

Lives Cut Short



A report on urgent measures to tackle deaths in epilepsy and support the bereaved during the COVID-19 pandemic

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SUDEP Action 
Making every epilepsy death count

For citation

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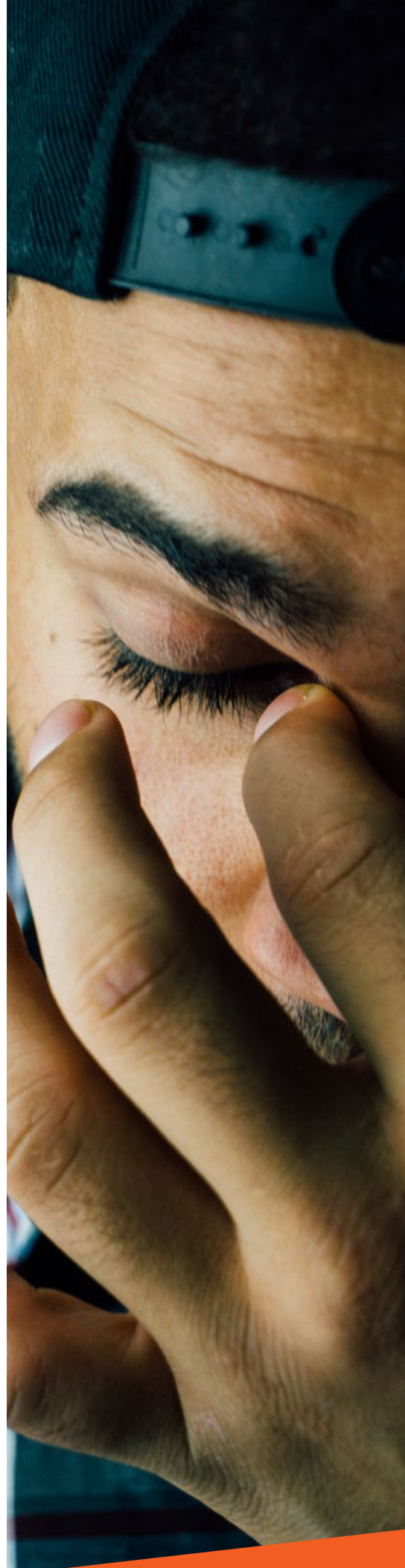
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OPENING STATEMENT

Over 600,000 people with epilepsy are living with greatly increased risk of death from the impact of COVID-19 on UK health care. An already stigmatised and discriminated population face dramatic challenges in access to health care, including essential medication, investigations and health contact. An exponential increase in social isolation, psychological and physical risk is building yet no response from the health service is in place. Years of lives lost, and lives ruined, await people with epilepsy and their families without the urgent actions proposed in this report.

SUDEP Action is the only organisation dedicated to tackling epilepsy deaths and specialised in supporting those bereaved by epilepsy. In May 2020, the charity [submitted evidence](#) to the Health and Social Care Select Committee predicting that deaths from Sudden Unexpected Death in Epilepsy (SUDEP) would be a leading cause of death in the 20 to 40 age group during the pandemic, due to societal and NHS and public service changes in the light of COVID-19 response¹. [SUDEP](#) is where a person with known epilepsy who is otherwise healthy, dies suddenly and no other cause of death is found. It is a major cause of epilepsy-related death which peaks in young adults, alongside suicide, accidents, and other causes where epilepsy plays a major contribution in premature mortality.

Public Health England had [reported](#), as recently as 2018, about rising deaths in people with epilepsy over a fourteen-year period (2001-2014), when deaths from all other conditions had fallen².

The report found of rising deaths in people with epilepsy, that most deaths were premature, and that people were three times more likely to die in deprived communities. Whilst the Government did not agree to multiple requests for a meeting to listen to bereaved families and experts, the report



Jane Hanna OBE
SUDEP Action CEO

did galvanise a strong movement of experts, policy makers and organisations behind SUDEP Action to tackle this urgent and preventable issue. [Evidence-based priorities](#) to inform planning to reduce epilepsy deaths were agreed³. Other official reports on deaths in mothers^{4 5} and deaths in people with learning disabilities^{6 7} have also made shocking findings.

For example, epilepsy was reported as the sixth most frequently recorded cause of death in people with learning disabilities and the second most frequently reported potentially treatable cause of death (2018-9).

Before COVID-19, epilepsy care and risk management were under-prioritised by national and local policy makers. In response, a research and innovation work programme was funded and supported by [SUDEP Action](#) (and collaborative partners), to contribute to remedying systematic failures, to prioritise and address epilepsy and epilepsy deaths. Despite the lack of system recognition, localised pockets of good practice regarding tackling epilepsy risks, were strengthening. By 2018, standardised risk communication and management tools (providing access to life-saving knowledge and empowering people to self-manage their condition) were shown to reduce risk in people with epilepsy, known to be previously at risk⁸. These initiatives, the award-winning clinical [SUDEP and Seizure Safety Checklist](#)⁹, and [EpSMon app](#)¹⁰ for people with epilepsy, were recognised as good practice to tackle deaths and improve care by NHS RightCare's Epilepsy Toolkit, published in 2020¹¹.

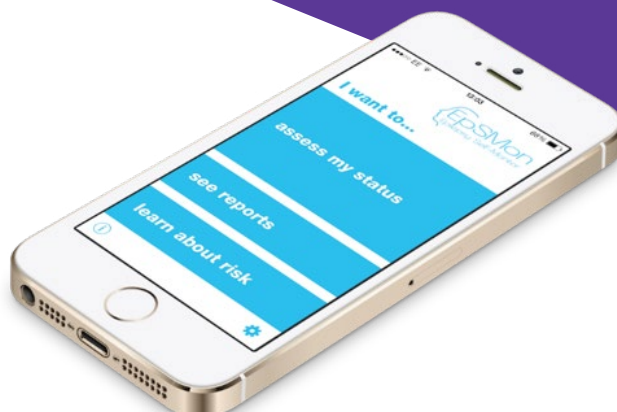


The Toolkit also recognised the importance of signposting to [SUDEP Action's free specialist bereavement services](#)¹² and of learning from epilepsy deaths through the [Epilepsy Deaths Register](#)¹³.

Due to the [NHS RightCare Epilepsy Toolkit](#), and the Optimum Epilepsy Pathway currently underway (led by NHS Specialised Commissioning)¹⁴, epilepsy mortality became more of a focus for prioritisation in the months before the COVID-19 pandemic, but has since been seriously delayed or put on hold. In August 2020, NHS England, in response to a letter from Ben Bradshaw MP, wrote that the planned promotion and implementation of the NHS RightCare Toolkit had been stopped because of the COVID-19 pandemic, giving no timescale for it to resume¹⁵.

The pandemic, particularly since the Government lockdown response in March 2020, has had a significant impact on the entire of the UK, particularly on the health system. Those with long term health conditions have faced change, disruption and uncertainty, to varying degrees depending on their condition and location. From early on, the epilepsy community has expressed concerns over the impact the pandemic is having on this vulnerable and at-risk population and on rising deaths.

Isolation is something many have struggled with, both in the epilepsy and epilepsy bereaved community, as well as the wider population. Living with epilepsy or epilepsy bereavement, however, adds extra complexity to this isolation, increasing risks, vulnerability and trauma.



The SUDEP Action Team have been supporting those bereaved suddenly by epilepsy throughout the pandemic; experiencing increasing demand on our services and an increasing complexity of caseload. For example, our specialist bereavement services team have supported families who have needed to challenge an epilepsy-related death being investigated only as a sudden cardiac death; families who have been waiting years for an inquest to happen, have had to face further delays; as well as helping recently bereaved families advocate for a Coroner to conduct a more thorough investigation or inquiry. This has necessitated a rapid COVID-19 statement for Coroners who are investigating epilepsy-related deaths¹⁶.

During the pandemic, the Chief Medical Officer spoke of different categories of harm, correctly warning of non-COVID-19 or 'indirect' deaths due to the pandemic and downscaling of health care¹⁷. It has already been reported that excess deaths from conditions, such as cancer, have increased.

There have been 30,260 excess deaths in private homes since March 2020 with 9 out of 10 deaths due to non-COVID-19 causes.

