

The SUDEP and Seizure Safety Checklist **An introduction for Health Professionals**

Here is a short guide to tell you about the SUDEP and Seizure Safety Checklist and how it helps clinicians to monitor and assess their patients' with epilepsy's risks.

What is the SUDEP and Seizure Safety Checklist?

The SUDEP and Seizure Safety Checklist is an evidence based clinical tool is designed to support risk communication as part of any review of an epilepsy care plan or consultation (if clinically appropriate). The SUDEP and Seizure Safety Checklist has been used in routine practice and welcomed by patients and clinicians in Cornwall. The development group includes UK-wide experts and GPs as well as people with epilepsy.

The 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.

The Checklist is an Excel spreadsheet listing the factors of interest with drop down 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, taking 5-10 minutes to complete. The Checklist can be repeated at the annual review, when the patient with unstable epilepsy or identified high risk returns for a follow up, or when there is a change of treatment. The assessment can then be filed in the patient's medical history.

You can find out more information and register for this tool at www.sudep.org/checklist.

Why is this Checklist needed?

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. In 2013 there were 680 deaths from epilepsy among people aged under 75 (973 deaths at all ages) in England and Wales. Comparing years of potential life lost from neurological disease, epilepsy is second only to stroke.

Sudden death in epilepsy is considered the most common cause of epilepsy-related death. SUDEP peaks in young adults, particularly men, for example 20 year old with epilepsy has a greater than 1% risk of dying before he reaches 30, before adding other known risks for sudden death.

Other causes are prolonged seizure(s) known as status epilepticus, accidents and suicide. The cause(s) 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.

The research on risk factors includes seizures in particular generalised tonic-clonic, nocturnal and status epilepticus seizures, and 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. In Cornwall research showed that people who have died are known to have had a worsening of risk factors in the 3 months before their death but only 20% were in contact with their specialist in the year prior they died. 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 step-up care when this is needed.

Further information regarding risk factors can be found on www.sudep.org in the '[Information](#)' and '[Research and Education](#)' sections.

How can I support my patients in monitoring their risks?

Using the SUDEP and Seizure Safety Checklist as part of your standard clinical practice for patients with epilepsy is a great start to supporting them as you are already openly discussing risk with them and can provide advice to help them address any risks that are flagged up. Ensuring your patients attend regular medical reviews will also support their self-management of their epilepsy.

In addition to this you may want to tell them about EpSMon, the mobile App for people with epilepsy to help them self-monitor their health risks in between visits to their doctors. EpSMon shows the user which health risks are getting better, which have worsened and which have stayed the same to encourage a discussion about these risks with their GP or epilepsy specialist. It can also help them decide whether to seek help earlier than their next planned appointment. Further information can be found at www.epsmmon.com.

You can get EpSMon information leaflets, cards and posters from us that can be given to patients or can be displayed in your practice from info@sudep.org

Who has developed the Checklist?

The SUDEP and Seizure Safety Checklist development group includes:

Project Lead

Dr Rohit Shankar, Consultant in Adult Developmental Neuropsychiatry, Cornwall Partnership NHS Foundation Trust

Secretariat

Jane Hanna OBE, Chief Executive SUDEP Action, SUDEP Action Lead

Dr Rosey Panelli, International Research Officer, SUDEP Action

Alex Osland, SUDEP Action

Specialist medical advisors

Dr Brendan McLean, Consultant Neurologist, The Royal Cornwall Hospitals NHS Trust

Professor Mathew Walker, Professor of Neurology and Clinical Epilepsy, UCL Institute of Neurology

Professor Josemir W Sander, Professor of Neurology and Clinical Epilepsy, UCL Institute of Neurology

Dr Craig Newman, Clinical Psychologist, Plymouth University

Professor Phil Smith, President Elect of the Association of British Neurologists, University Hospital of Wales

Dr John Craig, Consultant Neurologist, Belfast Health and Social Care Trust

Dr David Cox, Consultant Neuropsychiatrist Cornwall Partnership NHS Foundation Trust

Dr John-Paul Leach, Consultant Neurologist, Southern General Hospital, Glasgow

GP medical advisors

Professor Henry Smithson, Professor of General Practice, University College Cork & University of Sheffield (Hon)
Dr Tamsyn Anderson, GP Partner and board member of NHS Kernow, NHS Kernow CCG
Professor Leone Ridsdale, Professor of Neurology & General Practice, Kings College London

Specialist epilepsy nurse advisors

Caryn Jory, Epilepsy Specialist Nurse, Cornwall Partnership NHS Foundation Trust
Mary Parratt, Epilepsy Specialist Nurse, The Royal Cornwall Hospitals NHS Trust
Juliet Ashton, Epilepsy Specialist Nurse, Epilepsy Society

Other advisors

Dr Emma Carlyon, HM Coroner, Cornwall
Simon Lees, Person with Epilepsy, Advisor with lived experience
Nathan Trevena, Person with Epilepsy, Advisor with lived experience

For further information:

To find out more about the SUDEP and Seizure Safety Checklist, visit www.sudep.org/checklist.

For EpSMon information, please visit www.epsmon.com

Additional information and resources are also available on www.sudep.org

References

1. Brown S, Shankar R, Cox D, McLean B, Jory C. Clinical governance: risk assessment in SUDEP. *Clin Govern Int J* 2013;18(4):325-31.
2. Hanna J & Wannamaker BB. Judicial reports on avoidable deaths. In: Hanna J, Panelli R, Jeffs T, Chapman D, editors. *Continuing the global conversation. SUDEP Action, SUDEP Aware & Epilepsy Australia*; 2014. Available from: www.sudepglobalconversation.com.
3. Hanna NJ, Black M, Sander JWS, Smithson WH, Appleton R, Brown S, et al. The national sentinel clinical audit of epilepsy related death: epilepsy - death in the shadows: The Stationary Office; 2002. <https://www.sudep.org/national-audit-epilepsy-deaths-0>
4. Office for National Statistics. *Death registrations summary tables, England and Wales, 2013. 2014.* www.ons.gov.uk/ons/rel/vsob1/death-reg-sum-tables/2013/index.html
5. Shankar R, Jalihal V, Walker M, Laugharne R, McLean B, Carlyon E, et al. A community study in Cornwall UK of sudden unexpected death in epilepsy (SUDEP) in a 9-year population sample. *Seizure* 2014;23(5):382-5. <http://www.ncbi.nlm.nih.gov/pubmed/24630808>
6. Shankar R, Newman C, Hanna J, Ashton J, Caryn J, McLean B et al. Keeping patients with epilepsy safe: a surmountable challenge? 2015;4: doi:10.1136/bmjquality.u208167.w3252. <http://qir.bmi.com/content/4/1/u208167.w3252.full>
7. Thurman DJ, Hesdorffer DC, French JA. Sudden unexpected death in epilepsy: assessing the public health burden. *Epilepsia* 2014;55:1479-85