Source: UK House of Commons
Date: November 5, 2025
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https://questions-statements.parliament.uk/written-questions/detail/2025-10-27/85337
Ref: http://www.me-net.combidom.com/meweb/web1.4.htm#westminster

[Written Answers]

Chronic Fatigue Syndrome and Long Covid: Training

Navendu Mishra

To ask the Secretary of State for Health and Social Care, what steps his Department is taking to improve the (a) training and (b) awareness of healthcare professionals in (i) diagnosing and (ii) supporting people with (A) myalgic encephalomyelitis or chronic fatigue syndrome and (B) long COVID.

Ashley Dalton

The Department published the final myalgic encephalomyelitis, also known as chronic fatigue syndrome (ME/CFS), delivery plan on 22 July. The plan focusses on boosting research, improving education and attitudes, and bettering the lives of people with this debilitating disease.

To support healthcare professionals in the diagnosis and management of ME/CFS, as set out in the ME/CFS Final Delivery Plan, the Department has worked with NHS England to develop an e-learning programme on ME/CFS for healthcare professionals, with the aim of supporting staff to be able to provide better care and improve patient outcomes. All three sessions of the e-learning programme are now available on the NHS.UK website, with sessions one and two having universal access whilst the third session is only available to healthcare professionals, at the following link: https://learninghub.nhs.uk/catalogue/mecfselearning?nodeId=7288(opens in a new tab).

The Medical Schools Council will promote the NHS England e-learning programme on ME/CFS to all United Kingdom medical schools and will encourage those medical schools to provide undergraduates with direct patient experience of ME/CFS. The General Medical Council (GMC) is the regulator of medical schools, and it is important that education is reenforced 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.

There is also targeted advice for healthcare professionals to manage long COVID. Patients should be managed according to current clinical guidance, such as that published and updated by the National Institute for Health and Care Excellence, which is available at the following link:
https://www.nice.org.uk/guidance/NG188

Source: UK House of Commons
Date: November 5, 2025
URL:
https://questions-statements.parliament.uk/written-questions/detail/2025-10-28/86002

https://questions-statements.parliament.uk/written-questions/detail/2025-10-28/86003

https://questions-statements.parliament.uk/written-questions/detail/2025-10-28/86004
Ref: http://www.me-net.combidom.com/meweb/web1.4.htm#westminster

[Written Answers]

Chronic Fatigue Syndrome: Research

Tom Morrison

To ask the Secretary of State for Health and Social Care, what steps he is taking to ensure a strategic approach to biomedical research into myalgic encephalomyelitis and chronic fatigue syndrome.

To ask the Secretary of State for Health and Social Care, if he will make a comparative review into the adequacy of the level of funding for research into myalgic encephalomyelitis compared to other illnesses.

To ask the Secretary of State for Health and Social Care, if he will consider ringfencing funding for research into myalgic encephalomyelitis.

Dr Zubir Ahmed

The Department funds research through the National Institute for Health and Care Research (NIHR).

We are committed to working with the myalgic encephalomyelitis, also known as chronic fatigue syndrome (ME/CFS), community to identify and address barriers to research, with the ambition of supporting more research and capacity-building programmes. As part of our approach, together with the Medical Research Council (MRC), we are actively exploring next steps in ME/CFS research, as outlined in the ME/CFS Final Delivery Plan. This includes a new funding opportunity for a development award focussed on evaluating repurposed pharmaceutical interventions for post-acute infection syndromes and associated conditions, including ME/CFS. This funding opportunity is one component of our approach to improve evidence around 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 research, including ME/CFS and long COVID, in November to stimulate further research in this field.

We have previously discussed ringfenced funding with the ME/CFS community during the development of the Final Delivery Plan for ME/CFS, as well as at subsequent meetings and roundtables on ME/CFS and long COVID. However, this is not usual practice for research funders as applications in all areas should compete for the funding available to uphold transparency and accountability. The NIHR welcomes funding applications for research into any aspect of human health and care, including ME/CFS. Our position is that welcoming applications on ME/CFS to all programmes enables maximum flexibility both in terms of the amount of research funding and the type of research which can be funded.

There has been no specific comparative review on the level of funding for research into ME/CFS compared to other illnesses. The Department invests over 1.6 billion pounds each year on research through the NIHR, including on ME/CFS. Research funding is available, and applications are subject to peer review and judged in open competition, with awards made on the basis of the importance of the topic to patients and health and care services, value for money, and scientific quality.

Westminster ME debate - november19, 2025.

Go to,
https://x.com/tessamunt/status/1988933783014502698/photo/1
where,
4.30-5.30 Tessa Munt - Government support for people with
myalgic encephalomyelitis [DHSC]

See also,
https://x.com/MEAssociation/status/1988986564861415922/photo/1

Source: UK House of Commons
Library
Date: November 17, 2025
Author: Devyani Gajjar and Steven Kennedy
URL:
https://commonslibrary.parliament.uk/research-briefings/cdp-2025-0217/
Ref: https://whatson.parliament.uk/event/cal53589
Ref: http://www.me-net.combidom.com/meweb/web1.4.htm#westminster

[Research Briefing]

Government support for people with myalgic encephalomyelitis

There will be a 60 minute Westminster Hall debate on government support for people with myalgic encephalomyelitis on Wednesday 19 November at 4:30pm. This debate will be led by Tessa Munt MP.

What is Myalgic Encephalomyelitis?

The NHS explains that Myalgic encephalomyelitis, also called chronic fatigue syndrome (or ME/CFS), is a long-term condition that can affect different parts of the body. The cause of ME/CFS is unknown. ME/CFS can affect anyone.

