

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