

A System-Wide Approach to SUDEP Prevention: Implementation of a Safety Checklist and Workforce Training Programme in South Yorkshire

SUDEP AND SEIZURE
Safety Checklist (Adult)

sudep.org/checklist/

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BACKGROUND

- Over 1,000 epilepsy-related deaths occur annually in the UK, with mortality rates around three times higher in people with epilepsy than the general population.
- Sudden Unexpected Death in Epilepsy (SUDEP) is a significant and potentially preventable cause of premature mortality, particularly among people with a learning disability and autistic people.
- Learning from the South Yorkshire LeDeR Programme and the NHS England STEP TOGETHER – Mind the Gap epilepsy benchmarking report identified variation in SUDEP awareness, inconsistent risk discussions and limited use of structured safety planning.

AIM

To improve SUDEP awareness, standardise risk assessment, and support consistent seizure safety planning through workforce training and implementation of the SUDEP & Seizure Safety Checklist.

METHODS

South Yorkshire ICB commissioned SUDEP Action to deliver a SUDEP & Seizure Safety Programme comprising:

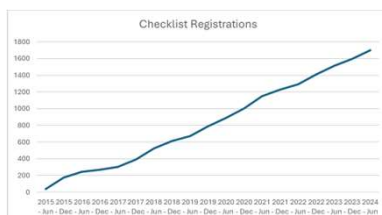
- multi-sector SUDEP awareness training
- promotion of Clive Treacey Guidance and both adult and children's SUDEP & Seizure Safety Checklists
- development of an accessible electronic SUDEP leaflet.

Nine 90-minute training sessions were delivered between June 2025 and March 2026 using the ECHO model, incorporating clinical expertise and lived experience.

Evaluation used a mixed-methods approach, combining quantitative pre- and post-training surveys with qualitative feedback to assess knowledge, confidence and intended practice change.

THE SUDEP AND SEIZURE SAFETY CHECKLIST

- The Adult SUDEP and Seizure Safety Checklist, launched in 2015, and updated in 2019, was created through a collaboration between UK charity, SUDEP Action and Cornwall Partnership NHS Foundation Trust.
- The Checklist is a risk-discussion tool designed for use by health professionals in clinics with their adult patients. There are currently over 2,500 registered users and the Checklist is additionally accessible to 80% of GP surgeries in the UK directly via EMIS Health and SystmOne patient record systems.

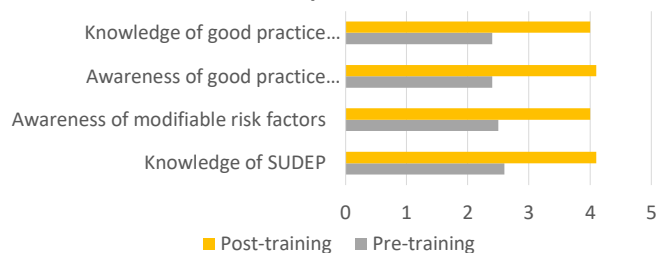


- Death-rates decreased by half when the Adult SUDEP and Seizure Safety Checklist (v.3) was implemented in Cornwall (2012-2018 compared to 2004-2012 figures).

RESULTS

- The programme engaged 1,135 participants across health, social care, education and VCSE sectors, demonstrating strong system-wide engagement and attracting interest beyond South Yorkshire.
- Evaluation demonstrated measurable improvements in self-rated knowledge and confidence. On a 1–7 scale, where 1 represented the highest level of knowledge/confidence, mean scores improved across all measures: knowledge of SUDEP (2.6 to 4.1), awareness of modifiable risk factors (2.5 to 4.0), awareness of good practice resources (2.4 to 4.1), and knowledge of good practice following a sudden epilepsy-related death (2.4 to 4.0).

Participant assessments of knowledge/confidence pre- and post-training on a 7-point scale



- The proportion of respondents rating themselves within the top three categories increased from 28% pre-training to 71% post-training.
- Qualitative feedback highlighted:
 - increased confidence in discussing SUDEP
 - awareness of risk-reduction strategies
 - improved understanding of how to use the checklist to support person-centred conversations, shared decision-making and safety planning.
- SUDEP Action also reported increased clinician and organisational registrations for the SUDEP & Seizure Safety Checklists, providing evidence of engagement with structured risk-reduction tools.

CONCLUSION

This programme demonstrates an evidence-informed, system-wide approach to reducing SUDEP risk.

Combining ECHO-based training with practical risk-reduction tools improved workforce knowledge, confidence and engagement with seizure safety planning.

LeDeR (2024) red flags epilepsy and the SUDEP gap and recommends system-wide training and early findings suggest this represents a scalable model for embedding consistent, person-centred epilepsy safety practices across health and care systems.