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National Epilepsy Week

23-29 May 2022 #EpilepsyTogether



National Epilepsy Week 2022

Let's spread the word - #EpilepsyTogether

It's currently **National Epilepsy Week** from **May 23–29**, and we're joining forces with other epilepsy charities to raise awareness of the condition. The theme of this year's campaign is **#EpilepsyTogether**

[Find out more here](#)

My Life with Epilepsy Project

We're excited to be leading the **My Life with Epilepsy** project, working with Speakup, Cornwall Partnership NHS Foundation Trust, University of Plymouth's Peninsula School of Medicine, and University of Sheffield's School of Education. We will be developing information and resources to help people with a learning disability and autistic people to better understand their epilepsy risks. The project has been made possible thanks to a grant from NHS England.



My Life with Epilepsy

[@SUDEPAction](https://sudep.org/my-life-epilepsy)
<https://sudep.org/my-life-epilepsy>

[Read more here](#)

EDR surpasses 1,000 registrations

More than 1,000 people bereaved by epilepsy-related deaths have now contributed their stories to the Epilepsy Deaths Register (EDR). Thanks to each and every one of you, the EDR has grown to become the largest and most powerful collection of information on epilepsy deaths in the world.

Through the information the EDR provides, researchers and clinicians can increase their understanding of epilepsy, circumstances around epilepsy death and risk factors.

[Learn more about the Register here](#)



Our position on sodium valproate

There has been significant press of late relating to the use of sodium valproate, a medication given to pregnant women with epilepsy over many decades without proper warnings about its potential risks to unborn children. We stand with these women; their stories have been neglected for too long. **We believe however, that discussions about sodium valproate must not take place in isolation and that SUDEP / mortality risks are also considered alongside so women can make informed choices.**

[Read our full statement here](#)



Could you take part in a sponsored run for SUDEP Action?

Could you take part in a sponsored running event and help us continue to support those with, or bereaved by, epilepsy?

From 5K or 10K runs to marathons and bouncy obstacle courses, there are lots of events to choose from set in locations around the country.

[Click here to find out more](#) or email fundraising@sudep.org if you would like us to help find an event for you.

Save the dates – and thank you!

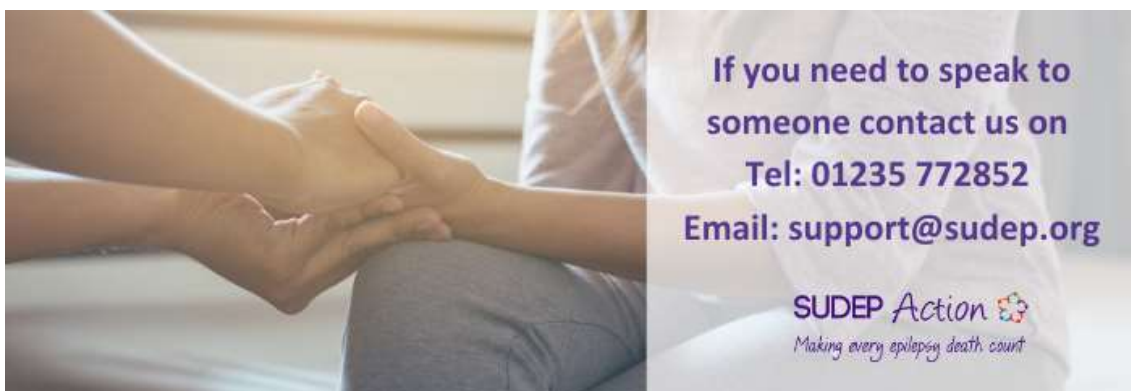
June 1-7 is Volunteering Week – follow us on social media for new stories and potential announcements

Wednesday October 19 is SUDEP Action Day! Want to get involved?
Drop us a line at info@sudep.org

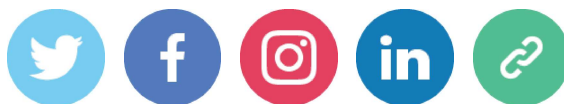
Thank you to everyone who supported [Purple Hearts for Purple Day](#) and our [Online Epilepsy Memorial Day](#).

If you missed Jane's blog on Online Epilepsy Memorial Day you can [read it here](#).

Because of you, these events were a great success.



You can also follow us on social media...



SUDEP Action and SUDEP Action Scotland are the working names of Epilepsy Bereaved Registered
Registered charity number 1164250 (England & Wales), SC047223 (Scotland).

Our mailing address is:

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