There is therefore grave concern that epilepsy is contributing to excess deaths in the young; deaths currently going unacknowledged by national policy makers and leaving families devastated across the country.



“

We know that progress in tackling epilepsy deaths is being set back decades with young people at greatest risk of dying suddenly. The lack of any current update by Government on excess mortality in people with epilepsy is deeply disturbing. The Government needs to listen to scientists and the families of those who have died more urgently than ever before if the Government does not wish to see more lives unnecessarily cut short.

SUDEP Action

”

The COVID-19 response during 2020 involved all countries transforming during an emergency and again during easing of restrictions. In the UK, a significant transformation was designed to ensure that the services in the UK were not overwhelmed¹⁸. A rapid review from National Voices between March-July 2020, found that across the UK many people experienced substantial harm and distress, in large numbers and across all groups and conditions, including long-term effects and ability to self-manage their conditions¹⁹.

Serious concerns across the epilepsy sector about the impact of this rapid transformation in epilepsy led to a united call from organisations led by Epilepsy Action for the resumption of vital epilepsy services²⁰. Inequalities of access to research funding for epilepsy pre-pandemic also threatens progress as a report from Epilepsy Research UK highlights that epilepsy receives only 0.3% of the £4.8 billion total spent on health-related research in the UK²¹.

Whilst the epilepsy third sector is having to respond on the ground to escalating epilepsy

risk and increased needs of the bereaved, the sector has not benefitted from funding support that has prioritised the third sector working directly on COVID-19. This reflects another inequality in the system which must be addressed by the Government²².

In March 2020, SUDEP Action moved swiftly to partner with Oxford University, Newcastle University and the Epilepsy Deaths Register to conduct research on the impact of COVID-19 on epilepsy and risk, and also its impact on those bereaved by epilepsy. This rapid review report highlights preliminary findings so that lessons can be learnt during the next phase of the COVID-19 response to improve the lives of those living with epilepsy and epilepsy bereavement during the pandemic, and so that urgent action can be taken to prevent young people disproportionately dying suddenly from epilepsy during the pandemic.

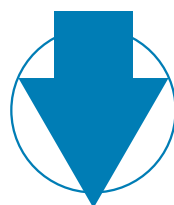
Jane Hanna OBE,
Chief Executive
SUDEP Action

KEY FINDINGS

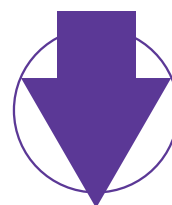
Fig 1. Epilepsy and Risk during the COVID-19 pandemic



**EXPOSURE
TO RISK**



**AWARENESS
OF RISK**



**WELLBEING
& ACCESS TO
HEALTHCARE**

While the surveys are available internationally, the information presented throughout this report focuses specifically on the UK data:

316

people with epilepsy

147

carers

60

healthcare workers

290

individuals bereaved
by epilepsy

People living with epilepsy and carers

The majority of 316 people with epilepsy (PWE) reporting to our research are experiencing an overall decline in health and wellbeing against the context of a rapidly changed healthcare and social care provision²³. This vulnerability is compounded by lack of access to tailored risk awareness and lack of engagement.

87% of people with epilepsy who reported changes to their health also reported their mental health had been challenged and worsened as a result of the pandemic, citing increased stress, worry, anxiety or depression – all things known to impact negatively on seizure control. 40% of people with epilepsy reported negative changes to their health during the pandemic; many reporting problems with access to services and support for medicines, all against a concerning picture of escalating risk and reduced risk monitoring.

Healthcare workers

Our provisional results with 60 Healthcare workers from across the UK reveal anxiety over the impact of redeployment, changes to how epilepsy services are able to run, and a dip in epilepsy

referrals. Given the expertise and personalised care required to help people with epilepsy effectively manage their condition and associated risks, clinicians are increasingly anxious about their patients.

Healthcare workers have reported they have, where possible, kept emergency contact processes in place to support existing patients. However, in some areas of the UK, these skeleton or non-existent epilepsy services **have left patients vulnerable to worsening seizures, increased risk and could have contributed to premature epilepsy deaths.**

Decreasing access to epilepsy (and other community health) services is a grave concern. **It suggests undiagnosed people with epilepsy may be either struggling to get onto the diagnosis pathway due to increased demand on GP/Primary care services or are not presenting to hospital despite either new or worsening seizures and epilepsy symptoms.** Data from The Epilepsy Deaths Register shows 10% of sudden epilepsy deaths reported were in those undiagnosed at the time of death, suggesting an urgent need for people with suspected epilepsy to have ready access and referral despite the pandemic²⁴.

Suddenly bereaved families

Our provisional results from 290 people with experience of traumatic bereavement, due to an epilepsy death, suggests that the COVID-19 pandemic and the societal response has had a disproportionately negative impact²⁵. 86% of those bereaved by epilepsy reported a negative impact on their mental health – 24% reporting this to be ‘major’ or ‘severe’. As a research population that has lived experience of false assurance about

risks in epilepsy, with family experience of worst outcomes, it is not surprising perhaps that many reported concerns for family members. This impact was consistent irrespective of the recency of their bereavement. As well as this, about 60% of those who found it difficult to ask for help before COVID-19 have found it more difficult during the pandemic to seek out help.

Urgent recommendations:

- 1 Official records of lives cut short during the COVID-19 pandemic of people with epilepsy must be counted and modelled with timely, accessible public data; so that lessons from the first phase of the COVID-19 response can be learnt swiftly and lives saved.
- 2 Government must commit to quickly implementing potentially life-saving epilepsy resources that already exist, including an annual epilepsy risk health check, to help local services prevent epilepsy deaths in their area, and to provide better support to bereaved families. Otherwise deaths in our young people will continue to rise. (*)
- 3 Epilepsy must be recognised as a high-risk condition – future COVID-19 planning must take this into account, so people with epilepsy are not put at excess additional risk of dying prematurely and avoidably. Epilepsy services should be protected, in particular doctors and nurses should not be re-deployed, to help keep people with epilepsy safe. Rapid access processes are needed for new or worsening seizures, and outreach to people who do not attend appointments.
- 4 Any change or delay of medication supply puts lives of people with epilepsy at risk. Any impact on epilepsy medications due to Brexit, COVID-19, or health planning, must be avoided to protect people with epilepsy – with changes only happening with patient consent and following a person-centred epilepsy risk discussion. (*)
- 5 The inequality of funding towards vital epilepsy research must be addressed. It must not be left to the charity sector to fund much of the research that improves and saves the lives of people with epilepsy. (*)
- 6 Policy makers, researchers, campaigners, and media, working with the suddenly bereaved, must recognise the trauma associated with epilepsy-related deaths. They must work sensitively to avoid unnecessary harm by consulting with SUDEP Action that is governed by and working alongside families with lived experience. (*)

(*) Asterisks indicate recommendations previously supported by evidence-based consensus from the 2018 Prevent21 Summit on Tackling Epilepsy Deaths²⁶ and the epilepsy coalition's continued work²⁷.

PRE AND POST COVID-19 CHALLENGES

At least 21 epilepsy deaths happen each week in the UK – this is a pre-pandemic figure.

Timely intervention to reduce epilepsy risk was already necessary pre-pandemic to save lives. The main challenges since SUDEP and epilepsy deaths were recognised over two decades ago concern how best to effectively enable research, policy and transformation^{28 29}.

Significant potential for avoidability of epilepsy deaths was established as far back as 2002, when Governments across the UK expressed shock at the findings of a National Clinical Audit, which examined deaths over a 12-month period³⁰. At the time, only one risk factor for epilepsy deaths was known, and national clinical guidance was limited. The audit nevertheless found that **42% of deaths were potentially avoidable**. Decades later, there is a substantial body of scientific evidence on epilepsy mortality risk factors, as well as national clinical and pathology guidelines^{31 32}. The main recommendation of the Audit, that there be **transformation to systematically integrate epilepsy risk management and support patients with tailored communication of risk, was not implemented**. Now, the most recent population-based research suggests that up to 80% could be avoided³³.

There is a significant concern that as a result of the pandemic and the impact this has had on epilepsy services, epilepsy related deaths will rise, resulting in excess mortality and many more lives cut short unless urgent action is taken to prevent them.

