

SUDEP Action submission to the All-Party Parliamentary Group on Coronavirus

SUDEP Action is the only UK charity dedicated to raising awareness of epilepsy risks, tackling epilepsy-related deaths (including those due to Sudden Unexpected Death in Epilepsy) and supporting those bereaved by the condition. Almost entirely funded by people bereaved suddenly by epilepsy – the organisation helped 13,800 people and nearly 300 organisations last year.

The charity's digital tools support clinicians and people with epilepsy to reduce epilepsy risks and improve learning opportunities from avoidable epilepsy deaths. These free, award-winning services are recognised 'best practice' for taking a risk management approach to epilepsy mortality by NHS Rightcare¹, the Learning Disabilities Mortality Review (LeDeR) Programme² & the Royal College of Pathologists³.

The charity team has agreed a 25% reduction in pay during the pandemic, so delivering our vital services can continue, as our work is not funded by any government emergency rescue package. While demands from excess epilepsy deaths have risen, fundraising events that we rely on have been postponed.

One of SUDEP Action's core priorities is working to ensure people living with epilepsy are able to live well, to live safely and are supported to manage their epilepsy risks; therefore, the topic of this inquiry aligns with this aim.

Executive Summary:

- Pre-pandemic, epilepsy deaths were identified and highlighted as a concern by the third sector due to lack of systematic support⁴. Epilepsy is not included as a priority for the majority of local/national health systems, with risk management practices varying nationally. **We are confident from our expert network that there will be more SUDEP deaths (Sudden Unexpected Death in Epilepsy, a leading cause of epilepsy death, especially in young populations) alone this year than the number of deaths due to COVID-19 in age group 20 to 40s.** This is likely to remain the case even with the addition of COVID-19 related mortality. People with epilepsy, already isolated, experiencing inequality and underserved are likely to further isolated and unable to access services; exacerbating current inequalities.
 - Therefore, we are calling for priority to be given by Government to announce the resumption of epilepsy services to avoid people with epilepsy becoming collateral damage during and beyond the pandemic.
- During and post-pandemic epilepsy deaths look set to increase. Extra support is needed to ensure these deaths are not just statistics, with the story behind each death recognised & opportunities for learning provided to the clinical and bereaved communities.
- To better understand the impact the COVID-19 pandemic is having on epilepsy clinicians, people with epilepsy & those bereaved by the condition, **SUDEP Action are leading 3 research projects involving the University of Oxford & Newcastle University, on impact of COVID-19 on epilepsy risk, their management and its impact on bereavement⁵.** So lesson can be learnt to save lives and improving services & support during the pandemic and beyond. Preliminary findings from the research has highlighted significant **cause for concern due to rising epilepsy risks, worsening mental health and increased isolation and trauma due to restricted or removed access to health services and support networks.**
- Rising levels of need are being picked up by third sector organisations from clinical, people with epilepsy and bereaved communities. There is varied and, in some areas, significant change to epilepsy service provision & access, with epilepsy specialists redeployed elsewhere. Concerns have been raised that patients are not accessing services during the current lockdown/pandemic and that new ways of service provision (eg Telehealth) while providing access, may be reducing the frequency of effective risk management reviews.
- Significant transformation work has involved neurology and epilepsy in the last 18 months. The pandemic hit at the time when implementing these resources was due to commence. It is imperative this work resumes as soon as safely possible to ensure epilepsy & the work completed does not once again fall off the agenda.

¹ NHS Rightcare Epilepsy Toolkit (Feb 2020): <https://www.england.nhs.uk/rightcare/products/pathways/epilepsy-toolkit/>

² The Learning Disabilities Mortality Review (LeDeR) Programme, [Annual Report 2019](#), published July 2020.

