

KAREN OSLAND

DEPUTY CHIEF EXECUTIVE

**SUDEP Action
National Conference 2016
Welcome**

SUDEP Action 
Making every epilepsy death count

STEPHEN BROWN

CHAIR

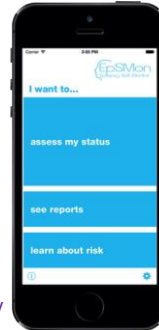
Setting the Scene


SUDEP Action 
Making every epilepsy death count



**Epilepsy Foundation SUDEP Institute
Announces Winner for Second Challenge:
“EpSMon” Mobile App - Preventing
Epilepsy Seizures**

The SUDEP Institute challenged participants to come up with ideas for a method of intervention to reduce the risk of seizures, especially convulsive seizures, with the purpose of preventing SUDEP. Over 300 participants registered for the challenge, and they submitted 83 solutions from 25 countries.



SUDEP Action 
Making every epilepsy death count

JANE HANNA

CHIEF EXECUTIVE

**Preventing Epilepsy Deaths –
The Power of Communities**

SUDEP Action 
Making every epilepsy death count

The Epilepsy Bereaved Community

- Your struggles, your journey
- The journey of our staff and trustees
- The values that bind us

SUDEP Action 
Making every epilepsy death count

Our Values

Determination:

The adversity our community suffers creates passion which drives our work and keeps those that have died at the heart of what we do

Respect:

That people should be treated how they would want to be treated or their family treated in life and after death.

Collaboration:

Working with individuals and partners that share our aims and our values to avoid waste and maximise effort

SUDEP Action 
Making every epilepsy death count

The Epilepsy Deaths Register



SUDEP Action 
Making every epilepsy death count

Deaths reported to our community through the EDR

- 379 reports from UK (Over 500 international)
- Mean Age of death is 28 years
- 45 deaths reported < 18

SUDEP Action 
Making every epilepsy death count

Emerging themes before death

- Risk not communicated
- Concerns about services

SUDEP Action 
Making every epilepsy death count

The problem: There is no UK wide NHS Plan to reduce the epilepsy burden

600,000 people in UK
1200 deaths/year



All causes of deaths before the age of 70

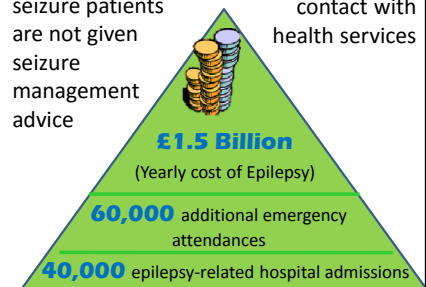


42% of deaths can potentially be prevented


Impact on the NHS

73% of first-seizure patients are not given seizure management advice

63% with no contact with health services



National Audit of Seizure management in Hospitals (NASH) – 2012 & 2015

SUDEP Action 
Making every epilepsy death count

- Most deaths at home
- Majority with SUDEP on death certificate
- Needs after a death as complex
- Satisfaction with SUDEP Action specialist services after a death

SUDEP Action 
Making every epilepsy death count


Impact

“The physical pain and guilt are overwhelming, and we are only just becoming able to talk about him to each other after 16 months has passed. The impact is total and devastating, and has affected both the physical and mental health of the whole family”

SUDEP Action 
Making every epilepsy death count

Hurdles ?



SUDEP Action 
Making every epilepsy death count

How long does it take to change these things?

- Talking about epilepsy deaths a total taboo
- SUDEP not recognised at all
- No understanding of cause
- No understanding of risk
- Epilepsy Bereaved community did not exist
- Ways of connecting did not exist
- Nothing happening

SUDEP Action 
Making every epilepsy death count

Support for our Community

- Listening, support and generic counselling
- Supporting your journey with services and tools that you say you want:
 - Helping you with your questions
 - Information
 - Conference and Coffee Clubs
 - Communications
 - Memorial Service

SUDEP Action 
Making every epilepsy death count


The nature of our community

Our Community has borne the impact of the taboo on epilepsy mortality. Most of us were carers of people with epilepsy and continue to bear a burden from this time. Many of us continue to struggle against ignorance and lack of concern.

