

Prevent21 Summit on Tackling Epilepsy Deaths: Consensus Recommendations Summary

Who are SUDEP Action?

SUDEP Action are the only UK Charity specialised in supporting and involving those bereaved by epilepsy. They are dedicated to raising awareness of epilepsy risks and tackling epilepsy-related deaths, including those from Sudden Unexpected Death in Epilepsy (SUDEP).

Founded in 1995, over 50% of SUDEP Action's Trustee Board and Staff Team (7 FTE) have direct family experience of the impact of epilepsy-related deaths, Sudden Unexpected Death in Epilepsy (SUDEP) or Sudden Death. The Charity has a proven track record of changing guidance and practice at global, national and local levels, helping over 11,000 people last year.

Leader of PREVENT21 movement to tackle epilepsy-related deaths and lever potentially life-saving improvements to epilepsy services on the ground. They provide innovating solutions and services to meet gaps in provision; achieving this through collaborating with research, clinical and policy champions, and through using digital tools to support relationships between health professionals and patients. They also provide a unique and responsive care pathway to support families bereaved by epilepsy, supporting them through the aftermath of an epilepsy death.

Epilepsy Deaths – An overview

There are at least **21 epilepsy-related deaths a week** (9x riskier than asthma). Sudden Unexpected Death in Epilepsy (SUDEP) accounts for about 50% and other causes are accidents, suicide and prolonged convulsive seizures (Status Epilepticus).

Epilepsy is in **top ten of all causes of mortality** as many years of life are lost, with deaths occurring in children & the young.

3% increase in people living and dying with epilepsy per annum. Death **varies 3-fold with deprivation** (high prevalence and poor control means more deaths) - *Public Health England: Deaths from Neurological Conditions Report, 2018.*

At least 42% of all epilepsy-related deaths avoidable. Epilepsy risk are often underestimated in decision-making between patients and health professionals, despite evidence that many can be reduced. There is wide variation in disclosing these potentially fatal risks to patients, with UK discussion rates varied from 4% - 80%. **Epilepsy has no regular monitoring** in contrast with asthma.

UK has 60,000 A&E attendances and 40,000 admissions due to epilepsy per year. Poor care was demonstrated by National Audit with 63% not seen in previous 12 months and 56% with no follow up.

The cost of epilepsy in the UK >£1Billion/year, yet epilepsy is not yet included in the NHS 10-year plan; neither was it prioritised in the 5 Year Forward plan.

National research grant giving bodies in the UK have a poor track record on funding relevant research looking at how change can be implemented to tackle epilepsy deaths now.

Report and outcomes

This report is the executive summary of the outcomes of the 2-day Prevent21 Summit conducted on the 2/3rd November 2018 by SUDEP Action at Corpus Christi College, Oxford. It has been endorsed by the All Party Parliamentary Group for Epilepsy (APPGE) and the Neurological Alliance:



71 delegates with expertise in epilepsy (clinical, advocacy & patient representatives), neurology, bereavement, health services, policy making, and the justice system attended the event; **representing 43 different organisations**.

The participants developed **7 recommendations as outcomes** and the commitment to implement these in order to further benefit people living with epilepsy, their families, clinicians and those who have lost a loved one to epilepsy.

During the run up to the Prevent21 Summit we asked delegates to join an on-line discussion. This interactive discussion focused on three topics:

- 1) **Recommendations on what is important to prevent future epilepsy-related deaths & support those bereaved by epilepsy (gathered from the bereaved community)**
- 2) **What can be done to tackle epilepsy deaths (what topics should we focus on at the conference)**
- 3) **What gets in our way (in tackling epilepsy deaths)**

The first topic received overwhelming support and we could therefore start the Summit by agreeing a mandate to adopt these four recommendations across the community (see page 2 for details of these Bereaved Family Recommendations).

The discussion in the on-line forum raised significant gaps in the processes and procedures surrounding care and services both before and after an epilepsy-death; in particular the lack of discussion about risks to people with epilepsy, and the communication both with the families and their clinicians in the aftermath of an epilepsy-related death.

