

Epilepsy Research UK Tonic-Clonic Seizure Alarm Report

October 2015

Important note: the information contained in this document does not constitute the endorsement of any of the seizure alarms or care solutions by Epilepsy Research UK (ERUK), or by any of the other epilepsy organisations who promoted the tonic-clonic-seizure alarm survey (see p.5).

Background information

Epilepsy charities often receive enquiries from people who have recurrent seizures about tonic-clonic seizure alarms. These are designed to detect movement/sounds/changes in breathing or heart rate that are associated with tonic-clonic seizures, and raise an alert to family/carers (who can provide prompt, possibly life-saving, assistance). They can be combined with a pager, care line, 'Nursecall' or smartphone app to alert people who are a distance away, and this is known as 'telecare'.

The decision to use a seizure alarm is a very individual one, and they are by no means perfect; but some people find them helpful and reassuring (particularly if a person has seizures at night, has very frequent seizures, or lives alone).

Types of alarm used in the UK

Important note: ERUK staff are not alarm experts. All of the information about alarms has come solely from our own online research. We cannot vouch for how up-to-date it is, and it doesn't take into consideration any offers that may be running. The purpose of this section is merely to give people an idea of the alarms that are available, and avenues through which they can be accessed, to help them in their own investigations.

There are various types of tonic-clonic seizure alarm available in the UK. Many are bed sensors that monitor seizures during the night, but there are also wrist/ankle devices that can be worn all the time. For any given alarm there are often different telecare systems via which help can be called, and you need to decide what is best for your circumstances. Table 1 gives a basic description of the main tonic-clonic seizure alarms used domestically in the UK (according to our research). Please note there are other alarms available, and some of the manufacturing companies have recently brought out new alarms/updated versions of existing alarms.

Table 1: A basic description of the main tonic-clonic seizure alarms used domestically in the UK

Manufacturer of alarm	Model	Brief description
Adris Technologies	Pulseguard	A wrist- or ankle-worn device that continuously monitors the wearer's pulse and transmits the data to an ipad app. An alert is raised if the wearer's pulse falls outside 'normal' set parameters. Data is stored and can be sent to healthcare professionals if necessary.
Alert-it ¹	Companion	Under the mattress bed sensor with bedside unit. Designed to detect movements associated with tonic-clonic seizures. Microphone to detect epilepsy-associated sounds and/or moisture sheet available (may be extra). Different alert options possible.
Emfit Ltd	Tonic-clonic seizure monitor	Under the mattress bed sensor with bedside unit. Designed to detect movements (including heart rate and breathing) associated with epileptic seizures and monitor absences from bed. Various alert options possible. Bed absence monitoring facility incorporated.
Medpage/Easylink ²	MP5	Under the mattress bed sensor with bedside unit and pager (two provided). Designed to detect a wide range of epilepsy-associated movements/sounds and raise an alert. Bed absence monitoring facility incorporated.
Possum in partnership with Danish Care Technology ³	Epi-Care Free Epilepsy Sensor	Wrist-worn sensor designed to detect movement associated with tonic-clonic seizures. Suitable for ages 10+. Various alert options possible.
Sensorium	SensAlert 200	Two under-the-mattress sensors linked to Intercall and other Nursecall systems. Designed to detect movement linked to tonic-clonic seizures.
Smart-Monitor	SmartWatch	Wrist-worn device that detects repetitive shaking motion and raises an alert.

¹Alert-it are bringing out a streamlined version of the Companion in December 2015, called the Companion Mini.

²Medpage recently brought out an updated version of the MP5 known as the MP5v2.

³Danish Care Technology also have a bed sensor available through Possum, called the Epi-Care 3000.

[Buying a tonic-clonic seizure alarm in the UK](#)

There are a number of ways in which you can access tonic-clonic seizure alarms, and these are shown below. Please note that **you may not need to pay VAT** on a seizure alarm system - contact the HM Revenue and Customs Helpline on 0300 200 3700, or visit www.hmrc.gov.uk, for more information.

Local authorities

Telecare systems are sometimes available through **housing associations** or **social services departments**, where they are also referred to as community alarms or lifeline systems. You can request an assessment of need from social services to help you decide

whether or not you might benefit from an alarm. The charity *Epilepsy Society* also offers help in this area (<http://www.epilepsysociety.org.uk/risk-assessment#.VhT27vIVhHw>). Many of the telecare systems supplied by housing associations and social housing departments come from the companies Tunstall Ltd and Possum (whose main business is selling alarms of all types (not just for epilepsy) to local authorities and care homes).

