Department
of Health &
Social Care

[redacted]
Parliamentary Under-Secretary of State
for Public Health and Prevention

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HM Coroner Brendan J Allen
Coroner's Office for the County of Dorset
BCP Civic Centre
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08 January 2026

Dear Mr Allen,

Thank you for the Regulation 28 report of 21 October 2025 sent to the Secretary of State for Health and Social Care about the death of Amber Grace Walker. I am replying as the Minister with responsibility for long term conditions, including epilepsy.

Firstly, I would like to say how saddened I was to read of the circumstances of Amber's death, and I offer my sincere condolences to their family and loved ones. The circumstances your report describes are concerning and I am grateful to you for bringing these matters to my attention. Thank you for the additional time provided to the Department to provide a response to the concern/s raised in the report

The report raises concerns over:

- The risk of SUDEP (approx. 1 in 1,000) was not explained to Amber despite uncontrolled nocturnal seizures. Declining an increase in medication was not linked to an elevated SUDEP risk during clinical consultations. Increasing Amber's medication could have reduced seizure frequency and SUDEP risk. No advice was given on the implications of refusing medication adjustment.

- Amber and her mother were unaware of SUDEP until after her death. Doctors may assume SUDEP has been discussed previously and avoid repeating it.

- SUDEP is not routinely covered in medical training, including for non-neurologists.

In preparing this response, my officials have made enquiries with NHS England to ensure we adequately address your concerns.

The National Institute for Health and Care Excellence (NICE) is responsible for producing clinical guidance for health and care practitioners. Their guidance on *Epilepsies in children, young people, and adults (NG127)* sets out best practice for diagnosis and management of epilepsy and includes specific recommendations on reducing the risk of epilepsy-related death, including SUDEP.

The key points raised in the guidance are:

Risk Awareness: Clinicians should be aware that epilepsy carries an increased risk of premature death, including SUDEP. Potentially modifiable risk factors include uncontrolled seizures, non-adherence to medication, alcohol or drug misuse, and having seizures during sleep without supervision.

Discussion with Patients and Families: NICE advises that clinicians should discuss the individual risk of epilepsy-related death, including SUDEP, with people diagnosed with epilepsy from the time of diagnosis and revisit this during ongoing care. Conversations should cover individual risk factors, such as uncontrolled seizures, missed medication, and nocturnal seizures, and provide practical advice on reducing these risks. This approach ensures patients and families are fully informed and able to take steps that improve safety and reduce the likelihood of SUDEP

Specific Guidance for Sleep Seizures: For people who have seizures during sleep, clinicians should provide information on minimising risks, such as taking medication as prescribed, and consider discussing night-time supervision options (e.g., monitors).

Medication Adherence: NICE emphasises that uncontrolled seizures significantly increase the risk of SUDEP. Supporting patients to take their medication as prescribed is a key intervention to reduce this risk.

These recommendations are designed to ensure that patients and families are informed and supported to reduce risks wherever possible. NICE guidance is not mandatory but represents evidence-based best practice, and healthcare professionals are expected to take it fully into account when planning care.

Further details can be found in the full guideline on the NICE website at the following link:
https://www.nice.org.uk/guidance/ng217

NHS England's RightCare Programme has developed an Epilepsy Toolkit, which is designed to support commissioners and clinicians in improving epilepsy care and reducing preventable deaths. The Toolkit supports conversations about SUDEP by making risk reduction a core priority within its guidance. It advises commissioners and clinicians to embed structured risk assessments into care pathways and encourages proactive discussions with patients about SUDEP and other epilepsy-related risks. The toolkit signposts to resources such as the SUDEP & Seizure Safety Checklist and professional training modules, ensuring clinicians have practical tools and confidence to address SUDEP openly and consistently. This approach aligns with NICE recommendations and promotes informed decision-making to improve patient safety.