NOTE: *At the conference speakers and representatives in attendance living with Epilepsy gave overwhelming support to the recommendation that the patients and their families were informed fully about the complete range of epilepsy risks associated with epilepsy deaths including information on SUDEP (Sudden **U**nexpected **D**eath in **E**Pilepsy).*

Other topics from the pre-work, included:

- Management of Epilepsy and its associated risks, inc SUDEP
- Learning lessons from Epilepsy-related deaths (inc SUDEP)
- Changing the behaviour of clinicians (incl. guidelines and best practice)
- Making the most of the research conducted and data being collected
- Collaboration between groups who support people with epilepsy in managing their condition; including epilepsy organisations, clinicians, specialist local teams, researchers and Government

This report outlines the 7 recommendations agreed at the Summit and is preceded by the Bereaved Family Recommendations.

The presentations and outcomes from the event will be documented in a special supplement in the journal *Epilepsy and Behaviour*; thank you to the journal for their support of the Prevent21 Summit.

The Bereaved family recommendations

These were approved by Summit Delegates at the start of the event and used to influence and focus discussions, as well as ensure the whole community kept People with Epilepsy and SUDEP in the forefront of their minds.

Families bereaved by epilepsy have outlined the following recommendations as being important to the Bereaved Community:

1. Timely signposting of bereaved families to specialist support services and the Epilepsy Deaths Register after a death
2. The roll out of tools that accelerate putting guidelines into practice on conversations about risk
3. Increased research funding being made available and prioritised to support projects on epilepsy deaths and the implementation of interventions to support clinicians and people with epilepsy, & avoid future deaths
4. Neurological Conditions (specifically highlighting Epilepsy and Epilepsy deaths) to be included in the upcoming NHS 10-year plan

Findings from the Epilepsy Deaths Register research registrations, consulted on by bereaved families at the SUDEP Action National Conference 2018

Key recommendations

The following seven recommendations are the outcomes of the Prevent21 Summit. The delegates discussed and debated the issues through four panel discussions (Friday 2 Nov) during which they were given the opportunity to discuss, capture and reflect on their perspectives. The captured information was used to fuel a collaboration workshop on Saturday 3rd Nov which led to the emergence of the 7 recommendations.

The steps taken to develop these recommendations and the prioritisation results can be seen through MeetingSphere (collaboration technology used in the Summit Pre-work and conference itself) at:

<https://tinyurl.com/sudep1>

The recommendations are listed below in priority order. Participants were asked to prioritise their ‘IMPACT’ – (the positive benefit this recommendation would have on for example care, services, clinicians, people with epilepsy & bereaved families) and ‘EASE’ (the degree of difficulty in delivering this recommendation).

**Note: ‘Collaborating organisations’ refers to organisations who sign up to these key recommendations & wish to collaborate with SUDEP Action to tackle epilepsy deaths in future.*

1	VOLUNTARY SECTOR COLLABORATION ON EPILEPSY-RELATED DEATHS	<p>SUDEP Action will lead on collaboration between epilepsy charities to tackle pathways and spread good practice that will avoid future epilepsy-related deaths; safeguarding bereaved families & people of all ages with epilepsy, and their families.</p> <p>Using existing data, technology and resources at national and local levels, to drive innovation, improve access to services and influence practice to avoid deaths. Helping to provide a lever to improve quality of life for those living with the condition.</p>
2	ADVOCACY ON EPILEPSY-RELATED DEATHS	<p>SUDEP Action will bring collaborating organisations* together and as part of this collaboration’s policy work, will lead on a standing item to the All Party Parliamentary Group for Epilepsy (APPGE) on Epilepsy-related deaths.</p> <p>On behalf of the collaboration, they will feed information on epilepsy-related deaths into policy work, working with organisations in England, Scotland, Wales & Ireland to have a broad and inclusive movement.</p>

