



The SUDEP and Seizure Safety Checklist
The past, the present, and the future.

Samantha Parker
7/7/18






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

Origins of the SUDEP and Seizure Safety Checklist

42% of epilepsy deaths were viewed as potentially avoidable (Hanna et al., 2002).


80% showed no specialist contact for their epilepsy 1 year before death

90% showed their epilepsy worsened 3-6 months before death.

SUDEP Action 
Cornwall Partnership 
NHS Foundation Trust

Version 1 launched in May 2015

Hanna N J, Black M, Sander JWS, Smithson WH, Appleton R, Brown S, Fish DR (2002) The National Sentinel Clinical Audit of Epilepsy-Related Death: Epilepsy—death in the shadows. The Stationery Office.
Shankar, R., Jalihal, V., Walker, M., Laugharne, R., McLean, B., & Carlyon, E. et al. (2014). A community study in Cornwall UK of sudden unexpected death in epilepsy (SUDEP) in a 9-year population sample. Seizure, 23(5), 382-385. <http://dx.doi.org/10.1016/j.seizure.2014.02.005>

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SUDEP AND SEIZURE SAFETY CHECK LIST (Adults)				Review Results		
ID	Risk Factor	Suggested Prompt	Evidence	dd/mm/yyyy	dd/mm/yyyy	dd/mm/yyyy
BACKGROUND						
1	Unclear seizure frequency or treatment history	Refer to patient notes. If history poor discuss with patient the benefit of regular monitoring.	Poor medical records highlighted as possible flag for risk (3, 19, 20)			
2	Duration of epilepsy more than 15 years	Refer to patient notes	Combined data from four SUDEP case-control studies found 2 fold increased risk (21)			
3	Early onset of epilepsy before aged 16	Refer to patient notes	1.7-fold increased risk of SUDEP compared to 16-60 age group (21, 22)			
4	Younger age	Refer to patient notes	Pooled data from SUDEP studies found most reported SUDEPs in age range 20-40 (4)			
5	Male sex	Refer to patient notes	Combined data from four SUDEP case-control studies found 2 fold increased risk (21)			
6	Presence of intellectual disability	Refer to patient notes. Consider patient capacity and involvement of carer in discussion.	Responses among those people with intellectual disabilities and epilepsy do have a substantially increased risk of mortality, particularly where seizures are ongoing (23, 24)			
7	Pregnancy	Is patient of child bearing age? Has she received pre-conception counselling. If pregnant review care.	Risk in pregnancy finding from reported maternal deaths (25, 26)			
SEIZURES						
8	Active seizures	How many seizures have you had in the last year?	Seizure freedom for 12 months found to be associated with a lower risk of mortality (12, 27, 3)			
9	Generalized Tonic-Clonic Seizures	Do you have generalized tonic-clonic seizures (GTCS)? (ie a loss of consciousness during a convulsive seizure). How many in the last 12 months?	The data on the relationship between epilepsy, auras and seizure types are limited. However, SUDEP is known to be associated with frequent GTCS (21) . Combined data from four case-control studies found frequent GTCS is a key risk factor for SUDEP. Increasing number of GTCS per year associated with statistically significant increased risk for SUDEP (21) . Compared to people without tonic-clonic seizures, 1-2 such seizures/year was associated with a 3-fold increase in risk, 3-50 seizures/year with an 8-9-fold increase. The risk was strongly associated with prolonged seizures lasting more than five minutes, or two or more seizures within a five minute period without the person returning to normal between them. Previous definitions used a 30-minute time limit. Convulsive status epilepticus has a high fatality rate if emergency treatment is delayed (28, 10, 41)			
10	Status Epilepticus / Prolonged Seizures	Do your seizures sometimes include convulsions that last longer than 5 minutes?	Nocturnal seizures identified as an independent risk factor for SUDEP (19, 29, 30)			
11	Nocturnal Seizures	Do you think you may have experienced a seizure during sleep? If no skip to 14	Nocturnal supervision found to be protective in SUDEP study (19) Lack of supervision frequently noted when SUDEP occurred in Epilepsy Monitoring Units (29) SUDEP is frequently unitnessed (30)			
RELATED RISKS						
12	Lack of surveillance at night	What happens if you have a night time seizure?	Systematic review highlights significant association between SUDEP and prone position (31)			
13	Prone position	No question to patient advised unless considered appropriate	Injuries have been identified as a risk factor for mortality (12)			
14	Injuries or use of emergency services	Have you had any injuries or ED/999 emergency service calls? Do you have any difficulties taking your medication as prescribed? e.g. at times forgetting to pick up a prescription, the taste of the medication	Non-adherence with AED associated with a 3 fold increase in mortality (32) Not collecting scripts for 91-192 days carried a higher mortality risk (12)			
				Background	Introduction	Check List (Adults)
				Example of use	References	Terms of Use



Development Group

SUDEP Action 

Making every epilepsy death count


























The SUDEP and Seizure Safety Checklist Version 2

Version 2 launched in September 2017

Over 550 clinicians registered

Risk separated into Primary, Additional and Background risk factors

Development group extended to bring on more expertise



SUDEP & SEIZURE Safety Checklist

Comwell Partnership NHS Foundation
SUDEP Action

SUDEP AND SEIZURE Safety Checklist (Adult)

