Department
of Health &
Social Care

[redacted]
Parliamentary Under-Secretary of State for Public Health and Prevention

39 Victoria Street London
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[redacted]

HM Coroner Debbie Rookes
Coroner's Office
37 Old Weston Road
Bristol
BS48 1UL

2nd September 2025

Dear Ms Rookes,

Thank you for the Regulation 28 report of 7 July 2025 sent to the Secretary of State for Health and Social Care about the death of Sarah Lewis**.** 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 Sarah's death, and I offer my sincere condolences to their family and loved ones. The circumstances your report describes are concerning and I am grateful to you for bringing these matters to my attention.

The report raises concerns over:

1. the provision of ME services across the country being inconsistent;
2. the diagnosis and validation of severe symptoms including outdated beliefs on ME;
3. the lack of research into ME including lack of funding;
4. other professionals misunderstanding ME, which causes barriers for patients trying to access support;
5. NICE guidance not being fully considered and implemented.

In preparing this response, my officials have made enquiries with NHS England to ensure we adequately address your concerns.

I understand that the National Institute for Health and Care Excellence (NICE) will be replying separately. I would like to reassure you that whilst NICE guidelines are not mandatory, the Government does expect healthcare commissioners to take the guidelines fully into account in designing services to meet the needs of their local population and to work towards their implementation over time. NICE has also recently published a Clinical Knowledge Summary on ME/CFS, available at the following link: Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) | Health topics A to Z | CKS | NICE.

While Clinical Knowledge Summaries are not equivalent to NICE guidance, we understand that they are well used, particularly in primary care.

The Department of Health and Social Care (DHSC) published the ME/CFS Final Delivery Plan on 22 July, which can be found here: https://www.gov.uk/government/publications/mecfs-the-final-delivery-plan. The plan focuses on boosting research, improving attitudes and education, and bettering the lives of people with this debilitating disease. We have worked closely with ME/CFS patients, carers, clinicians, charities, research funders and researchers throughout the development of the interim and final delivery plans. This engagement has enabled us to develop new and more ambitious actions that deliver meaningful change for the ME/CFS community.

NHS England remains committed to collaborating with DHSC on the implementation of the ME/CFS Final Delivery Plan, with a view to supporting integrated care boards to ensure equitable access and evidence-based care, including implementation of the 2021 NICE guidance on ME/CFS. This partnership will support the integration of best practices and insights to enhance service quality and consistency across the system. More specifically, within the ME/CFS Final Delivery Plan, NHS England will co-design resources for systems to improve services for mild and moderate ME/CFS. Additionally, DHSC, with NHS England, will explore whether a specialised service should be prescribed by the Secretary of State for Health for very severe ME/CFS.

Education and training

In relation to the issue of some people still perceiving ME/CFS as not being real and healthcare and other professionals misunderstanding ME/CFS, the Department has been working closely with NHS England to develop an e-learning course on ME/CFS for healthcare and other 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 session, published in January 2025, again with universal access, aims to inform and empower community-based healthcare practitioners with the knowledge and tools needed to effectively diagnose, manage and support patients with ME/CFS. The third session, aimed specifically at clinicians, is being finalised and is due to be published shortly. It focuses on severe ME/CFS and management in secondary care and, alongside the first and second sessions, will form a comprehensive package for NHS staff to be able to provide better care for patients with ME/CFS.

Whilst the training is not mandatory, there is a range of actions in the ME/CFS Final Delivery Plan aimed at increasing the uptake of NHS England e-learning sessions, to both improve professionals' and the public knowledge of ME/CFS, and to create greater awareness and visibility of the condition across professions.

The Royal College of General Practitioners, the Chartered Society for Physiotherapists and the Royal College of Occupational Therapists agreed to share and promote NHS England's e-learning modules. The Royal College of Physicians (RCP) will also rely on

NHS England’s e-learning modules, which the RCP considers to be suitable, for their members, all of whom the RCP is wants to undertake the e-learning by the end of 2025. The Medical Schools Council has shared NHS England's e-learning package on ME/CFS with all UK medical schools, encouraging them to provide undergraduates with direct patient experience. NICE has also added the e-learning to its tools and resources page, with further modules to be added as they become available.

The Department for Education will also encourage special educational needs and disability (SEND) and medical condition organisations to signpost the NHS England e-learning on ME/CFS on their websites, and will signpost it to providers.

DHSC will continue to reach out to its networks, including the Royal College of Nursing, to promote the e-learning, and will issue targeted communications regarding the e-learning via wider sector networks, such as the Health and Wellbeing Boards, adult social care provider networks, and representative bodies and charities.

Research

DHSC funds research on health and social care through the National Institute for Health and Care Research (NIHR). The NIHR and Medical Research Council (MRC, part of UK Research and Innovation) remain committed to funding high-quality research to understand the causes, consequences, and treatment of ME/CFS.

The NIHR welcomes funding applications for research into any aspect of human health, including ME/CFS. 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. As mentioned above, the level of research funding awarded is directly related to the number and quality of research applications received and, unfortunately, despite our efforts to stimulate highquality research in this area, we have historically received a small number of applications for funding in this area. Between the 2019/20 and 2023/24 financial years, the UK Government, through NIHR and MRC committed around £6.5 million in research into ME/CFS. This includes £3.2 million towards the DecodeME study into the genetic underpinning of ME/CFS. This study will help increase our understanding of the condition and therefore contribute to the future development of diagnostic tests and targeted treatments for ME/CFS.

Together with the MRC, we are actively exploring next steps for research in ME/CFS. In the ME/CFS Final Delivery Plan, we have outlined the research actions and additional support that we will offer to the research community to increase the volume and quality of applications. This includes a new funding opportunity for a development award focussed on evaluating repurposed pharmaceutical inventions for post-acute infection syndromes and associated conditions, including ME/CFS. This funding opportunity is a key component of our response to the need for further research-based evidence related to the diagnosis, management and treatment of post-acute infection conditions, including ME/CFS. We are also planning an NIHR and MRC hosted showcase event for post-acute infection conditions (including ME/CFS and long COVID) research later this year to stimulate further research in this field.

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.

Lastly, I understand the effect that having a long-term condition like ME/CFS can have on a person’s mental health and I note that Ms Lewis had a history of anxiety and depression. NHS Talking Therapies Long Term Conditions services provide evidence-based psychological therapies for people with depression and anxiety disorders, who also have a long-term physical health condition, such as ME/CFS. All integrated care boards are expected to expand services locally by commissioning NHS Talking Therapies services integrated into physical healthcare pathways. In addition, anyone in England experiencing a mental health crisis can speak to a trained NHS professional at any time of the day by calling 111. Trained NHS staff will assess patients over the phone and guide callers with next steps.

I hope this response is helpful. Thank you for bringing these concerns to my attention.

Yours sincerely,

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