

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

**50%**

Up to 50% of  
epilepsy related  
deaths are SUDEP

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



**52%**

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



**70%**

**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