



## Anti-Suffocation Pillows

*A Family Company,*

*run by Healthcare Professionals, focussed on Healthcare Integrity.*

[www.sleep-safe.co.uk](http://www.sleep-safe.co.uk)

Connect with us!  @sleepsafepillows  #sleepsafepillows

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

*...Someone at risk from seizures?*

		
A normal pillow BLOCKING the nose and mouth	Sleep-Safe pillows WON'T BLOCK the nose and mouth	Air-flow THROUGH 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!

**Partnering with Sleep-Safe  
provides everyday support for people  
with epilepsy and their caregivers –  
to take charge of their lives**

National epilepsy nonprofits focus wholly on fundraising for research, which of course is highly commendable. However, research outcomes are often long-term and remote from the immediate practical, day-to-day needs of families affected by epilepsy.

**By contrast, Sleep-Safe Epilepsy Safety Pillows provide immediate, practical, everyday support by reducing the risk of suffocation during sleep seizures.**

– Anti-suffocation pillows change the status quo of seizures from crisis management to active management.

**Epilepsy Nonprofits can help more people with epilepsy by sourcing Sleep-Safe Epilepsy Safety pillows at a deep discount from the 'headline' price: from USD173 each down to USD85 each.**

### **Contents:**

1. Partnering helps Nonprofits help more people with epilepsy
2. What's included with each Sleep-Safe pillow?
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## **1. Partnering helps Nonprofits help more people with epilepsy**

*US Nonprofits Partnering with Sleep-Safe can reduce the shipped price of each Sleep-Safe Pillow from the headline price of USD173 to as low as USD85.*

- Sleep-Safe pillows can be vacuum-packed which reduces their size significantly.*
- Order quantities of just 6 Sleep-Safe can reduce greatly the shipped price.*

*This low-volume bulk shipping overcomes the high shipping cost of single Sleep-Safe pillows which is often a barrier to individual users and caregivers.*

**In the US we Partner with** the DannyDid Foundation, the Chelsea Hutchison Foundation, the Epilepsy Advocacy Network and Ribbonsforkellsey.

**These nonprofits provide Sleep-Safe pillows free of charge** or at a much lower price to parents and caregivers in their group. **For example**, 80 Sleep-Safe pillows to Ribbonsforkellsey for free distribution in the Illinois and Iowa Quad Cities Region, made possible by a gift from a local benefactor. **Further examples:** the DannyDid Foundation Grant program has given financial assistance to purchase many Sleep-Safe pillows, and the Epilepsy Advocacy Network funds free supply to people in need.

*Since 2003 we've supplied over 2,000 Sleep-Safe pillows by Partnering with the DannyDid Foundation, the Chelsea Hutchison Foundation and Ribbonsforkellsey, all for the benefit of people with epilepsy and their caregivers.*

*Everyone in nonprofits works very hard to raise funds:  
Partnering with Sleep-Safe gives an opportunity to make those funds go much further and to help many more people with epilepsy and their caregivers.*

*The Sleep-Safe Anti-Suffocation Pillow is UKCA 'Conformity Assessed'  
- It is a Class I Medical Device registered at the Medicines & Healthcare products Regulatory Agency (the MHRA) and conforms with the requirements of the Medical Devices Regulations.*

MHRA is the Medicines and Healthcare products Regulatory Agency which is an executive agency of the Department of Health and Social Care in the United Kingdom and is responsible for ensuring that medicines and medical devices work and are acceptably safe.

*UKCA is an implicit declaration that Sleep-Safe pillows comply with all UK laws and applicable British conformity assessment procedures.*

## 2. What's included

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

*Information to help family, caregivers and users understand the diagnosis and treatment options, how to manage living safely with epilepsy and to reduce the risk of SUDEP.*

1. A concise 28 page 'Caregiver and User' 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, epilepsy nurses, users, caregivers...)*

2. The Sleep Seizure Harm Prevention Clinical Guideline
3. 'I Have Epilepsy' First Aid Help Cards for wallet / purse
4. An MHRA leaflet – 'Some Questions and Answers about Side Effects'
5. an MHRA "Yellow Card" to report medication side effects
6. from a pharmacist, opt-in email 'signposts' and news about epilepsy

## Who else uses SLEEP-SAFE Pillows?

- UK National Health Service Hospitals, Social Services, leading Health and Social Care providers in the UK and overseas...

About **1 in 10** Sleep-Safe pillows are supplied to the **USA**

About **1 in 10** Sleep-Safe pillows are supplied to **France**

**200** Sleep-Safe pillows to **EU Dravet Foundation** in **Spain**

**60** Sleep-Safe Pillows to **Children Special Needs Support**, **Kenya**

## ...and Why?

**To 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

### 3. How the Lower Shipped Price is Achieved

***We provide 20% online discount links for our Partner epilepsy nonprofits.***

Epilepsy affects ‘only’ 1 in 140 people but such a small proportion of the population is difficult and expensive to reach. This means that about 20% of the ‘headline’ price of Sleep-Safe is taken up by promotional costs: networking, mailshots, publicity etc.

