

Be a part of SUDEP Action Day – 23 October 2019 #5ForEpilepsySafety

Launched on 23 October 2014 by <u>SUDEP Action</u> (as SUDEP Awareness Day), this international day supported by over 80 epilepsy organisations worldwide, shines a light on one of the largest causes of death in people with epilepsy, helping empower people through increased awareness.

#SUDEPACTIONDAY2019

Why is it called SUDEP Action Day?

Because there are **21 epilepsy deaths a week** in the UK alone – awareness is not enough, it's time to take action!

Many people with epilepsy are not told about SUDEP. They are unaware of the risks linked to epilepsy/SUDEP, so cannot take steps to reduce any risks they have or make informed choices about their epilepsy.

SUDEP = Sudden Unexpected

Death in Epilepsy

When someone with epilepsy dies and no other cause can be found

It is thought many deaths can be prevented with positive action, meaning the lives of many young and otherwise healthy people could be saved each year.

As leaders in SUDEP and epilepsy deaths for over **24 years**, SUDEP Action know the topic of SUDEP raises questions and can be worrying for some to think about. But SUDEP Action Day is here to help **people take small positive steps** towards reducing their epilepsy risks.

How can MPs and Policy Makers help?

Join us and take **#5forEpilepsySafety** against the challenges linked to SUDEP. Whether you have lots or a little time to give, you and your colleagues can play an important part in helping us bring epilepsy and SUDEP out of the shadows to help save lives.

Help make a difference and show your support of SUDEP Action Day by taking 5 minutes to:

Share a supportive social media message about SUDEP Action Day on October 23rd

Suggested message:

Today is #SUDEPACTIONDAY2019

Today I stand alongside @SudepAction to raise awareness of #SUDEP and how people with #epilepsy can take positive steps to reduce their risks

Find out more & join me in supporting this important day: www.sudepactionday.org

(Alternatively a recorded message would be fantastic!)

Spread word about SUDEP Action Day 2019 through your constituency newsletter & surgeries

Suggested text:

SUDEP Action Day (October 23rd) shines a light on one of the largest causes of death in people with epilepsy, helping empower people through increased awareness. There are 21 epilepsy deaths a week in the UK, many of them preventable, and this international event helps people take small positive steps to reducing epilepsy risks; steps which could be lifesaving for some.

Many people with epilepsy are not told about SUDEP (Sudden Unexpected Death in Epilepsy), so do not know about its risks and what they can do to reduce them. That is why SUDEP Action Day is so important – helping people with epilepsy around the world to live well.

<u>SUDEP Action</u> who run the day, have created free resources and information to help people get involved in raising awareness. There are also many ideas on how you can help at <u>www.sudepawarenessday.org</u>

Wear orange and a SUDEP Action badge in Parliament on October 23rd

Post your picture on SUDEP Action Day using #SUDEPACTIONDAY2019 (this image could accompany the supportive social message above)

Contact SUDEP Action via campaigns@sudep.org for a badge



Raise SUDEP Action's key asks in Parliament and put down some Parliamentary questions on epilepsy deaths and SUDEP to Ministers

The MP Briefing is available to download here

Please contact SUDEP Action via campaigns@sudep.org for Parliamentary Questions

Sign your name to SUDEP Action & the epilepsy coalition's letter calling for Government to keep people with epilepsy safe regardless of Brexit outcome

See the open letter <u>here</u>

Add your name by contacting campaigns@sudep.org and encourage colleagues to also support