Source: UK House of Commons
Date: May 1, 2024
Time: 16:30:40 BST
URL:
https://hansard.parliament.uk/Commons/2024-05-01/debates/9BE269EC-BE67-439A-9546-7C72A7043C59/WorldMEDay
WebTV:
https://www.parliamentlive.tv/Event/Index/0c36b6f9-7b6b-4607-8219-24b6db5bc132
Ref: http://www.me-net.combidom.com/meweb/web1.4.htm#westminster

[Westminster Hall Debate]

Source: UK House of Commons
Date: May 7, 2024
URL:
https://questions-statements.parliament.uk/written-questions/detail/2024-05-01/24494

https://questions-statements.parliament.uk/written-questions/detail/2024-05-01/24495
Ref: http://www.me-net.combidom.com/meweb/web1.4.htm#westminster

[Written Answers]

Chronic Fatigue Syndrome: Research

Owen Thompson

To ask the Secretary of State for Health and Social Care, what steps her Department is taking to ensure myalgic encephalomyelitis receives a proportionate share of National Institute for Health and Care Research funding.
To ask the Secretary of State for Health and Social Care, if she will instruct the National Institute for Health and Care Research to increase the level of funding available for myalgic encephalomyelitis research.

Andrew Stephenson

The Department funds research on health and social care through the National Institute for Health and Care Research (NIHR). The NIHR welcomes funding applications for research into any aspect of human health including myalgic encephalomyelitis. These applications are subject to peer review and judged in open competition, with awards being made based on 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.

Source: UK House of Lords
Date: May 7, 2024
URL:
https://questions-statements.parliament.uk/written-questions/detail/2024-04-29/hl4176

https://questions-statements.parliament.uk/written-questions/detail/2024-04-29/hl4177

https://questions-statements.parliament.uk/written-questions/detail/2024-04-29/hl4178
Ref: http://www.me-net.combidom.com/meweb/web1.4.htm#westminster

[Written Answers]

Chronic Fatigue Syndrome: Health Services/Medical Records/Hospitals
----

Baroness Scott of Needham Market

To ask His Majesty's Government what steps they are taking to develop a pathway of care for people with severe myalgic encephalomyelitis who require hospitalisation.

To ask His Majesty's Government what steps they are taking to ensure accurate coding of a diagnosis of myalgic encephalomyelitis on both primary and secondary care records.

To ask His Majesty's Government what assessment they have made of hospital compliance with National Institute for Health and Care Excellence guidelines for the treatment of inpatients with severe myalgic encephalomyelitis.

Lord Markham

The National Institute for Health and Care Excellence's (NICE) guideline, Myalgic encephalomyelitis (or encephalopathy)/chronic fatigue syndrome: diagnosis and management, published in October 2021, outlines the expectations for inpatient care for patients with severe myalgic encephalomyelitis (ME), also known as chronic fatigue syndrome (CFS), who require hospitalisation.

The National Health Service commissions services across England that provide support for people living with ME. In October 2023, the British Association of Clinicians in ME/CFS published the ME/CFS National Services Survey 2023. This report provides insight into the services being delivered for adults, children, and young people with ME.

No assessment has been made of the extent of hospital compliance with the NICE guidelines on ME. It is the duty of clinicians to keep themselves appraised of best practice, in particular guidance issued by the NICE. Whilst guidelines are not mandatory, clinicians and commissioners are expected to take them fully into account when designing services that meet the needs of their local population. The NICE promotes its guidance via its website, newsletters, and other media.

The Department is working with NHS England to develop an e-learning course on ME for healthcare professionals, with the aim of supporting staff to be able to provide better care, and improve patient outcomes. The Medical Schools Council will promote the NHS England e-learning package on ME to all United Kingdom medical schools, and encourage those schools to provide undergraduates with direct patient experience of ME.

Systematized Nomenclature of Medicine Clinical Terms (SNOMED CT) is used in the NHS to ensure accurate coding of medical conditions, including ME, in both primary and secondary care records. Within SNOMED CT, all content for ME is contained within a single overarching code, with linked codes for mild, moderate, and severe forms. These can be used by all NHS healthcare providers, including general practitioners. It is estimated that there are over 250,000 people in England and Wales with ME.

Sajid Javid: People with ME have been ignored for far too long.

Go to (no paywall),

https://archive.ph/https://www.thetimes.co.uk/article/people-with-me-have-been-ignored-for-far-too-long-gv2nhq28m

Source: UK House of Commons
Date: May 15, 2024
URL:
https://questions-statements.parliament.uk/written-questions/detail/2024-05-07/25093
Ref: http://www.me-net.combidom.com/meweb/web1.4.htm#westminster

[Written Answers]

Chronic Fatigue Syndrome: Health Services

Navendu Mishra

To ask the Secretary of State for Health and Social Care, what steps her Department is taking to help improve specialist services for patients diagnosed with myalgic encephalomyelitis.