“

Wards and investigations and surgery were closed. I am used to seeing excess mortality in normal times but reported deaths already show epilepsy deaths rising sharply during the first peak of the pandemic. We also saw a surge in requests from Coroners at this time to look at anti-epilepsy medications in the blood of those who likely have died suddenly, which suggested very early on that there was a rise in excess deaths.

”

Professor Ley Sander,

Consultant Neurologist, National Hospital for Neurology and Neurosurgery and Head of the Department of Clinical & Experimental Epilepsy at UCL, Queen Square Institute of Neurology, London.

(Quote given in October 2020)



The nature of the issues that contribute to deaths in 2020 are identical to those highlighted in the National Audit – Epilepsy Deaths in the Shadows in 2002.

Access to services and communication about risk

Since 2004, there has been consensus for many years that people living with epilepsy and their carers, should be enabled by tailored information on epilepsy and risk. UK clinical guideline development in 2004 happened fast and was world-leading, including SUDEP and epilepsy and risk and guidelines on the investigation of epilepsy-related deaths. A funded epilepsy annual review was cut in 2013. Vital measures to help support implementation of good practice for epilepsy was agreed by NHS RightCare in February 2020 but was stopped during the COVID 19 pandemic.

Access to medicines

Access to medicines and medicines management was an issue highlighted in the National Audit in 2002, and became an issue of urgent concern during 2019, because of changes in regulations aimed at managing medicines shortages^{34 35}. Challenges during the pandemic include, concerns about warnings from the Association of the British Pharmaceutical Industry (ABPI) and the European Federation of Pharmaceutical Industries and Associations (EFPIA) about the long and short-term impact of COVID-19 and trade deals on access to medicines, and the worsening of the strain on supply chains during the pandemic³⁶.

Access to research funding

Inequalities of access to research funding have always been and continue to be a major challenge for the epilepsy community. A report from Epilepsy Research UK, highlights that research into epilepsy receives only 7% of neurological research funding, and just 0.3% of the £4.8 billion total spent on health-related research in the UK, and highlights the importance of this gap being tackled³⁷. Previously, the majority of research funding has funnelled towards a genomic research

agenda, though this approach, as a solution now to tackling epilepsy deaths, has proved elusive³⁸, and an expensive exercise, although it is recognised it may deliver in the longer term for certain groups. Research teams across the UK interested in innovation have also experienced challenges, with reasons given for failed applications, including economic value because of the numbers of deaths. It took ten years to secure epilepsy clinical trial funding for a wearable nocturnal device that had already proved effective in people with sleep apnoea because UK funders did not consider SUDEP a priority; however, crowdfunding by bereaved families helped secure €2 million in 2016³⁹. Nevertheless, a substantial body of research evolved over this period due to research funded by the UK's epilepsy third sector and from funding sources outside the UK. Whilst the viewpoint that epilepsy deaths are not a research priority is now slowly changing, it remains a grave concern.

Understanding the support needs of bereaved families

The 2002 National Clinical Audit found that only 1% of deaths were in people with epilepsy who had been informed of the risk of sudden death. Data from over 600 reports from The Epilepsy Deaths Register (EDR) also found that **95% of bereaved families before 2001 did not know about the risk of sudden death until it was too late, improving to 37% being uninformed between 2016 and 2020.**

This lack of awareness however leaves families traumatised, with unanswered questions and often no one to talk to. How services support bereaved families in the aftermath of their loved one's death, can also significantly impact on the complexity of the trauma they face. Early signposting to, and intervention by, the SUDEP Action specialist bereavement service has been recognised as helpful⁴⁰. The main challenge, is the bereaved being told in a timely way about this free service.



Julia

Case Worker,
SUDEP Action



“

I know first-hand the problems bereaved people face after a sudden death from epilepsy. Many are parents whose children have died young. Those left behind face traumatic grief. They also become part of the bureaucracy of the investigation by the state. They have no choice about this. Even when things go right, it is hard. In our experience many things often go wrong; worsening trauma.

Carelessness can have a profound effect on the bereaved, for example: when the wrong name is used, when someone else's death certificate is sent out, when post mortem reports have basic errors or casually offensive language is used. Questioning from bereaved families is not always welcomed – leading to accusations of looking for someone to blame or being a problem themselves for not just accepting the death. Often, they have to chase and press for answers. Communication can be delayed, impatient, rude. Sometimes families can wait over a year for the investigation to end, facing delays and uncertainties.

Investigations go wrong too when the realities of epilepsy-related deaths are not understood by professionals and guidelines, created to help with this, are not followed. Families are left to advocate for this and without support through the process, this may not happen. The risk is that epilepsy deaths are not recognised, not certified and underestimated.

During the pandemic I have seen these problems worsen because of the added pressure on the Justice system: uncertainty about whether inquests will happen and who can attend. We have helped people get answers, but those who are not told about our service at SUDEP Action may struggle to do this.

I work within SUDEP Action's support team and know about the impact on those bereaved by epilepsy. The impact can lead to PTSD and potentially, suicide. The investigation process can re-traumatise, and it shouldn't be like this. With specialist support, some of the trauma may be alleviated and the bereaved may have a chance to get the answers they need.

”

COVID-19 IMPACT RESEARCH WHAT WE DID AND WHY

Method

Two research collaborations were set up at the start of the UK Government's lockdown measures in March 2020, to gain a better understanding of what the impact the COVID-19 pandemic is having on the epilepsy and bereaved communities:

SUDEP Action and the University of Oxford – focusing on people with epilepsy, their carers and healthcare workers



SUDEP Action, Newcastle University and The Epilepsy Deaths Register – focusing on those bereaved by epilepsy



Both projects have undergone approval by ethics panels (University of Oxford approval reference - R69353/RE001, Newcastle University approval reference - 2394/2020).

The COVID-19 research surveys launched in May 2020 and continue to collect data on the ongoing impact of the pandemic. The data represented throughout this report covers the period from 23 March 2020 to 30 September 2020. The surveys for people with epilepsy, their carers and healthcare workers are available in 11 languages.

While the surveys are available internationally, the information presented throughout this report focuses specifically on the UK data:

316 – people with epilepsy

147 – carers

60 – healthcare workers

290 – individuals bereaved by epilepsy



Further details about the projects can be found [here](#).

Why

The impact of COVID-19 is wide-reaching, and its effect has rippled across communities. The epilepsy community has been historically underfunded, unprioritised by policy and burdened by stigma. People with epilepsy already face potentially life-threatening risks, requiring careful management, that if left unmonitored can lead to premature death.

Similarly, at a time of greater potential risk, health services have had to be rapidly redistributed across the world to respond to the pandemic; reallocating healthcare workers away from their usual roles, and adapting or closing specific specialties and services to redirect efforts to tackling COVID-19.

This research aimed to explore the impact of these rapid changes and their impact on people with epilepsy and their epilepsy risks – in order to document any challenges, concerns or actions required to keep safe this potentially vulnerable population both during the pandemic and beyond.

Similarly, those suddenly bereaved by epilepsy, experiencing long-term and complex trauma and grief are often neglected from epilepsy research and policy work. Yet their experiences can provide important insight into the issues those suddenly bereaved face daily, and how societal structures and public policy can better represent and support this vulnerable group.



COVID-19 IMPACT RESEARCH FINDINGS

Access/changes to services

Access to health, social and community services has changed dramatically as a result of the COVID-19 pandemic and Government lockdown responses. The impact on epilepsy services has varied nationally and this is reflected in the responses gathered from both healthcare workers and people with epilepsy:

18%

of adult respondents report seeing a health professional less than once a year

33%

of people had difficulties receiving epilepsy care during the pandemic

8%

had their pre-planned appointments cancelled

22%

have not heard updates from clinicians regarding an upcoming appointment

57 people with epilepsy also shared experiences of difficulties with their medication...



28%

reporting delays in their prescription deliveries



25%

having trouble ordering their prescriptions



25%

having issues in collecting their prescription.

“

I had a bout of severe grand mal seizures for a week. Normally I would have gone to A&E and, based on the last several times this occurred, would probably have had to stay in hospital for a few days to control it. I didn't because I was worried about contracting COVID.

