

SUDEP Action Recruitment Pack

Welcome!

We're delighted you're interested in joining [SUDEP Action](#) as a member of our team. We're looking for someone to join our Bereavement Services team to help us make sure we can continue to support as many people bereaved by epilepsy as possible – could this be you?

Our Bereavement Services are at the heart of the work we do, so this is an important role in the charity. Included in this pack is some background information about the role and to help you get to know the charity, if you don't already. We are committed to fostering an inclusive environment where all individuals are valued and respected. Our charity recognizes that diverse perspectives strengthen our decision-making and enrich our work. We welcome applications from people of all backgrounds, experiences, and identities, and actively encourage those from underrepresented groups to apply. We strive to create a culture where everyone feels empowered to contribute and where differences are celebrated.

SUDEP Action is the only UK charity focused on stopping preventable epilepsy-related deaths. We have the only epilepsy bereavement service freely available to anyone suddenly bereaved by epilepsy (including SUDEP – [Sudden Unexpected Death in Epilepsy](#), when someone with epilepsy dies and no other cause can be found for their death). By representing the voices of those who have died and who are bereaved, we aim to learn from deaths, and use research, policy and campaigns to raise awareness and take action that helps save lives.

A large proportion of our supporters have been bereaved by epilepsy, with the majority of them being unaware of the risks linked to epilepsy before their loved ones' death. They work alongside us to do all we can to prevent epilepsy deaths and to ensure anyone bereaved by the condition has access to services to help them navigate the life-long devastation and grief they face. Because of this, a significant proportion of our board of trustees have direct experience of epilepsy bereavement or living with epilepsy.

This is an exciting time to join SUDEP Action, as we embark on our new strategy and continue to grow as a charity in our reach and impact. Our ambition is to:

- Stop preventable epilepsy deaths, and
- Be the 'go to' bereavement service for anyone who has experienced an epilepsy death.

To do this we will focus on:

- **HEAD** – continuing to show our leadership, ambition and collaborating with others to make change happen faster.
- **HEART** – providing meaningful supporter engagement as a central part of the work we do
- **VOICE** – speaking with a polished, cohesive voice, reflected in appearance and actions.

We're looking for someone with passion, sensitivity and enthusiasm to join us. We hope to hear from you soon,

Best wishes,

John Hirst
Chair of SUDEP Action Board of Trustees

Sammy Ashby
SUDEP Action Chief Executive

Who are SUDEP Action?

SUDEP Action is the only UK charity focused on stopping preventable epilepsy-related deaths. We have the only epilepsy bereavement service freely available to anyone suddenly bereaved by epilepsy (including by SUDEP, Sudden Unexpected Death in Epilepsy) – offering telephone support, counselling, expert help through inquests & investigations, and involvement in research through our Epilepsy Deaths Register. With nearly 3-decades experience in supporting the bereaved and fighting to stop deaths – we know the importance of working together to help others.

By representing the voices of those who have died and who are bereaved, we aim to learn from deaths, and use research, policy and campaigns to raise awareness & take action that helps save lives. Our supporters and volunteers are our heart – helping us raise awareness, funds & sharing their powerful personal experiences to drive our work forward.

We aim to break the isolation felt by people bereaved by epilepsy, providing world-leading advocacy to those who are struggling, and enable them to contribute to the work needed to prevent deaths. We also work with experts and organisations worldwide to provide free, award-winning resources and information on epilepsy risks, such as our EpSMon app and SUDEP and Seizure Safety Checklist, to help health professionals, people with epilepsy and their families to talk openly and improve safety.

We are a team of 14 but have exciting plans to grow over the coming years so we can achieve our ambitious strategy. Most of our team are based near our office in Wantage (Oxfordshire), though we have members of the team based in Wales, London, Buckinghamshire and Kent. You can read more about our fantastic team [here](#).

Why what we do is important:

- At least 21 epilepsy deaths each week in the UK – this figure is likely to be underestimated. Many of these deaths happen in people who are young and otherwise healthy.
- Up to 50% of these are SUDEP (Sudden Unexpected Death in Epilepsy - when someone with epilepsy, who is otherwise well, dies suddenly and no other cause can be found).
- It has been long thought that 42% of deaths were preventable, however recent research suggests today this figure could be between 50-80%.
- Despite the risks linked to epilepsy deaths being well researched, many people with epilepsy and their families still aren't told about them, so can't take steps to reduce them.
- Half of the bereaved people completing our Epilepsy Deaths Register were unaware epilepsy could be fatal before their loved one died. Yet research has also shown that regular risk communication and reviews can help people with epilepsy to lower their risks and live safer lives.
- We need all people with epilepsy & their families to know about risks, how they apply to them & how they may change over time, so they can take positive steps to reduce them and make informed choices that are right for them about their epilepsy care/treatment and lifestyle.
- Some groups are particularly vulnerable such as people with a learning disability, women during/after pregnancy, and young adults. However, SUDEP & preventable epilepsy deaths (eg: because of accidents/injuries, drownings, suicide & Status Epilepticus) can happen to anyone, at anytime, so should not be downplayed.

For more information and our annual report, visit our website: www.sudep.org

About the role:

We are looking for a new member of our Bereavement Services team, to grow our capacity and help us reach even more people bereaved by epilepsy. Our bereavement services are provided for free, completely confidentially, to anyone who needs us. Often via telephone or email support, though we also have a thriving and complex Casework Service, helping bereaved navigate the inquest or investigation into their loved one's death.