We can offer that 20% as a discount to nonprofits which provide a link on their website for visitors to purchase Sleep-Safe - because we don’t have to spend money to ‘reach’ those visitors, we can pass-on the saving.

***However, for caregivers in the US the 20% product discount is dwarfed by the high shipping cost for single and double pillows.***

***So, the shipped price of single Sleep-Safe pillows is clearly a barrier to children and families who could benefit from the pillows.***

***‘Nonprofit Partnering’ enables low-volume bulk purchasing which dramatically lowers the shipped price of Sleep-Safe pillows.***

***Nonprofits can then provide the pillows to caregivers either at a lower price or as ‘giveaways’.***

**The Lower Shipped Price is achieved...**

- **By giving a product discount of 20%** - made possible by lower materials costs through increased volume of supply to nonprofits.

***We pass-on that saving to you.***

- **By nonprofits purchasing in ‘low-volume’ bulk quantities** – this significantly lowers shipping costs: ‘Bulk’ means multiples of 6: a package of 1 x 6 pillows costs much less to ship than 6 x packages of 1 pillow. Also, it’s less expensive to pack and ship in 6’s 12’s and 18’s than it is to pack and ship singles.

***We pass-on that saving to you.***

The following figures show that the lowest-cost and quickest way of supplying pillows is by air shipping in multiples of 6, a consignment of 18 being the most cost effective.

**Shipping gets cheaper as the quantity increases**, which can lower the final price dramatically:

- 1 x Sleep-Safe shipped to you: shipped total cost of each pillow including shipping = USD138
- 6 x Sleep-Safe shipped to you: shipped total cost of each pillow including shipping = USD119
- 12 x Sleep-Safe shipped to you: shipped total cost of each pillow including shipping = USD103
- 18 x Sleep-Safe shipped to you: shipped total cost of each pillow including shipping = USD85

***We pass-on that saving to you.***

***This is supported greatly by the US policy of ‘open trade’ with other nations, which benefits US citizens – see below, ‘US Customs charges’.***

## 4. US Customs charges

**No US Import Duty is payable on personal imports of less than \$800**

**USA Trade Facilitation and Trade Enforcement Act of 2015:**

'This bill amends the Tariff Act of 1930 to increase from \$200 to \$800 the general de minimis aggregate fair retail value in the country of shipment of duty-free articles imported by one person on one day.'

**This means that if the declared product value in a consignment shipped to an individual is below USD800 there will be no import duty.**

***As such, orders exceeding USD800 in value can be 'split-delivered' to several individuals within a single nonprofit.***

'Personalised' information packs can be created, featuring a specially printed 'signifier' such as your nonprofit's logo along with choice of text... 'Supplied by' 'Provided by' 'Presented by' ... whatever you feel is appropriate... *Examples:*

## Your SLEEP-SAFE PILLOW

PROVIDED BY THE



*Information for Caregivers*

## Your SLEEP-SAFE PILLOW

PROVIDED BY



*Information for Caregivers*

## Your SLEEP-SAFE PILLOW

PROVIDED BY

HOPE

THE CHARITY FOR  
PAEDIATRIC  
EPILEPSY IN  
LONDON

*Information for Carers*

## 5. A Brief History of Sleep-Safe Pillows

When our son started having seizures my wife Chris and I were desperately concerned about his safety while he slept. However, we were dismayed that there were no specialist items of bedding designed to help keep him safe while he slept. During the seizures his breathing became spasmodic and laboured and for brief periods he would cease breathing entirely: We feared that becoming tightly entrapped in bedding during a sleep seizure could lead to brain injury - or even death - due to lack of oxygen. Sheets and blankets could be minimised, but all standard domestic pillows seemed fundamentally unsafe.

Much later we discovered that an 'anti-suffocation' pillow *had* been available, however, production ceased when the manufacturer closed down. We obtained a used sample of the pillow, re-designed it, and launched it as 'SLEEP-SAFE', which have been continually enhanced and improved over 32 years.

Much work is now done now by people with learning disabilities, some of who have epilepsy and other seizure disorders, see '9. Our Team at the Oakenholt Centre'.

We don't supply through commercial dealerships because that would mean adding an additional profit margin to a product which is supplied principally to lower-income families. According to research published in the British Medical Journal, epilepsy is more prevalent in poorer communities.

In the UK we liaise regularly with nearly 400 hospital neurologists and epilepsy specialist nurses so as to supply as many people with epilepsy as possible at the lowest possible price.

We supply mainly to the UK, the United States and France and we're currently discussing a supply arrangement with Epilepsy New Zealand.

