

SUDEP Action

SUDEP.ORG



Interim CEO

Candidate Information Pack

October 2024

Welcome

We're delighted you're interested in joining [SUDEP Action](#) as interim CEO. With our current CEO going on maternity leave, we're looking for someone with CEO experience who can efficiently step into this position and keep the work of the charity positively progressing towards achieving our ambitions and goals.

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 those who are bereaved, we aim to learn from their deaths and use research, policy and campaigns to raise awareness and take action that helps save lives.

A large proportion of our supporters are bereaved by epilepsy, with the majority of them being unaware of the risks linked to epilepsy before their loved one's 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.



John Hirst

Chair of SUDEP Action

Board of Trustees



Sammy Ashby

SUDEP Action

Chief Executive

Who are SUDEP Action?

With nearly 3-decades experience in supporting the bereaved and fighting to stop epilepsy related deaths – we know the importance of working together to help others. Our supporters and volunteers are our heart – helping us raise awareness, and funds as well as 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 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](#).

At SUDEP Action 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.

Why what we do is important

- There are 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 (e.g. because of accidents/injuries, drownings, suicide & Status Epilepticus) can happen to anyone, at any time, so should not be downplayed.

For more information and our annual report, visit our website: <http://www.sudep.org/>



About the role

Having recently embarked on our new strategy for the coming years, SUDEP Action has exciting times ahead.

The first phase of our strategy focuses on ‘polishing up’ the things we already do at the charity to make our work more impactful and efficient; so we can streamline people’s workloads, get long-standing ‘to do’ projects completed and reach even more people. This will take time but will lay the foundations for the next phase of our strategy which is more outward facing and will see us grow and seize new opportunities for the benefit of the epilepsy and epilepsy bereaved communities. This interim CEO role will play a key part in the polish phase of our strategy – the team have clear plans for this phase and will need a steady, experienced CEO to oversee, guide and champion this important part of our work. There will likely be strategic opportunities that need attention and nurturing during this period, though we anticipate that the taking on of any new opportunities will be kept to a minimum to allow the team to focus on what needs to be done.

This is an important time in the charity’s history, with a growing team working hard to meet the increasingly complex needs of epilepsy and epilepsy bereaved communities, so we need an interim CEO who isn’t afraid to get stuck in and can quickly get up and running to play a leading role in increasing our reach, impact and opportunities.

Across the team, there is a wealth of knowledge and expertise that the right candidate will tap into and nurture as part of their leadership. They will be supported in their role by the Deputy CEO (who heads up our Bereavement Services), a strong Management team and the Board of Trustees. While we’re currently in a good financial position and have a solid income stream from our fantastic Community Fundraisers, we cannot be complacent and need someone financially astute to ensure the charity remains sustainable and is able to continue to grow.

We’re looking for a positive communicator who can be clear, decisive and a champion for the charity whilst also showing real empathy for our mission, cause and our vulnerable audiences (especially those bereaved by epilepsy). Dealing on a daily basis with the devastation of preventable epilepsy deaths needs resilience, patience and a fair bit of creative determination – could this be your next challenge?

Role Description: Interim CEO

Key Information

Job Title:	Chief Executive Officer (Maternity cover)
Remuneration:	Circa £60k pro rata
Contract Type:	Fixed term contract starting in January
	The role will be for approximately 12 months, ideally with some handover time with the current CEO ahead of their maternity leave beginning, and the same on their return.
Accountable To:	Chair of the SUDEP Action Board
Location:	Hybrid working – This role will require office-based working at least 1-2 day per week. 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.
Time commitment:	3-4 days a week (21-28 hours)
Benefits:	25 days annual leave plus bank holidays & birthday leave, flexi time scheme, ride to work scheme
Probation Period:	3-month probation period
Notice Period:	3-month notice period

Key Responsibilities

- To provide leadership and strategic direction to SUDEP Action.
- To extend and champion the mission and work of SUDEP Action.
- To inspire and lead staff and management, ensuring a culture of continuous learning, inclusion, and support.
- To deliver a sustainable charity with strong funding and diverse income streams.
- To develop and maintain external relationships and partnerships.

