a way to prevent SUDEP. For example, it has been proposed that timely stimulation (e.g., through shaking) of a subject with cardiorespiratory depression following a seizure might help arouse the subject and restore cardiorespiratory function (34,35). Currently, no devices are available that have been proven to prevent SUDEP. Yet, since SUDEP most often occurs during sleep, some people with seizures at night may be helped by having a way to let others know if a seizure occurs. Ideally, they could get help more quickly. However, as SUDEP is closely related to GTCs, a sensitive ambulatory device detecting GTCs is a realistic first step towards SUDEP prevention.

Can seizure alert devices prevent status epilepticus?

Status epilepticus and injuries related to seizures are a major risk to patients. The annual incidence of status epilepticus is about 10–20/100,000 (36) of which about a third occur in people with a history of epilepsy. The earlier an intervention can take place to stop GTC status epilepticus, the better the prognosis is in terms of mortality, cognition, and functional outcome. More accurate and earlier detection of seizures will give caregivers the opportunity to administer emergency medication, such as rescue midazolam, thus, reduce treatment delay.

Can seizure alert devices prevent injuries?

Accidents and injuries are more frequent in people with epilepsy compared with the general population, and the majority of accidents occur at home. Convulsive seizures in particular are a risk factor for both seizure-related injuries. Most injuries are due to falls, burns, traffic accidents, and swimming-related incidents. Nocturnal seizures may cause the subject to fall out of bed, aspirate, or wander (postictal confusional wandering). Early detection of seizures may help prevent injuries. However, it may not help prevent injuries that occur at seizure onset.

Do seizure detectors have benefits for caregivers?

The caregivers of people with epilepsy feel that they should be there when a potentially harmful seizure occurs. This psychological burden affects the health-related quality of life of caregivers. Installation of a video observation system was found to improve parent-reported quality of family life. Reliable nocturnal seizure monitoring with a seizure detector may help caregivers cope better with the uncertainty of epilepsy and improve their quality of life.

Are there benefits for medical staff?

In-home seizure monitoring may provide clinicians with valuable information. Self-reported seizure frequencies are notoriously unreliable, especially in the case of nocturnal seizures. Long-term monitoring in a video-EEG monitoring unit is costly, and the change of environment often influences seizure frequency. More possibilities for in-home monitoring and telecare could reduce the number of hospital visits. In some cases, more accurate information may improve diagnosis and treatment, which could influence the disease course.

Are there disadvantages of seizure detection?

There are also disadvantages to seizure detection in epilepsy care. Primarily, an automatic device is never foolproof and could give caregivers a false sense of security. Moreover, caregivers need to be able to cope with the system and use it correctly. They should also appreciate the limits and uses of a detection system — a seizure detector is not necessarily a vital sign monitor. Thus, clear information about what a detector can and cannot do is needed to ensure the proper use and acceptance of a device.

Another aspect of automatic detection is the risk of “alarm fatigue”. Seizures occur in varying frequencies and not all seizures require care. Every device will also occasionally produce false alarms. A device that leads to such alarm fatigue defeats its purpose.

What are the limitations of a seizure alert device?

- Seizure alert devices may not be practical for people who live alone or who don’t want others to check on them.
- Focal dyscognitive or non-convulsive seizures are usually not picked up by devices that detect shaking movements.
- More studies and research is needed to determine the accuracy of these detectors. The evidence that these devices work to detect seizures often comes from studies performed in hospital epilepsy monitoring units and in some situations, in home settings. Some of the devices have not been studied in a systematic fashion so we don’t know how well they work in the ‘real world’.
- Most available devices do not alert caregivers of breathing problems or changes in heart rate, which may be important in SUDEP.
- More scientific evidence is needed to prove how well seizure alert devices work and if they are helpful in preventing SUDEP.
- Also, the availability of devices might stimulate unnecessary monitoring by overprotective caregivers. A child might (un)consciously trigger the alarm to attract the attention of the caregiver.
- Monitoring might reveal a higher seizure frequency than expected or show that treatment does not make any difference. This knowledge can be hard for caregivers to cope with if treatment options are limited.
- An alarm system gives caregivers the responsibility to respond to an alarm and to provide proper ictal and postictal care, and they may feel guilty if they ignore a ‘real’ alarm.
- Privacy is also an issue with video monitoring systems, especially in children and people with learning disabilities.

