

REGULATION 28: REPORT TO PREVENT FUTURE DEATHS (1)

*NOTE: This form is to be used **after** an inquest.*

	REGULATION 28 REPORT TO PREVENT FUTURE DEATHS THIS REPORT IS BEING SENT TO: 1) Secretary of State for Health And Social Care
1	CORONER I am Brendan Joseph Allen, Area Coroner, for the Coroner Area of Dorset
2	CORONER'S LEGAL POWERS I make this report under paragraph 7, Schedule 5, of the Coroners and Justice Act 2009 and regulations 28 and 29 of the Coroners (Investigations) Regulations 2013.
3	INVESTIGATION and INQUEST On the 25 th April 2023, an investigation was commenced into the death of Amber Grace Walker, born on the 2 nd November 2000. The investigation concluded at the end of the Inquest on the 7 th October 2025. The Medical Cause of Death was: 1a Sudden Unexpected Death in Epilepsy 1b 1c 2 The conclusion of the Inquest recorded that Amber Grace Walker died as a consequence of natural causes.
4	CIRCUMSTANCES OF THE DEATH Amber Grace Walker had a past medical history that included epilepsy, for which she was prescribed lamotrigine and topiramate, and attention deficit and hyperactivity disorder. In August 2022 Amber experienced a cluster of seizures and was taken to hospital, where she had a further seizure. As a consequence

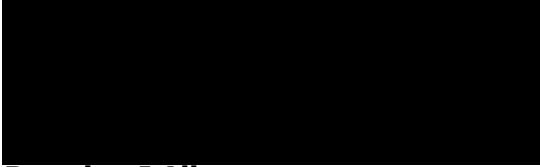
	she spoke with an epilepsy nurse specialist in November 2022 and had a face-to-face consultation with a consultant neurologist on 8th March 2023. Amber had experienced two further seizures in the month prior to the consultation. Amber declined an increase in her topiramate medication. An increase in her medication may have reduced the risk of further seizures, which, in turn, may have decreased Amber's risk of Sudden Unexpected Death in Epilepsy ("SUDEP"). There was no discussion in the consultation about SUDEP and Amber's increased risk, given her uncontrolled generalised tonic-clonic seizures that she experienced at night. Amber was found deceased in her bedroom at her home address on 19th April 2023, having been well when last seen at around midnight. A post mortem examination revealed the medical cause of death was Sudden Unexpected Death in Epilepsy ("SUDEP").
5	<u>CORONER'S CONCERNS</u> The MATTERS OF CONCERN are as follows: 1. During the inquest evidence was heard that: i. SUDEP is the leading cause of death for patients diagnosed with epilepsy. The risk of death is widely quoted as 1 in 1,000 of those diagnosed with epilepsy, but the individualised risk may be higher or lower depending on the risk factors for the particular patient. Although the mechanism of death from SUDEP is not well understood, modifiable risk factors are known, and there are measures that can be taken by patients and those treating them to mitigate the risk. Patient awareness of SUDEP and the measures they can take to mitigate their risk is vital in ensuring patient's can make informed choices about the management of their condition. ii. Amber's mother, Mrs Walker, attended all neurology appointments with Amber. Mrs Walker gave evidence that Amber's family supported Amber in managing her epilepsy, including with medication compliance. Mrs Walker explained that she only became aware of SUDEP after Amber's death: the risk

of SUDEP had not been discussed at any neurology appointments that Mrs Walker had attended with Amber. Amber was at increased risk of SUDEP as she was experiencing uncontrolled tonic-clonic seizures at night and she slept alone, albeit in the family home. An increase in her medication may have mitigated Amber's risk of seizures and therefore her risk of SUDEP. Although an increase in medication was discussed at the consultation on 8th March 2023, Amber was not advised that declining an increase in her medication in response to her uncontrolled seizures meant she remained at an elevated risk of SUDEP.

- iii. The consultant neurologist that saw Amber on 8th March 2023 gave evidence that conversations with patients surrounding SUDEP are challenging. Prior to Amber's death, he was not aware of the "SUDEP checklist", created by SUDEP Action, a charity with the stated aim of stopping preventable deaths from epilepsy and that provide support to those who have lost loved-ones to epilepsy. He explained that he now routinely uses the SUDEP checklist, which he finds a useful tool to introduce the subject of SUDEP with a patient. It is not used universally. He also explained that there may be a presumption that colleagues who had seen a patient previously will have discussed SUDEP with a patient, negating the need to repeat the conversation. He accepted that when meeting a patient for the first time, or when the risk of SUDEP has changed, SUDEP must be discussed with a patient. He also explained that in his medical training, SUDEP was not taught. This is significant as there were opportunities for other medical professionals to raise SUDEP with Amber, for example, her GP and the Emergency Department medical professionals she saw in August 2022.

2. I have concerns with regard to the following:

	i. Doctors can be reluctant to discuss SUDEP with patients and/or presume it is a discussion that has been had at previous appointment(s) with colleagues that does not need repeating. There are tools, such as the SUDEP Action-produced "SUDEP Checklist", that can facilitate such a discussion, but they are not used universally. The SUDEP Checklist can be used by any medical practitioner who may come into contact with a patient with epilepsy. Discussions about SUDEP ensure that patients are aware of the general risks of SUDEP, the risks that are specific to the patient and the measures that can be taken to mitigate the risk. ii. SUDEP is not covered in the medical training of doctors, despite is being the leading cause of death in patients with a diagnosis of epilepsy. It is not only neurologists that will encounter patients with epilepsy where a discussion regarding SUDEP may be required, as demonstrated by Amber's experience.
6	ACTION SHOULD BE TAKEN In my opinion urgent action should be taken to prevent future deaths and I believe you and/or your organisation have the power to take such action.
7	YOUR RESPONSE You are under a duty to respond to this report within 56 days of the date of this report, by 16th December 2025. I, the coroner, may extend the period. Your response must contain details of action taken or proposed to be taken, setting out the timetable for action. Otherwise, you must explain why no action is proposed.
8	COPIES and PUBLICATION I have sent a copy of my report to the Chief Coroner and to the following Interested Persons: (1) [REDACTED] (Amber's parents) (2) Guy's and St Thomas' NHS Foundation Trust I have also sent it to SUDEP Action and the Epilepsy Society who may find it useful or of interest. I am also under a duty to send the Chief Coroner a copy of your response.

	The Chief Coroner may publish either or both in a complete or redacted or summary form. He may send a copy of this report to any person who he believes may find it useful or of interest. You may make representations to me, the coroner, at the time of your response, about the release or the publication of your response by the Chief Coroner.	
9	Dated 21st October 2025	Signed  Brendan J Allen