SUDEP Action 
Making every epilepsy death count

What empowers us

- A determined united Community
- Doctors and Nurses working alongside us
- Extensive local, national and global network
- Knowledge
- Funding
- Tools

SUDEP Action 
Making every epilepsy death count

SUDEP and Seizure Safety CheckList For over 16s – childrens' version coming next



SUDEP Action 
Making every epilepsy death count

Background: EpSMon developed over 5 years of work including:

Extraction of risk factors from scientific evidence of over 300 peer reviewed papers

Tested as a SUDEP Safety Checklist in clinical and deceased populations of epilepsy patients in Cornwall

GP Practice finding 117 patients flagged up risks not known by GPs

Safety checklist applied to 350 + PWE 98% well received

Communication of person centred recorded risk 80% + vs. 10% in 2010, 36% UK

0 SUDEP in LD service. 7 in mainstream vs. expected 25-30 for the population (Coroner & Public Health)

UK-wide Professionals include

Professor Mathew Walker – Consultant Neurologist National Institute of Neurology & Neurosurgery

Mrs. Caryn Jory – Epilepsy specialist nurse

Dr Tamsyn Anderson – GP - Kernow Clinical Commissioning Group Medical Director

Dr Elizabeth Emma Carlyon - HM Coroner for Cornwall

Professor Henry Smithson – GP (epilepsy & medication adherence)

Professor Leone Ridsdale – GP (epilepsy mortality and primary care)

Dr John Paul Leach – President International League Against Epilepsy (ILAE)

Professor Phil Smith - President Association of British Neurologists (ABN)

Mrs Juliet Ashton – Sapphire nurse: National Epilepsy Commissioning

SUDEP Action



SUDEP and Seizure Safety Checklist

E3		dd/mm/yyyy				
A	B	C	D	E	F	G
17	RELATED RISKS					
12	Lack of surveillance at night	What happens if you have a night time seizure?	Nocturnal supervision found to be protective in SUDEP study (18) Lack of supervision frequently noted when SUDEP occurred in Epilepsy Monitoring Units (29) SUDEP is frequently unwitnessed (30)			
13	Prone position	No question to patient advised unless considered appropriate	Systematic review highlights significant association between SUDEP and prone position (31)			
14	Injuries or use of emergency services	Have you had any injuries or ED/999 emergency service calls?	Injuries have been identified as a risk factor for mortality (12)			
15	Medicines non-adherence issues	Do you have any difficulties taking your medication as prescribed? e.g. at times forgetting to pick up a prescription; the taste of the medication is bad; at times questioning the benefits of the medication or feeling that they need more information or support to take the epilepsy medication.	Non-adherence with AED associated with a 3 fold increase in mortality (33) Not collecting scripts for 91-132 days carried a higher mortality risk (12) Patients seizure free with AEDs showed no excess mortality (32) AEDs at efficacious doses may reduce SUDEP (34) AEDs at non-therapeutic levels showed greater variability in SUDEP cases (35)			
16	Frequent AED prescribing changes	Refer to patient notes	Frequent changes of AED dosage compared with unchanged dosage found to be a risk factor for SUDEP (13, 35)			
17	Depression or other psychiatric disorder	Have you experienced any feelings of depression, periods of low mood, or extreme sadness? Physician to note any psychiatric history.	Increased mortality associated with psychiatric comorbidity (8, 12, 36)			
18	Abusing alcohol	Do you find yourself needing alcohol daily or binge drinking?	Alcohol misuse associated with increased mortality (12, 36)			
19	Taking substances of abuse	Do you use any recreational drugs?	Substance misuse associated with increased mortality (36)			

SUDEP Action 
Making every epilepsy death count

For people living with epilepsy : EpSMon risk assessment app

Accessible to anyone
with a mobile phone

Free

Encourages engagement
with health services

Seizure & risk
management advice
at the finger tips of
patients



SUDEP Action 
Making every epilepsy death count

Where are we now?

