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Young Epilepsy

Night Time Safety Equipment

The following information gives examples of the range of safety equipment available and suppliers which stock them. Our list is not exhaustive, there are alternative products and suppliers available, and product information 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 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.

For more information about VAT exemption visit: www.gov.uk/financial-help-disabled/vat-relief

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. As a result 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),

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they have discontinued using them because they did not provide the security that the family had hoped for.

Most seizure bed alarms monitor movement and so are most appropriate for convulsive seizures. However, there are also monitors which can be used for a person whose heart rate changes during a seizure, they activate if the heart rate rises or falls beyond the configured settings.

The Muir Maxwell Trust supplies free seizure alarms for children with a confirmed diagnosis of epilepsy www.muirmaxwelltrust.com. Due to high demand they are operating a waiting list at present. To find out the latest situation contact Ann-Marie Nelson at info@muirmaxwelltrust.com or ring 01312 735 256.

There are a variety of companies that supply seizure bed alarms. 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 allow a trial period 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, as a result 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.

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.

Out of bed alarms/door monitoring systems for nonconvulsive 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.

Most of the companies mentioned below also sell 'out of bed' monitoring systems, as do many other alarm firms. It is well worth spending some time researching what kind of monitor 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. Both types of monitors are available from most large stores such as Mothercare,

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Boots and Asda. You can find many other suppliers of monitors on the internet.

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. These pillows should not be used for babies and children under three years old.

In some cases anti suffocation pillows may be funded by Epilepsy Sucks UK. See www.esuk.uk.com for more information.

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.

Night time safety equipment suppliers:

Alert-it www.alert-it.co.uk/epilepsy Tel: 08452 179 951

Aremco alarms Tel: 01622 858 502

Email: aremco@ontel.com

Easylink (Medpage) www.easylinkuk.co.uk Tel: 01536 264 869

Emfit www.emfitcorp.com Tel: 0800 328 2950

Epilepsy Solutions www.epilepsysolutions.co.uk Tel: 01438 821 251

Health and Care www.healthandcare.co.uk Tel: 02079 318 766

Pulmolink – oxygen level monitor www.pulmolink.co.uk
Tel: 01233 713 070

Pulseguard – heart rate monitor www.pulseguard.org
Tel: 01622 321 111

Sensorium www.sensorium.co.uk Tel: 08000 565 454

SJS Services www.sjs-services.co.uk Tel: 01463 871 950

Sleep Safe – anti suffocation pillows www.sleep-safe.co.uk
Tel: 07092 255 916

The Helpful Hand – anti suffocation pillows www.thehelpfulhand.co.uk
Tel: 01625 424 438