**The 'Lower Shipped Price Plan' mirrors how we have worked in the UK for many years – we Partner with epilepsy charities to supply Sleep-Safe Pillows in bulk which they provide free of charge or at low-cost to help meet the needs of low income families.**

**A great example is HOPE for Paediatric Epilepsy...**

Visit <https://www.hopeforepilepsylondon.org.uk/>

Then scroll down to ANTI-SUFFOCATION PILLOW SCHEME



## 6. Who Else is Using Sleep-Safe Pillows?

### Leading health and social care providers in the UK and overseas

that provide Sleep-Safe Anti-Suffocation Pillows to protect their patients with epilepsy and other seizure disorders include:

***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.***

**DannyDid Foundation** - We work toward advancing public awareness, education and disclosure between medical professionals and families impacted by Sudden Unexpected Death in Epilepsy (SUDEP).

**Epilepsy Advocacy Network** - Serving 60 counties in Northwest and Central Illinois, our mission is to optimize the lives of individuals with epilepsy and seizure disorders by promoting community education and awareness, self-advocacy and empowerment, and access to proper care.

**University Of Pennsylvania Health System** - a major multi-hospital health system headquartered in Philadelphia, Pennsylvania.

**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.

***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

... And thousands of individual private purchasers with seizure disorders.

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

***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***



## 7. Expressions of Support for Sleep-Safe 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, FRCPC

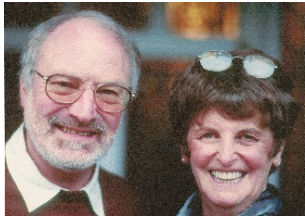
***“Anti-suffocation pillows are likely to significantly reduce the risk of suffocation in children (and even adults) who experience frequent nocturnal seizures and particularly if these nocturnal seizures are tonic-clonic (also called Grand Mal) seizures. There is no evidence that the use***

*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 anti-suffocation pillows.” ‘Sudden unexpected death in epilepsy (SUDEP) and sleep’ published in *Sleep Medicine Reviews, Volume 15, Issue 4, August 2011, Pages 237-246* Lino Nobili, Paola Proserpio, Guido Rubboli, Nicola Montano, Giuseppe Didato, Carlo A. Tassinari

## 8. Brief Biographies



**Don Alderton is a military veteran who** served for twelve years in British Army Medical Corps hospitals and field medical units (known in the US as p'MASH' or Combat Support Hospitals) including 4 years in the Gulf, after which left the army to go to university and to qualify as a pharmacist.

He has managed and owned a number of pharmacies and has worked as the medical devices registration specialist for a leading surgical equipment manufacturer.

His experience in medical device regulation makes him well qualified to ensure that Sleep-Safe Anti-Suffocation Epilepsy Safety pillows conform to the essential requirements of UK legislation and the relevant EU Directives.

Don is registered with the Royal Pharmaceutical Society of Great Britain and his vocation as a pharmacist ensures that he keeps well up to date with health care issues. For six years Don was Secretary of the Chester Branch of Arthritis Care (400+ members) with overall responsibility for co-coordinating the group activities including hydrotherapy, holidays and branch meetings. During that time he negotiated a substantial 3-year National Lottery grant which enabled the introduction of new local initiatives aimed at reducing the problems of social isolation stemming from age, disability and low income.

**Chris Alderton** has worked in the UK National Health Services for over 40 years and is a qualified general nurse and midwife. She is also a health visitor, and this additional qualification in public health enables her to work with families to give pre-school-age children the best possible start in life. She has wide-ranging knowledge and experience within health promotion and preventative care for families, especially children and their parents.

Chris is a trained psychotherapist and mindfulness teacher, with wide experience of providing outreach therapy in primary care settings and courses for health and education professionals and members of the general public, including caregivers.

**Chris says,** 'I'm very aware of the detrimental effects of long term stress and anxiety on the lives of families and especially on caregivers. I've witnessed the transformative effects and stress reduction that evidence-based practical medical solutions can bring.

'It's a situation I experienced at first-hand: our infant son's seizures were extremely worrying, causing deep concerns about his night-time safety – the unpredictability of convulsions, possibly resulting in cessation of breathing, brain damage and even death due to lack of oxygen. We could minimise the risk with breathable bedding but standard domestic pillows were fundamentally unsafe.'

'This is why, personally and professionally, I endorse the use of Sleep-Safe Anti-Suffocation Pillows as an important aid to safe sleeping and alleviating the anxiety and concerns of parents and caregivers.'

***The information that Don and Chris provide is based on the principle that patients and caregivers get the best support when there is inter-professional communication between colleagues from different health and social care disciplines.***

***Chris and Don's aim is to promote a sense of personal empowerment that will enable everyone affected by seizures to manage more effectively the underlying medical condition.***

## 9. Our Team at the Oakenholt Centre

# Oakenholt

Manager - Christine Mann



### Information

Oakenholt offers a diverse and personalised service for a wide variety of people, ranging from people with special needs to those ready to access the community. A team of qualified and experienced professionals, and multi-disciplinary partners offer activities to meet all needs and tastes.

Our service provides a personalised environment that enables people to:

- Learn skills
- Increase confidence
- Develop life skills
- Experience employment skills
- Be introduced to the community
- Pink Pinny Cafe - Open to the public every Wednesday

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