³ Royal College of Pathologists Guidelines on autopsy practice: [Deaths in patients with epilepsy including sudden deaths](#) (July 2019)

⁴ Hanna, J et al, [Executive summary and recommendations](#), Epilepsy & Behavior, Volume 103, 106650

⁵ <https://sudep.org/epilepsy-risks-and-COVID-19-survey-people-epilepsy>, <https://sudep.org/epilepsy-risks-and-COVID-19-survey-health-professionals> & <https://sudep.org/epilepsy-bereavement-and-COVID-19-survey>

- Downgrading of systems for information, questioning, learning and accountability after an epilepsy death is already being experienced by bereaved families; leading to increasing demand on SUDEP Action's specialist epilepsy bereavement support services (which include counselling and case-support). Many newly bereaved remain unaware of & aren't signposted to the specialist support available following an epilepsy death, leading to increased uncertainty and trauma.

1. **Neurology services have reported to SUDEP Action a dip in epilepsy referrals and a reluctance from patients to engage with existing services**, likely as a result of the pandemic. This is a grave concern as it suggests undiagnosed people with epilepsy are either struggling to get onto the diagnosis pathway due to increased demand on GP/Primary care services (a referral should happen within 2 weeks⁶), or are not presenting to hospital despite either new or worsening seizures and epilepsy symptoms.

"We have seen a collapse in referrals from General Practice. Neurologists redeployed to intensive care".

Midlands based Senior Clinician

"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)**

- a. Currently Neurology is not an NHS priority and epilepsy remains highly stigmatised. But **21 people with epilepsy die weekly in the UK**, many of which are in young and otherwise healthy people. **50% of all epilepsy deaths are thought to be potentially avoidable (pre-COVID-19)**⁷. We would anticipate avoidable deaths to increase as result. We are receiving concerns of rising epilepsy risks during the pandemic, on top of epilepsy risks already identified since 2018⁸.
- b. Sudden Unexpected Death in Epilepsy (SUDEP) accounts for a large proportion of epilepsy deaths each year in the UK, with those aged 20-40 being at elevated risk. Our clinical networks are voicing concern that continued flexing of staff away from epilepsy to COVID-19 care will result in increased SUDEP in the 20-40 age range, at a higher number than those of the same age dying due to COVID-19. Because of this fear, SUDEP Action are calling on Government to announce resumption of epilepsy services (like has already occurred for fertility & cancer services) to avoid people with epilepsy becoming collateral damage because of the pandemic.
- c. The Epilepsy Deaths Register contains data showing 10% of deaths reporting to the register were in those undiagnosed at the time of death⁹.
- d. 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 increased 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 & increased mortality risk, but all of which can be better managed if **care is patient-centred**¹⁰. These warning signals could currently be being missed if people with epilepsy (or awaiting diagnosis) are not able to, or aware of the importance of engaging with epilepsy services. Research into the impact of COVID19 on people with epilepsy has highlighted that 26% have experienced difficulty receiving care since the pandemic & Government measures began, with many also sharing concerns about engaging with healthcare¹¹:

"I had a bout of severe grand mal seizures for a week. Normally I would have gone to A&E and based on 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)**

- e. Already vulnerable groups such as those who are pregnant^{12 13}, who have a Learning Disability (LD)¹⁴ or other comorbidity, or are living in deprivation¹⁵ are known to be at increased risk of premature death (pre-COVID-

⁶ NICE, <http://www.nice.org.uk/guidance/cg137/chapter/1-guidance#information>

⁷ Mbvizo, G et al. [Epilepsy-Related Deaths Are A Major Public Health Problem: Results From A National Study Using Linked Administrative Health Data To Determine The Burden Of Epilepsy-Related Deaths And The Proportion That Are Potentially Avoidable](#). Epilepsia 2019;60(S2):S5-S248

⁸ Public Health England, report into [Deaths Associated with Neurological Conditions](#), March 2018

⁹ Thomas RH, Osland K. [Learning from Deaths – the Epilepsy Deaths Register](#), Epilepsy Behav. 2020 Feb;103(Pt B):106454. Epub 2019.

¹⁰ Shankar R, Jalihal V, Walker M et al. [A community study in Cornwall UK of sudden unexpected death in epilepsy \(SUDEP\) in a 9-year population sample](#). Seizure 2014;23(5):382-5.

¹¹ <https://sudep.org/epilepsy-risks-and-COVID-19-survey-people-epilepsy>

¹² MBRRACE maternal deaths report 2019, [summary via SUDEP Action](#).