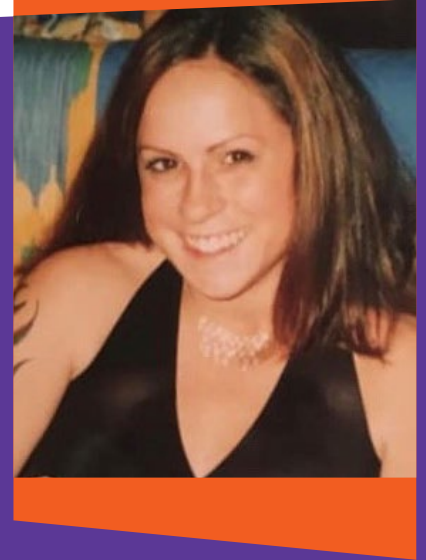
”

Research Survey Respondent
(Person with Epilepsy)





Nicki



“

It is over a year since my sister Nicki died suddenly at home. Nicki was 37. In Nicki's memory we have a new bench in our local park with a butterfly plaque. She had epilepsy and was seeing the same doctor since 1995. My family struggled that not only had we lost our beautiful Nicki, but that she died suddenly shortly after her medication was changed because of a shortage of her usual medicine. We were devastated to learn about SUDEP after her death.

Paul, a brother whose sister died due to epilepsy

”

However, while some people with epilepsy have experienced challenges due to their access to services as a result of the pandemic, 54% of respondents are satisfied with the changes made to their neurology care, highlighting the benefits of instant communication via telephone and email:

“The support I have from my Epilepsy Nurse is almost 24/7. I can email her at anytime and she comes back with a plan of action almost immediately.”

“I think if I had concerns about my epilepsy then I would be able to contact my consultant and/or my GP by phone or online so that doesn't worry me.”

On the other hand, 18 respondents have experienced difficulties in transitioning to alternative means of communication, expressing a need for face-to-face contact:

“Only telephone services are available [for me]. I am deaf so [I'm] unable to simply contact my neurologist for advice.”

“I find it hard to get out what I needed to ask or get help on. Realised after the phone call I forgot to tell the Specialist a lot of things I think they needed to know. Phone calls give me anxiety.”

“Telephone appointments do not work for me. My Neuropsychology exercises need to be face to face so I have lost this support... I was not given enough time to talk with the on call GP's... and they didn't know how complex my epilepsy was.”

Healthcare workers have expressed concerns over their redeployment to front line COVID-19 services and the impact this may have on people with epilepsy being able to access support:

Healthcare workers have reported a dip in epilepsy referrals and their perception of a reluctance from patients to engage with existing services, likely as a result of the pandemic.

“We are wondering where have all the patients gone... you have a legitimate concern that patients might not be reporting.... and might not make an appointment for an annual epilepsy review.”
Research survey respondent (GP)



Sarah

A Paramedic whose friend died due to epilepsy

“

Currently, there is a very large focus on Covid-19 and associated patients, but it's also really important that we remember to care as best we can for epilepsy patients and to remain aware of the associated risk factors.

During this time, people with epilepsy may be having difficulty in collecting medications when self-isolating, difficulty getting through to their GPs due to increased GP workload or perhaps not wanting to feel a burden on GPs during the pandemic - this could be really detrimental if risk factors are increasing, e.g. seizure frequency increasing etc.

At this time, there is also the potential for increased alcohol consumption as this can often accompany boredom in people staying at home. Also, a lack of regular contact with relatives/friends who may have helped to monitor or pick up on changes in people with epilepsy could put people more at risk.

People with epilepsy may be struggling to get the full support that they deserve. I myself lost my friend to epilepsy/SUDEP in 2018, so I know first-hand that SUDEP Action are a vital charity that continue to work to prevent epilepsy deaths.

”



Those bereaved by epilepsy have similarly lost access to health services, who can play a core role in supporting them with their trauma, and health conditions that have developed as a result of the death of their loved one. The shutdown of wider community services, such as bereavement groups, counselling, and other networks used to help them with their grief, has also had a devastating impact on this community:

16%

have not been able to have virtual communication with their friends and family since lockdown began.

57%

of people who found it difficult to ask for help before are now finding it more difficult during the pandemic.

69%

of respondents have reported a negative impact on their access to support networks (30% 'Major' or 'Severe').

"My support network after losing my daughter and grandson, were daily routines, keeping busy. And visiting friends. Physically seeing a counsellor was so much better, than on phone."

"I have struggled with not being able to attend a local child bereavement group that I had been going too. While it is now happening via Zoom online, I struggle to participate in this way. Although I am grateful for the amount of effort they put into making this happen, it doesn't work for me, and I find I am dwelling more on my negative thoughts since our Son passed away. My husband and older son are both on the furlough scheme and I am dreading them going back to work, even though my husband is losing pay, I feel slightly less desperate with them at home."

However, added to this difficulty in accessing support, those bereaved (like many of the people with epilepsy who shared their experiences), have also felt added guilt for burdening services during the pandemic:

"Don't want to bother health professionals with it at this time, nor family members as they have their own worries right now."



COMMENTARY

Decreasing access to epilepsy (and other community health) services is a grave concern. It suggests undiagnosed people with epilepsy may be either struggling to get onto the diagnosis pathway due to increased demand on GP/Primary care services (a referral should happen within 2 weeks⁴¹), or are not presenting to hospital despite either new or worsening seizures and epilepsy symptoms. People with newly suspected or worsening seizures must have rapid access to epilepsy specialists regardless of pressures on their local health services. Data from The Epilepsy Deaths Register shows 10% of sudden epilepsy deaths reported were in those undiagnosed at the time of death⁴², suggesting an urgent need for people with suspected epilepsy to have ready access and referral despite the pandemic.

Issues regarding epilepsy medications and people's access to them also give cause for concern, given medication adherence is a critical method of epilepsy mortality risk reduction. SUDEP Action have campaigned on this issue (in relation to Brexit) since January 2019; and it remains an issue of concern, particularly with the added context of supply issues brought about due to the pandemic. The Charity has also learnt from services commissioned by Coroners, about a surge in demand for testing for presence of

antiepileptic medications in people who died suddenly, during the first phase of the COVID-19 pandemic.

Healthcare workers throughout the data have expressed anxiety over the impact redeployment could have on people with epilepsy, given the expertise and personalised care required to help people with epilepsy, effectively manage their condition and associated epilepsy risks.

Where possible healthcare workers have kept emergency contact processes in place to support existing patients. However, in some areas of the UK, these restricted epilepsy services have left patients vulnerable to worsening seizures, increased risk and could have resulted in premature epilepsy deaths.

People with epilepsy being able to readily access the healthcare team who support them with their epilepsy, is vital should their condition change for the worse. The benefits of supporting people with epilepsy on their seizures, mental health, and overall condition management, despite services being redeployed to the COVID-19 frontline, can be seen throughout the responses shared.

The dangers of not providing timely access to epilepsy services has been well researched. Research exploring epilepsy risk by examining death records found only 20% of people with epilepsy who had died suddenly had been in contact with specialist services in the previous

year. In 90% of these deaths there was an increase in seizure frequency 3-6 months before death; half had a record of alcohol misuse, and a quarter had been taking drugs to treat depression or anxiety. All of which can lead to worsening seizures and increased mortality risk,

but all of which can be better managed if care is patient-centred⁴³. These warning signals could currently be being missed if people with epilepsy (or those awaiting diagnosis) are not able to, or aware of the importance of engaging with epilepsy services.

