University Hospitals of North Midlands NHS Trust

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[redacted]

9 April 2024

STRICTLY PRIVATE & CONFIDENTIAL
Mr Daniel Howe
H M Assistant Coroner
Stoke on Trent and North Staffordshire

[redacted]

[redacted]

Dear Mr Howe

Joshua BURGESS

Further to your letter 13 February 2024, I am pleased to provide a response under paragraph 7 of Schedule 5 of the Coroners and Justice Act 2009 and Regulations 28 and 29 of the coroner's (Investigations) Regulations 2013, addressing your concerns surrounding the death of Joshua Burgess.

This response is provided on behalf of Brooke Medical Centre and the University Hospitals of North Midlands NHS Trust.

Recorded Circumstances of the Death
Joshua Burgess was a 27 year old male who had severe acquired brain injuries, communication difficulties, impaired executive functioning and severe learning difficulties. He developed epilepsy from the age of 6 years and had a diagnosis of Lennox-Gestaut syndrome for which he was under the care of the Department of Neurology at Royal Stoke University Hospital. In 2019 the Department of Neurology commenced Mr Burgess on 2.5ml twice daily Brivaracetam to control his seizure activity. The dosage was increased to 10ml twice a day in 2020 and responsibility for prescribing the medication was transferred to Mr Burgess' General Practitioner at the Brook Medical Centre, Bradeley, Stoke-on-Trent. The reason for the change in prescriber was for the sake of convenience as the GP were the prescriber for other medications.

Although the Brook Medical Centre were responsible for prescribing Brivaracetam there were no consultations between the surgery and Mr Burgess or his mother regarding the management of his seizures or a review of medication, these continued to be undertaken by the Department of Neurology at the Royal Stoke University Hospital.

In July 2020 the Consultant Neurologist agreed with Mr Burgess' mother that the dosage of Brivaracetam should be reduced by 2ml every 2 weeks and to be reviewed in 4 months. A letter was sent from the Department of Neurology at Royal Stoke University Hospital to the Brook Medical Centre advising of this

planned reduction. No amendment to the prescription was requested and no changes were made following the letter. The prescription remained as Brivaracetam 10ml twice daily.

In November 2020 a letter was sent from the Department of Neurology at Royal Stoke University Hospital to the Brook Medical Centre advising that the dose of Brivaracetam had been reduced to 3ml twice daily but then back up to 5ml twice daily. No amendment to the prescription was requested and no changes were made following the letter.

In January 2021 a letter was sent from the Department of Neurology to the Brook Medical Centre advising that the dose of Brivaracetam was at 4ml twice daily and the deceased's seizures were "relatively stable". No amendment to the prescription was requested and no changes were made following the letter. The prescription remained as Brivaracetam 10ml twice daily.

On 22 July 2022 Mr. Burgess was moved out of his parent's care by Stoke-on-Trent social services into a supportive living placement in Leicestershire run by Godfrey Care. This was undertaken on an emergency basis. When Mr. Burgess arrived at the placement it was reported by staff that the medication bottles were unlabeled and so could not be given to Mr Burgess until confirmation of the prescription was received in writing by the prescriber. The evidence at inquest was that this was a Care Quality Commission requirement.

The deceased did not receive any Brivaracetam between 22 July 2022 and 26 July 2022.

On 25 July 2022 a "Best Interests Meeting" was undertaken involving Mr Burgess' mother, Godfrey care and social services during which the Mr Burgess' mother advised that the correct dosage of Brivaracetam was 4ml twice daily and not 10ml twice daily. The same information was provided by the Department of Neurology to Godfrey Care however the medication was not provided as the information regarding the correct dose had not been provided by the prescriber.

On 26 July 2022 the deceased was given Brivaracetam 10ml twice daily. The evidence at inquest was that this was likely due to a manager from Godfrey Care being given the prescription details during a call to the 111 service.

On 27 July 2022 a letter was sent from the Department of Neurology to the Brook Medical Centre explaining that Mr Burgess had been moved to a care organisation on an urgent basis and there was confusion over what medication he should be taking. A request was made to forward a list of his medication but also included information from his last review within the Department of Neurology that Brivaracetam at 4ml twice daily was the appropriate dose.

On 28 July 2022 the Brook Medical Centre sent a list of prescribed medication to Godfrey Care. As there had been no changes to prescription since July 2020 the recorded prescribed dose of Brivaracetam was 10ml twice daily although the dose that he has been given during the preceding 2 years was 4ml twice daily.

Mr Burgess continued to receive Brivaracetam at dose of 10ml twice daily until 5 September 2022 when he was seen in a clinic at Department of Neurology at Leicester Glenfield Hospital and established that there had been a sudden increase in the Brivaracetam dose from 4ml twice daily to 10ml twice daily. The plan was for the medication to be reduced to 9ml twice daily and then to continue to reduce by 1ml twice daily at weekly intervals until he was back to the "well tolerated" dose of 4ml twice daily.

Prior to 22 July 2022 whilst being given Brivaracetam at 4ml twice daily Mr Burgess experienced 5-6 seizures per week. Following the cessation of medication between 22-26 July 2022 and the increase in Brivaracetam to 10ml twice daily he was experiencing about 5 seizures per day and of longer duration.