Any charges for community alarms vary from one authority to another, and also according to the service provided. Please note the choice of alarm open to you is likely to be limited, but it may still suit your needs (and perhaps at a lower cost – particularly if you are eligible for funding support).

TSA

The **TSA** (Telecare Services Association - <http://www.telecare.org.uk/>) enables you to search for all of the alarm service providers in your area (<http://www.telecare.org.uk/service-provider-directory>). Again the choice of alarm may be limited, but you may find lower cost solutions than you would otherwise.

Free alarms for children

If you are looking for an alarm for a child with uncontrolled epilepsy, the **Muir Maxwell Trust** invites applications for free Sensorium SensAlert 200. Please note there is often a waiting list as demand exceeds supply (<http://www.muirmaxwelltrust.com/>, 0131 273 5256).

The Daisy Garland (<http://www.thedaisygarland.org.uk/>, 01803 847 999) also offers free alarms to children, but again waiting lists apply depending on availability.

Buying from manufacturers or suppliers

It may be that you have a specific alarm in mind, and/or you require it urgently, in which case you can buy one either direct from the manufacturer (only possible in certain cases) or a reseller. It is worth exploring all of the options so that you get the product (and telecare system) you want, at the best price. **Remember to check your VAT status** (see p.2).

Direct from the manufacturer

As far as we are aware, only **Adris Technologies**, **Alert-it** and **Medpage** sell their alarms directly to the public in the UK. Table 2 gives some pricing guidelines for the alarms produced by these manufacturers:

Table 2: Details of seizure alarm manufacturers that sell directly to the public, and price guidelines for the systems they offer:

Manufacturer	Website	Telephone	Price guideline (inc VAT)
Adris Technologies	www.pulseguard.org	0800 862 0365	Pulseguard sensor alone: £112 Pulseguard Prime System (including ipad mini): £899
Alert-it	http://www.alert-it.co.uk	0845 217 9952 or 01530 231215	Companion with Pager: £395 (Companion mini with pager: £220 – not available until December 2015)
Medpage/Easylink	http://www.medpage-ltd.com/	01536 264 869	MP5 with pager: £246.00 MP5v2 with pager: £382.99

UK-based re-sellers

Some companies purchase alarms and re-sell them in conjunction with a variety of telecare options. Table 3 shows the principal re-sellers of tonic-clonic seizure alarms in the UK, and some price guidelines for the systems they offer (where available online).

Table 3: Details of the principal re-sellers of tonic-clonic seizure alarms in the UK, and price guidelines for the systems they offer:

Company name	Website	Telephone number	Epilepsy alarms supplied & price guideline (inc VAT)
Aremco	http://www.disabilityworld.com/co/company.php?ID=3460	01622 858 502	Aremco (Alert-it Companion re-branded): <i>Price not shown online</i>
Epilepsy Alarms UK	https://www.epilepsyalarms.co.uk/epilepsy-alarms.htm	0800 180 8833	Alert-it Companion With pager: £529.99 With care line (12 months): £669.00 Emfit tonic-clonic seizure alarm With pager: £539.99 With care line (12 months): £679.99 Epi-Care Free Epilepsy Sensor With pager: £1,399 With care line (12 months): 1,399 With android app: £995 Pulseguard Sensor plus ipad mini: £899
Epilepsy Solutions	http://epilepsysolutions.co.uk/	01438 821 251	Alert-it Companion With pager: from £390 SmartWatch From £329 (includes android app)
Possum (distributes several alarm systems, including the Epi-Care range, directly to the public)	http://www.possum.co.uk/static/catalogues/telecare-assisted-living_catalogue.pdf	01296 461 000	Alert-it Companion Emfit tonic-clonic seizure alarm Epi-Care Free Epilepsy Sensor Epi-Care 3000 (bed sensor) <i>Prices not available online</i>
Safety Systems Distribution Ltd	http://www.safetysystemsdistribution.co.uk/emfitepilepsy.htm	0800 328 2950	Emfit tonic-clonic seizure alarm From £300
Sanctuary365	http://www.sanctuary365.co.uk/	0330 123 3365	Emfit tonic-clonic seizure alarm <i>Price not shown online</i> Epi-Care Free Epilepsy Sensor <i>Price not shown online</i>
SJS Services	http://www.sjs-services.co.uk/#!epilepsy-alarms/c158h	01463 871 950	Medpage MP5 With pager: £240 Medpage MP5v2 With pager: £380

Tonic-clonic seizure alarm survey 2015

Purpose

There is very little impartial information available to people who wish to buy tonic-clonic seizure alarms, and unless a specific alarm has been recommended by (e.g.) a social worker, or offered at a low (or no) charge, it can be difficult to make a choice .

