



Stopping preventable epilepsy deaths: SUDEP Action strategy for 2024-2027



SUDEP Action wants to see a world where no one dies unnecessarily from epilepsy and where those bereaved are aware of our services. This strategy sets out our vision for the future.

Stopping preventable epilepsy deaths is a huge challenge and one we can't achieve on our own. It will take collaboration, personal experiences, and determination to make this happen, but we won't stop, until deaths do.

Polish and Propel

We need to make sure we are ready to turn our vision for the future into a reality. We will therefore take time to 'polish' aspects of work that we do already and improve them, to increase and maximise impact.

We know we must grow in some areas if we want to 'propel' our work into the future – identifying new opportunities and ways of helping others, to reach more people who need us. To do this we will focus on three key areas.

HEAD

What we do, and the services we provide aren't replicated anywhere else in the world. We need to be bigger and bolder but remain true to what makes our work unique.

We are world-leaders in the field of understanding epilepsy deaths, their prevention and the provision of bereavement support following a death. With this comes the responsibility of continuing to push

for and influence change – which can be a challenge for a relatively small team looking to make a global difference.

To do this we will:

- Have a clear, ambitious plan, building on what we already do well to improve further and achieve our goals.
- Work positively with others, collaborating with those who recognise and value our mission.

Make a vision a reality

HEART

Our heart is our biggest strength – it helps us act with integrity and build long-lasting bonds with our supporters and wider networks.

We must continue to represent the bereaved community and challenge ourselves to make sure we're doing this well - keeping their experiences as the powerful beating heart of our work.

We need to grow our networks, audiences, and supporter base

through honest, personal and accessible engagement.

Maintaining relationships must be part of our clear plan.

To do this we will:

- Continue to provide opportunities for engagement with our supporters and wider networks. We will ask for feedback in various ways and review this regularly. We will seek feedback through social media and from events we hold, such as coffee clubs and conferences.

- Be honest with our supporters about the challenges ahead, helping them to easily play a part in our progress.

- Explain the breadth and complexity of our work regularly, succinctly and in different ways to galvanise support and show expertise.

- Show the power of our community, and the urgent need for change by sharing personal stories, testimonies and experiences.

Meaningful supporter engagement

VOICE

Being nimble and reactive to the world around us is a strength of SUDEP Action. It means we can quickly seize opportunities and act when it counts most.

We must balance this reactivity with a proactive plan, so we aren't distracted from achieving our ambitious mission.

We will review the services, information and resources we provide to make sure they're the best they can be. This will help us,

and our supporters to speak with a clear, united voice on the things that are most important – stopping preventable deaths and ensuring the bereaved have access to meaningful support.

To do this we will:

- Streamline how we work so we can remain focused on the challenges ahead while making sure we stick true to our mission.
- Keep our information crisp, short & punchy so:
 - we can continue to share the

latest, evidence-based information with those who need it.

- Help our supporters to be fantastic champions.
- Show where progress is happening and change is needed.

- Do all we can to raise the profile of epilepsy, epilepsy deaths and the work we do.

Getting media opportunities, celebrity endorsements and wider public attention isn't easy – but we'll be honest about this and make responsible progress where possible.

Speak with one consistent voice in all we do and say

Our three-year plan

Three years is a long time in the charity world, and our plans will need to adapt and grow over time. In the short to medium term, we will:

- Refresh our information, leaflets and resources.
- Create a new version of our EpSMon app.
- Share the SUDEP and Seizure Safety Checklist with more health professionals, both in the UK and internationally – removing barriers which are preventing these vital

discussions from taking place.

- Offer more opportunities for those bereaved by epilepsy to meet others who are bereaved like them. This will mainly be via coffee clubs, conferences, events and webinars.
- Expand our Bereavement Services so we can provide more expert, confidential support to anyone bereaved by epilepsy or fighting for answers through inquests and investigations.
- Raise more awareness of key issues facing our supporters with

MPs, policymakers, Government and the NHS.

- Collaborate with others across the epilepsy and bereavement communities to extend our reach, amplify our voice, and achieve more.
- Continue to fund vital but often neglected research into epilepsy deaths, their impact and their prevention.
- Refresh our training and education services for health professionals.

Clear objectives to take us forward

*We can't do all this without you.
You can you help us by:*

- Telling others about us and the work we do.
- Signing up to our e-newsletters to stay up to date with our work, the latest research, projects, resources and key awareness and fundraising events throughout the year.
- Pledging your support. This could be by getting involved in fundraising events, donating or leaving a gift in your will. SUDEP Action receives no Government funding – we're mostly funded by people like you who help us continue to be there for others.
- Following us across our social media platforms (including Facebook, Instagram, Twitter, LinkedIn & YouTube) and sharing our posts with friends, family and colleagues.

Thank you!

Let's take the journey together



SUDEP Action

Making every epilepsy death count

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Reg charity 1164250 (England & Wales), SCO 47223 (Scotland). Epilepsy Bereaved (founded 1995) is part of SUDEP Action.