
Thursday, 01 April 2021

Sent by email to: [REDACTED]

Dear Coroner C Topping

**Re: Lucy Patricia Colgate
Regulation 28 – Action to Prevent Future Deaths**

We have read carefully your report regarding the tragic and untimely death of Lucy Colgate and have discussed this with senior colleagues within the RCPCH Epilepsy Programme Board and with the British Paediatric Neurology Association's British Paediatric Epilepsy Group in order to respond to your request.

The RCPCH supports, educates and develops paediatricians, and the wider child health workforce and services, to deliver high quality safe care for infants, children and young people. Given that we do not have all the details of the tragic death of Lucy Colgate, the RCPCH is unable to comment on the specifics of the case.

Children and young people with epilepsy need support to engage in an ongoing individualised assessment of risk and consideration of tailored accident prevention. The RCPCH Epilepsy12 audit supports trusts in England and Wales to measure on an ongoing basis how well they are evidencing risk assessment. The September 2020 report found that the majority (80%) of children and young people diagnosed with epilepsy had evidence of discussion regarding general participation and risk.¹ The RCPCH continue to monitor and share audit results with local and regional teams and further urge quality improvement in this area.

The Sudden Unexpected Death in Epilepsy charity (SUDEP Action)) has produced resources for parents and carers to support individualised understanding and balancing risk for children living with an epilepsy.² There may be opportunity to adjust specific advice regarding door opening in their information resources. At the moment the information leaflet makes this recommendation only for bathroom doors.

We will share learning around the circumstances of this death with our paediatric specialty groups who lead care for children with epilepsy and with OPEN UK³ (Organisation of Paediatric Epilepsy Networks) to disseminate warnings of these types of risks. We hope

¹ https://www.rcpch.ac.uk/sites/default/files/2020-09/epilepsy12_2020_national_report_final_2.pdf

² https://sudep.org/sites/default/files/sudep_childrens_hi.pdf

³ <https://www.rcpch.ac.uk/resources/open-uk-organisation-paediatric-epilepsy-networks-uk>

that in doing so, families will be more aware of the key factors that are critical to ensuring suitable home environments for children and young people with epilepsy.

We are pleased that you have shared your report with Epilepsy Action who have a collection of useful resources to support safety at home.

Thank you for raising this case with us and reminding us of the importance of this work.

Yours sincerely



President, Royal College of Paediatrics and Child Health