Patient Name:		ID:	DOB:	Clinician Name:
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Risk Factor (Y/N)	Date	Date	Date	Actions - Considerations	
Primary factors	Active seizures * injury?	Y			<p>Review medical. Consider patient plan that addresses risk and remediation. Further see on avoid patient self-management in the UK (www.epilepsy.org.uk)</p> <p>Review with patient to a note. Consider shared care. The last one in three will be added to the existing Seizure System. Does status require an emergency plan or rescue medication?</p> <p>Consider nighttime surveillance systems (http://www.epilepsy.org.uk/epilepsy/monitoring)</p> <p>Advice of patient organisations: http://www.epilepsy.org.uk/011-00096500</p>
	Generalised Tonic-Clonic Seizures, Status Epilepticus & Prolonged Seizures?	Y			
	Nocturnal Seizures?	Y			
	Surveillance?	Y			
	Poor medicines adherence * medication changes?	Y			
Additional factors	Alcohol * and/or Substance abuse?	Y			<p>Consider discussion / referral with GP, community services or specialist</p> <p>Consider discussion / referral with GP, community services or specialist</p> <p>Are users informed of further counselling required? Review risk (a) to see success this (http://www.epilepsy.org.uk/epilepsy/psychological)</p> <p>Consider referral to specialist and engaging in Seizure Pregnancy Clinic (http://www.epilepsy.org.uk/epilepsy/011-00096500) & Pregnancy. Options, if not pregnant, discuss women undertake medication and need to plan pregnancy.</p>
	Depression or other psychiatric disorder	Y			
	Presence of Intellectual Disability	Y			
	Pregnancy	Y			
Background factors	Unclear seizure frequency or treatment history	Y			<p>Encourage / plan a regular review</p> <p>Review patient is up to date with seizure care and understanding</p> <p>Review patient is up to date with seizure care and understanding</p> <p>Draw attention to high risk activities / situations in this age group</p>
	Duration of epilepsy more than 15 years	Y			
	Early onset of epilepsy before aged 16	Y			
	Young adult age (peak risk at 20-40yrs)	Y			
	Male sex	Y			

This Checklist considers risk factors associated with epilepsy mortality including SUDEP

Action - Ref - Steps

The Checklist is intended to be used alongside national standards or guidelines


Add Checklist to patient notes alongside any additional comments and action points discussed. Patient could be provided with a copy of this sheet if desired to help support self-management

The Checklist can be repeated at the annual review or more regularly if clinically appropriate

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This Checklist cannot be used without permission (www.epilepsy.org.uk) Transfer with SUDEP Action to receive the full Checklist and training content.

SUDEP Action provides the latest information on epilepsy risk, SUDEP & mortality: www.epilepsy.org Free supporting resources available via: <http://uk.s3.amazonaws.com>




Neurologists
Learning Disability Nurses
Pharmacists
Care homes
School nurses
Substance abuse clinics

Epilepsy Nurses
GPs
Paediatricians
Trainee Clinicians
Homeless clinics
Prison service

"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"
(Clinician Checklist user)

"I have first hand experience in losing a son to epilepsy & none of my colleagues previously realised people could die - nobody had heard of SUDEP - so now they understand the importance of using tools like the Checklist to monitor risk"
(Clinician Checklist user and bereaved parent)



Using the Checklist helps to lower risk in patients

Checklist administered to **259 PWE in 2 groups**

1st group = 1st time at a Neurology clinic
(new, re-referred or treatment resistant PWE)

2nd group = LD & Epilepsy clinic
(where risk discussion was already routine since 2010)

Checklist redone **1 year later**


Top 25% of both groups (flagged to be most at risk during baseline review) showed their **risk levels had improved by next review**
(noticeable change in LD group, significant change in general group)

Risks already well managed in LD population, but still showed **potential to reduce risk**
(improved risks esp related to mental health / depression)


Showed **reduction in seizure frequency & severity** (at least 25% change for 6+ months)

Challenges the view that attitudes to epilepsy risks / SUDEP can't be changed through counselling

Shankar, R., Henley, W., Boland, C., Laugharne, R., McLean, B., & Newman, C. et al. (2018). Decreasing the risk of SUDEP: Structured communication of risk factors for premature mortality in people with epilepsy. *European Journal Of Neurology*. <http://dx.doi.org/10.1111/ene.13651>



Future directions




Methodology paper- Checklist Journey


Feedback study- how the Checklist is shaping practice

Children's Checklist in early stages

Goal of integration in to NHS for Checklist and EpSMon

International uptake

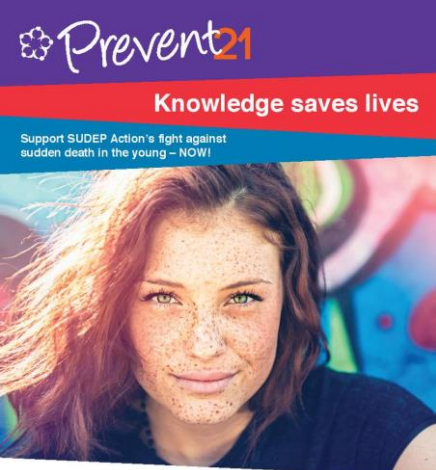
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THANK YOU

The SUDEP and Seizure Safety Checklist
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#Prevent21
Find out more at www.sudep.org/prevent21

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