



#### **Anti-Suffocation Pillows**

A Family Company. run by Healthcare Professionals, focussed on Healthcare Integrity.

www.sleep-safe.co.uk





From Don Alderton, Pharmacist 👚 a Member of the Royal Pharmaceutical Society

...Someone at risk from seizures?



BLOCKING the nose

and mouth





the Sleep-Safe pillow AND AROUND the nose and mouth

#### Essential for anyone who is 'at risk'

For children and young people... For older people... For people of all ages with special needs...

Protects **THEM** while they sleep – and gives YOU peace of mind!

Dear Colleague, On behalf of The Voice for Epilepsy, please share these leaflets with colleagues in the health, social care, voluntary and community sectors, also support and advocacy groups working to improve the lives of people who have epilepsy and seizures, Many thanks.

This communication and everything enclosed with it can be viewed, downloaded and shared with colleagues by forwarding this link to them... www.sleep-safe.co.uk/hw424/ Copies of the booklets we provide for users/carers with each Sleep-Safe pillow are enclosed

In the UK, each year, epilepsy alone results in nearly 44,000 emergency hospital admissions and 1,200 deaths among people of all ages<sup>6</sup>, and most of these are sudden and unexpected and occur usually at night.

But... How can someone be protected against suffocating during seizures... While they're asleep? - and avoid a panic-led emergency hospital admission?

- by using SLEEP-SAFE Anti-Suffocation Pillows...

and a limited number of FREE Anti-Suffocation Pillows Are available from The Voice for Epilepsy

When / if all FREE pillows have been provided funding will be available to supply pillows at 22% Discount and VAT-free

## Save £10 each £49.95

**FREE Pillows Apply Here** 



22% Discount Pillows **Buy Here** 

www.sleep-safe.co.uk/bntvfe/

https://thevoiceforepilepsy.co.uk/antisuffocation-pillow/ (Then scroll down)

These Free and Discount leaflets <u>really do</u> give much needed help: so far, 802 FREE Pillows and £13,250 of savings have been provided to people with epilepsy.

They also help to Ease 'The 'Cost of Living Crisis' which is more badly affecting people with epilepsy in poorer communities, where epilepsy is more prevalent – as evidenced in Epilesia and in the British Medical Journal<sup>7,8</sup>.

- So, people with epilepsy are more likely than most to be in need of some help.

As headlined, the toll of epilepsy each year in the UK includes nearly 54,000 emergency hospital admissions for children under 4 years old, and 1,200 deaths among people of all ages...

## But why are ordinary pillows risky?

 Death from suffocation can result within minutes when a child or an adult having a seizure becomes entrapped in an ordinary pillow which blocks the nose and mouth. Even if saved from death, oxygen starvation brain injury may result in lifelong disability and dependency.

However, no research has been conducted into the total deaths from all causes of seizures and convulsions, for example, diabetes, stroke and head injuries, so the actual mortality is probably very much greater.

The benefits of Sleep-Safe anti-suffocation pillows go beyond helping to prevent the death or injury of the person who is actually affected by seizures.

- Sleep-Safe pillows also provide reassurance to parents and carers by breaking the cycle of fear that can result in disturbed sleep patterns, anxiety and depression, often leading to a profound deterioration in the quality of life for the entire family.

Electronic alarms and monitors can provide valuable surveillance, but these are expected to function with 100% certainty for 100% of the time, and are limited by the availability of a nearby carer or caregiver who can respond. However, that kind of excellence is usually found only in specialised electro-medical monitoring equipment used in hospital settings, and 100% reliability shouldn't always be relied upon.

Sleep-Safe pillows don't require carer intervention in order to "work properly" - they are designed to help prevent fatal suffocation events during sleep seizures occurring in domestic or care settings where 24-hour continuous monitoring is not entirely possible.

This means that Sleep-Safe also help to reduce greatly the "carer anxiety" of sleep seizures - the fear of the consequences of suffocation — helping to put carers and patients back in control of their lives by relieving a significant cause of family stress.

- As such, managing the medical condition that causes the seizures becomes much less demanding.
- So SLEEP-SAFE Pillows are not just for epilepsy but also for the management of seizures caused by most conditions that disrupt the normal functioning of the brain. These include the ongoing effects of developmental and congenital conditions such as autism spectrum disorder, Down syndrome and cerebral palsy, also acquired brain injury following falls, vehicle accidents and assaults and the aftermath of meningitis, stroke, brain tumour and substance dependency.

## Who Else Uses SLEEP-SAFE PILLOWS?

- NHS Hospitals, Social Services, leading Health and Social Care providers in the UK and overseas

See overleaf for details...