3	<p>COMMUNICATING, REVIEWING & MANAGING EPILEPSY RISKS</p>	<p>The Community supporting people with epilepsy will ensure an epilepsy review is undertaken at least annually, with the SUDEP & Seizure Safety Checklist informing this practice. This will:</p> <ol style="list-style-type: none"> 1. help communicate information in a person centred and holistic manner 2. be done with all people with epilepsy to provide advice of changes needed to reduce risks 3. support future working and risk communication across clinical settings, enabling effective risk flagging and patient referral to appropriate services.
4	<p>ADOPTION OF BEREAVED FAMILY RECOMMENDATIONS ACROSS THE EPILEPSY COMMUNITY</p>	<p>The Epilepsy Community support the development and implementation of:</p> <ol style="list-style-type: none"> 1. a national protocol to standardise the reporting of all epilepsy deaths. 2. an educational training programme based around existing safety tools and SUDEP Action e-learning materials on risk. 3. a consistent bereavement pathway, supported by best practice guidelines after an epilepsy-related death.
5	<p>SUPPORTING CLINICIANS TO CHANGE BEHAVIOURS</p>	<p>The Epilepsy Community will work together to:</p> <ol style="list-style-type: none"> 1. highlight the inequality of epilepsy service provision both geographically & in comparison to other long-term conditions. 2. lobby Government & Policy-makers across the UK to: <ol style="list-style-type: none"> a. promote Epilepsy best practice regarding tackling epilepsy deaths via available channels (eg: via Local transformation hubs, e-learning & membership organisations) b. support clinicians to review patients (including risk/SUDEP) at least annually; identifying potential to embed an alert for GP/epilepsy specialist when review is required. c. identify systems & process which alert clinicians when a patient dies from their epilepsy, so lessons can be learnt, and bereaved families can be supported.
6	<p>CONSISTENCY OF ACCESS TO SERVICES, AND MANAGING PEOPLE WITH EPILEPSY IN DEPRIVATION</p>	<p>The Epilepsy Community will work towards:</p> <ol style="list-style-type: none"> 1. ensuring community outreach and into A&E services so people not traditionally engaged in epilepsy services are also managed & supported, especially regarding risk reduction eg: <p>Those in the prison system; living in remote areas; who need professional interpreters; with comorbidities such as mental health conditions; who don't attend appointments, and those in transition (children to adult services).</p> 2. flagging and referring urgently those living with epilepsy who are potentially vulnerable & requiring additional support to manage their condition eg: training, medications advice & support with risk reduction strategies.
7	<p>MAKING MORE OF RESEARCH DATA</p>	<p>The Epilepsy Community will strive to integrate a nationwide system for capturing epilepsy and comorbidity data (this is a long-term goal).</p> <p>In the meantime, it will strive to:</p> <ol style="list-style-type: none"> 1. embed new NICE/SIGN guidance & Quality Standards so that an epilepsy death without prior documented safety checklist/discussion should not happen 2. re-establish an epilepsy Quality Outcome Framework (QoF) in General Practice (or equivalent review process) and ensure it includes a risk checklist (see recommendation 3) 3. support non-specialist clinicians with robust practical e-learning tools 4. raise the profile of SUDEP/Epilepsy deaths research with grant giving bodies; ensuring this is recognised as priority by encouraging themed calls (eg: to support 'on the ground', innovative or clinic-based research) and collaboration with other funders.

Please note the following activities are open for viewing (we welcome any additional comments; please feed in via SUDEP Action).

- 1) **Forum Discussion:** The Summit pre-work contributions in their original form with summaries of the comments by the Summit facilitators
- 2) **Panel Session discussions:** Showing delegates engagement with & discussion about each speaker presentation
- 3) **Collaboration Workshops – Key Recommendations:** The 3rd Nov Summit session that converged into the 7 recommendations
- 4) **Prioritisation Results:** The recommendations ranked by 'Positive Impact' and 'Ease of Implementation' by delegates (full results including scoring)
- 5) **Outcomes in Priority order:** A list of the original text from the recommendations (as above minus scoring)

A full report (Word document) version of the Summit is available on request.

Thank you to all those who contributed and engaged with us during the Prevent21 Summit on Tackling Epilepsy Deaths. The event demonstrated it is 'Time to Listen' and that through working together as a community, there is much we can do and achieve to prevent many of the future epilepsy-deaths happening across the UK.