This new position will provide first-hand support to the existing team of 3, learning from their experiences and expertise about how we support people bereaved by epilepsy, and how this way of working influences the work we do across the charity.

You'll be learning the ropes from day 1, getting stuck in with any tasks needed to help support the Bereavement Services team – this could range from admin tasks, answering initial enquiries from bereaved supporters (via phone or email), and will eventually lead to you taking initial calls with bereaved supporters, sharing with them the different ways the charity can support them, and helping us understand how best we can help them. There is a real potential for this role to grow and develop with the right candidate.

Role:	Bereavement Services Officer
Location:	Hybrid / Remote. The SUDEP Action offices are based in Wantage, Oxon. All staff are expected to visit the office every 6 weeks for a team meeting as a minimum.
Accountable to:	Bereavement Services Manager (who is also the Deputy CEO)
Salary:	£24-28k
Hours:	3-4 days (21-28 hours) a week or full time (35 hours) considered
Probation & Notice	<ul style="list-style-type: none"> • 3-month probation period • 1-month notice period

Main responsibilities:

- **To support the Bereavement Services team with administrative duties to enable them to support even more bereaved individuals.**
 - Keeping records, spreadsheets and databases up to date with any Bereavement Services activities
 - Understanding the data collected by the Bereavement Services team and supporting them to interpret the data to feed into wider charity working and to help us show our impact, reach and how we're achieving our strategic ambitions.
- **To be the initial responder for all general charity enquiries and signpost them to the relevant staff members, or information/resources.**
 - Most contact with the charity is from bereaved individuals or people with epilepsy with questions or asking for help from the charity via email or phone.
 - This role will be the first point of contact for many, so plays a key part in 'triaging' what each contact needs and helping them receive this in a timely manner.
 - Understanding when requests are urgent (ie: time-sensitive or a safeguarding risk) and escalating to the Bereavement Services Manager for prioritisation.
 - A personable, sensitive approach is vital for this role given the nature of our work. Establishing a relationship of trust with supporters is important.
 - As is the ability to cope with vulnerable people sharing their personal, traumatic experiences.

- **To learn the Bereavement Services model used at the charity and how it affects our work.**
 - Each member of the SUDEP Action team has their areas of specialism and responsibility. Having a strong understanding of this will help the triage aspect of this role work smoothly and effectively. The successful candidate will also recognise when questions, support or areas of their role are outside of their remit, and seek support from either the Bereavement Services team or others in the wider charity team.
 - Over time, the right candidate will begin to take on more responsibility in this role, assisting the Bereavement Services team with a wider range of activities to help them support more people. For example, this could include beginning to take initial bereavement support calls and/or helping gather initial data from bereaved supporters wishing to engage with our Casework Service.

Things we all do at SUDEP Action:

- Act as a champion internally and externally for the work of SUDEP Action
- Attend and assist at SUDEP Action events and activities as required (this involves very occasional evening/weekend work)
- Adhere to SUDEP Action's policies and procedures
- Other ad hoc duties on occasion as required

Personal specification:

Essential:

- Empathetic approach to the issue of sudden epilepsy deaths and bereavement.
- Commitment to the organisation's strategic goal to stop preventable epilepsy deaths and providing first-class bereavement services to those who need it.
- A sensitive and open communicator, you will work collaboratively with your team and charity supporters to ensure delivery of a high-quality service where people feel listened to, safe and empowered.
- Confident in speaking with people over the telephone, some of which will be vulnerable.
- Able to act with confidentiality, particularly around information sharing and the rules around data protection - you lead by example, drawing on your own professional experience and working within established guidelines.
- A warm, inclusive approach to achieving goals quickly and correctly.
- Ability to work across multiple projects with accuracy and to set deadlines. Willingness to adapt to changing priorities.
- Self-disciplined to work in an office environment and at home.
- Friendly and able to work collaboratively as member of a team. Self-awareness to know when to ask others for help and advice.
- Practical and people-oriented - you will thrive working at a fast pace whilst maintaining accuracy and be a confident user of IT (including MSOffice).

Desirable:

- Applications will be particularly welcome from those who have worked in a bereavement setting, on a helpline/advisory/care service or a charity.
- A practical knowledge of issues facing people suddenly bereaved, and the long-term impact of grief on lives and communities – aware that being responsive to others needs and concerns, is essential.

What happens next:

Interested? Please send us a short covering letter (2-sides of A4 max) outlining your motivations for applying for the role and why you think you'd make a good fit for the SUDEP Action team. Please give specific examples to demonstrate your suitability to the role.

SUDEP Action is an equal opportunities employer, and we're committed to treating applications fairly. Initial shortlisting will be conducted by the Bereavement Services Manager, CEO and another relevant member of the team.

If you are shortlisted for this role, you'll receive an invitation for the next stage (a virtual interview). We'll send you details on anything you need to prepare. We usually have a maximum of a three-stage process before a final decision is made.

If you require any reasonable adjustments to be made as part of the application process, please email us via sarah.harris@sudep.org and we'll discuss this further with you.

Interviews: Tuesday 15th October 2024 (with the potential for a short 2nd interview Wednesday 16th October)