

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.

There are approximately 1000 sudden epilepsy-related deaths each year, with half of these from SUDEP (1.16 per 1000 people with epilepsy).

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.

The Checklist covers risk factors associated with both SUDEP & Epilepsy mortality.

The above a just some of the known risk factors.

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.

Reports and judicial inquiries 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 more about the research underpinning the 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

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SUDEP Action, registered charity
1164250 (England & Wales), SC047223 (Scotland)
Epilepsy Bereaved (founded 1995) is part of SUDEP Action


SUDEP & SEIZURE
Safety Checklist

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QUICK CHECK

ABOUT

The Checklist is designed to support epilepsy risk communication between patient and clinicians, as part of a consultation or annual review.

The **SUDEP & SEIZURE** Safety Checklist has been developed and used in routine practice in Cornwall. It is supported by a UK Development Group of leading experts in the field.

The Safety Checklist includes 18 risk factors and is underpinned by 47 key scientific references on the topic of epilepsy mortality and SUDEP.

TEN MINUTE RISK ASSESSMENT TOOL

- Helps clinicians to open positive discussions with patients about epilepsy, risk monitoring & actions to minimise them.
- Supports a person-centred discussion of risk, focusing on whether known risk factors apply to a particular patient and how these may change over time.
- Helps clinicians educate people with epilepsy about their personal risks and possible lifestyle changes and actions / treatment that might reduce those risks.
- Provides clinical documentation on repeated risk discussion and management decisions.
- Provides some assurance to families bereaved by epilepsy if a death occurs, that every effort was made to reduce risk.

SUDEP & SEIZURE Safety Checklist

HOW IT WORKS

The Checklist is a Word document listing risk factors flagged as being significant to epilepsy mortality and SUDEP (Sudden Unexpected Death in Epilepsy). Giving clinicians a tool to check flagged risks and note actions available to reduce them.

It works alongside and enhances existing risk assessment practices already in place.

An initial risk assessment is carried out with the patient during their first consultation to provide a baseline rating. The Checklist can then be repeated at annual review. However it should also be repeated at more regular intervals when a patient had unstable / changing epilepsy or is undergoing a change in treatment. Those identified previously as high risk may also benefit.

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 Checklist is being used by clinicians working with people with epilepsy across clinical and community settings. They have found the tool simple and quick to use:

“The checklist has supported me to hold difficult discussions, to educate people and to provide reassurance/advice”

“All epilepsy nurses in our team and all consultants use the Checklist”

“I do talk more about SUDEP with patients and carers than I did before. It has made it easier to bring it up as part of the wider risk assessment.”

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



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