- To positively promote the charity and its activities as widely as possible.

The interim CEO will work with the Board of Trustees, Senior Management and the wider team to deliver the following:

Strategy:

- Set and oversee the strategy for the charity.
- Nurture and develop existing strategic opportunities and relationships.
- Line manage members of the team to oversee the operational progress of the strategy.

Governance:

- Work with the Board of Trustees to implement the Charity's strategy, leading on the implementation of strategic goals and providing regular updates.
- Ensure that all charitable activities are legally compliant, meet regulatory requirements, and are in line with the aims of the Charity (for example duties relating to staff wellbeing, safeguarding and data protection).
- Ensure that all major risks are identified and regularly reviewed, and that systems and procedures are in place to mitigate all such risks.
- Work with the Chair to plan Board meetings, develop Trustees and produce the Annual Report for the Charity.

External Relations:

- Nurture collaborations with existing supporters, funders and partners.
- Build and manage effective relationships, partnerships and collaborations with new organisations that will further the aims of the Charity.
- Represent SUDEP Action and communicate confidently about what the Charity does and how.
- Oversee all external communications and partnerships to effectively promote SUDEP Action and its work.

Finance and Fundraising:

- Ensure that the Charity's financial resources are managed effectively.
- Oversee the overall budget for the Charity and report regularly to the Board and to funders as required.
- Oversee the creation and implementation of a fundraising strategy.
- Help to secure core and project funding to support the aims of the Charity.

Management:

- Oversee a stable, effective and thriving team, where staff and volunteers are able to work to their full potential towards the aims of the Charity.
- Alongside the Senior Management Team, take responsibility for high quality line management and support systems for staff.
- Provide mentoring and support to colleagues.
- Line manage the Senior Management Team and other members of the team as required.

Person Specification

Essential:

- Previous senior management or CEO experience within the not for profit sector.
- Commitment to further SUDEP Action's aims.
- Ability to inspire and motivate others, with the experience of leading and developing a staff team.
- Ability to oversee financial processes.
- Experience in successful fundraising.
- Excellent interpersonal, listening, collaboration and communication skills.
- Strong time management, self-management and organisational skills, with proven ability to organise and prioritise own and others' workloads.
- Commitment to supporting the mental wellbeing of staff and volunteers, and the safeguarding of those seeking the Charity's support.
- Flexibility to adapt and respond to different challenges in order to meet changing needs and priorities.

Desirable:

- Applications will be particularly welcome from those who have previously worked in a similar charity, or bereavement setting.

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.

How to Apply

Eastside People is supporting **SUDEP Action** in the recruitment for this role. Please [click here](#) to apply by submitting a CV and a covering letter.

Please use the cover letter (max 2 pages) as an opportunity to add to the information you have shared in your CV and ensure that you cover the following:

- Why you are interested in the interim CEO role at SUDEP Action and how the position is a good fit for your skills
- Your strategic experience as a senior leader in a not for profit organisation
- Key experience/knowledge in relation to the other skills and experience specified in the job description and person specification

If you would like a call to discuss the role in more detail, please email Bernice at bernice@eastsidepeople.org to arrange a convenient time. Having a call of this kind will not influence the success or otherwise of your application.

We want you to have every opportunity to demonstrate your skills, ability and potential. Please contact us if you require any assistance or adjustment so that we can make the application process work for you.

The closing date for applications is **25th November** with online shortlisting interviews taking place that week. Interviews with SUDEP Action will take place in early to mid December.

Eastside People is fully committed to equality of opportunity and diversity and works with our clients to ensure that we recruit inclusively, seeking to address the underrepresentation of some groups of people in leadership teams.



Eastside People

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