SUDEP stands for SUDDEN UNEXPECTED DEATH in EPILEPSY. It is when a person with epilepsy dies suddenly and prematurely and no other cause of death is found.

There are 600,000 people with EPILEPSY in the UK.

21 people with EPILEPSY die every week in the UK.

1 in 103 people are diagnosed with epilepsy.

Over 1,000 epilepsy deaths a year.

The causes of SUDEP are currently unknown.

It can happen to both adults and children with epilepsy.

Up to 50% of epilepsy related deaths are SUDEP.

The best way to lower risks of SUDEP is by achieving seizure freedom.

In the UK 52% of people with epilepsy are seizure free.

70% could become so with the right treatment and advice.

52%

70%
RISK FACTORS INCLUDE

- Having seizures at night or seizures when asleep
- Not taking medication regularly and as prescribed
- Having tonic clonic seizures (sometimes called Grand-Mal or Convulsive Seizures)
- Having active seizures not controlled by medication
- Having complex health needs eg: learning disability, other health conditions or pregnancy

Risks vary between people and can change over time – speak to your Health Professional about your individual risks.

You don't have to have frequent seizures to be at risk from SUDEP. Even if your seizures are controlled you should still take your medication and have a regular review.

Don't make any changes to your epilepsy treatment without first speaking with your Health Professional.
TAKE POSITIVE ACTION

Be aware
of your epilepsy risks – knowledge saves lives; risk doesn’t have to be scary with the right information

Be open
with yourself and others about your epilepsy and any risks you may face – help smash the stigma

Be proactive
about risk – take positive actions to reduce them, for example:

Discuss epilepsy/SUDEP risks with your Health Professional – take information to support you if helpful

Request a regular review with your Health Professional to discuss your epilepsy, risks and any changes

Create a care plan with your Health Professionals to show the best ways to help you live well

Take control of checking your epilepsy in-between medical appointments: tools like seizure diaries, medication reminders and risk monitoring apps can help you stay aware and in control

#SUDEPActionDay2021
www.sudepactionday.org