About 8 in 10 Sleep-Safe pillows supplied to the UK About 1 in 10 Sleep-Safe pillows supplied to the USA About 1 in 10 Sleep-Safe pillows supplied to France

## ...AND WHY?

### To help prevent seizure injuries and avoidable hospital admissions...

- **To help** reduce the risks of seizures to patients and prevent seizures becoming panic-led hospital admissions
  - **To support** people with epilepsy to remain at home and avoid the need for acute hospital bed-based care
  - **To provide** the *right* care, in the *right* place, at the *right* time

#### **Produced in the UK, Sleep-Safe Pillows are:**

- **Designed** and developed by a UK Pharmacist
- **Tested** for effectiveness at a UK University
- Compliant with UK Product Safety Regulations
  References & Evidence: www.sleep-safe.co.uk/hw424





## What's included with each SLEEP-SAFE Anti-Suffocation Pillow?

- a 28 page 'Patient, Parent and Carer' focused summary of the 154 page
   Online NICE Clinical Guideline NG 217 'Epilepsies in children, young people and adults'
   (The 154 page Online Guide contains detailed guidance for everyone in the epilepsy care pathway: consultants, GPs, nurses, patients, parents & carers...)
  - The Sleep Seizure Harm Prevention Clinical Guideline
  - 'I Have Epilepsy' First Aid Help Cards for wallet / purse
- an MHRA leaflet 'Some Questions and Answers about Side Effects'
  - an MHRA "Yellow Card" to report medication side effects
- from a pharmacist, opt-in email 'signposts' and news about epilepsy

## Who Else Uses SLEEP-SAFE Anti-Suffocation Pillows?

670 Sleep-Safe Pillows supplied through DannyDid Foundation United States 300 Sleep-Safe Pillows supplied to Association ASPEC Le village du Perche France 200 Sleep-Safe Pillows supplied to the European Union Dravet Syndrome Foundation 60 Sleep-Safe Pillows supplied to "Castelnouvel" home for children with epilepsy France 60 Sleep-Safe Pillows supplied to Children with Special Needs Support, Kisumu, Kenya

**Leading health and social care providers in the UK and overseas** that provide Sleep-Safe Anti-Suffocation Pillows to protect their patients and service users with epilepsy and other seizure disorders include:

#### In the UK: (Not a complete list)

Young Epilepsy (formerly The National Centre for Young People with Epilepsy) - the UK's leading provider for children and young people aged 5 to 25 with complex epilepsy and other neurological conditions

Charing Cross Hospital - referral centre for neurosurgery which houses the serious injuries centre for west London Merseycare NHS Foundation Trust - 40 community units housing people with learning disabilities

Cornwall Partnership NHS Trust - 107 community units housing people with learning disabilities

**United Response** - 40+ community units supporting people with learning disabilities, mental health needs and physical disabilities

#### In the United States: (Not a complete list)

About 1 in 10 of all Sleep-Safe are supplied to care provider organisations and individuals in the United States.

**Dungarvin Inc** - a national organization of privately owned companies that are dedicated to providing high quality, community-based supports to people with varying support needs.

MaineGeneral Health - the leading regional health care system in Maine, recognized for clinical excellence and service, high value, and impact on community health.

Medical Fund Advisors - a national provider of medical claims administration and advisory services for trust funds or custodial arrangements set up for the benefit of an injured individual or class.

Northwestern Memorial Hospital - the primary teaching hospital for Northwestern University's Feinberg School of Medicine. University Of Pennsylvania Health System - a major multi-hospital health system headquartered in Philadelphia, Pennsylvania.

In France: A further 1 in 10 of all Sleep-Safe are supplied to the French Social Services and Epilepsy Societies.

... and since 1992, worldwide, thousands of individual personal purchasers with seizure disorders.

### **Expressions of Support for Anti-Suffocation Pillows**

Personal: "My son was admitted to the Foothills Hospital Seizure Monitoring Unit here in Calgary.

They showed me a video one of the seizures in the middle of the night. My son turns his head to the right side at the onset of his seizures. I watched the video of my son laying on his right side, turning his head to the right, with his face directly in to the pillow. Of course, this was alarming! **But even as I was watching, I knew he was OK because he was sleeping with Sleep-Safe pillows that I recently purchased from your company.** When my son was admitted to hospital, I brought his Sleep-Safe pillows to the hospital, because now that I have them, I no longer feel comfortable with him sleeping with any other pillows".

#### Clinical:



Richard E Appleton, Consultant Paediatric Neurologist Alder Hey Children's Hospital, Liverpool

MRCS LRCP, MB BS, DCH, MA (Oxon), FRCP, FRCPCH

"Anti-suffocation pillows are likely to significantly reduce the risk of suffocation in children (and even adults) who experience frequent nocturnal seizures and particularly if these nocturnal seizures are tonic-clonic (also called Grand Mal) seizures. There is no evidence that the use of an anti-suffocation pillow will completely stop the possibility of a child (or adult) not suffocating during a tonic-clonic seizure, but it is likely these pillows will greatly reduce the risk of suffocation. It would therefore be reasonable, if not wise, to consider using an anti-

suffocation pillow in any child (or adult) who is known to experience nocturnal tonic-clonic seizures." (Provided to Sallieann Gould the Founder of the Epilepsy Sucks charity, and used with permission)

Academic: "In patients with recognized higher SUDEP risk, prevention measures should be suggested, such as the use of antisuffocation pillows." 'Sudden unexpected death in epilepsy (SUDEP) and sleep' published in Sleep Medicine Reviews, Volume 15,

suffocation pillows." 'Sudden unexpected death in epilepsy (SUDEP) and sleep' published in *Sleep Medicine Reviews, Volume 1*:

Issue 4, August 2011, Pages 237-246 Lino Nobili, Paola Proserpio, Guido Rubboli, Nicola Montano, Giuseppe Didato, Carlo A.

