



Department  
of Health &  
Social Care

Parliamentary Under-Secretary of State for Public Health and Prevention

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Our ref: [REDACTED]

Ms Deborah Archer  
HM Assistant Coroner  
Coroner area of The County of Devon, Plymouth and Torbay  
County Hall  
Topsham Road  
Exeter, EX2 4QD

By email: [REDACTED]

2 December 2024

Dear Ms Archer,

Thank you for the Regulation 28 report of 7 October 2024 sent to the Secretary of State / the Department of Health and Social Care (DHSC) about the death of Maeve Boothby O'Neill. I am replying as the Minister with responsibility for long-term conditions, including myalgic encephalomyelitis / chronic fatigue syndrome (ME/CFS).

Firstly, I would like to say how saddened I was to read of the circumstances of Maeve's death. The circumstances your report describes are deeply concerning and I am grateful to you for bringing these matters to my attention. I met with Maeve's mother Sarah last week to offer my sincere condolences to her and her family, and to discuss how we can improve care for people with ME/CFS and work together to try and ensure no other families lose a loved one in such tragic circumstances.

The report raises concerns over:

- i. no specialist hospitals or hospices, beds, wards or other health care provision in England for patients with severe ME/CFS;
- ii. no current available funding for the research and development of treatment and further learning for understanding the causes of ME/CFS;
- iii. extremely limited training for doctors on ME/CFS and how to treat it, especially in relation to severe ME/CFS;
- iv. the 2021 National Institute for Health and Care Excellence (NICE) guidelines on ME/CFS not providing any detailed guidance at all on how severe ME/CFS should be managed at home or in the community and, in particular, whether or not there is any necessary adaption needed to the 2017 guidance, *Nutrition support for adults: oral nutrition support, enteral tube feeding and parenteral nutrition*.

In preparing this response, DHSC officials have liaised with NHS England, NICE and the Medical Schools Council to ensure a comprehensive approach to fully addressing your

concerns. Those organisations will be replying separately to you, focusing on the concerns that fall within their competence. My response, therefore, will primarily focus on the matters of concern relating to the funding of research into the causes of ME/CFS and the development of treatments for ME/CFS, and training for doctors on ME/CFS.

## **Research**

On the issue of funding for research and development of treatment and further learning for understanding the causes of ME/CFS, it is not accurate to say that there is no funding available. The Government is committed to funding high-quality research to understand the causes, consequences and treatment of ME/CFS, and is actively exploring next steps for research in this area. Government research funding is currently available for ME/CFS through the National Institute for Health and Care Research (NIHR) and UK Research and Innovation.

DHSC funds ME/CFS research through the NIHR and welcomes funding applications for research into any aspect of human health, including ME/CFS. We do not usually “ring-fence” funding for any specific condition as these applications are subject to peer review and judged in open competition, with awards being made on the basis of the importance of the topic to patients and health and care services, value for money and scientific quality. In all areas, the amount of NIHR funding depends on the volume and quality of scientific activity.

The Government is aware of the devastating effect ME/CFS can have on those suffering from the condition and recognises that it is an under-researched area. Unfortunately, despite our efforts to stimulate high-quality research in this area, we have received a low number of research applications on ME/CFS. We will, however, continue to work with the community, to identify new opportunities to increase research in this area.

I can also reassure you that over the last five years, the DHSC, through NIHR, has invested over £3.6 million in research programme funding for ME/CFS. This includes over £1.5 million to the DecodeME study, co-funded with the Medical Research Council, into the genetic underpinning of ME/CFS. The study will analyse samples from 25,000 people with ME/CFS to search for genetic differences that may indicate underlying causes or an increased risk of developing the condition. This study aims to increase our understanding of the disease and therefore contribute to the research base on diagnostic tests and targeted treatments for ME/CFS.

I hope that this provides reassurance that we take seriously the challenge of ME/CFS and are committed to ensuring that those living with it have the opportunity to participate in and benefit from research, with the aim of better understanding the causes of ME/CFS, identifying new treatments and improving patient outcomes.

## **Training and education**

In relation to the issue of training for doctors on ME/CFS and how to treat it, especially in relation to severe ME/CFS, the Department is working with NHS England to develop an e-learning course on ME/CFS for healthcare professionals, with the aim of supporting staff to

be able to provide better care and improve patient outcomes. NHS England's e-learning package comprises three sessions. In May 2024, NHS England published the first session, with universal access, providing an overview of the condition, and aiming to increase awareness and reduce stigma around ME/CFS. The second and third sessions, currently in development, are aimed specifically at clinicians and, alongside the first session, will form a comprehensive package for NHS staff to be able to provide better care for patients with ME/CFS.

The second session will focus on management in primary care, covering personalised activity plans, concomitant conditions, such as mast cell activation syndrome and postural tachycardia syndrome, the psychological impact of being diagnosed with the condition, and what is not ME/CFS. The third session will cover management in secondary care, focusing on patients with more severe ME/CFS that require hospitalisation. This includes information on treatments and their potential benefits and risks, management of a patient who requires hospital admission, provision of a minimum stimuli environment, and support for healthcare professionals.

The Medical Schools Council will promote the NHS England e-learning package on ME/CFS to all United Kingdom medical schools, and encourage medical schools to provide undergraduates with direct patient experience of ME. The General Medical Council (GMC) is the regulator of medical schools, and it is important that education is reinforced at different stages of medical training. Royal Colleges play an important role in this. The GMC has included ME/CFS in the content map for the new national exam so all medical schools will need to teach it as a subject.

NICE supports the development of e-learning materials that are consistent with NICE guidance and will promote the NHS England e-learning package on the guideline page on their website when available.

## **Next steps**

Under the previous government, the Department published the ME/CFS interim delivery plan in August 2023, alongside a public consultation which closed in October 2023. It has been my priority since my appointment to publish a summary of responses to this consultation, which we are intending to publish in December. Following the publication, we will reconvene the ME/CFS Task and Finish Group, including senior DHSC and cross-government officials, and ME/CFS specialists and representatives from NHS England, NICE, devolved governments and ME/CFS charities and organisations. The consultation responses, alongside continued stakeholder engagement via the ME/CFS Task and Finish Group, will inform the development of the final delivery plan for ME/CFS, which we aim to publish by the end of March 2025. The plan will focus on boosting research, improving attitudes and education, and bettering the lives of people with this debilitating disease.

NHS England has agreed to support the implementation of the final delivery plan and is also establishing a specific working group to determine if additional support can be provided to commissioners of ME/CFS services. A stock take of existing ME/CFS services in England is being undertaken as an initial step. NHS England has offered to update you on progress.

NHS England colleagues in the south west of England have engaged with Royal Devon University Healthcare NHS Foundation Trust (RDUH) on your report and Maeve's care. RDUH is in the process of developing formal pathways for acute admission and emergency admission for patients with ME/CFS. NHS England has agreed to share this with you in due course.

NICE has agreed to review the evidence on dietary management and strategies for people with severe ME/CFS published since the 2021 NICE guidelines were introduced, and amend guidance as needed. It will consider appropriate amendments to the guideline on ME/CFS to emphasise the need for appropriate nutritional support. NICE will work with colleagues from RDUH to determine examples of good practice to link into NICE guideline pages.

I hope this response is helpful in demonstrating our commitment to bolster care and support for people living with ME/CFS. Thank you for bringing these concerns to my attention.

Yours sincerely,

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