Helpline: 01342 831342 Email:helpline@youngepilepsy.org.uk

Night Time Safety Equipment

The following information gives examples of the range of safety equipment available and the suppliers which stock them. Our list is not exhaustive, there are alternative products and suppliers available, and both product information and prices may have changed since the publication of this material.

Young Epilepsy does not recommend or endorse any of the products or companies mentioned. We would strongly recommend that before you consider buying any safety equipment, you discuss the subject in detail with your child's medical team.

When buying equipment we also suggest that you contact a number of companies to discuss your child's particular needs, so you can compare prices and the relative advantages and disadvantages that each company's equipment offers.

Always check the terms and conditions before committing yourself to any expense. It's also worth knowing that when ordering any item that it is for someone with epilepsy, you may not have to pay VAT.

VAT exemption on equipment

VAT Exemption applies to certain items which have been designed to be used by someone who is chronically sick or disabled. In order to waive VAT on your purchase, the government requires a simple declaration to be made as to the nature of your child's disability at the time of ordering.



Seizure bed alarms

Many parents worry that they may not be aware if their child has a seizure during the night. It's not uncommon for some parents to resort to having their child sleeping in the same room as them, or even in the same bed.

Depending on what type of seizures a child has, a seizure bed alarm may be of use. There is little research on the advantages of monitoring equipment, but it is worth discussing with a child's medical team whether or not they think this may be a suitable option for the family. Because of a strong desire to protect children in any way they can, people sometimes end up buying inappropriate or unnecessary equipment.

Some families have used bed seizure alarms in the past and for a variety of reasons (including false alarms), they have discontinued using them because they did not provide the security that the family had hoped for.

In the past, The Muir Maxwell Charitable has supplied free seizure alarms for any child with a confirmed diagnosis of epilepsy www.muirmaxwelltrust.com.

Due to high demand their waiting list is at present closed, but they hope in the future to continue this service. To find out the latest situation contact Ann-Marie Nelson at: info@muirmaxwelltrust.com or ring 01312 735256.

Better futures for young lives with epilepsy

There are a variety of companies that supply seizure bed alarms. Some companies will allow a trial period before you buy; others will allow you to rent them. We would strongly suggest that before buying a bed monitor you contact the company and ask if they offer a trial period, and if so, for how long.

Some companies will only allow a 14 day trial period; others offer a month's trial, while some will allow you to rent an alarm for a specified period. If a child does not have frequent seizures, you may not get the opportunity to give the seizure alarm a fair trial before you have to pay for it, with the result that you could end up with a seizure alarm that is not entirely suitable.

If you are in contact with any parents who are successfully using a bed alarm and whose child has similar seizure types, it may be useful to talk through the advantages and disadvantages of seizure alarms before you commit yourselves. If you do not have any contacts, the child's epilepsy specialist nurse may be able to give you the contact numbers of other such parents.

Below is a list of some of the companies that supply seizure bed alarms:

www.sensorium.co.uk Tel: 08000 565 454. Price £445 plus £127 for a pager or £149 for a receiver.

Aremco alarms email: aremco@ontel.com Tel: 01622 858 502. Prices range from £300 upwards.

www.healthandcare.co.uk Tel: 02079 318 766. Price around £299.

www.medpage-ltd.com Tel: 01563 744 788. Prices start from around £165.

www.easylinkuk.co.uk Tel: 01536 264 869. Prices range from around £200 upwards.

www.emfit.com Tel: 0800 328 2950. Prices from around £300.

www.alert-it.co.uk/epilepsy Tel: 08452 179 951. Prices from £300 upwards.

www.sjs-services.co.uk Tel: 01463 871 950. Price £160.

The prices mentioned above are a rough guide as the final price may vary if you add on a pager or a receiver. Check with the company concerned that the price includes all the equipment that you will need. When costing the alarm, bear in mind that some alarms will be more expensive than they first appear because the manufacturer may recommend that the sensor pads are replaced every year (at a cost of around £70).

Out of bed alarms/door monitoring systems for non convulsive seizures at night

If a child has a non convulsive seizure (e.g. focal seizures) at night, and tends to wander around in a confused state, it might be worth thinking about an alarm system that would alert you to movement, an empty bed or even some kind of door monitoring.