¹³ Nashef L. [SUDEP and pregnancy](#). In: Hanna J, Panelli R, Jeffs T, Chapman D, editors. Continuing the global conversation [online]. SUDEP Action, SUDEP Aware & Epilepsy Australia; 2014

¹⁴ Royal College of Psychiatrists, Good Psychiatric Practice Guideline, [Management of epilepsy in adults with intellectual disability](#) (July 2017).

¹⁵ See reference 5

19) & often require regular multi-disciplinary team support which includes epilepsy care & risk management alongside other health management needs. An inability or reluctance to access these services due to the pandemic & its long-lasting effect could lead to increased avoidable deaths among these populations.

"I have had to fight for the appropriate medical practitioners to see me and my baby since the day I found out I was pregnant. None of which have been specialists in Epilepsy. I pray now that should I have a breakthrough seizure at any point in my pregnancy, delivery or as a Mother, that it will happen in a lucky location where I can access the correct medical care. Keeping my fingers crossed is all I have." **Research survey respondent**

2. **Risk management is vitally important to reducing avoidable epilepsy-related deaths**, highlighted in research, NICE Guidelines, Prevention of Future Death reports and Fatal Accident Inquiries. Moves to new methods of holding appointments put the already varied national practices of risk communication/review further at risk.

a. SUDEP Action's free award-winning clinical tool to support all clinicians involved in epilepsy patient care to support discussion and management of these risks (the [SUDEP and Seizure Safety Checklist](#)), demonstrating these fatal risks can be reduced if regularly discussed in a standardised way¹⁶; over 950 clinicians currently use the tool to manage epilepsy risks with their patients. The Checklist is cited as a key tool to be used for epilepsy risk discussions in the 2019 LeDeR report into deaths in people with Learning Disabilities and recognised as best practice in the NHS Rightcare Epilepsy Toolkit.

"Currently, there is a very large focus on COVID-19 and associated patients, but it's really important that we remember to care as best we can for epilepsy patients & to remain aware of the associated risk factors. During this time, people with epilepsy may be having difficulty collecting medications when self-isolating, getting through to their GPs or perhaps not wanting to feel a burden during the pandemic. This could be detrimental if risk factors are increasing, e.g. seizure frequency increasing. At this time, there is also potential for increased alcohol consumption as this can often accompany boredom in people staying at home. Lack of regular contact with relatives/friends who may have helped to monitor or notice changes in their 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." **A Paramedic working on the front line**

3. **Telehealth can help support engagement in healthcare for people with epilepsy**, who can struggle to attend appointments due to restrictions the condition places on them (eg: driving)¹⁷. The SUDEP & Seizure Checklist was successfully piloted in this way; showing increased patient/clinician engagement, allowing for early clinical intervention when potentially fatal risks were flagged. Standardised uptake of the tool as part of new methods of working would help ensure epilepsy risks & their reduction remain core to epilepsy care during & beyond the pandemic.

a. A third of clinicians involved in the research investigating the impact of COVID19 on epilepsy & risk cited using teleconference consultations more than 75% of the time, though 79% reported being less confident diagnosing patients in this way¹⁸.

"Telephone consultations generally ok. My biggest challenge is not being able to provide face to face epilepsy and midazolam training to care providers, which could ultimately put patients at risk." **Research Survey Respondent (Epilepsy Specialist Nurse)**

b. Consideration of continuing with such methods post-pandemic must include provision to enable vulnerable people with epilepsy such as those from deprived backgrounds or those with LD¹⁹ and the elderly, to effectively engage with these vital epilepsy services. As those in deprived areas are 3x more at risk of dying prematurely²⁰, and those with LD or other comorbidities are at significantly higher levels of risk²¹.

