



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

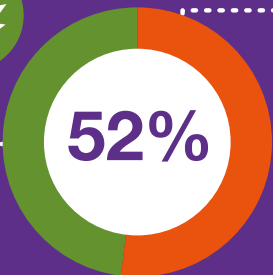


It can happen
to both adults
and children
with epilepsy

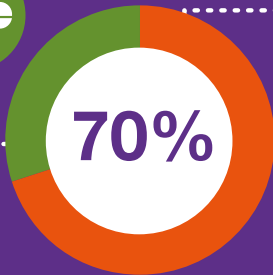


Up to 50% of
epilepsy related
deaths are SUDEP

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

RISK FACTORS INCLUDE



Having active seizures not controlled by medication



Not taking medication regularly and as prescribed



Having tonic clonic seizures (sometimes called Grand-Mal or Convulsive Seizures)



Having seizures at night or seizures when asleep



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

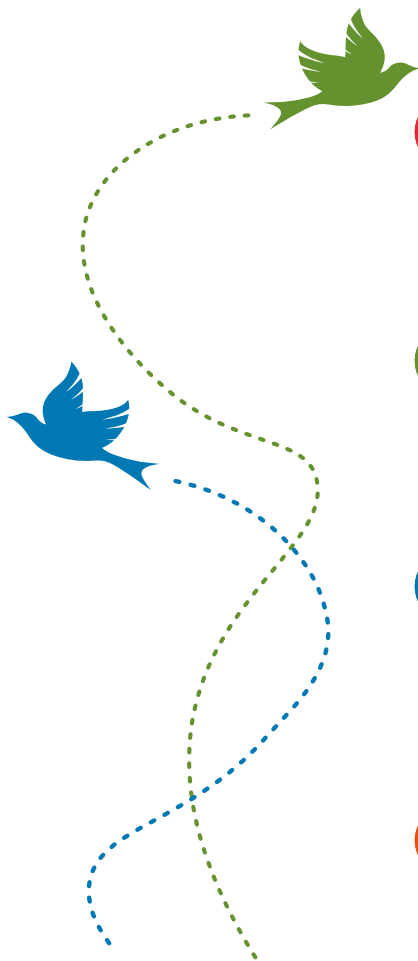
of your epilepsy risks – knowledge saves lives;
risk doesn't have to be scary with the right information


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

#SUDEPACTIONDay2020

www.sudepactionday.org