Finalists for HSI awards in 2 categories 'Patient Safety' & 'Using Technology to improve outcomes'

ILAE UK 2015 –1st prize for poster presentation

Both Checklist & EpSMon part of the national Epilepsy Commissioning

Regional TV and Radio (36), Newspapers (26); Guardian and ITV news; social media campaign supported by 43 organisations

Android launch
countdown

14th March



How can you help?

408 people downloading in last 30 days !
Can you tell people about EpSMon?

Answer these questions about the last 3 months...

EPILEPSY

Have you experienced increased seizure frequency?

Yes No

Have you experienced a Generalised Seizure or Generalised Tonic-Clonic Seizure? (i.e. loss of consciousness during a convulsion, sometimes called 'grand-mal')?

Yes No

Have you experienced a seizure during sleep?

Yes No



SUDEP Action 
Making every epilepsy death count

Our E-learning Tool – Coming April


For all GPs who are members of the RCGP



SUDEP Action 
Making every epilepsy death count

World interest in our work

- **Partners Against Mortality Epilepsy**
JUNE 23 - 26, 2016 | WASHINGTON, D.C.
- **Centre for SUDEP Research (CSR).** UK partner for involving bereaved families
- **World Epilepsy Congress Sept 2017 –**
EpSMon Self-Monitor in first session on technologies to enhance safety

SUDEP Action 
Making every epilepsy death count

2016 -the Race hots up



Making every epilepsy death count

The Future - Electronic Devices to Help Prevent Epilepsy Deaths?



SUDEP Action 

Making every epilepsy death count

What anyone can do to help

- Get the media to cover our news and learn about our Community!
- Share your story with us so we can help the world to understand our Community
- Campaign through us so our Community is heard
- Helping other initiatives to connect with us

SUDEP Action 
Making every epilepsy death count

Connection



SUDEP Action 
Making every epilepsy death count

Sharing your story

Making every epilepsy death count

Call us now on 01235 772850

[Home](#) [Information](#) [Get involved](#) [Someone has died](#) [Epilepsy Deaths Register](#) [Research & Education](#) [About us](#) [News](#)

Someone has died

You are here: [Home](#) > [Someone has died](#) > [I want to meet others](#) > [My Story](#)

Epilepsy Deaths

How we can help

Support

Supported involvement

Counselling

I'm worried about the investigation

I've so many questions

I'm struggling

Different types of grief

I'm moving forward

I want to meet others

My Story

Forum

My Story



My Story - is an important and powerful way for you to join our campaign. As 'the voice of the bereaved' for over 20 years, we use information shared with us to good purpose. We are very experienced in supporting those who wish to share their stories and who find it helpful to know that they are part of the 'voice.'

The stories are those of people who have died from epilepsy, whatever the cause. With permission we share these stories where they will have most impact in highlighting epilepsy mortality.

Latest news

more

SUDEP Action's epilepsy self-monitoring app wins prestigious international prize - 9th Mar 2016

SUDEP Action celebrates international challenge win - bringing EpSMon to America to help reduce epilepsy risks and tackle sudden deaths - 7th Mar 2016

People with neurological conditions must be prioritised - 26th Feb 2016

Features

more

Andy Browne walks 120 miles for his grandson Charlie Burns - 4th Feb 2016

Family honours Ravin Dattani's memory through Big Fun Run and Tough Mudder events - 4th Feb 2016

Charlie's Sunflower Ball - 4th Feb 2016

SUDEP Action

Making every epilepsy death count

Nikey aged 23



Nik started having seizures two days before her seventh birthday. For eight years she went through read story

Emily aged 22



Our younger daughter Emily was beautiful, joyful and very very much loved. And now she is dead read story

