

21 November 2024

Deborah Archer
Assistant Coroner
HM Coroners Office (Administration)
County of Devon, Plymouth and Torbay
By email: [REDACTED]

Your reference: [REDACTED]

Our reference: [REDACTED]

Dear Ms Archer

Re: Regulation 28 Prevention of Future Deaths Report in respect of Maeve Bernadette Boothby O'Neill

I write in response to your regulation 28 report regarding the tragic death of Maeve Boothby O'Neill. I would like to express my sincere condolences to Maeve's family and loved ones.

We have reflected on the circumstances surrounding Maeve's death and senior clinical advisers within our patient safety team have reviewed the concerns raised in your report.

Following discussions with colleagues in the NHS and at the Department of Health and Social Care (DHSC), we understand they will respond fully to points 1 to 3. We make the following observations.

- 1. During the course of the evidence it became clear that there were no specialist hospitals or hospices, beds, wards or other health care provision in England for patients with severe Myalgic encephalomyelitis (ME). This meant that the Royal Devon and Exeter Hospital had no commissioned service to treat Maeve and patients like her.**

Our guideline on myalgic encephalomyelitis (or encephalopathy)/chronic fatigue syndrome (ME/CFS): diagnosis and management [NG206] recommends that care for people with ME/CFS should be supported by advice and direct clinical consultation from an [ME/CFS specialist team](#). Service commissioning and delivery is the responsibility of the relevant NHS body.

- 2. During the course of the inquest it became clear that there was no current available funding for the research and development of treatment and further learning for understanding the causes of ME / Chronic Fatigue Syndrome (CFS).**

NICE guidelines are developed by independent committees. During development, committees often identify areas for which there are uncertainties in the evidence or for which robust evidence is lacking. They can make recommendations for research that are likely to inform future decision-making (based on a systematic assessment of gaps in the current evidence).

During development of the NICE guideline on ME/CFS, the committee made a number of recommendations for research, including one on dietary strategies.

- 3. During the course of the inquest it became clear that there was extremely limited training for Doctors on ME/ CFS and how to treat it – especially in relation to severe ME.**

NICE has supported the development of e-learning materials consistent with NICE guidance on ME/CFS. They have been produced by the NHS England Technology Enhanced Learning team and we will link to them from the guideline page on our website as they are published.

- 4. During the course of the inquest it became clear that the 2021 NICE guidelines on ME did not provide any detailed guidance at all on how severe ME should be managed at home or in the community and in particular whether or not there is any necessary adaptation needed to the 2017 guidance on Nutrition support for adults : oral nutrition support , enteral tube feeding and parenteral nutrition .**

The remainder of our response focuses on point 4 as actions to address this concern are within NICE's control.

Our guideline includes recommendations on [care for people with severe or very severe ME/CFS](#) (section 1.17). They include general recommendations on dietary management and strategies. We were not able to make more specific recommendations due to a lack of good quality evidence. For this reason, the committee made the research recommendation noted above.

This section does refer to the NICE guideline on [nutrition support for adults: oral nutrition support, enteral tube feeding and parenteral nutrition](#) [CG32].

While this guideline (CG32) is not specific to ME/CFS, there are recommendations on [indications for nutrition support in hospital and the community](#) (section 1.3). They say that healthcare professionals should consider enteral tube feeding in people who are malnourished or at risk of malnutrition, defined as having eaten little or nothing for more than 5 days and/or being likely to eat little or nothing for the next 5 days or longer (recommendation 1.3.2).

There is also guidance on [what nutrition support to give](#) (section 1.4) and how to [monitor nutrition support](#) (section 1.5). It also includes a specific section on [supporting patients in the community with enteral feeding](#) (section 1.9).

Actions proposed

In response to your report, and our learning and reflections following Maeve's death, we will:

- review the evidence on dietary management and strategies for people with severe or very severe ME/CFS published since NG206 was introduced to determine if any specific amendments to the guideline are needed in this area.
- work with colleagues from the Royal Devon University Healthcare NHS Foundation Trust to see if there are examples of good practice that we can link to from our guideline pages.
- consider appropriate amendments to the guideline on ME/CFS to emphasise the need for appropriate nutritional support.

Additionally, we are already working with colleagues from our external supplier that produces NICE Clinical Knowledge Summaries (CKS) to determine if any updates to the section on fatigue are possible. CKS topics are a source of advice and information primarily for health professionals working in primary care, but they do not constitute formal NICE guidance.

I hope this response is helpful in confirming what NICE recommends and the actions that we will take because of your report relating to Maeve. I would like to reiterate my condolences to her family.

Yours sincerely


Chief Executive