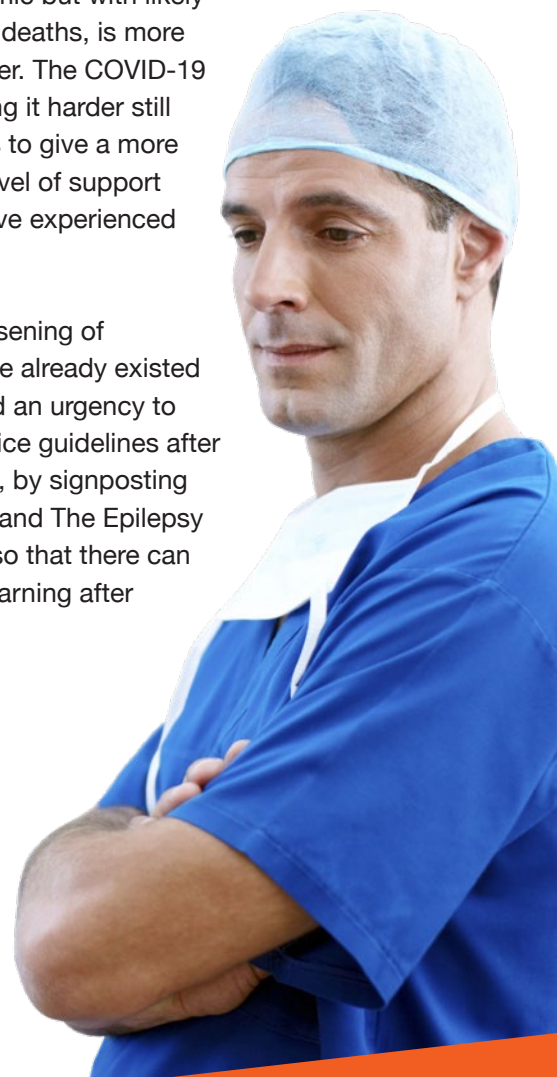
The experiences of those bereaved by epilepsy expressing concerns about accessing help, highlights additional burden being added onto this already vulnerable group. Prior to COVID-19, our analysis of 600 detailed reports to The Epilepsy Deaths Register show that the most helpful things to a bereaved family after a death are:

- 'someone to talk to',
- 'finding answers to questions',
- 'understanding investigations of death'
- And 'learning more about epilepsy-related death' (64-86%).

Whilst SUDEP Action offers the only service to meet this need and signposting is recognised as good practice, only 22% of people reporting deaths in recent years, have been invited to talk with a professional who could help signpost to this service.

There is also still no system to inform the medical team that someone has died, and relatives may still receive routine letters informing them of epilepsy appointments. Over half of relatives who had not been 'invited to talk about a death', report dissatisfaction with their medical team, as opposed to about a third where there has been an invitation. Necessary steps and signposting to help the suddenly bereaved were not in place before the pandemic but with likely increased excess deaths, is more important than ever. The COVID-19 response is making it harder still for medical teams to give a more comprehensive level of support to people who have experienced a sudden death.

This shows a worsening of shortfalls that have already existed in the system, and an urgency to follow good practice guidelines after an epilepsy death, by signposting to SUDEP Action and The Epilepsy Deaths Register, so that there can be support and learning after a death.



RISING RISKS AND DECREASING RISK COMMUNICATION

Worryingly, many people with epilepsy who took part in the research indicated that their epilepsy, seizures, mental health and overall wellbeing has worsened as a result of the pandemic and Government response. Through their responses, they indicate that many risk factors known to be linked to premature epilepsy mortality, including those linked to SUDEP, were rising – and some respondents were unaware of these risks.

40%

of people with epilepsy reported negative changes to their health during the pandemic, which suggest rising epilepsy mortality risks among this population.



Fig. 2. Changes to the health of people with epilepsy

Responses as %

Despite these rising risks, 20% of people with epilepsy had not engaged in patient-clinician communication on any listed risk factors in the past 12 months, with only 15% reporting they had discussed SUDEP with their healthcare workers in the previous 12 months (even though it is a NICE Guideline recommendation).

The table below illustrates the varied communication rates about many core epilepsy risk factors linked to epilepsy deaths, the discussion of which are recognised as being best practice for tackling premature deaths:

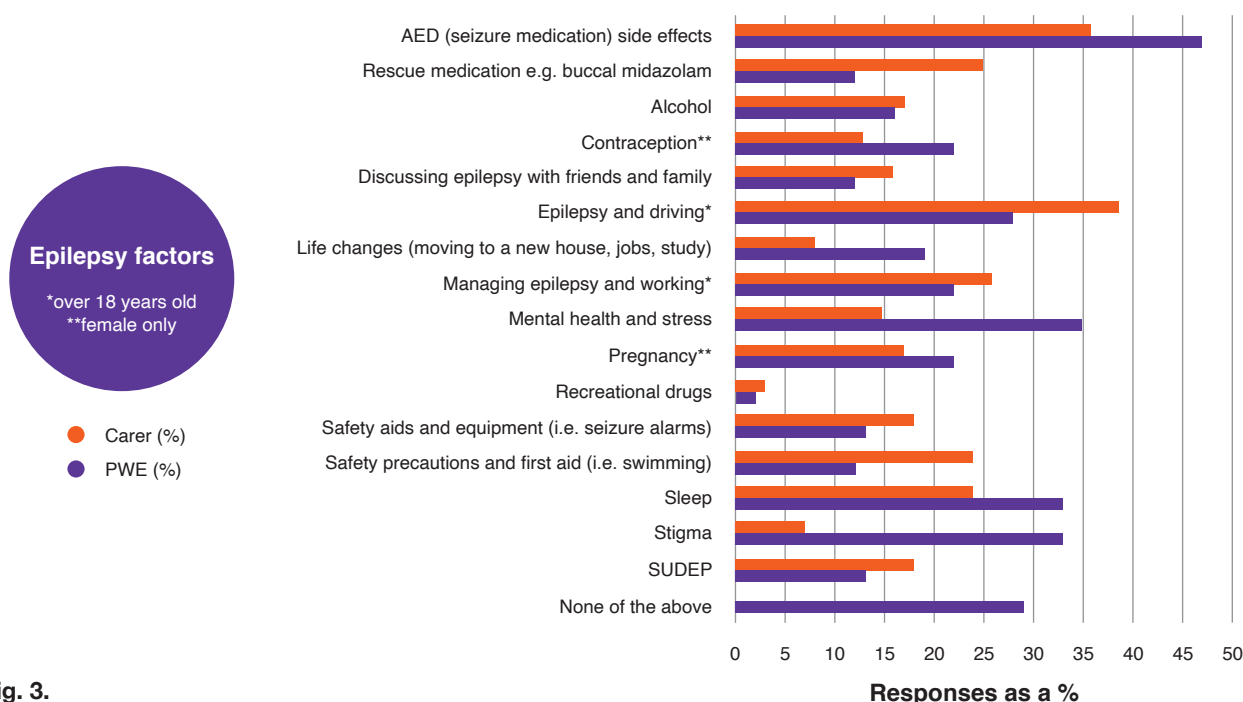


Fig. 3.

Seizures and Injuries:

Having seizure control or seizure freedom is a core way to reduce epilepsy-mortality related risks. However, 48% of respondents have been experiencing changes in the number, type or length of their seizures during the COVID-19 pandemic.

38% (176 people with epilepsy) had suffered injuries or needed emergency care in the past 12 months for reasons such as:

- Seizures while driving
- Unplanned hospital admissions
- Broken bones
- Head injuries
- Respiratory arrest
- Being alone while having a seizure

Worryingly over 40% of these individuals are currently living alone during lockdown (46 people).

13% (57 people with epilepsy) shared that they had been having difficulty taking their medication on time, which may account for some of the seizure changes reported. Reasons for this included:

- Forgetfulness
- Changes to their everyday routine
- Difficulties with their epilepsy medication prescription
- Stress

COMMENTARY

Worsening epileptic seizures are a clear risk factor for premature mortality⁴⁴.

Injuries are a known risk factor for epilepsy mortality as they suggest seizures are not well controlled and that there may be issues with epilepsy management. The range of injuries shared with us through this research show nearly 100 people have required additional, unplanned and emergency support for their epilepsy during the past 12 months. With many respondents experiencing higher number of seizures, this need will inevitably continue, and possibly increase, putting additional strain on a health system already coping with the COVID-19 pandemic.

Previous research suggests over 100,000 emergency and unplanned attendances⁴⁵ were due to epilepsy, and considering the experiences shared through this research, this figure could be significantly increased during the pandemic and Government lockdown response. The fact that 41% of people requiring this emergency care are now living alone, is a significant concern. This could suggest their usual support networks are less accessible as a result of the Government lockdown response, isolating these individuals and putting them at increased risk of premature mortality or serious injury. Due to the risk factors associated with mortality, early intervention and support during and immediately following a seizure, should be a core part of all epilepsy care plans for people experiencing seizures⁴⁶ - something which may currently be inhibited, and putting people more at risk, as a result of the pandemic.