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Most of the companies mentioned above also sell 'out of bed' monitoring systems, as do many other alarm firms. Sensorium also sells door monitoring systems using magnetic door contacts. It is well worth spending some time researching what kind of monitor, if any, will suit a family's needs.

Audio/video Monitors

Audio and video monitors allow you to watch/listen to a child when in another room. If the child's seizures are noisy, many parents are able to use just the audio (listening) monitor. Other parents feel more reassured if they can see and hear what their child is doing.

The price range of these monitors starts from around £30 for the audio monitors and for the video monitoring systems the prices range from around £100 upwards.

Both types of monitors are available from most large stores such as Mothercare, Boots and Asda. You can find many other suppliers of monitors on the internet. Below are a few examples:

www.babymonitorsdirect.co.uk Tel: 0333 088 1078. Prices from around £50 - £100.

www.safetots.co.uk - Tel: 01438 728 888. Prices range from £30 - £80 (for audio) and £60 - £160 (for audio/video).

www.monitormybaby.co.uk e-mail customer@monitormybaby.co.uk. Prices range from around £100.

www.amazon.co.uk Infant-Night-Video-Monitors. Prices start from around £50.

Safety pillows

Some parents decide that they would like to buy a safety or anti suffocation pillow. These are normally made of soft, highly porous foam that permit greater airflow than conventional pillows. They have a gentle rippled surface which provides an abundance of air cavities between the surface of the pillow and the net cover. There is no data however to support the use of anti-suffocation pillows, but if you do decide that you would like to buy one they can be bought from the following companies. Sleep-Safe pillows should not be used for babies and children under three years old.

Sleep Safe Tel: 07092 255 916. Price £39.95 inc. p&p. www.sleepsafe.co.uk

The helpful hand Tel: 01625 617 857. Price £20 & £5 p&p www.thehelpfulhand.fsnet.co.uk

Mobile seizure detectors

Below are a variety of seizure alarms that can be worn or carried by someone with epilepsy.

Some of these devices will detect tonic clonic seizures and automatically dial an emergency number, while others can attract the attention of passersby in the event of someone having a seizure and provide a pre-recorded message.

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If it is decided that giving a child an alarm would make them (and you) feel more secure, we strongly advise that you give careful thought to which type of alarm would suit the child's particular requirements and that you phone the various companies before purchase to discuss the options that each alarm offers.

Epdetect is a mobile phone application that will automatically detect tonic clonic seizures. By attaching the phone to the user's belt, it can detect rhythmic shaking movements and will then dial a preset emergency number and provide location information. If it falsely identifies a seizure there is a cancel button to enable the wearer to cancel the alarm. It is supplied free of charge.

www.epdetect.com/epilepsy_mobile_phon e_application_features.html

Man Down Emergency mobile phone can detect when someone falls, and it will automatically dial an emergency number when the phone is tilted more that 45°.

www.easylinkuk.co.uk Tel: 01536 264 869. Price £122.99 inc VAT delivery £9.25.

Press don't panic is an audio device which communicates vital information in a medical emergency. Those assisting the wearer of the device will then know what to do and who to contact. www.pressdontpanic.com Tel: 01721 730 511. Price £35 Personal Alarm Badge is a small detector capable of detecting a user falling and lying unconscious for more than 15 seconds. It will then call a pager (outdoor range 450m). www.alert-it.co.uk/Epilepsy/ Tel: 08452 179 952. Price for the fall badge is £85 and the pager £122.

Cessation of breathing alarms

Cessation of breathing alarms are designed to monitor the movements of a sleeping person. Before considering buying one of these monitors we would stress the importance of talking to your child's doctor as to whether or not it would be suitable for your child.

The Nanny apnoea monitor www.healthandcare.co.uk Tel: 0207 931 8766. Price £99.99

Sensorium apnoea monitors (claim to detect a lack of breathing of over 20 seconds.

www.sensorium.co.uk/product/assistive/ap noea_monitor.html Tel: 0800 565 454. Price £305.

Safetots supply a variety of movement monitors either as those that clip onto a nappy, or those that are sensor pads positioned under the mattress. These alarms will alert after 20 seconds of inactivity. www.safetots.co.uk _Tel: Ol438 728 888. Prices range from £50 - £100.