In June 2015 ERUK tried to address this by developing a questionnaire to capture information about people's personal experiences of using alarms. The aim was to collect enough data to produce an unbiased information document that would help others in the future.

Process

In the survey respondents were asked to identify the alarm that they use/have used from a drop-down menu, and rate the following criteria out of 10:

- Ease of installation
- Helpfulness of the company's support services
- Ease of use
- Reliability in detecting seizures
- Ease of cleaning (bed sensors)
- Peace of mind given

For each one they were given the opportunity to add their own comments, and they were also asked for their views on the frequency of false alarms produced and cost of the alarm. At the beginning of the survey they were asked to comment on whether it was easy to obtain the necessary information when they were choosing their alarm.

The survey was circulated a number of times to ERUK supporters between July and September 2015 (via a monthly newsletter, Twitter and Facebook). Other organisations including **Epilepsy Action**, **Epilepsy Society**, **Young Epilepsy**, **Matthew's Friends** and **Dravet Syndrome UK** also promoted the survey in various ways.

Results

ERUK would like to thank everyone who took the time to complete the survey. Unfortunately the number of responses received (67) was significantly lower than we had hoped, and those that could actually be used in our analysis totalled 47. Submissions were discounted if: there was no identification of the alarm used; elements of the response raised a strong suspicion of bias; the alarm indicated was not in fact a tonic-clonic seizure alarm, or the alarm was no longer being manufactured.

Amongst these 47 'eligible' respondents, 44 were parents or carers of someone with epilepsy, and the majority of those who indicated their country of origin were from the UK and Republic of Ireland.

Table 4 shows the number of responses received for each of the specific alarm options in the survey (an 'other' alarm option was also available, and respondents were asked to specify if they selected this).

Table 4: Number of responses received for each of the specific alarm options given in the survey:

Make and model of alarm	Number of responses
Possum (Epi-Care Free Epilepsy Sensor)	3
Emfit (Tonic-clonic seizure monitor)	13
Medpage Easylink (MP5)	13
Sensorium (SensAlert 200)	10
Alert-It (Companion)	3
Smart-Monitor (SmartWatch)	2
Adris Technologies (Pulseguard)	2

The problem with having so few responses per alarm (only two in some cases), is that it is very difficult to any draw firm conclusions from them. As the criteria assessed were highly subjective (and people’s expectations/standards differ greatly), the scores for each one were wide-ranging, and there were insufficient of them get a meaningful average. Surveys are also self-selecting, i.e. the people who take the time to respond may have a personal reason for getting their view point across (positive or negative), and results can be skewed a certain way. We cannot say that this is definitely the case, but by the same token we cannot be sure it is not. This is why we encouraged as many people as possible to take part in the survey – so that we could be more confident that any bias were ‘countered’ by a large volume of ‘neutral’ responses. If, despite this information you wish to see a table of average scores, please see appendix I.

The additional comment boxes did allow us pick out some of the positive and negative experiences that respondents reported had with their seizure alarms. These are shown in table 5. Again please bear in mind that these come from very few respondents (in some cases only two or three), so it is difficult to assess how common/significant the drawbacks are for those using particular type of alarm.

Table 5: Positive and negative comments concerning a range of tonic-clonic seizure alarms made by the respondents to the ERUK survey:

Model	Main positive points experienced	Some of the drawbacks reported
Epi-Care Free Epilepsy Sensor (wrist-worn)	<ul style="list-style-type: none"> - Easy to use - Gives confidence - Supplier support very good 	<ul style="list-style-type: none"> - Sounds when doing every day activities - Obviously a medical alarm - Careline and pager options still restricted to indoor use
Emfit tonic-clonic seizure monitor (bed sensor)	<ul style="list-style-type: none"> - Warning given if power supply compromised - Good peace of mind 	<ul style="list-style-type: none"> - Battery facility uses batteries quickly (rechargeable batteries recommended) - Not very discrete or portable
Medpage/Easylink MP5 (bed sensor)	<ul style="list-style-type: none"> - Problems quickly resolved by suppliers - Discrete - MP5v2 available 	<ul style="list-style-type: none"> - Sensitivity settings difficult to configure and frequently need altering - One person reported seizures being missed - Sensors require frequent battery changes - Moving locations can cause problems
Sensorium SensAlert 200 (bed sensor)	<ul style="list-style-type: none"> - Free alarms available for some children from the Muir Maxwell Trust (waiting lists apply) 	<ul style="list-style-type: none"> - Three people reported seizures being missed - Frequent false alarms (can be set off by vacuum cleaner, 'getting comfy' in bed or getting up) - Value for money questioned
Alert-it Companion (bed sensor)	<ul style="list-style-type: none"> - Reliable - Good peace of mind - Good support service from suppliers 	<ul style="list-style-type: none"> - Difficult to set up (instructions not clear) - Moisture mat difficult to clean - Old-fashioned appearance
SmartWatch (wrist-worn)	<ul style="list-style-type: none"> - Good support services - Style discrete and appealing for a man - Different coloured bands available 	<ul style="list-style-type: none"> - Inconvenient to charge - Issues with loss of connection via mobile phone - Sounds in response to every day arm movement (e.g. when talking) - Bulky style for a woman/child
Pulseguard wrist- or ankle-worn)	<ul style="list-style-type: none"> - Rapid and friendly support services - Reliable - Discrete - Good peace of mind 	<ul style="list-style-type: none"> - Requires charging every day and battery life is only 9 hours - Takes time for personal heart rate parameters to be configured

False alarms

All of the alarm types received one or more of reports of false alarms, particularly soon after set-up (although some reported their alarm being generally sensitive to every day movement/noise than others – see table 3). People's experiences with the same alarm differed in this respect, and with so few responses (especially for certain types of alarm) it was difficult to get a true sense of the significance of false alarms. Amongst those who commented on false alarms, most said that the reassurance they gained from having their device (and knowing that it worked) outweighed the frustration caused.

The cost of alarms

There were a lot of comments about the high price of alarms, and how it is difficult for some people to afford them without assistance. However there were also many who felt that the peace of mind brought by having an alarm made the costs worthwhile. Evidently a person's attitude towards the cost will depend on their (or their family's) financial situation, and there will be people who are not eligible for assistance, and simply cannot afford an alarm. Some of these have been able to create their own monitoring system using baby monitors (if the person consistently makes a sufficient amount of noise during a seizure), but this is not ideal beyond a certain age when the person may feel belittled and embarrassed by using a baby monitor.

'Other' alarms

There was one eligible response relating to a different alarm to those specified in the survey. This referred to a free iPhone app designed to detect when someone is having a tonic-clonic seizure and text an alert family/carers (<http://www.epdetect.com/>). The report was positive, although amongst the small number of online reviews, there are some that mention problems, e.g. the app suddenly crashing/freezing and false alerts being sent out.

Other comments

One respondent commented that the Alert-it Companion seemed to interfere with the function of the Medpage MP5, if used in the same room.

Another respondent said that they intended to buy a newly developed smart watch called the Empatica 'Embrace' (<https://www.empatica.com/>). This is designed to use a range of physiological measurements to detect when seizures are taking place. It is not clear when this will be available in the UK.

Appendix I: Mean scores (/10) received by different makes/models of tonic-clonic seizure alarm, across a variety of features, during the ERUK survey (blacked out cell means feature not applicable).

Make and model of alarm	Number of responses received	Ease of Installation (/10)	Helpfulness of support services (/10)	Ease of use (/10)	Appearance of alarm (/10)	Reliability (/10)	Ease of cleaning (bed monitors) (/10)	Peace of mind (/10)
Possum (Epi-Care)	3	8.3	6.7	9.3	6.7	8.7		8.3
Emfit (Tonic-Clonic Seizure Monitor)	13	8.1	9.4	9.3	8.8	8.6	9.4	9.3
Medpage Easylink (MP5)	13	7.1	7.7	6.9	7.2	6.7	8.7	6.9
Sensorium (SensAlert 200)	10	8.0	7.1	8.0	7.6	5.2	8.1	5.9
Alert-It (Companion)	3	6.0	7.0	8.0	7.0	9.3		9.3
Smart-Monitor (SmartWatch)	2	6.5	7.5	5.0	7.5	5.0		4.0
Adris Technologies (Pulseguard)	2	9.0	10.0	9.0	9.0	8.5		9.5