"Telephone appointments do not work for me. My Neuropsychology exercises need to be face to face so I have lost this support at the same time my medications were taken off me. I was not given enough time to talk with the on-call GP's and they didn't listen to my previous intolerance to the generic version nor did they know how complex my epilepsy was." **Research Survey Respondent (Person with epilepsy)**

¹⁶ Shankar, R., Henley, W.H., Boland et al, [Decreasing the risk of SUDEP: structured communication of risk factors for premature mortality in people with epilepsy](#). *Eur J Neurol*. 2018;

¹⁷ Brown, S Will teleneurology hit the big time? *The Lancet Neurology*, Volume 3, Issue 9, 517 - 518

¹⁸ <https://sudep.org/epilepsy-risks-and-COVID-19-survey-health-professionals>

¹⁹ See reference 10

²⁰ Public Health England, report into [Deaths Associated with Neurological Conditions](#), March 2018

²¹ See reference 2

4. **Systems are flexing to meet the needs of the pandemic, at the expense of other services. There are serious concerns among the clinical community we engage with that epilepsy services are being diminished & redeployed to support the COVID-19 pandemic** to such an extent that epilepsy patients are not able to adequately engage with healthcare about their epilepsy - putting lives at risk and resulting in increased deaths. National policy is not fully considering local service issues and pre-existing staff shortages - a balance between COVID-19 and existing health conditions is highly important.

“Wards and investigations and surgery closed. I have seen 4 deaths already in very short time. We are used to seeing excess mortality in normal times, but preliminary reports seem to suggest rising premature mortality in people with epilepsy” Professor Ley Sander, Academic Neurologist, UCL, London

“When lockdown started, we had very few people contact the emergency helpline for one once weekly urgent telephone clinic. As time has progressed, calls have become more frequent. I am concerned that reducing from 13 clinics per week to one is not sustainable for very long without significant risk. Additionally, in our trust, all neurologists (8) have been redeployed, bar one.” Midlands based Specialist Clinician

5. **Many epilepsy services are already incredibly stretched for their patient caseload. There is a growing concern among clinicians that services will not return to normal post-pandemic**, leaving even larger resource gaps. Any move towards services providing a ‘minimum standard’ of care could prove fatal to patients in some areas if it allows services to reduce their current offering. Especially as many services’ pre-pandemic were not able to provide a core epilepsy service beforehand.
6. With CQC also halting routine inspections of the services they monitor, there is a danger that epilepsy care and the varied standards for this nationally could be left to decline. Given the high risk of many people with LD & epilepsy of premature death, this is a worrying issue as it weakens this accountability system for ensuring patient safety.
7. The wider health and social impact on people with epilepsy is also a cause for concern, with worsening mental health, increased isolation and loss of income being shared with our COVID19 research team – added pressures which can impact on a person’s epilepsy, their condition management, risk levels and overall wellbeing:

“Because of social distancing I am alone a lot of the time which makes me feel unsafe if something was to happen my children would like have a huge responsibility.”

“Due to them not classing people with epilepsy as high risk. My partner chose to self-isolate due to the complex needs of my son’s epilepsy. In doing so. His company sacked him.”

“I have experienced increased anxiety. This was exacerbated after a seizure related fall and then things spiralled. My epilepsy & anxiety, like others is intertwined & every measure I had in place was removed at lockdown. It’s hard & it was sudden.” Research Survey Respondents (people with epilepsy)

8. **Since the pandemic hit, SUDEP Action have been supporting more bereaved families experiencing more complex trauma** (over 150 contacts for April-march). The bereaved are negotiating challenging post-death services yet there are further barriers due to COVID-19 as investigations & coronial services change. Those bereaved by epilepsy are also saying they feel excluded from public narrative about sudden grief, which is dominated by COVID-19 19 grief.
9. SUDEP Action’s support team, who are specialists at epilepsy bereavement counselling & casework, try to alleviate this experience of trauma with tailored support²², and the need for these services is set to be even more acute in future because of the wide-ranging impact of COVID-19. This is especially important as many of their coping strategies are now impossible due to the lockdown.

“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 heart-breaking, like I had forgotten him, although this could never happen. I wanted to scream so much the pain was so hard.” Research Survey Respondent (Bereaved Parent)

10. Despite this rising need, signposting to SUDEP Action’s free specialist service is not consistent (despite it being recommended by NHS Rightcare & the Royal College of Pathologists²³) & is concerning as the bereaved are increasingly isolated due to the pandemic.

²² Cowdry et al, [Learnings from supporting traumatic grief in the aftermath of sudden epilepsy deaths](#), Epilepsy & Behavior, V.103, 106416

²³ See reference 1 & 2.