Jane Hanna OBE (SUDEP Action Chief Executive)

Sammy Ashby (SUDEP Action Deputy Chief Executive)

Steve Bather (Realise Group, Prevent21 Summit Facilitator)

Appendices

Appendix 1: Outline of event process

During October this year in preparation for the PREVENT21 Summit Steve Bather of Realise (Europe) Ltd was engaged to help design and facilitate the Summit. There were two main elements to this support:

- 1) An on-line discussion forum conducted for 6 weeks prior to the Summit on the 2 and 3rd of November 2018. This forum invited participants to actively participate in an on-line discussion of the key topics in advance of the Summit. There were 184 logins to the on-line Forum, run in MeetingSphere.com; an online and face to face collaboration technology that allows participants to contribute ideas, questions and comments on the posed topics. During this pre-Summit process the participants contributed to three topics:
 - a. Their responses to the Recommendations posed by the Bereaved Community Recommendations
 - b. Insight into ‘What can be done?’ (to tackle Epilepsy deaths in the immediate and long term
 - c. What barriers and challenges organisations face in tackling Epilepsy deaths.
- 2) Facilitation and collaboration technology support for the 2-day Summit, where the 50+ participants responded and commented on presentations from all of the main contributors to the Summit and a workshop to converge on a clear set of recommendations for how to organise the shared objectives and strategies to alleviate the management of PWE and in particular SUDEP.

Prior to the Summit the main conclusions and outcomes of the pre-summit forum were summarised and presented to the Summit. These conclusions were included in the workshop during the Summit to converge on the outcomes and recommendations reported here.

The key features of the collaboration technology (MeetingSphere.com) allowed participants capture, simultaneously and anonymously, their perspectives and contributions to ensure the final recommendations were agreed by and bought in to by the participants.

The collaboration process and outcomes captured during the Summit can be viewed using this web link:

<http://tinyurl.com/sudep1>

The process included:

- 1) the full transcript of the pre-summit contributions and summary statements by the facilitator.
- 2) the captured comments and questions from the Panel discussion (all 4) with answers contributed by the presenters during and after their panel sessions.
- 3) The full contributions from the Collaboration Workshop held on the Saturday morning using a World Café approach to discussing and concluding recommendations from the table discussion
- 4) The prioritisation of the recommendations (7 in total) to show what participants thought were ‘most impactful’ and ‘easiest to deliver’. The recommendations appear in the priority order based on the sum of the means scores of the rating results.

The process for conducting the Summit received very positive feedback, in particular, it was seen as a productive way of ensuring the discussion was wide ranging, inclusive and not dominated by the few. Ensuring the documentation of each stage of the process ensures that the decisions/recommendations that emerged are audited and reflect the views of the participants.

More information on the Summit process is available from Steve Bather (stevebather@realisegroup.com 07885175396)

