

11 February 2020

Mr Christopher Morris
HM Assistant Coroner
Coroner's Court
1 Mount Tabor Street
Stockport SK1 3AG

Your ref: 9341/RD
Our ref: EH-304215



Dear Mr Morris,

Thank you for your letter of 3 January 2020, regarding the death of Mr James Thomas Wheeler. I was very sorry to read of Mr Wheeler's death.

I have considered the circumstances surrounding Mr Wheeler's death, and your concern that there is no national guidance on how to monitor people with refractory epilepsy (both in hospital and community care settings), including the use of assistive technology for those thought to be at high risk of seizures.

We have published guidance on the diagnosis and management of epilepsies (CG137). This guideline includes specific recommendations relating to sudden unexpected death in epilepsy (SUDEP). Recommendation 1.3.12 says the risk of SUDEP can be minimised by optimising seizure control and being aware of the potential consequences of nocturnal seizures.

The guideline also includes specific recommendations relating to people with learning disabilities (section 1.16). Recommendations 1.16.3.7 and 1.16.3.8 discuss the higher risks of mortality in this group, and the need for assessment. The recommendations state:

"1.16.3.7 Healthcare professionals should be aware of the higher risks of mortality for children, young people and adults with learning disabilities and epilepsy and discuss these with them, their families and/or carers".

"1.16.3.8 All children, young people and adults with epilepsy and learning disabilities should have a risk assessment including:

- *bathing and showering*
- *preparing food*
- *using electrical equipment*
- *managing prolonged or serial seizures*
- *the impact of epilepsy in social settings*
- *SUDEP*
 - *the suitability of independent living, where the rights of the child, young person or adult are balanced with the role of the carer".*

This guideline (CG137) is currently in the early stages of being updated.

We expect to consult on the updated draft guideline from in November 2020 and plan to publish the final updated guideline in June 2021 (these dates are subject to change).

As part of this update, the guideline committee will be considering the available evidence for the following review questions:

- What is the effectiveness of new technologies (for example, night monitors, wearable devices and apps) in detecting seizures in people with epilepsy?
- What are the risk factors for epilepsy-related mortality, including SUDEP, and what is the magnitude of risk of the factors?
- What interventions are effective in reducing the risk of seizure related mortality, including SUDEP?

Your concerns have been passed to the guideline committee to help inform their work.

Yours sincerely,

A handwritten signature in black ink, appearing to read 'Andrew Dillon', with a long horizontal line extending to the right.

Sir Andrew Dillon
Chief Executive