Additional assistance by epilepsy specialists could help these people with epilepsy gain better seizure control, help alleviate this burden, improve their safety and quality of life, and prevent some avoidable deaths. Medication issues, particularly those due to shortages is an area of concern SUDEP Action have been highlighting since January 2019 – particularly in relation to any impact Brexit, or a hard-Brexit may have on epilepsy medication supply chains. Not taking medication as prescribed is known to increase risk of premature mortality by 3 times⁴⁷. Anything which may affect access to epilepsy medication, could lead to an increase in epilepsy-related deaths, and this impact should be adequately understood and mitigated against by policy makers and health services.

Mental Health:

One of the Government's core health priorities, mental health, has been a key strand of national news surrounding the pandemic since Government's lockdown responses have been put in place^{48 49}.

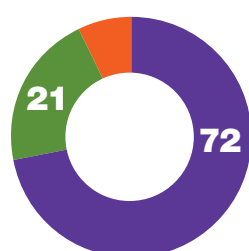
87% of people with epilepsy who reported changes to their health also reported their mental health had been challenged and worsened as a result of the pandemic, citing increased stress, worry, anxiety or depression – all things known to impact negatively on seizure control.

86% of those bereaved by epilepsy also shared with us that the pandemic and Government lockdown response had had a negative impact on their mental health – 24% reporting this to be 'major' or 'severe' and 43% of participants already having a pre-existing, diagnosed mental health condition.

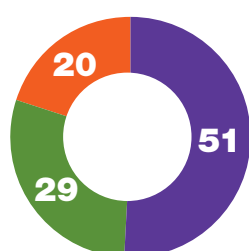
This has manifest in various ways for those bereaved by epilepsy as shown below:

Fig. 4

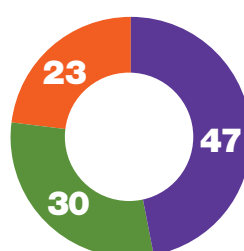
● % Agree
 ● % Neither Agree nor Disagree
 ● % Disagree



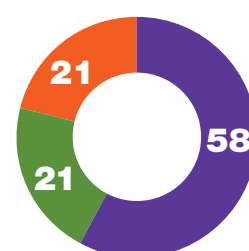
I have been thinking more about the person who died



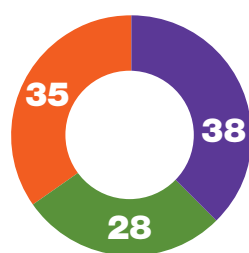
I have had more distressing flashbacks to the time of the death



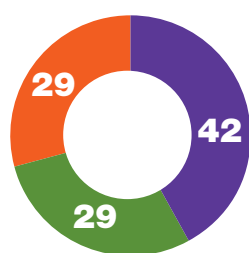
I have experienced more distressing memories of the person who died



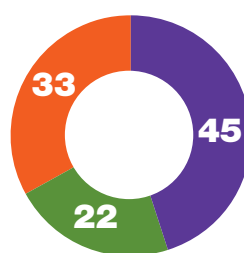
I have had increased difficulties getting to sleep and staying asleep



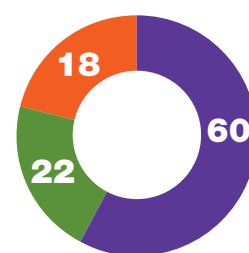
I feel more angry



I feel more irritable when with other people



I have experienced more feelings of guilt about the death



I feel more isolated

“The anniversary fell in May. Normally, we would distract ourselves with a day out focusing on happy memories, but this was not possible, and we all experienced flashbacks and experienced emotional memories.”

Further evidence suggests an ever-increasing burden on healthcare worker’s wellbeing, with 38% reporting that the pandemic had an impact on their mental health. However, a higher proportion of healthcare workers expressed greater concern for family members, with 55% reporting some or significant levels of concern.



COMMENTARY

The cost of mental health pre-pandemic on the UK was thought to be over £105 billion a year⁵⁰. This is likely to rise significantly as a result of the pandemic and Government lockdown response – and should further lockdown measures need to be continually used in lieu of a vaccine, could have an ever-increasing impact and demand on the NHS, wider community services and on the third sector.

Mental health conditions are more likely for people with epilepsy and are a risk factor for premature mortality⁵¹. It is vital the health system recognises this link and provides additional support to those who need this, particularly in any case of rapid changes to their mental health status.

Many people bereaved by epilepsy both recently and in the past represent a vulnerable group who have built up a variety of support strategies to help them manage, and live with, their grief. The circumstances of these sudden medical deaths are usually traumatic. The Epilepsy Deaths Register with over 600 reports of people with lived experience corroborates this finding.

The COVID-19 survey on the impact of the pandemic has found people bereaved through epilepsy are increasingly isolated. This represents an increased need for support at a time when public services are overstretched and when coping strategies have been stripped away at times by the COVID-19 pandemic response.

For many this includes health services, counselling, and support groups. For others, these strategies are grounded in lifestyle factors, such as exercise, employment and commemorating the death with family. During COVID-19, many of these strategies have been stripped away. People with lived experience of traumatic grief are experiencing more of the ‘traumatic grief-symptoms’ associated with the death of a family member, or friend, including anxieties about the safety and well-being of those closest to them. This represents an increased need for support, just at a time when services are overstretched and when bereaved people themselves are finding it more difficult to ask for help. This is extremely concerning as a preliminary finding from 290 bereaved families and may well be a predictor of the tsunami of mental health issues for people impacted by sudden medical deaths during the pandemic for decades to come.

Particularly at risk groups:

Men with epilepsy are known to be at higher risk of SUDEP⁵² – however only 20% of those who took part in this research identified as male. This is concerning as it suggests this population, who are potentially at increased risk, are trickier to engage with when discussing sensitive topics of epilepsy risks and epilepsy deaths.

Added to this, the largest group of people with epilepsy were in the age bands associated with being at higher risk of SUDEP (18-40s)⁵³ – making up 278 of the 463 total responses. The fact that this age range are engaging in research on epilepsy risks is encouraging. Yet, the evidence suggesting their epilepsy risks are rising, and not currently well controlled during the COVID-19 pandemic, is very concerning as it could indicate they are at significantly higher risk of premature mortality as a result.

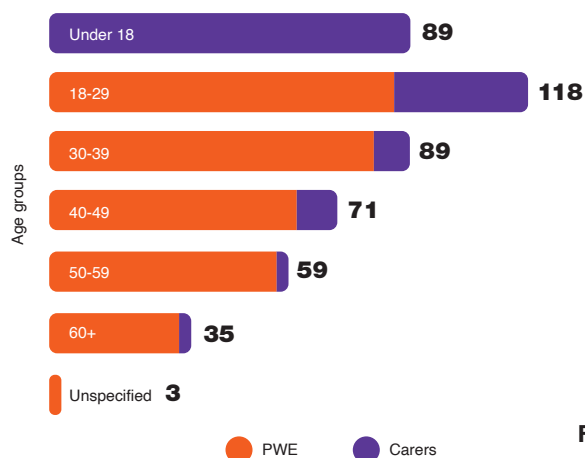
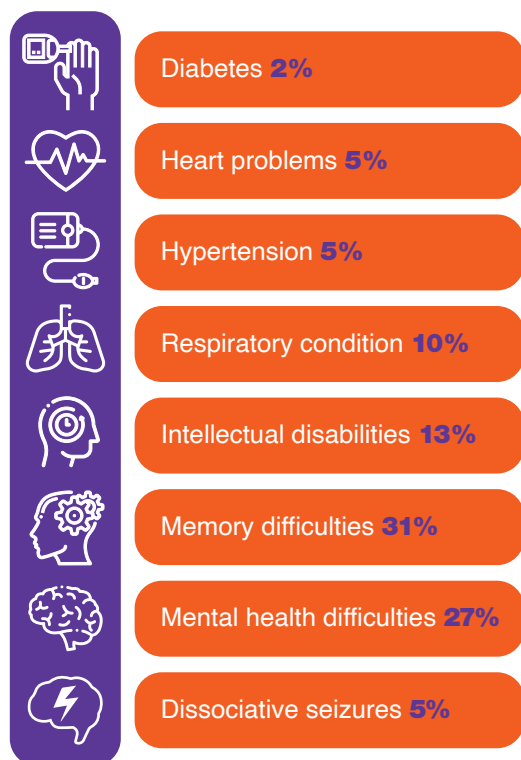


Fig. 5



A number of people with epilepsy who shared their experiences have additional health conditions that may also increase risks, either directly or indirectly as a result of the COVID-19 pandemic. These conditions include:

Fig. 6



*percentages as a proportion of total respondents

Those who have disclosed any of the above conditions have reported higher levels of poor health outcomes. 45% of those who had additional health problems said their health had worsened during the COVID-19 pandemic, compared with 26% in the group of people who

did not report other health problems. Further, 35% of people with other health conditions found difficulty in receiving epilepsy care, compared with 27% of people without other health conditions. Women with epilepsy who are currently pregnant during the pandemic are another important group to highlight. Maternal epilepsy deaths have been rising^{54 55 56}, yet research has demonstrated that reducing epilepsy mortality risks is possible for these women if a holistic approach to care and risk management is taken⁵⁷.