11. Our research into the impact of COVID19 on those suddenly bereaved by epilepsy has highlighted the increasing impact the pandemic & Government's measures have had on this already traumatised community²⁴.
- 73% have been thinking more about the person who died since the outbreak started
 - Over 1/2 have experienced increased difficulties sleeping & increased distressing flashbacks
"I still miss him 15 years later. Flashbacks to [the] day of death, [are] worse during lockdown" **Research Survey Respondent (Bereaved person)**
 - 85% reported that the COVID outbreak and government response measures had negatively impacted on their mental health. 24% reported this was 'major' or 'severe'.
 - 67% reported that the COVID outbreak and government response-measures had negatively impacted on their access to support networks.
"I'm unable to have counselling, and I only have my husband to talk to, and he's also grieving, so I don't like burdening him with my sadness too much." **Research Survey Respondent (Bereaved person)**

Examples of the service changes affecting those bereaved by epilepsy due to COVID-19:

12. Investigations, Inquests and COVID-19

When someone is bereaved by epilepsy, there are many questions about the death, how it happened and what can be done to prevent others dying in the future. Bereaved families need answers as part of their grief. The investigation / inquest process can help this and also bring learning to the wider system, including researchers and clinicians. Since the pandemic we have noticed a down-grading of the system after death – of post-mortems; adjourned inquests, or not held at all, and aspects of the investigation process not happening.

"We are advocating for families bereaved by epilepsy to have inquests (even if they are delayed) and for investigations to be carried out so that they can get the answers they need, which helps with their complex, traumatic grief." **Tracy Cowdry, Dip. Couns Reg. MBACP, Bereavement Services Manager, SUDEP Action**

- COVID-19 and the need for social distancing means that some inquest hearings are using videoconferencing. SUDEP Action are hearing from those we support how this affects their ability to participate and ask questions – increasing the sense of isolation & being unheard.
- Alarmingly, we are seeing barriers to learning from deaths increasing. The Chief Coroner has issued guidance that inquests should not consider systematic issues relevant to avoidability of deaths²⁵. We share the concerns expressed by the BMJ and others – there is significant impact of on learning from deaths & also on bereaved families experiencing this²⁶. The coronial system has, before COVID-19, always included questioning and verdicts that include avoidable deaths reports, sending these to any involved institutions to consider how they can prevent future deaths.

13. Communication with a Trust during lockdown

A bereaved family (who have already waited many months for a clinical meeting to ask questions about their child's death), had the process halted in March due to lockdown. The process (dealing with questions and complaints) is underway again but will be further delayed arranging meeting (even if virtual) due to backlogs and clinical availability as a result of COVID-19. Delayed grief can exacerbate trauma. Models of communication with view to compassionate resolution for both family and clinician do exist and could be implemented.

14. Families bereaved by epilepsy experiencing COVID-19 deaths

SUDEP Action's specialist bereavement support team are supporting 3 families bereaved by epilepsy and who are now also experiencing COVID-19 deaths. One family had experienced two COVID-19 deaths following an epilepsy death earlier this year.

- Epilepsy deaths are particularly traumatic because it is sudden and unexpected. Some aspects of the experience of bereavement by COVID-19 will mirror & compound this impact.

15. **There is an imbalance of public reporting on COVID-19 deaths at time of rising excess mortality from other conditions.** Since 2013 SUDEP Action has collected data on epilepsy deaths (UK and internationally). 900 reports so far gather experiential data of services and impact before and after a death - this research enables lessons to be learnt from deaths so future lives can be saved²⁷. The charity & its research partners receive no systematic support, yet there is potential for this system to improve national understanding of epilepsy deaths if there was visibility.

²⁴ <https://sudep.org/epilepsy-bereavement-and-COVID-19-survey>

²⁵ Chief Coroner's Guidance No.37. [COVID-19 deaths and possible exposure in the workplace](#) (April 2020)

²⁶ BMJ [COVID-19: Coroners needn't investigate PPE policy failures in deaths of NHS staff, new guidance says](#) 2020;369:m1806 doi:

10.1136/bmj.m1806

²⁷ www.epilepsydeathsregister.org