**WHY IS THIS CHECKLIST NEEDED?**

Epilepsy is not a benign condition. Fatalities including SUDDEN UNEXPECTED DEATH IN EPILEPSY (SUDEP) do happen in some people with epilepsy.

The best protection is being aware of these risks and putting steps in place to improve known risk factors.

An estimated 1.16 per 1000 people with epilepsy die suddenly each year with approximately half of these from SUDEP. Comparing years of potential life lost from neurological disease, epilepsy is second only to stroke.

SUDEP is considered the most common cause of epilepsy-related death. Other causes are prolonged seizures (status epilepticus), accidents (such as drowning & falls) and suicide.

The causes of SUDEP like SIDS remain under investigation but there is a good and growing body of evidence on risk factors that can be used to support people take simple actions to reduce risk.

**RESEARCH SHOWS RISKS FACTORS INCLUDE**

- Having either generalised tonic-clonic, nocturnal or status epilepticus seizures.
- Life-style and well-being risk factors such as not taking medications or picking up prescriptions; alcohol and substance abuse and depression.
- Pregnancy is also associated with higher risk for mother and unborn child.

Evidence has shown that many people who died from epilepsy, especially those of a younger age were not appropriately accessing health services prior to their death.

National reports and judicial inquiries going back to 2002 have established many thousands of deaths might be avoided through improved awareness of risk and simple measures such as a care plan which steps-up care when this is needed.

**REMEMBER**

To learn more about the SUDEP & SEIZURE Safety Checklist, please visit: www.sudep.org/checklist

Where you can register you interest in the Checklist and read the BMJ article about this tool.

For information and research on SUDEP visit [www.sudep.org](http://www.sudep.org) and [www.sudepglobalconversation.org](http://www.sudepglobalconversation.org)

**SUDEP Action**

*SUDEP.ORG*
The SUDEP & SEIZURE Safety Checklist is an evidence-based clinical tool for health professionals. It is designed to support risk communication as part of any review of an epilepsy care plan or consultation for adults (if clinically appropriate).

The SUDEP & SEIZURE Safety Checklist has been developed and used in routine practice in Cornwall. The development group includes UK-wide experts and GPs as well as people with epilepsy.

**TEN MINUTE RISK ASSESSMENT TOOL**

- assists clinicians to open a positive discussion with people about epilepsy and risk assessment.
- supports a person-centred discussion of risk, focusing on whether known risk factors apply to a particular patient.
- helps clinicians educate people with epilepsy about their personal risk and possible lifestyle changes which might reduce those risks.
- promotes the goal of patient safety by identifying modifiable risk factors which may guide treatment.
- creates documentary evidence for clinicians on the impact of the treatment plan over time, and demonstrates effective clinical governance while enhancing patient safety.
- provides some assurance to bereaved families that every effort was made to reduce risk and prevent a fatality if a death occurs.

**SUDEP & SEIZURE Safety Checklist**

**HOW IT WORKS**

The Checklist is an Excel spreadsheet listing the factors of interest with boxes for the responses to each factor.

An initial risk assessment is conducted with the patient during their first consultation to provide an individual baseline risk rating.

The Checklist can be repeated at the annual review. However it should also be repeated when a patient with unstable epilepsy or identified high risk returns for a follow up, or when there is a change of treatment.

The SUDEP & SEIZURE Safety Checklist includes 19 factors and 64 key scientific references.

Factors for sudden death include generalised tonic-clonic seizures and nocturnal seizures, non-adherence and absence of supervision.

**HOW CAN I SUPPORT MY PATIENTS?**

- Use the Checklist as part of your standard clinical practice for patients with epilepsy.
- Openly discuss risk with your patients while completing the Checklist.
- Give advice about flagged risks at the same time.
- Ensure your patients attend regular medical reviews.
- Encourage them to become proactive in managing their epilepsy.
- Tell them about EpSMon, the mobile App (based on the Checklist) for people with epilepsy to help them self-monitor their health risks in between visits to their doctors.

www epsmon com

Epilepsy clinicians have found the tool simple and quick to use (5-10 minutes in clinic)

The assessment can be filed in the patient’s medical history