

SUDEP Action



SUDEP.ORG



RAISING AWARENESS OF EPILEPSY RISKS AND TACKLING EPILEPSY DEATHS

 @SUDEPAction.org
 @SudepAction

What we do

WHAT WE DO

SUDEP Action exists to prevent epilepsy related deaths and to support those bereaved from epilepsy. Founded as a charity in 1995, we are the only UK charity specialised in supporting and involving people bereaved by an epilepsy related death. Epilepsy deaths can be traumatic, and in particular, some deaths from Sudden Unexpected Death in Epilepsy (SUDEP) leave many questions unanswered. It is this desire to answer questions that led to the creation of the charity, starting simply as five women determined to find out why their loved ones had died.

There are many more of us, collaborating, informing & supporting as many people as possible. We do this because we want to prevent the deaths we can, & make those we can't, matter.

We have five pillars to our work:

- Supporting the bereaved.
- Making every epilepsy death count.
- Producing research aimed at saving lives.
- Providing information.
- Involving everyone we can to help save lives.

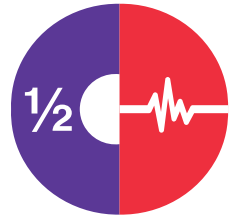
WHY IS THIS IMPORTANT?



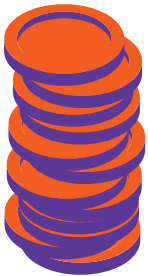
There are 3 epilepsy deaths each day in the UK (Approximately 1200 each year)



Epilepsy is in the TOP 10 causes of death in the young (under 35)



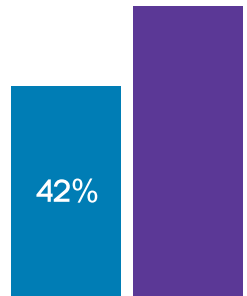
1/2 of all epilepsy deaths are SUDEP



Sudden death is 24 times more likely in people with epilepsy



Under 20% of clinicians openly discuss SUDEP & epilepsy risks with patients – this rises to over 80% where our Checklist & App are used



42% of epilepsy deaths are potentially avoidable



SUPPORTING THE BEREAVED

A sudden death is very traumatic. No two losses are the same, and no two people will grieve in the same way. So we are here, waiting to help, either emotionally or practically. We have qualified counsellors, with a special expertise in sudden death who understand the coroner and inquest process, staffing our support line.



WHAT WE PROVIDE

- Email and telephone support.
- Counselling.
- A valuable listening space.
- Opportunities to be with others who have been bereaved by epilepsy.
- Understanding of the investigation process and/or post mortem.
- Providing opportunities to meet and/or ask questions of experts in epilepsy and SUDEP.

“ Often, I would contact her, during the night via email, or if any nice things happened, the support and understanding was always there for me. The same person, so she knew all about me! I didn't need to explain, it just continued. ”



MAKING EVERY EPILEPSY DEATH COUNT

Making every death count and every life matter is important to us. As our commitment to this we created **The Epilepsy Deaths Register**, which is the single point for reporting all epilepsy-related deaths in the UK. This offers an online research platform for people to share their experiences. It also gives researchers the valuable chance to highlight recurring problems and themes, which can help prevent future deaths. It is through **The Epilepsy Deaths Register** that the information can go towards saving lives in the future.

If you can provide information about the death of someone with epilepsy, you can help. Please fill in the form at www.epilepsydeathsregister.org or provide information by phone on **0330 088 1220** or by email support@epilepsydeathsregister.org

The more information we have on epilepsy deaths, the sooner we will understand how best to stop them.

“ Without this critical information, others will not be able to benefit. As painful as it is, the form is simple and the results captured are vital to research. ”

PRODUCING RESEARCH AIMED AT SAVING LIVES

Research is essential in helping us prevent epilepsy deaths. Collaborating with various research facilities and clinicians both in the UK and internationally, is at the heart of what we do. We have worked on numerous award-winning projects and are always interested in more ways to collaborate. Above all, we make sure the research and projects we support not only reach policy makers and clinicians, but also the general public. Research needs to be in the hands of those that need it most. We cannot prevent every death, but further research can help us prevent more avoidable deaths.



SOME RECENT PROJECTS HAVE INCLUDED

Funding a clinical research trial of a **Wearable Apnoea Detection Device** which alerts people when someone with epilepsy stops breathing.

Collaborating in the development of the **SUDEP & Seizure Safety Checklist**, a free award winning tool to support clinicians in discussing and monitoring risk with their patients.

Creating **EpSMon**, an award winning smartphone app designed to allow people with epilepsy to measure their risk factors, their overall wellbeing and take positive steps to keep themselves safer.

The publication and dissemination of mortality research highlighting the risk of depression and suicide amongst people with epilepsy.

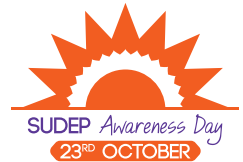
“EpSMon is another step forward. It brings life-saving knowledge to the fingertips of people with epilepsy.”

“We were impressed with the use of technology to overcome barriers and empower health professionals and patients to prevent deaths. The results are outstanding.”

PROVIDING INFORMATION

We want to ensure that all the research and information reaches the people that need it most. To do this we:

- Produce leaflets aimed at people with epilepsy and their carers to help them learn how they can reduce their risk.
- Created an award-winning app which people with epilepsy can download free from www.epsmon.com to help them monitor their risk.
- Publish latest epilepsy deaths and SUDEP research on our website.
- Created an award-winning Checklist for clinicians to support their risk communication with their epilepsy patients. Downloadable free from www.sudep.org/checklist
- Commission articles from the world's leading SUDEP experts to create a global resource for professionals and bereaved families at www.globalconversation.com
- Provide training, support & tools to doctors, carers and epilepsy support staff to help them talk to people with epilepsy about risk and SUDEP.
- Engage actively on social media.
- Organise a national conference and attend conferences to share our information.
- Created the annual SUDEP Awareness Day campaign which brings organisations and people together to raise awareness of SUDEP worldwide www.sudepawarenessday.org



INVOLVING EVERYONE WE CAN TO HELP SAVE LIVES

Central to our cause is involving everyone we can. We started as five, now we are many, with your help we could be more. There are various ways you can get involved. You can make a donation, start fundraising, or simply spread the awareness of risk. Even the simple action of telling someone about SUDEP can help prevent a death.

However you choose to help, we are thankful for your contribution. Please don't hesitate to get in touch should you have any ideas. We are only able to achieve our aim of reducing the number of epilepsy deaths through the efforts of people like you, standing with us and supporting us in achieving our goals.



WHAT NEXT?

At a time when simple health checks on people with epilepsy are no longer funded and general counselling services have long waiting lists, it is more vital than ever that we reach more people. Epilepsy deaths are often sudden and such deaths can lead to complicated grieving processes. With no care pathway after a sudden death, expert services like ours can be a lifeline for the bereaved. We will continue to work on the five pillars that we have mentioned here, but also we hope to significantly shine a focus on the fact that too many children are dying unnecessarily. There is much work to be done in this area.

A large part of our future can also include you. So please, join us help us, become part of our volunteering or fundraising team.

Why not even, simply pass this leaflet onto someone you feel may need it. You will be helping not just our future, but someone else's.

SUDEP Action is almost entirely funded by our fantastic supporters & bereaved families; without their support our work wouldn't be possible. If you can help us achieve our goals, get in touch at www.sudep.org or on **01235 772 850**

Special thanks to Luke Devereux for supporting the charity in production of this leaflet

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Epilepsy Bereaved (founded 1995) is part of SUDEP Action.