Are there economic benefits to seizure alert devices?

Automatic seizure detection should be affordable, but detectors for continuous monitoring are expensive. However, as epilepsy detectors might reduce costs, by reducing the need for long-term in-hospital diagnostic monitoring, reducing the need for 24-hour care, and reducing hospital admissions for SE, the government may not cover costs of these devices. An economic cost–benefit analysis will be complex, as potential benefits in health-care utilization will probably be outweighed by benefits to the quality of life of caregivers.

How Can I obtain funding for a seizure alert device?

1. Variety - The Children’s Charity

Provides financial assistance for children under the age of 19 who have special needs with the costs of a wide range of equipment, therapies, and educational, social and recreational programs. As well, they have Emergency Response Grants to help children and their families access medical care, supplies, and related services not covered by MSP, Pharmacare, hospitals or other agencies.

2. The BC Lions Society for Children with Disabilities

Their mandate is to support children with disabilities throughout BC. They also fund Easter Seals camps and houses.

3. President's Choice Children's Charity

Provides funding for mobility equipment, environmental modifications, or therapy for children under the age of 18 months with a developmental disability.

4. CKNW Orphan's Fund

Provide funding for medical equipment and services for children, particularly for those with disabilities and in financial need.

Where can I learn more about seizure alert devices?

Watch the PAME Webinar "Preventing SUDEP: Current Thinking and Strategies" for an overview of the use of seizure monitoring devices.

<https://www.pathlms.com/pame/events/226>

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Table 1: Comparison of Available Seizure Alert Devices

Seizure Detector	Measures or detects	Pros	Cons	Seizures types detected
Commonly Used Seizure Detectors				
Mattress sensor	Movement, noise	Detect nighttime GTC. No need to place electrodes. Parameters can be adjusted for each patient	Only detects seizures with rhythmic movements. Weight limitation for some. Uncomfortable for some. Low sensitivity.	GTC, focal dyscognitive seizures with motor component
Accelerometer	Movement	Great sensitivity, good night detection. User friendly	Only detects seizures with a motor component and when there is a free limb movement. Battery system needs to be optimized	GTC, secondarily generalized, myoclonic, clonic, tonic and hypermotor
Video	Movement	No discomfort for patients in marker-free video	Mainly detects seizures with a motor component. Limited to the area covered by video, the patient must be visible and properly placed. Attached markers could dislocate or produce discomfort.	Focal, hypermotor, myoclonic, clonic
Seizure alert dog	Subtle behavioral changes detected by dogs	Alert before the seizures. Increase in QOL, possible reduction in seizure frequency	Few studies while the patient is on EEG. They also alarm to psychogenic seizures. Cannot detect while dogs sleep.	Focal dyscognitive seizures, GTC
Less Commonly Used Seizure Detectors				
EEG	Brain excitability	Gold standard, sensitive	Discomfort, movement artifact	
Electromyogram (sEMG)	Muscle	Early detection in stiffening (tonic) phase. Good sensitivity and night time detection	Only detects seizures with a motor component. Electrodes could detach, move or be uncomfortable	GTCs, tonic seizures, hypermotor seizures
Electrodermal Activity (EDA)	Sweating	Good detection rates, including focal dyscognitive seizures.	Susceptible to motion and pressure artifacts, could be uncomfortable	GTCs, focal dyscognitive seizures
EKG	Heart rate changes	Heart rate relatively easy to detect. Can be recorded from on channel.	Seizures without HR changes go undetected. HR changes occur in many everyday activities and seem to be patient specific. Electrodes might be uncomfortable or unstable in long term.	Focal seizures, secondarily generalized seizures, GTCs
Cerebral oxygen saturation sensor	Cerebral blood flow	Can detect seizures up to 18 min before clinical onset	Few studies, only in 2 seizure types	GTC, temporal lobe seizures
Near-infrared Spectroscopy (NIRS)	Regional cerebral oxygenation	Good detection, including focal dyscognitive seizures	Big diversity in hemodynamic changes. Electrode could be uncomfortable and must be surrounded by a black cloth	Focal seizures, including focal dyscognitive seizures, absence seizures
Implanted advisory system	Brain excitability	Gold-standard. Good seizure prediction in an ambulatory setting	Invasive procedure with potentially serious adverse effects	Focal seizures