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11 April 2024

Dear Coroner,

Re: Regulation 28 Report to Prevent Future Deaths – Chloe Ann Tapp who died on 8 October 2021.

Thank you for your Report to Prevent Future Deaths (hereafter "Report") dated 28 February 2024 concerning the death of Chloe Ann Tapp on 8 October 2021. In advance of responding to the specific concerns raised in your Report, I would like to express my deep condolences to Chloe's family and loved ones. NHS England are keen to assure the family and the coroner that the concerns raised about Chloe's care have been listened to and reflected upon.

In your Report you raise concerns over pressures being placed on neurology departments and that there was a recognised shortage of neurologists amid an increase in demand. This response focuses on the concerns raised relevant to NHS England national programme or policy. Many of your concerns around the quality of care delivered to Chloe sit within the remit of Mid and South Essex NHS Foundation Trust, and I note that you have also addressed your Report to them.

In preparing my response I have consulted with the National Clinical Director for Neurology and the Getting It Right First Time (GIRFT) Neurology Clinical Lead. GIRFT is a national programme designed to improve the treatment and care of patients through in-depth review of services, benchmarking and presenting a data-driven evidence base to support change. It is part of an aligned set of programmes within NHS England and has the backing of the Royal Colleges and professional associations.

The GIRFT Programme National Specialty Report for Neurology, published in September 2021, provides an in-depth analysis of the current neurology service within England. The GIRFT methodology is to identify unwarranted variations between services, to highlight those that are beneficial and are working well and to identify those with suboptimal performance and those where resources are lacking to understand their situation so they can address them. The key findings relevant to the observations made in your Report are summarised below:

Outpatient services

- There is marked variation in access to neurology outpatients across different Clinical Commissioning Groups (CCGs), ranging from 400 to 1,600 per 100,000 population for new patients and from 600 to over 3,000 for follow-ups.
- Neurology outpatient departments have limited capacity and demand outstrips supply.

Specialist nursing

- Specialist nurses play an important role in the management of many chronic neurological disorders.
- There is marked variation in access to neurology nurses between neuroscience regions as reported in the Getting it Right First Time (GIRFT)/Association of British Neurologists (ABN) questionnaire, ranging from 5 to 26 per million.

Distribution of consultant posts

- There is marked variation in the number of consultants by neuroscience region, ranging from one consultant per 52,000 non-elective population to one consultant per 200,000 (excluding the National Hospital for Neurology and Neurosurgery). The average is one consultant per 79,000 across England.
- There is also very marked variation between sites. For example, one Trust covering a population of 360,000 had one consultant, while another covering 250,000 had five (three whole-time equivalents); at another site, 37 consultants were covering a population of 3.4 million.

Having considered your Report and the concerns raised, a GIRFT visit to Mid and South Essex NHS Foundation Trust has been arranged to review the specific situation within their Neurology department.

Transition pathways from paediatric to adult services are a particular point of risk with variable processes across the country, with both paediatric and adult neurology services stretched. This is particularly a recognised issue for epilepsy. NHS England's Paediatrics Programme recently published the national bundle of care for children and young people with epilepsy. Published in October 2023, and builds on existing guidance from the National Institute for Health and Care Excellence (NICE), it is aimed at clinicians by outlining specific recommendations for integrated care systems on the provision of care for children and young people with epilepsy particularly around transition.

NHS England's Neurology Programme is in the process of developing guidance and specifications to support Systems and NHS Trusts to develop integrated care for neurology services, including epilepsy. However, this cannot directly impact issues arising from funding shortfalls in individual services or challenges with recruitment and retention of appropriately qualified medical and nursing staff in some parts of the country, as raised in your Report.

NHS England is also working at a national level to deliver the Long Term Workforce Plan which was published in June 2023. This is a robust and effective strategy to ensure we have the right number of people, with the right skills and support in place to be able to deliver the kind of care people need. It heralds the start of the biggest recruitment drive in health service history, but also of an ongoing programme of strategic workforce planning. It includes ambitious commitments to grow the workforce by significantly expanding domestic education, training and recruitment, as well as actions aimed at improving culture, leadership and wellbeing so that more staff are retained in NHS employment over the next 15 years. These actions will aim to close anticipated staffing shortfalls in the NHS in the long term, however Trusts have a responsibility to ensure safe staffing levels in the current day to day operation of their hospitals. This is in line with Care Quality Commission (CQC) Regulation 18 which states that providers must deploy enough suitably qualified, competent, and experienced staff to enable them to meet all other regulatory requirements.

NHS England has also engaged with Mid and South Essex NHS Foundation Trust on the concerns raised in your Report. We note that Chloe's initial telephone consultation took place during the COVID-19 pandemic, and that she was considered clinically vulnerable and at risk if exposed to infection. We have also been sighted on the Trust's Serious Incident Review into Chloe's care and subsequent action plan and note that this includes a review of neurology department clinical and administration services and safety netting information for patient with dose change regimes. I refer you to the Trust for their formal response to your Report, which we have also asked to be sighted on.

I would also like to provide further assurances on national NHS England work taking place around the Reports to Prevent Future Deaths. All reports received are discussed by the Regulation 28 Working Group, comprising Regional Medical Directors, and other clinical and quality colleagues from across the regions. This ensures that key learnings and insights around preventable deaths are shared across the NHS at both a national and regional level and helps us pay close attention to any emerging trends that may require further review and action.

Thank you for bringing these important patient safety issues to my attention and please do not hesitate to contact me should you need any further information.

Yours sincerely,

National Medical Director