Tassinari

#### Ref 1. 1,100 deaths and 44,000

Community Equipment: Use and Needs of Disabled Children and their Families: DH 1841 3.02
 BB/JW/DL, Social Policy Research Unit, University of York, Heslington, York YO10 5DD

Nearly 54,000 emergency admissions

Nuffield Trust Emergency admissions for children with chronic conditions

https://www.nuffieldtrust.org.uk/resource/emergency-admissions-for-children-with-chronic-conditions-1

Children aged 0 to 4 have the highest emergency admission rate for epilepsy, at 83 admissions per 100,000 population in 2020/21.  $65000000/100000 = 650 \times 83 = 53,950$ 

Ref 2. where epilepsy is more prevalent - as evidenced in Epilesia1 and in the British Medical Journal,

Use refsesn 2

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References & Evidence: www.sleep-safe.co.uk/refsesn





Hello, hope you're keeping well and managing to avoid whichever variants of Covid / 'flu / RSV / are lurking about...

Thanks for providing these leaflets, which <u>really do</u> give much needed help: so far, epilepsy nurses have enabled £13,250 of savings for patients by giving them epilepsy support group £10 saving leaflets.

See the Evidence Reference on page 3 - people with epilepsy are more likely to live in socially and economically deprived areas and to be educationally disadvantaged, so are more likely than most to be in need of some help:

Despair stemming from food and fuel poverty highlights the importance of at-home seizure self-management—to help reduce anxiety that may precipitate seizures and result in panic-led, bed-blocking emergency admissions.

**'Free'** anti-suffocation pillows (i.e. funded from donations) are now being provided by two epilepsy <u>support groups</u> (*not <u>charities</u>* – see the enclosed brochure) namely, **HOPE for Paediatric Epilepsy London** and **the Jon Shaw Foundation**.

See a video of Sleep-Safe Pillows featured on the HOPE for Paediatric Epilepsy website...

https://www.hopeforepilepsylondon.org.uk/about-us

(scroll down to 'HOPE ANTI- SUFFOCATION PILLOW PROJECT') Scan here →

<u>All</u> the epilepsy support groups supply deeply-discounted pillows, much of their funding comes from Grant Giving Trusts such as the Aviva Community Fund, the Greggs Foundation and the Lewis Trust, which has ensured that the 'free and low-cost epilepsy pillow initiative' is able to continue.

IMPORTANTLY - The leaflets that Epilepsy Nurses provide to patients empower all the epilepsy support groups to reach as many people with epilepsy as possible and offer their £10 saving.



## - To help prevent seizure deaths and brain injuries resulting from

the ongoing effects of epilepsy, congenital and developmental conditions such as Down's syndrome, Dravet Syndrome, cerebral palsy and autism spectrum disorder. **Also acquired brain injury** following falls, vehicle accidents and assaults **and the aftermath of** meningitis, stroke and brain tumour.

Suggest Stroke, Dementia, Down's syndrome, Dravet, Cerebral Palsy, Autism, Meningitis,

See a video of Sleep-Safe Pillows featured
on the HOPE for Paediatric Epilepsy website... Scan here →
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(scroll down to 'HOPE ANTI- SUFFOCATION PILLOW PROJECT')



\* Copies of the booklets supplied with each Sleep-Safe pillow are enclosed \*

During the past year, since October '22, Epilepsy Nurses have enabled 861 patients with epilepsy to benefit from FREE and Low-Cost Sleep-Safe pillows... that's 137 more patients than during October '21-22 (+19%).

 Every pillow helps to reduce the 1,100 epilepsy deaths and 44,000 seizure-panic led emergency hospital admissions each year in the UK

The 'unmet need' revealed by this initiative has inspired a Family Charitable Trust to provide funds which will enable it to continue at this increased level through 2024.

If you're not already participating in this project, and would like to, or you need to order more special epilepsy support group £10 saving leaflets for your patients...

Email Don Alderton: Scan here → → or dma@sleep-safe.co.uk



Subject Line: More ESN epilepsy support group leaflets please
In the body of your message, please include your name and full
postal address including Mailpoint (if used)

Thanks again for supporting this initiative!



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#### www.sleep-safe.co.uk

Order online or phone 07773 619552 Email to enquiries@sleep-safe.co.uk





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