Further details can be found at the following link: https://www.england.nhs.uk/rightcare/wp-content/uploads/sites/40/2020/03/rightcare-epilepsy-toolkit-v2.pdf

Health Education England, now part of NHS England, has also developed an Epilepsy Programme in collaboration with SUDEP Action, which is designed to strengthen knowledge and confidence among healthcare professionals, particularly those who are not epilepsy specialists, in managing epilepsy safely and reducing risks such as SUDEP

The Programme includes evidence-based training modules delivered through the NHS England e-Learning for Healthcare platform, which ensures flexible access for professionals across primary and secondary care settings. These modules provide practical guidance on diagnosing and managing epilepsy, supporting medication adherence, and addressing special management issues and are aligned with NICE guideline NG217 and incorporate best practice for risk reduction.

The training emphasises SUDEP risk factors and equips clinicians with strategies to discuss these risks sensitively with patients and families. This supports NICE's recommendation that clinicians should explain SUDEP risk from diagnosis onwards and revisit the conversation during ongoing care.

By improving awareness and clinical confidence, the Epilepsy Programme contributes to safer care, better patient engagement, and reduced variation in epilepsy management across the NHS.

The SUDEP & Seizure Safety Checklist, developed by SUDEP Action, is recognised as an important tool for improving epilepsy safety and reducing the risk of SUDEP, and has been incorporated by NHS England into several key commissioning and clinical guidance frameworks, primarily to improve safety for vulnerable groups and standardise risk communication.

The aforementioned NHS RightCare Epilepsy Toolkit highlights the Checklist as a practical tool to support structured risk assessments and conversations about SUDEP. It encourages commissioners and clinicians to embed the checklist into care pathways to identify modifiable risk factors and improve patient safety, aligning with NICE guidance on discussing SUDEP from diagnosis onwards.

Similarly, the Checklist is featured in e-learning modules on the NHS England e-Learning for Healthcare platform. These modules equip clinicians with practical skills to use the checklist and hold sensitive conversations about SUDEP risk.

The National Bundle of Care for Children and Young People with Epilepsy recommends the use of structured risk assessment tools, including the Checklist, to support conversations about SUDEP. It advises clinicians to incorporate the checklist into routine care to identify modifiable risk factors, improve safety planning, and ensure families receive consistent, evidence-based information on reducing SUDEP risk.

The Checklist has also been integrated into the Clive Treacey Safety Checklist. This Checklist was developed following the independent review into the death of Clive Treacey, to improve epilepsy care for people with a learning disability and/or autism. Its purpose is to provide commissioners and providers with a structured framework to identify and mitigate risks associated with epilepsy, ensuring safer care for vulnerable groups. Evidence shows that individuals with a learning disability or autism are at higher risk of SUDEP due to factors such as complex health needs, communication challenges, and reliance on carers for medication and seizure monitoring. By embedding systematic risk assessment and safety planning, the Clive Treacey Checklist helps ensure that SUDEP risk is discussed, modifiable factors are addressed, and care teams take proactive steps to prevent avoidable deaths.

In relation to the education and training of doctors, individual medical schools set their own undergraduate medical curriculum. These have to meet the standards set by the General Medical Council (GMC), which monitors and checks to make sure that the standards are maintained.

The curricula for postgraduate specialty training are set by individual royal colleges and faculties, and the GMC approves curricula and assessment systems for each training programme. Whilst not all curricula may necessarily highlight a specific condition, they all nevertheless emphasise the skills and approaches a doctor must develop in order to ensure accurate and timely diagnoses and treatment plans for their patients.

Doctors are ultimately responsible for keeping their clinical knowledge up to date and for identifying their learning needs as part of their continuous professional development. They should regularly review emerging research and developments in clinical guidance, such as that produced by NICE, to ensure they can continue to provide high-quality care to all patients.

All doctors registered in the UK are expected to meet the professional standards set out in the GMC’s Good Medical Practice. In 2012, the GMC introduced revalidation, which supports doctors in regularly reflecting on how to develop or improve their practice. This process helps ensure doctors remain up to date, gives patients confidence in their care and promotes improved clinical governance.

I hope this response is helpful. Thank you for bringing these concerns to my attention.

Yours sincerely,

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