NHS England

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National Medical Director
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[redacted]

24 March 2025

Dear Coroner,

Re: Regulation 28 Report to Prevent Future Deaths – Charlie Marriage who died on Saturday 26 June 2021

Thank you for your Report to Prevent Future Deaths (hereafter "Report") dated 24 January 2025 concerning the death of Charlie Marriage on Saturday 26 June 2021. In advance of responding to the specific concerns raised in your Report, I would like to express my deep condolences to Charlie's family and loved ones. NHS England are keen to assure the family and the Coroner that the concerns raised about Charlie's care and the circumstances surrounding his death have been listened to and reflected upon.

Your Report raises concerns over the risks to patients who are medication dependent, who may be at significant risk of sudden crisis or death without their medication. You have raised that these patients may not be fully aware of the risks of death associated with not being medicated, and that the potential urgency and level of danger created by an absence of medication is not quickly identified and understood when patients seek medical advice and/or medication.

Your Report raises important insights around "cliff-edge conditions" such as epilepsy, particularly where a patient's condition may deteriorate very rapidly without any obvious worsening signs or where their potential vulnerability is not recognised. You have also noted that sending patients to a pharmacy may not reliably mitigate their risks quickly, especially where their medication is not easily available on an ad hoc local basis and may not be in stock.

NHS England has instigated the Medicines Safety Improvement Programme which has been working to improve access to "Time Critical Medicines". The focus of attention is to identify people with "cliff-edge conditions" and then to ensure they have the time critical medicines they need to prevent rapid deterioration. The programme started in 2024 and has identified a small number of "cliff-edge conditions" that may benefit from improved processes. Epilepsy is one of the conditions identified, and a key ambition of the programme is to improve care for people with epilepsy. This programme is being delivered in partnership with Epilepsy Action and Parkinson's UK (alongside other charities) and is planned to run until March 2027. It will take into account the learning from Charlie's death.

All NHS Services are required to adhere to the National Institute for Health and Care Excellence (NICE) guidelines. This is a professional and contractual imperative. The NICE Guidelines on Epilepsy (NG217, published in April 2022 and updated in January 2025) require specialist clinicians to: *"Discuss with people with epilepsy, and their families and carers if appropriate, their individual risk of epilepsy-related death, including SUDEP, from the time of diagnosis onwards."* (see 10.1.4). It is also a requirement to: *"Arrange regular (at least annual) monitoring reviews for adults with epilepsy"*, including those with "*a high risk of sudden unexpected death in epilepsy (SUDEP)"* (see 4.4.1).

The September 2021 national specialty report for neurology from the Getting It Right First Time (GIRFT) programme focuses on improving access to care for patients with neurological disorders across England, including patients with intermittent and unpredictable conditions such as epilepsy (Neurology - Getting It Right First Time - GIRFT). This programme follows on from Charlie's death and will increase the opportunity for patients to have these important discussions.

The National Institute for Health and Care Excellence has also published guidance for pharmacists on making an emergency supply of medication, which reinforces the guidance of the Royal Pharmaceutical Society which states: "*The pharmacist should consider the medical consequences of not supplying a medicine in an emergency*" and *"If the pharmacist is unable to make an emergency supply of a medicine the pharmacist should advise the patient how to obtain essential medical care."*

NHS England, alongside the Department of Health and Social Care (DHSC), previously issued guidance in November 2019 on how clinicians should manage instances where medication is needed urgently and when it is in short supply. This states: *"In all cases of medicines supply issues, community pharmacies should endeavour to communicate any supply issues and relevant information about resupply dates and the proposed management plan clearly with patients. They should also undertake counselling to support affected patients where possible."* (see 11.1.3).

This guidance is further supported by the service specification for the NHS Pharmacy First service that was launched on 31 January 2024 (NHS England » Launch of NHS Pharmacy First advanced service). In cases where medication that is urgently required is not in stock at the pharmacy, the service specification states that, with the agreement of the patient, the pharmacist should identify another pharmacy that provides the service and forward the electronic referral to them (see 4.19). If the patient is unable to get to the premises, the pharmacist must ensure that the patient is able to obtain the supply in a timely manner by discussing all reasonable options for accessing their medicines (see 4.20).

Current technology does not allow the tracking of stocks of medication across community pharmacies. This is being investigated as a strategy to better manage high-impact national shortages of medication.

The Royal Pharmaceutical Society (RPS) and the Royal College of General Practitioners (RCGP) have published a toolkit for GP practices to use, to assess and improve the safety and effectiveness of their repeat prescribing systems. This toolkit highlights the need for practices to ensure that they have taken into account high risk medicines. The medicines it identifies as high risk are those that are most commonly associated with serious adverse reactions, but it is not specific to medication for epilepsy. The toolkit recommends using the following text as an example of information that practices might share with patients about repeat prescriptions:
"Please try not to run out of your medicines. When you are running low, e.g., have two weeks' supply remaining, please request the next prescription. If you accidentally run low or run out, we will try to process your request as quickly as possible, but please remember that the request process must be carried out thoroughly and safely and that GP practice teams are extremely busy. Emergency supply requests for medicine can be requested from NHS 111 or 111 Online in an urgent situation. The pharmacy will check the GP record/National Care Record to ensure that they are not making duplicate supplies to ensure your safety and reduce waste."

When a patient identifies to NHS 111 that they have run out of medication, the caller will establish when the next dose is due. If a prescription cannot be sourced from the patient's own GP within this time period, the patient is referred to an open local pharmacy under the Pharmacy First Scheme, once it has been confirmed that the patient does not need a symptomatic assessment.

All medications are treated with the same high priority. Due to the variable use of medications for different presentations, the use of brand names and alternative descriptions for conditions, it is not safely possible to differentiate between different levels of urgency.

We note that at the time of this incident, England still had legal restrictions in place to prevent Covid-19 deaths. Primary care and community pharmacies were under huge amounts of pressure, whist maintaining necessary but burdensome infection prevention measures. Since this time, we have taken steps to increase access to primary care services, including a shift to digital services and a reduction in the bureaucratic load on general practice, and the commissioning of the Pharmacy First to better support people who need urgent access to medicines.

I would also like to provide further assurances on the 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 events, such as the sad death of Charlie, are shared across the NHS at both a national and regional level and helps us to 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,

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National Medical Director