

## **Care Quality Improvement Directorate**

Royal College of Physicians The Spine 2 Paddington Village Liverpool L7 3FA Tel: +44 (0)151 318 0000

Email: cqid@rcp.ac.uk www.rcp.ac.uk

Miss Nadia Persaud, HM Coroner East London Coroner's Court 124 Queens Road Walthamstow E17 8QP

Letter by email to:

20 May 2024

Dear Miss Persaud,

Thank you for your contact raising concerns related to the care of Andrew Erwin-Ripp in your Regulation 28 notice dated 2 April 2024.

The Royal College of Physicians brings together multiple medical specialities and oversees training of Physicians.

In relation to your concerns for this specific case we have sought expert advice from the Association of British Neurologists (ABN). They confirm the following:

- National guidance on monitoring NICE (https://www.nice.org.uk/guidance/ng217) (section 4.5), and SIGN 143 (https://www.sign.ac.uk/our-guidelines/diagnosis-and-management-of-epilepsy-in-adults/) containing information on SUDEP and ideal models of care in both primary and secondary care.
- For annual follow up in primary care, people with epilepsy were previously included within the
  primary care Qualities Outcomes Framework up to 2014, but no longer. The Association of
  British Neurologists would welcome reinstating annual reviews for people with epilepsy in
  primary care as suggested by the independent neurologist.
- For guidance on longer term monitoring of people with epilepsy, and safe discharge timing it is
  not possible to provide guidance on this that suits all patients with epilepsy as it depends on
  many variables. The ABN therefore do not feel that it would be appropriate to make specific
  recommendations regarding timing for discharge. Many patients are now enrolled in patientinitiated follow-up schemes (or equivalent) rather than being fully discharged. Fewer routine
  reviews may aid seeing people when most needed.
- It is good practice to include comments in letters on discharge regarding the importance of
  continuing to maintain good compliance with antiseizure medication after discharge, and to
  notify the GP if there is seizure recurrence. If a patient has been discharged from secondary

- care, they would normally need a new referral and the contact with secondary care will be via the GP which ABN agree should also be made clear in the discharge letter.
- The UK has the lowest number of neurologists per head of population in Europe, with an approximate average of 1 consultant neurologist per 91 000; the European average is about 1 per 10 000. The prevalence of epilepsy specialist nurses is similarly very low, for example in Edinburgh, there is presently less than 2 WTE nurses to cover a population of close to 1 million. Many people with epilepsy do not have access to an epilepsy nurse specialist. This means that many centres are finding it difficult to review patients urgently and provide urgent appointments. However, many units will have an on-call telephone advice system with a duty consultant/registrar for more immediate advice to GPs. It will of course vary depending on local service set up and workforce.

The Royal College of Physicians supports the position of Association of British Neurologists and continues to advocate for an expansion in the neurology workforce.

Please do let me know if you need any further information.

Yours sincerely,

**Clinical Vice President**