Andrew Stephenson

Integrated care boards (ICBs) are responsible for commissioning specialist myalgic encephalomyelitis (ME), also known as chronic fatigue syndrome (CFS), services that meet the needs of their population, subject to local prioritisation and funding. The process of commissioning services should take into account best practice guidance, such as the National Institute for Health and Care Excellence's (NICE) guidance on ME and CFS diagnosis and management, published in October 2021.

In October 2023, the British Association of Clinicians in ME/CFS published the ME/CFS National Services Survey. This report provides insight into the services being delivered for adults, children, and young people with ME and CFS. The Department published My full reality: an interim delivery plan for ME/CFS in August 2023, which sets out a number of actions to improve the experiences and outcomes for people living with the condition, including better education of professionals and improvements to service provision.

Alongside the publication of the interim delivery plan, we ran a public consultation to build a picture of how well the interim plan meets the needs of the ME and CFS community, and to understand if there are any gaps where further action may be necessary. The Department is currently analysing over 3,000 responses to the consultation, and will publish a summary of the consultation responses in due course. Those consultation responses, along with continued close engagement with key stakeholders, will drive the development of the final cross-Government ME/CFS Delivery Plan, which will be published later this year.

Source: UK House of Commons
Date: May 20, 2024
URL:
https://questions-statements.parliament.uk/written-questions/detail/2024-05-13/25988
Ref: http://www.me-net.combidom.com/meweb/web1.4.htm#westminster

[Written Answers]

Chronic Fatigue Syndrome: Health Services

Daisy Cooper

To ask the Secretary of State for Health and Social Care, what progress her Department has made on the Interim Delivery Plan for ME/CFS.

Andrew Stephenson

In August 2023, the Department published My Full Reality, a cross-Government interim delivery plan on myalgic encephalomyelitis, also known as chronic fatigue syndrome (ME/CFS), which sets out a number of actions to improve the experiences and outcomes for people with the condition through an expansion of research, better education of professionals, improvements in attitudes towards the condition, and improvements to service provision.

Alongside the publication of the interim Delivery Plan, we ran a public consultation to gather the views and experiences of healthcare professionals, organisations, and individuals with lived experiences of ME/CFS. The aim of the consultation is to build a picture of how well the interim delivery plan identifies and meets the needs of the ME/CFS community, and to understand where there are any gaps where further action may be necessary.

The consultation received well over 3,000 highly detailed responses, which are in the process of being analysed. The consideration and analysis of these responses is progressing steadily, and we are on track to publish a summary of the consultation responses shortly. The consultation responses, along with continued close engagement with stakeholders, will inform the development of the final delivery plan, which we aim to publish later this year.

Source: UK House of Commons
Date: May 21, 2024
URL:
https://questions-statements.parliament.uk/written-questions/detail/2024-05-16/26662

https://questions-statements.parliament.uk/written-questions/detail/2024-05-16/26663
Ref: http://www.me-net.combidom.com/meweb/web1.4.htm#westminster

[Written Answers]

Chronic Fatigue Syndrome: Medical Treatments
Chronic Fatigue Syndrome: Health Services

Fabian Hamilton

To ask the Secretary of State for Health and Social Care, whether her Department (a) has and (b) plans to provide funding for new treatments for ME or chronic fatigue syndrome.

To ask the Secretary of State for Health and Social Care, if she will make an assessment of the adequacy of NHS provision of specialist ME or chronic fatigue syndrome services; and if she will take steps to increase the number of clinicians who specialise in ME or chronic fatigue syndrome.

Andrew Stephenson

The Department, through the National Institute for Health and Care Research (NIHR), provides funding for research projects which aim to understand the underlying causes of myalgic encephalomyelitis, also known as chronic fatigue syndrome (ME/CFS), and find new treatments for the condition. As part of this, the NIHR and the Medical Research Council have funded the world's largest genome-wide association study of ME/CFS. This 3.2 million pounds study, termed DecodeME, 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. By helping us to understand ME/CFS better, this research has the potential to lead to new treatments for the condition.

Integrated care boards (ICBs) are responsible for commissioning specialist ME/CFS services that meet the needs of their population, subject to local prioritisation and funding. The process of commissioning services should take into account best practice guidance, such as the National Institute for Health and Care Excellence's guidance on ME/CFS diagnosis and management, published in October 2021. In addition, in October 2023, the British Association of Clinicians in ME/CFS published the ME/CFS National Services Survey. This report provides insight into the services being delivered for adults, children, and young people with ME/CFS.