www.realisegroup.com

realise

Appendix 2 – Delegate List*

Anissa Tonberg	Epilepsy Scotland	Kim Morley	Epilepsy Specialist Nurse/Midwife Practitioner, Hampshire Hospitals NHS Foundation Trust
Alex Stirling	Trustee, SUDEP Action	Linda Magistris	Chief Executive, Good Grief Trust
Caoimhe Twohig-Bennett	Research Manager, ERUK	Lindsay Hill	Chief Executive Officer, The Meath
Carol Long	Chief Executive, Young Epilepsy	Lucy Atkinson	Senior Policy Adviser, Ministry of Justice
Chris James	Senior Parliamentary Assistant, House of Commons	Matthew Chapman FCA	Chairman, Wantage & District Chamber of Commerce
Dr Arjune Sen	Consultant Neurologist, The John Radcliffe Hospital	Maxine Smeaton	Chief Executive, ERUK
Dr Brendan McLean	Consultant Neurologist, Royal Cornwall Hospitals Trust	Nicola Swanborough	Publications Editor, Epilepsy Society
Dr Colin Dunkley	Consultant Paediatrician, Sherwood Forest Hospitals NHS Foundation Trust	Olivia Garvey	Pharmacist, Boots
Dr Craig Newman	Senior Research Fellow, University of Plymouth	Paul Marcham	Finance and Operations Manager, SUDEP Action
Dr Elaine Hughes	Paediatric Neurosciences Consultant, Kings College London	Paula Sherriff MP	Chair, All Party Parliamentary Group for Epilepsy (APPGE)
Dr Fergus Rugg-Gunn	Consultant Neurologist & Honorary Senior Lecturer, UCL Institute of Neurology	Peter Murphy	Chief Executive, Epilepsy Ireland
Dr Heather Angus-Leppan	Executive Director, ABN	Phil Lee	Chief Executive, Epilepsy Action
Dr John Craig	Consultant Neurologist, Belfast Health and Social Care Trust	Phil Tittensor	Epilepsy Specialist Nurse, Epilepsy Nurse Association (ESNA)
Dr John Paul Leach	Neurologist & Head of Undergraduate Medicine, Glasgow University	Professor Esther Rodriguez-Villegas	Chair of Low Power Electronics in the Department of Electrical and Electronic Engineering, Imperial College London
Dr Lina Nashef	Consultant Neurologist, Kings College London	Professor Hannah Cock	Professor of Epilepsy & Medical Education & Consultant Neurologist St George's, University of London
Dr Manny Bagary	Consultant Neuropsychiatrist, Birmingham and Solihull Mental Health NHS Foundation Trust	Professor Henry Smithson	Department of General Practice, University College Cork
Dr Owen Pickrell	Clinical Lecturer (WCAT), Swansea University Medical School	Professor Leone Ridsdale	Professor of Neurology and General Practice, Kings College London
Dr Rhys Thomas	Honorary Consultant in Epilepsy & Intermediate Clinical Fellow, Newcastle University	Professor Maria Thom	Honorary Consultant and Professor of Neuropathology, UCL Queen Square Institute of Neurology
Dr Rohit Shankar MBE	Clinical Director Cornwall Partnership NHS Trust Hon. & Associate Cl. Professor Exeter Medical School	Professor Mike Kerr	Trustee, SUDEP Action & Professor, Cardiff University
Dr Rosey Panelli	International Consultant, SUDEP Action	Professor Pauline Heslop	LeDeR Programme Manager, Bristol University
Dr Susan Duncan	Consultant Neurologist, Western General Hospital Edinburgh	Professor Phil Smith	Consultant Neurologist and Professor, Cardiff School of Medicine
Ed Vaizey MP	President, SUDEP Action	Rachel Shah	Trustee & Event Sponsor, SUDEP Action
Emily Handley-Cole	Premature Mortality Governance & Development Lead & London Regional Coordinator, NHS England	Rosemarie Pardington	Director of Integrated Care, Young Epilepsy
Ivan Lewis MP	Labour MP, Bury South	Rt Hon Norman Lamb MP	Liberal Democrat Party, House of Commons
Jackie Roberts	Senior Nurse, John Radcliffe Hospital	Sammy Ashby	Deputy Chief Executive, SUDEP Action
James Cusack	Deputy Chief Executive, Autistica	Sandra Smith	Maternity Transformation Programme & Early Adopter Programme Lead, NHS England
Jane Hanna OBE	Chief Executive, SUDEP Action	Sarah Harris	Executive Assistant, SUDEP Action
Dr Jean Knox	Retired GP – Patient Representative	Sarah Tittenson	Epilepsy Nurses Association & University Hospitals Birmingham NHS Trusts
Professor Jo Martin	President of the Royal College of Pathologists, Professor of Pathology & Director of Academic Health Sciences, Barts Health NHS Trust, Queen Mary University of London	Shelly Johnson	Communications Officer, SUDEP Action
John Hirst CBE	Trustee Chair & Chair of SUDEP Research Initiative, SUDEP Action	Simon Lees	Trustee, SUDEP Action; Patient Representative
Johnny Manson	SUDEP Action supporter - Event sponsor	Stephen Brown	Trustee, SUDEP Action
Julia Stirling	Case Worker, SUDEP Action	Steve Bather	Facilitator
Juliet Bransgrove	Adult Epilepsy Specialist Nurse, Dereham Hospital	Sulaiman Jalloh	University of Oxford
Juliet Solomon	Executive Director, ILAE British Branch	Torie Robinson	International Public Speaker & Consultant, Epilepsy Sparks; Patient Representative
Karen Osland	Epilepsy Deaths Register (EDR) Special Projects Lead, SUDEP Action	Tracy Cowdry	Bereavement Support Services Manager, SUDEP Action
Katie Vale	Community Services and Fundraising Coordinator, SUDEP Action	Vicky Masters-Read	Outreach Coordinator, SUDEP Action

*Please note above delegates registered their attendance at the Summit, though not all were in attendance during the event itself