REGULATION 28 REPORT TO PREVENT FUTURE DEATHS

THIS REPORT IS BEING SENT TO: 1) Sir Andrew Dillon, Chief Executive, National Institute for Health and Care Excellence; 2) Ms Pam Smith, Chief Executive, Stockport Metropolitan Borough Council; and 3) Rt. Hon. Matt Hancock MP, Secretary of State for Health and Social Care.

CORONER

I am Chris Morris, Area Coroner for Greater Manchester South.

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.
http://www.legislation.gov.uk/ukpga/2009/25/schedule/5/paragraph/7
http://www.legislation.gov.uk/uksi/2013/1629/part/7/made

INVESTIGATION and INQUEST

On 12th February 2018, I opened an inquest into the death of James Thomas Wheeler who died at Cheddle Lodge residential care home in Stockport on 22nd January 2018, aged 23 years. The investigation concluded at the end of the inquest which I heard between 18th- 22nd November 2019.

The inquest concluded with a narrative conclusion, to the effect that Mr Wheeler died as a consequence of a nocturnal epileptic seizure which occurred whilst he was unobserved and not actively monitored.

CIRCUMSTANCES OF THE DEATH

Mr Wheeler had a history of cerebral palsy and global developmental delay with severe learning disability. His cerebral palsy was associated with the development of epilepsy. He had no traditional means of communication, was confined to a wheelchair and in later years fed with a Gastrostomy due to dysphagia.

At the age of 18, Mr Wheeler moved to Cheddle Lodge, a 13 bedded specialist care facility principally for young adults run by the Stockport Cerebral Palsy Society, a Registered Charity now known as Supportability.

Mr Wheeler was considered to be partially eligible for Continuing Healthcare Funding and as such, his health and care package was commissioned jointly by the local Clinical Commissioning Group in conjunction with Stockport Metropolitan Borough Council. At Cheddle Lodge, he needed support with all aspects of his life.

Mr Wheeler was known to be at risk as a result of his epilepsy, which by 2018 had become refractory to treatment with seizures still being experienced notwithstanding high doses of anti-convulsant medications. Evidence was heard in court that Mr Wheeler's seizures could be unpredictable, and variable in their presentation.

Whilst he did not have a specific epilepsy or seizure care plan as such, central to Mr Wheeler's care was the Individual Plan for administration of buccal Midazolam (also known as rescue medication). This plan was something all staff caring for Mr Wheeler were expected to be aware of and trained to act upon.

In broad terms, the Plan required staff on becoming aware of Mr Wheeler having a seizure to start timing it, and should it persist for 5 minutes or longer, to administer Midazolam into his buccal cavity. The Plan contained details for how staff should act in the event of any difficulties administering the medication, or in the event James were to show other signs of illness in the course of the seizure.

Inherent in the system for administration of rescue medication was the need for staff to have a process in place whereby a seizure could be promptly identified and acted upon. Overnight, staff at Cheddle Lodge sought to achieve this by means of:

a) Hourly breathing and wellbeing checks; and

b) A Wi-Fi baby monitor which consisted of a microphone and camera unit placed in Mr Wheeler's bedroom with an audio receiver with video capability placed on a water-cooler in the main lounge area.

In 2015, staff at Cheddle Lodge had sought advice from Epilepsy UK as to the use of a baby monitor to detect seizure activity overnight. The monitor in use at the time of James's death was purchased on 5th December 2017 to replace a similar unit already in use which was perceived as defective.

No further advice as to other options for monitoring was obtained in 2017, and the instruction manual for the baby monitor purchased made it abundantly clear that the monitor is not a medical device and is not intended to be used as such.

At approximately 05:30 on 22nd January 2018, a carer checking on Mr Wheeler found him to be unresponsive. A paramedic crew arrived at just after 05:45 and pronounced Mr Wheeler dead a short time thereafter.

The medical cause of Mr Wheeler's death was:

1) a) Sudden unexpected death in epilepsy

II Cerebral palsy.

I determined as a matter of fact at the inquest that the carer looking after Mr Wheeler on the night of his death had not activated or sought to use the baby monitor.

CORONER'S CONCERNS

During the course of the inquest the evidence revealed matters giving rise to concern. In my opinion there is a risk that future deaths will occur unless action is taken. In the circumstances it is my statutory duty to report to you.

The **MATTERS OF CONCERN** are as follows. –

1. **To Sir Andrew Dillon, Chief Executive, National Institute of Health and Care Excellence**

The court heard that there is currently an absence of authoritative guidance in the United Kingdom as to the monitoring of people with refractory epilepsy, both in hospital and community care settings.

A particular feature of this case was the absence of guidance as to the availability and use of assistive technology in monitoring individuals thought to be at high risk as a result of seizures.

2. **To Ms Pam Smith, Chief Executive, Stockport Metropolitan Borough Council**

The court heard evidence that, notwithstanding the Local Authority's statutory obligations under the Care Act 2014 in this regard, Mr Wheeler (and indeed many other eligible service users) did not receive annual Care Act Reviews as required by law.

Whilst the court heard evidence about the process of transformation of adult social care underway within the Local Authority, it is a matter of concern that the default position still appears to be that an obligatory Care Act Review will not take place, unless some exceptional circumstance is identified about the case.

3. **To Rt. Hon. Matt Hancock, Secretary of State for Health and Social Care**

The court heard evidence that, whilst parliament had conferred on Local Authorities a statutory duty to undertake annual reviews pursuant to the Care Act 2014, insufficient resources had been made available to enable councils to discharge this duty alongside existing statutory obligations.

ACTION SHOULD BE TAKEN

In my opinion action should be taken to prevent future deaths and I believe you and your organisation have the power to take such action.

YOUR RESPONSE

You are under a duty to respond to this report within 56 days of the date of this report, namely by 28th February 2020. 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

COPIES and PUBLICATION

I have sent a copy of my report to the Chief Coroner and to Mr Wheeler's mother, [redacted]

I have also sent it to Stockport CP Society via its solicitors, Weightmans LLP and to the Care Quality Commission 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.

Dated: 3rd January 2020

Signature:

Chris Morris HM Area Coroner, Manchester South.