

Hello, everyone, good to see you and to put 'faces' to 'names' after many years of email communications!

Sleep-Safe Pillows – Sleep-Safe Pillows and HOPE

HOPE for Epilepsy and I (i.e. Sleep-Safe) have worked together now for 13 years, since 2010, when the HOPE founder Scott Liddle contacted me.

Scott was impressed with the Sleep-Safe pillow after using one to help manage his son's complex epilepsy. However – he wanted to discuss making the pillows more widely available through HOPE for Epilepsy and if this would reduce the price. I replied that direct supply would save about £6 per pillow – which was the cost of achieving each supply to a person with epilepsy (mail shots, advertising etc) – and that could be given as a discount for each pillow supplied directly through HOPE. We agreed on that as a way forward, and reducing the price by the cost of promotion has worked satisfactorily since then. The discount is now 22% which includes a 5% saving by not making online payments.

A short time after Scott spoke to me an epilepsy nurse in a newly established post contacted me for some Sleep-Safe leaflets, after she has learned about the HOPE lower price arrangement. She suggested that it might be worthwhile contacting more epilepsy nurses.

At that time NHS Hospitals were linked into about 150 Primary Care Trusts so to address letters / postcards to 'The Epilepsy Nurses' at each of the Neurology Departments in each NHS hospital seemed a straightforward way ahead.

HOWEVER... at that time most of the PCTs / Hospitals weren't 'online' so all those contacts had to be found by visiting a library, photocopying pages from the Social and Health Services Annual Handbook and then typing the addresses into an Excel spreadsheet.

So for the past 12 years that's been the basis for 'reaching' as many people with epilepsy as is possible: periodic leaflet pack mail-outs to epilepsy nurses on behalf of parent-led epilepsy charities and support groups which fund free and low-cost Sleep-Safe anti-suffocation epilepsy safety pillows.

NICE Strategy 21 to 26 and the HOPE plan in response

This way of working took on an extra dimension two years ago, when NICE, the National Institute for Health and Care Excellence, launched its 'New Strategy 2021-26'. This includes easier access to medical technology innovations and

importantly, it also included new “living guidelines” which are to be constantly updated for clinicians and the public to access.

This new strategy should benefit people with epilepsy so the HOPE Trustees decided that a case should be made to NICE to make the pillows available on NHS prescription.

Easier and wider availability would help to reduce panic-led emergency admissions and the adverse mental health consequences of the diagnosis.

Seizures often can't be prevented - but they can be managed so that the risk of a suffocation fatality or oxygen deficit brain injury is reduced. As such, patient and carer anxiety and family stress is diminished greatly. This moves patient care 'Closer to Home' and reduces demand on hospitals by helping to prevent seizures becoming panic-led admissions needing acute hospital bed-based care.

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

It would also help in realizing the Government strategy of 'Making care closer to home a reality' - a recent King's Fund report says...

“Despite successive governments repeating a vision of health and care services focused on communities rather than hospitals, that vision is very far from being achieved.”

This is highlighted in Hospital Episode Statistics for Epilepsy...

HES data for epilepsy in 2009-10 show that:

- Most (84 per cent) of hospital admissions for epilepsy are emergency admissions, rather than from waiting lists.

The average time that patients remained in hospital was 3.8 days.

- The majority of patients admitted to hospital for epilepsy (73 per cent) don't undergo procedures.

The importance to patients and the value to the NHS of reducing the number of emergency admissions has been highlighted in evidence from Dr Dougall McCorry, Consultant Neurologist and clinical lead for epilepsy at the University Hospital Birmingham:

'It's been estimated that preventing just 15-20 admissions to hospital would save the salary of an epilepsy nurse'.

HOPE has obtained substantial funding from a grant-giving trust, one of whose family members is disabled and has epilepsy. The trust is particularly keen on the HOPE objective of helping people with epilepsy to be fulfilled to the greatest extent possible.

To gather evidence for this plan HOPE has been communicating with everyone who has been provided with a pillow from HOPE:

We would like to remind everyone that we are engaged in a research project with Professor Rohit Shankar MBE, FRCPsych, about the advantages of anti-suffocation pillows for children experiencing nocturnal convulsive seizures. Professor Shankar is a world leading authority on Sudden Unexpected Death in Epilepsy (SUDEP). To learn more about Professor Shankar's background, please click the link.

