

## Be a part of SUDEP Action Day – 20<sup>th</sup> October 2021

#Time2Change #SUDEPACTIONDAY2021

**SUDEP Action Day** is an international day supported by over 100 epilepsy organisations worldwide, shines a light on one of the largest causes of death in people with epilepsy, helping empower people through increased awareness.

### Why is it needed?

**Because there are at least 21 epilepsy deaths a week in the UK alone.** 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*

**Over 42% of epilepsy deaths are thought to be preventable with positive action**, meaning the lives of the mostly young, and otherwise healthy people who die could be saved each year. **Many people with epilepsy are still not told about SUDEP or epilepsy risks – its #Time2Change this** – so everyone receives this vital health information which could help them get access to the right care and save lives.

As leaders in SUDEP and epilepsy deaths for over 25 years, [SUDEP Action](#) know the topic of SUDEP, and 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 show its #Time2Change what people think about SUDEP & epilepsy risks this SUDEP Action Day. You and your colleagues can play an important part in bringing epilepsy and SUDEP out of the shadows to help save lives.

#### 1. Share a supportive social media message about SUDEP Action Day on October 20<sup>th</sup>

##### Suggested message:

*Everyone with #epilepsy should be told about #SUDEP & epilepsy risks, but many still aren't – it is #Time2Change this, which is why I support #SUDEPACTIONDAY2021. Find out more & join me in supporting this important day: [www.sudepactionday.org](http://www.sudepactionday.org)*

(Alternatively, a recorded message would be fantastic!)

Consider also wearing orange and/or a [SUDEP Action Day badge](#) in Parliament on October 20<sup>th</sup>.

#### 2. Table some Parliamentary questions on epilepsy deaths and SUDEP, & help SUDEP Action get access to Ministers (bereaved families have written 12 times since 2018 – can you help them?)

Please contact SUDEP Action via [sarah.harris@sudep.org](mailto:sarah.harris@sudep.org) for Parliamentary Questions

#### 3. Spread the word about SUDEP Action Day 2021 through your constituency newsletter & surgeries

##### Suggested text:

SUDEP Action Day (October 20<sup>th</sup> 2021) shines a light on one of the largest causes of death in people with epilepsy; Sudden Unexpected Death in Epilepsy, or SUDEP. It helps 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 and epilepsy risks, so cannot take simple actions to reduce any risks they face. But there are often many things which can be done to reduce epilepsy risks if people are told about them. That is why SUDEP Action day is so important – helping people with epilepsy around the world to live well.

[SUDEP Action](#) who run the day, have created free resources and information to help people get involved in raising awareness – the theme this year is #Time2Change – as it is unacceptable that people with epilepsy & their families are still not receiving this vital, life-saving health information.

There are many ideas on how you can help available here: [www.sudepactionday.org](http://www.sudepactionday.org)