Eve aged 21



Karen aged 36



Telephone counselling



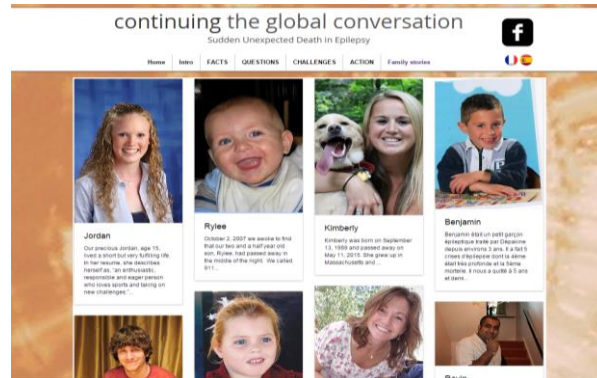
SUDEP Action

Making every epilepsy death count

15

Our community: sharing their stories across the world

www.sudepglobalconversation.com



SUDEP Action 

Making every epilepsy death count

SUDEP-the Global Conversation: provides short summaries of key SUDEP research

www.sudepglobalconversation.com



SUDEP Action 

Making every epilepsy death count

SUDEP Awareness Day: 23rd October



Home What is SUDEP? About Get involved - Downloads Register Press

Are you SUDEP Savvy?

In it's third year!



Home

Welcome to SUDEP Awareness Day, an annual event aimed at raising awareness of Sudden Unexpected Death in Epilepsy. This day is the brainchild of SUDEP Action and is part of our Call for Openness Campaign that has attracted global support. This year we have some great materials put together working with organisations from USA, Europe and Australia and with our partners on SUDEP –the Global Conversation. [Click here](#) to find out which organisations near to you are supporting the Day.

www.sudepawarenessday.org

SUDEP Action SUDEP.ORG

SUDEP Awareness Day – 23rd October

Over 130 Supporting organisations worldwide!



SUDEP Action
Making every epilepsy death count

Supported Involvement in the cause of the Community

- Listening to you to give us direction
- Epilepsy Deaths Register
- Helping you share your story – we know grief can be triggered at any time
- Looking out for your interests as world interest increases demands on families after a death
- Our community fundraising offers you a supportive context – we know that grief can be triggered at any time

SUDEP Action 

Making every epilepsy death count

Help us develop the way forward ?

- How we spend our funds
- Understanding your struggles – Jumping the hurdles workshop
- How we strengthen our Community
- Charter of the Bereaved – who we are/what we want
- UK meeting with organisations supporting

SUDEP Action 

Making every epilepsy death count

What can you do ?

- SUDEP Action receive no statutory funding
- Total funds carried forward to do our work £279, 725.84
- A reserve of about 6 months from general funds
- £123,500 held for WADD - £41,000 still needed

SUDEP Action 
Making every epilepsy death count

What we want to do

Safety first: Reducing exposure to known risk

- 2016 update and promotion of Safety Tools (SUDEP & Seizure Safety Checklist & EpSMon)
- Children's /Carer/Learning Disability
- Support other sites working with us on the Tools - UCL, Oxford, Norfolk, Johns Hopkins

Future: Research on risks and Responding to life-threatening crisis:

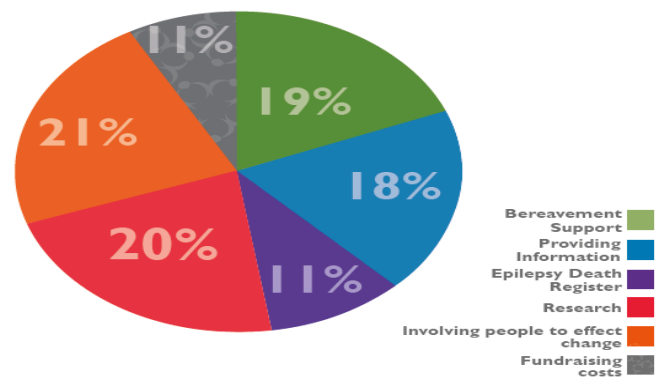
- Trial on WADD/ Wearables with EpSMon

SUDEP Action 
Making every epilepsy death count

How much do we spend on all this?

In 2015, we received an income of just over £377,000.

What we spent was divided up as follows:



SUDEP Action 
Making every epilepsy death count