The medication was reduced as per the instruction from Department of Neurology at Leicester Glenfield Hospital. On 23 September 2022 Mr Burgess was taken back into care of his mother. Although there had been a hospital attendance on the 15 November 2022 the seizures had stabilised to a similar frequency as before the sudden interruption and increase in medication.

On 19 November 2022 Mr Burgess was sadly found unresponsive at his home address with death being verified by a paramedic. He had passed away after vomiting and aspirating during an epileptic seizure.

Concerns

During the course of the inquest, you felt that evidence revealed matters giving rise for concern. In your opinion, matters for concern are as follows:

1. The Neurology department of the Royal Stoke University Hospital operated a system whereby it did not instruct the prescribing GP to amend the prescription of Brivaracetam when changes to dosage had been agreed with Mr Burgess' mother. The evidence from the Consultant Neurologist was that an assumption was made that when changes to medication had been discussed and agreed that Mr Burgess' mother would attend the GP surgery to discuss the changes in medication. The same witness gave evidence that it was assumed a pharmacist within the GP surgery would read the correspondence from the neurology department and make the necessary changes to prescriptions without express instructions to do so.

2. The 'workflow' within the Brook Medical Centre was such that letters sent from the Neurology Department discussing changes in medication (albeit not containing a request to amend the prescription) were processed by support staff and not referred to a clinician to consider and so no changes were made to the prescription.

3. The letter of 27 July 2022 from the Neurology Department to Brook Medical Centre seeking clarification as to the correct dosage of Brivaracetam was processed by support staff and a summary medication sent without referral to a clinician.

4. Godfrey Care were informed by Mr Burgess' mother and the Neurology Department of Royal Stoke University Hospital that the appropriate dose of Brivaracetam was 4ml twice daily. Medication was withheld between 22-26 July 2022 due to the information not being in writing from the prescriber, however the evidence at inquest was that 10ml twice daily was commenced on 26 July following a call to the 111 service.

You reported this matter under Paragraph 7, Schedule 5 of the Coroners and Justice Act 2009 and Regulations 28 and 29 of the coroners (Investigations) Regulations 2013.

In your opinion, action should be taken to prevent future deaths.

Action Taken

The University Hospitals of North Midlands NHS Trust has taken the issues highlighted during the inquest seriously and indeed, I am grateful that you have raised your concerns.

We have taken this opportunity to work together with our partners in primary care and have consulted with colleagues from the wider the Integrated Care System (ICS).

1. The Trust's outpatient clinic letter standards describe the structure of clinic letters based on standard headings. You will recall that [redacted] (GP) gave evidence at the inquest to the effect that there were areas in the acute Trust setting which already provided discharge information which he considered to be of a 'gold standard.' The Trust is committed to working towards improving compliance with these standards. To support this, we are working towards creation of a standardised template in our 'Medisec' system (system where letters are created). This will include a section for changes to medications and clear actions for those in the primary care setting, for example, instructions for the prescribing GP to amend prescriptions.

2. We have discussed the above process with nominated individuals from the ICS. Due to the timeframes that would be required for the creation of standardised template for clinic letters within the 'Medisec' system across the Trust, we are reiterating the Trust standards and [redacted] has agreed, with immediate effect, that all clinic letters received from neurology will be reviewed by a GP at Brook Medical Centre. This has been implemented due to the acknowledgement that neurological conditions are often complex, and it is more likely that they will require frequent medication changes, titration and/or closer monitoring.

3. This concern will also be addressed by the interim solution implemented by Brook Medical Centre, in that all correspondence from the neurology department will be reviewed and triaged by a GP.

4. Whilst this concern is not directly addressed to the acute Trust (UHNM) or Brook medical Centre, it has been considered as part of the wider learning following Joshua's death. Medications for epilepsy is considered across the healthcare economy to be 'critical'. The National Patient Safety Agency (2010) defined critical medicines as 'medicines which can result in patient death or serious harm if there are delays in their administration'. Whist the Coroner found that the delay in administering medications on this occasion did not contribute to Joshua's death, we believe that further education within the care home setting is required. With this in mind, we will work together with the local authority to ensure that up to date communications are shared across the Stoke on Trent and North Staffordshire health and social care economy to reiterate this message. Whilst this has not yet been implemented, it will be taken forward by end of May 2024.

Whilst some changes have been implemented with immediate effect, other planned changes may take longer. However, we are committed to ensuring that correspondence between service providers is provided in an accurate and consistent manner.

We do hope that the above information provides assurance that the Trust and Brook Medical Centre have taken the concerns raised at the inquest seriously and that we are working together to ensure that communication of medication changes is clear and unambiguous between partners across the Staffordshire and Stoke on Trent health economy.

Should you wish to discuss any aspect of this report further, please do not hesitate to contact us directly.

Yours sincerely

[redacted]

[redacted]

CHIEF EXECUTIVE

[redacted]
(electronically approved)

[redacted]

BROOK MEDICAL CENTRE