<https://www.plymouth.ac.uk/staff/rohit-shankar>

We would urge you to participate in our brief questionnaire as this research could assist us in securing funding to continue to buy pillows for children in need, as well as establish the necessity for anti-suffocation pillows to be available through the NHS.

All responses will be treated confidentially. To share your input and support our research, please click the following link:

<https://forms.gle/17kjt6BdAQpoMJ3x7>

***We are very grateful to those who have already taken the time to participate
Sent from my iPhone***

Limitations to evidence gathering

However - at the same time as this evidence gathering commenced, an Excel 'heat map' of pillows supplied revealed that these clustered in a relatively small number of areas, corresponding to about 25 – 30 NHS hospitals.

This indicated that HOPE was providing only a relatively small number of free anti-suffocation pillows to patients in response to leaflets given by epilepsy nurses.

There may be several reasons why some nurses do not 'engage' with this initiative:

1. Providing the leaflets may be seen as 'recommending' or 'endorsing'.
2. The pillows have not undergone an RCT to establish their effectiveness
3. Nurses are uncomfortable about providing information which highlights the downsides/danger of the diagnosis.

Resolving these limitations and managing 'Topic Avoidance' and 'Moral Distress'

1. It's not a 'profit' product in terms of dividends or income, all revenue generated is used for more pillow materials and literature.
(I pay higher rate tax on my pensions and certainly don't need money from Sleep-Safe!).

This keeps the price low **but** it means there's no money for research.

2. See the Non-RCT Evidence of Effectiveness link on this page
3. Nurses apprehension about discussing the risks of epilepsy - 'Topic Avoidance' - it isn't a 'blame' issue –simply a 'recognition of fact' see the links at on this page <https://www.sleep-safe.co.uk/refsesn/>

BUT – it can result in nurses own personal and ethical conflicts about not acting with integrity – causing them 'Moral Distress'.

I spotted this concept of 'Topic Avoidance' when reading a post on the King's Fund health and social care website, **and I can acknowledge its existence from my own professional experience** and empathise with anyone else who has experienced it.

For example, one of the problems pharmacists face is dealing with patients' reactions to the information supplied with their medicines. The format of Patient Information Leaflets is relentlessly factual and tends to convey risk information in a way that often provokes feelings of fear and anxiety which can significantly impede the ability to make an informed decision about the prescribed medication.

I found that an effective way of handling this difficult situation was to direct them to a patient group of people with whom they shared the same diagnosis, because the help and advice provided would be based on day-to-day lived experience.

- Which is exactly what my wife Chris and I did following our son's diagnosis.

National organisations such as Epilepsy Action, the Epilepsy Society are excellent in their fields of research and advocacy but best for helping in the day-to-day management of the condition when they provide local contact between people with epilepsy and parents of children with epilepsy.

So my experience- based advice to epilepsy nurses who may find it difficult to give information which relates to epilepsy risk is to:

- Point parents and people with epilepsy towards other parents and people with epilepsy, where they can get help, advice and most importantly, *reassurance*, based on 'lived experience'.

HOPE help and support... for parents, children *and for epilepsy nurses*

HOPE provides all of this *in abundance*, and the HOPE website link and QR code printed on each of the leaflets links through to a wide range of help and support: HOPE, Parent-to-Parent support, Family Support sessions, Family Day Trips, the HOPE Anti-Suffocation Pillow Project and Ongoing Support and Information

The HOPE Team is made up of parents of children affected by epilepsy and epilepsy professionals including medical professionals from Great Ormond Street Hospital, University College London Institute of Child Health, St George's Hospital London, Cambridge University Paediatric Society, genomics expertise via Genomics England and Young Epilepsy. There is a fantastic team including an educational professional who are there to advise or simply listen to parents who are in need to speak to someone who understands. They offer ongoing support to families through monthly support sessions, website, social media, email and phone calls.

Current development path for Sleep-Safe pillows

The integration of wearable technology, molecular monitoring by continuous smart sensing of electrical conductance and biochemicals in skin secretions.

BUT – keeping the price as low as possible to ensure greater availability means that there is no money for research.

This can be achieved by 'Technology sharing' – 'smart patch' developers can use the pillows as a source of measurable biochemical entities.