- Five women were pregnant – though the care they are receiving during the pandemic varied dramatically, with only 2 out of 5 receiving specialist epilepsy care.
- 28 women (aged between 18-59) are currently taking Sodium Valproate – yet only 39% reported having pre-conception counselling in the last 12 months.

This is concerning due to the risk of maternal mortality associated with epilepsy, and the mandatory introduction of the Pregnancy Prevention Programme^{58 59}. It could suggest these women are currently not having discussions with their clinician about the risks associated with Sodium Valproate – or may not (either as well or at all) be having balanced discussions that include communication about epilepsy mortality risks so they can make fully informed choices about their care.





Samantha



Samantha died on the 4th December 2004. She was twenty-five years old and was seven months pregnant with our first grandchild. We only found out it was a little boy after she had died and we were able to give a name as she had chosen the name Regan for if it was a boy.

From the age of sixteen, Samantha developed epilepsy. She only ever had a seizure as she was coming out of sleep and they only occurred two or three times a year. We made sure she slept in a low bed and that there was no furniture around so she could be safe. She was determined to not let the epilepsy control her life and was in the final year of a nursing degree.

When she became pregnant the seizures became more frequent and she was referred to the local hospital. Only a week before we found her, she received a letter from the consultant to say she was a low-risk patient and had nothing to worry about.

It was an exciting time for us all. A new baby. A degree completed. I remember saying to her that it would be a tough year but that it would all be worth it.

The day we found her was the worst day of my life. Everything changed. Nothing meant anything anymore and it was dark all of the time. The first time we heard of SUDEP was when the coroner gave it as the cause of death. We had no answers and so many questions. As I started searching frantically for answers, I came across a website for SUDEP Action. They returned my call and I was offered bereavement support. They also provided all the information I needed to understand more about SUDEP.

I also wanted to introduce my daughter Samantha to you all. She was a beautiful girl who you never got to meet but who you can now get to know.

Christine, a mother whose daughter and grandson died due to epilepsy



WORSENING TRAUMA, ISOLATION AND HEALTH OF THOSE SUDDENLY BEREAVED



Triggering and disenfranchised grief

For months it has been impossible to escape information and updates relating to the COVID-19 pandemic, from news outlets, health services, community news, friends and families – it has been a core topic of conversation. For those bereaved suddenly by epilepsy, this brings additional challenges and trauma, on top of their daily battles with grief. ‘Sudden death’ being everywhere brings bereaved people back to their grief – with many aspects of COVID-19 deaths and bereavement resonating with their own experiences.

For many, this has been triggering, bringing the trauma they experienced when their loved one died, back to the forefront of their mind; something that is then magnified by the lockdown measures, making it difficult for them to escape. 72% have been thinking more about the person who died and 51% have had more distressing flashbacks to the time of death.

“I am always distressed when hearing of sudden death. When it’s unexpected for families it always has a greater effect on me. This has obviously increased at the moment.”

Epilepsy deaths have historically been ‘in the shadows’ (as signified by the title of the 2002 national audit on epilepsy deaths⁶⁰), with other health conditions, and bereavements taking a more prominent place in both public perceptions, service provision and policy making. This neglect has compounded as a result of the pandemic with bereaved individuals sharing feelings of being ‘forgotten’ and ignored, despite the many similarities between epilepsy and COVID-19 bereavement. For some, this has caused feelings of distress and injustice as it can feel that their grief is not seen or felt significant enough of attention compared to other sudden bereavements.



Bereaved partner who is also working in the NHS



“

I work for the NHS on the frontline, so I have not incurred any employment or financial difficulties. However, the huge focus on COVID at work and in society has meant my grief has been forgotten, as everything is about COVID.

Whilst work has provided some occupational therapy, it has also been very difficult to work in these conditions. I hate wearing PPE, as it is hot and it affects your ability to communicate effectively with patients. Our patients are told to wear masks also, which makes it difficult to gauge how they are coping with the examination and you cannot see the expressions on their face.

I feel irritable all the time and have to act to get myself through the day. Once home, I open a bottle of wine immediately and mainly just sit and cry whilst watching the television. Since my partner died I now live alone - we had no children.

Prior to COVID I was at least able to meet up with friends, or go and sit in a café or pub alone, but so I was amongst other people. Now I have no option but just to go home every evening, which I find lonely and depressing. It compounds my grief.

No one asks how I am anymore and no one recognised the anniversary of his death, which was last weekend. Many of my friends have not even lost their parents, so I don't think they can relate to my grief at all. Losing a partner suddenly to SUDEP is so traumatic and it was so unexpected. At least with parents we are conditioned to losing them and with an illness you have time to say goodbye. I did not have a chance to say goodbye.

”

COMMENTARY

Experiences of those bereaved by epilepsy can aid learning in understanding those affected by COVID-19 bereavement in the future. Whilst there are differences in relation to who is most at risk, there are also similarities between COVID-19 deaths and epilepsy-related deaths in that they can occur quite suddenly, be relatively unexpected and, partly because of social-distancing as well as the inherent circumstances themselves, those who are bereaved may not have an opportunity to say 'goodbye' or come to terms with the prospect of a death in advance of it happening.

The form of the grief may be different but is of equal importance and should not be lost by the focus on sudden deaths as a result of COVID-19. Importantly, the findings from this research may be of relevance in the future as people bereaved by a sudden death related to COVID-19 may find themselves in a similar position in the future.

Isolation and loss of coping strategies

Many of the bereaved individuals who shared their experiences with us, shared their feelings of isolation as a result of the pandemic. A majority also stated that the coping strategies they had carefully put in place to support them with their grief, were no longer available to them, or possible as a result of the Government's lockdown response. 58% reported a negative impact on their anxiety and 72% experienced increased anxiety in relation to safety and well-being of others.

"It has taken away my part-time job, which was my only source to socialise and get out of the house, but more importantly, it has stopped me from seeing and being with my two young grandchildren, that my daughter left behind when she died from epilepsy. (SUDEP). So, in one swoop, it has taken away ALL of the things that I had left to hold on to after [she] died."

"During my time in isolation it was my son's birthday. For the first time in 16 years I was not able to go to his grave to put fresh flowers or celebrate his life in any way. Then his anniversary came Easter Saturday and what is usually a time to celebrate [his] life and remember him with friends and family for the first time we could not do this. It was heartbreaking, like I had forgotten him, although this could never happen. I wanted to scream so much the pain was so hard."

However, for some of the bereaved families who contributed to this research, the Government's lockdown response to the pandemic has provided some relief by giving space and time to sit with their grief as a family:

"Strangely, being in isolation has not been a negative experience in relation to our grief. In the 2.5 years since [my son] died, we have been trying to manage grief, resuming work, and the complex needs of our [other] son, who was severely impacted by his brother's death. We have felt that the pace of life is so hectic. There is no space to process what has happened and there are too many distractions. Friends and family also try to keep you busy/going. This can lead to avoiding the pain of grieving. For me, the Coronavirus lockdown has meant that we can isolate, be in the moment, spend more time together as a family, get off the treadmill and finally sit with our feelings and grief. We will never be the same people and this time has helped us to help others start to see that."



SUDEP Action have seen an increase in demand on our specialist support and caseworker services, since the start of the pandemic in the UK. Not only from new families being signposted (either recently bereaved or bereaved during the period of the main Government Lockdown response), but from long-term bereaved individuals who have used the services over many years.

The effect of lockdown has caused added distress to those bereaved by epilepsy regardless of when the death happened. The lockdown has highlighted the long-term impact of sudden epilepsy bereavement and the complex nature of this type of grief⁶¹. There is no timeline to grief, it is long-lasting and complex - services and policy needs to understand and recognise this in order to better support this vulnerable community; especially in light of future lockdown measures that may be required.

