

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 your interest in the Checklist and read the **BMJ** article about this tool.

For information and research on SUDEP visit **www.sudep.org** and **www.sudepglobalconversation.org**

SUDEP Action 
SUDEP.ORG

Royal Cornwall Hospitals 
NHS Trust

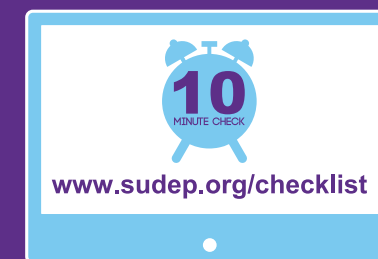
Cornwall Partnership 
NHS Foundation Trust

The **SUDEP & SEIZURE** Safety Checklist is a collaboration between SUDEP Action, Cornwall Partnership NHS Trust and Cornwall Royal NHS Foundation Trust. The Checklist Project was part sponsored by SUDEP Action helped by Kt's Fund.

SUDEP Action & SUDEP Action Scotland are the working names of Epilepsy Bereaved.
Registered charity 1050459 (England & Wales), SC045208 (Scotland).


SUDEP & SEIZURE
Safety Checklist

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Evidenced Epilepsy Management for clinicians

Assess your patients over time
Prioritise clinical activity

the **bmj** awards
WINNER 2016



ABOUT

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 **41 key scientific references**.

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

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

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.epsmmon.com



epsmmon.com