The COVID-19 pandemic has exposed vulnerabilities across all of society. For a community that has already experienced severe trauma, it can amplify concerns about the health, wellbeing and safety of family and those close to them. It can trigger experiences of struggles in the past to access help and services, when these have been needed to safeguard life. This is also a community which have experienced the harm of false assurance about health, or economic risks, which may increase questioning and anxieties.

The lack of interest in Government or public communications in the indirect harms of COVID-19, may also resonate with those bereaved who feel that epilepsy deaths do not seem to count in the same way as other deaths. The prioritisation by policy makers in recent decades on tackling the 'big killers' like cancer, and heart disease, has meant that epilepsy (which accounts for 21 or more deaths a week) is not seen as important. Considerations of the years lost because deaths peak in young adults; the public burden of these deaths in the young; and the relatively simple and cheap interventions to provide health checks for people at risk, have not been considered relevant to NHS management priorities for delivery at a local level.



RECOMMENDATIONS & URGENT ACTIONS

The recommendations that follow, highlight serious concerns about worsening of excess deaths, based on a body of knowledge developed over decades.

Many of the recommendations in this report are already supported by NHS RightCare's Epilepsy Toolkit and existing clinical guidelines. However, the experiences shown in our research, mean these recommendations are even more urgent,

and the implementation of good practice to tackle epilepsy mortality must be prioritised, now more than ever.

Note:

- Asterisks indicate recommendations previously supported by evidence-based consensus from the 2018 Prevent21 Summit on Tackling Epilepsy
- The most urgent actions within the recommendations are placed in **boxes.**

Recommendations for Government, National and Local Select Committees

- 1 Include lives cut short due to SUDEP, suicide and other epilepsy-related causes in official counting and modelling of expected deaths during the pandemic. Commit to including excess deaths in people with epilepsy in the scope of the promised inquiry into deaths during the COVID-19 pandemic. Give access to existing data on epilepsy deaths to SUDEP Action and their epilepsy coalition. Providing visibility to epilepsy deaths and enabling work to continue to monitor these sudden deaths.
- 2 Listen to the experts and engage with them to stop further lives being cut short. SUDEP Action brings experiences of bereaved families relating to 22,000 deaths over 25 years; supported by an epilepsy coalition of experts and organisations as part of the Prevent21 movement to stop preventable deaths. Listen to the evidence-based consensus on what needs to happen to save lives now⁶² by meeting with SUDEP Action and the epilepsy coalition. (*)
- 3 Re-introduce an annual epilepsy risk health check. Follow through on the Government commitment to promote and implement NHS RightCare Epilepsy Toolkit, prioritising tackling epilepsy deaths as the best measures now, to focus on reducing the numbers of avoidable excess deaths and support bereaved families. Urgently review the decision to stop this planned activity. (*)
- 4 Prioritise epilepsy as a high-risk condition, with all efforts made to ensure that transformation during COVID-19, does not reduce the standard of service for people at risk of sudden death. Specialist epilepsy teams, including epilepsy specialist nurses and learning disability staff, who provide a vital service engaging with people with epilepsy, to be protected from reallocation to non-epilepsy related duties. NHS staffing shortages should be mitigated by careful planning to avoid any increasing risks from the COVID-19 response, and a plan to avoid any increasing risks to staffing recruitment and staff retention from all causes⁶³. (*)
- 5 The mental health needs of people with epilepsy should be adequately prioritised in community-based services as a high risk group with significant co-morbidity and risk of death.

- 6 Special groups including pregnant women with epilepsy, people with epilepsy and autism and/or learning disabilities, and children with rare epilepsy syndromes (such as Dravet Syndrome), should be adequately prioritised as high risk groups.
- 7 Those designing epilepsy services need to give consideration that transformation through remote consultations will have negative as well as positive impacts and that evidence is limited. Options for preferred consultation methods should be accommodated as far as possible, especially to ensure reasonable adjustments for people with epilepsy as people with disabilities^{64 65}.
- 8 Any change or delay of medication supply is a significant mortality risk for people with epilepsy. Therefore, the publication of an inequalities impact statement is crucial. Consideration of any significant risks during 2020 from; worsening of supply chains, measures taken to mitigate risks, and that no change of medication, is made for people with epilepsy that departs from the MHRA 2017 regulations, without their knowledge and without discussion of SUDEP and seizure safety, should be included.

Recommendations for all professionals in clinical and advocacy sectors

- 1 Timely signposting of the bereaved to SUDEP Action, who have an expert team and service in-keeping with the care pathway, that the bereaved report they need following a death. Including: answering questions, support with death investigations, specialist support following traumatic deaths, and referral pathways to other sources of help. This practical and simple recommendation is relevant to any professional working with any bereaved families across any clinical or advocacy setting and is recognised good practice^{66 67 68}. (*)
- 2 Signposting people with epilepsy to patient organisations for information, advice and support. (*)
- 3 This is a good opportunity to use the evidence-based SUDEP & Seizure Safety Checklist⁶⁹ as part of discussion of epilepsy risks and risk reduction. Helping develop key understanding of individualised risk from seizures, and explore options of personalised care and risk reduction, helping to meet national clinical and GMC guidance. (*)

Recommendations for all research funders and researchers

- 1 That the inequality in funding of epilepsy research is tackled and the call for match funding for future charity research over the next three years via a Life Sciences-Charity Partnership Fund is supported. (*)
- 2 Where research funding is limited, funders are encouraged to consider the following priorities:
 - i Ensuring adequate funding is targeted at preventing worst outcomes in a timely way over the next 2-5 years.
 - ii Ensuring adequate funding for maximum impact on avoidance of worst outcomes for the greatest number of people.
 - iii Research is prioritised which supports the implementation of recognised good practice and which is readily scalable as quickly as possible.
- 3 Policy makers, researchers, campaigners and media working with the bereaved and vulnerable groups, recognise trauma associated with epilepsy-related deaths and work sensitively to avoid unnecessary harm by consulting with SUDEP Action.
 - i Consult with SUDEP Action on stories and projects that concern epilepsy deaths.
 - ii Consult with SUDEP Action about how to avoid retraumatising bereaved families.
 - iii Follow the guide for involving bereaved families in research to reduce risk of worsening of trauma. (*)



FOR MORE INFORMATION

COVID-19 Epilepsy and Epilepsy Bereavement surveys

www.sudep.org/covid-19-impact-research

National epilepsy service improvement resources:

NHS RightCare Epilepsy Toolkit

www.england.nhs.uk/rightcare/products/pathways/epilepsy-toolkit/

Risk Communication tools and resources:

SUDEP and Seizure Safety Checklist

www.sudep.org/checklist

EpSMon App

www.sudep.org/epsmon

Bereavement Services:

www.sudep.org/someone-has-died

Or contact the specialist support team via **01235 772852** or support@sudep.org

Epilepsy Deaths Register

www.epilepsydeathsregister.org

For further information about this report of the work of SUDEP Action, please contact: info@sudep.org or **01235 772850** or visit www.sudep.org

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SUDEP Action 
Making every epilepsy death count

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- 5 SUDEP Action (Dec 2019), [New enquiry report highlights increasing maternal epilepsy related deaths](#)
- 6 The Learning Disabilities Mortality Review (LeDeR), Annual Report 2019: http://www.bristol.ac.uk/media-library/sites/sps/leder/LeDeR_2019_annual_report_FINAL2.pdf
- 7 SUDEP Action web article on the 2019 LeDeR report: <https://sudep.org/article/charity-calls-urgent-action-learning-disability-mortality-report-has-epilepsy-spotlight>
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- 9 [SUDEP and Seizure Safety Checklist](#)
- 10 [EpSMon](#)
- 11 NHS RightCare (Feb 2020) [Epilepsy Toolkit](#)
- 12 SUDEP Action [Specialist Support Services](#)
- 13 [Epilepsy Deaths Register](#)
- 14 NHS Specialised Commissioning, [Optimum Epilepsy Pathway Draft](#)
- 15 [NHS England Reply to Ben Bradshaw MP enquiry about NHS RightCare’s Epilepsy Toolkit](#) (Aug 2020)
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