The 4 main symptoms of ME/CFS are:
* feeling extremely tired all the time (fatigue)
* sleep problems
* problems with thinking, concentration and memory (brain fog)
* symptoms getting worse after physical or mental activity, and possibly taking weeks to get better

There is no specific diagnosis test for ME/CFS. It is diagnosed by symptoms and by ruling out other conditions. It can take a while to diagnose ME/CFS.

Treatment

There is currently no cure for ME/CFS. Treatments include
* advice about how to make best use of the energy a person have without making their symptoms worse
* cognitive behavioural therapy (CBT)
* medicine to control symptoms such as pain and sleeping problems

The NHS webpage on Treatment for ME/CFS has further details.

In October 2021, the National Institute for Health and Care Excellence (NICE) published guidelines for the diagnosis and management of ME/Chronic fatigue syndrome.

Prevalence of ME

According to a recent study, people with ME/CFS 'report lengthy diagnostic delays and prevalence estimates vary greatly due to uneven diagnosis and misdiagnosis'.

The study estimated there are around 404,000 people with ME in the UK. White British people were more likely to be diagnosed with ME compared to Asian and Black British people. Lifetime prevalence was found to be 0.92% in women and 0.25% in men.

For a brief discussion of the study, see this short press release from the University of Edinburgh.

UK government activity - Delivery plan on ME/CFS

In December 2024, the Department of Health and Social Care along with the Department for Education and Department for Work and Pensions published an interim cross-government delivery plan on myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS).

In July 2025, the final delivery plan on ME/CFS was published. The plan focuses on 3 areas where the government says it is seeking to improve care and support for those with ME/CFS:

Research

New research investments announced in the plan include:
* 845,000 pounds for a Medical Research Council funded partnership award (called Building Infrastructure for Patients, Researchers and Industry for Myalgic Encephalomyelitis (PRIME)) to build infrastructure to enable ME/CFS biomedical research.
* A 1.4 million pounds National Institute for Health and Care Research programme (called the HERITAGE study) to explore the cost-effectiveness of existing healthcare for ME/CFS and for long COVID, to improve quality of care.

Attitudes and education

The plan aims to increase knowledge of ME/CFS for healthcare professionals and for the public through:
* E-learning modules on ME/CFS for staff
* a public awareness initiative led by the Department of Health and Social Care

Living with ME/CFS

There are various initiatives in the plan to improve health services for people with ME/CFS, including:
* NHS England will develop a template service specification for mild and moderate ME/CFS
* DHSC and NHS England will explore if there should be a specialised service for very severe ME/CFS

Measures relating to welfare and employment support (most of which are not aimed exclusively at people with ME/CFS, but at disabled people and people with health conditions more broadly) include:
* Initiatives aimed at ensuring that people with ME/CFS and their unpaid carers have a full understanding of how to access the benefits system and of the claims process, that the right decisions are made the first time, and that support is provided where needed throughout the application process.
* Detailed proposals to reform the system of health and disability benefits, and to improve benefits assessment processes, set out in the March 2025 green paper Pathways to Work: Reforming Benefits and Support to Get Britain Working. The government has already legislated to 'rebalance' support in Universal Credit (UC), which will see the additional health element cut for new claimants from April 2026, alongside above-inflation increases in the standard allowance for all UC claimants. The government also intended to make controversial changes to the eligibility criteria for Personal Independence Payment (PIP), but these were abandoned. The government now says it will only make changes to PIP eligibility rules following a review being led by the Minister for Social Security and Disability, Sir Stephen Timms. The Timms review of PIP is being 'co-produced' with disabled people, the organisations that represent them, clinicians, experts, MPs, and other stakeholders, and is expected to conclude by Autumn 2026. The government has yet to announce details of how it intends to proceed with other linked reforms

announced in the green paper, including abolishing the Work Capability Assessment from 2028/29. The government's green paper consultation response published in October 2025 noted: 'we will share details of our proposals in due course.'
* An additional 1 billion pounds a year to provide a new 'pathways to work offer' for disabled people and people with health conditions, including those with fluctuating chronic illnesses such as ME/CFS. This will bring together both current and new interventions to establish a guaranteed offer of tailored, one-to-one help alongside access to appropriate employment, health and skills support.
* Consulting on the future of the Access to Work scheme. Chapter 4 of the Pathways to Work green paper outlined some of the ways the government thought the scheme could be changed.
* The Keep Britain Working review commissioned following the Get Britain Working white paper, looking at the role of UK employers in creating and maintaining healthy and inclusive workplaces. The final report of the Keep Britain Working review, which was led by Sir Charlie Mayfield, was published on 5 November 2025 and the government gave its initial response in a written statement on the same day.

Stakeholder commentary on the government's delivery plan

The charity Action for ME has welcomed the plan as 'an important step towards recognising the scale and seriousness of the condition' but has said the plan 'does not go far enough' and that it 'lacks a strategic approach to research investment, ambition, and accountability structures'.

Similarly, the charity The ME Association has called for a 'more ambitious long term research strategy linked to dedicated funding'. It has critiqued various aspects of the plan, including:
* a lack of a clear strategy to consistently implement NICE guideline recommendations across the country, which is says could lead to 'a postcode lottery in diagnosis and access to specialist care'
* a lack of focus in the plan on severe and very severe ME
* a lack of funding for long covid clinics

Further reading

Parliamentary Questions

Chronic Fatigue Syndrome: Research (5 November 2025)
https://questions-statements.parliament.uk/written-questions/detail/2025-10-28/86002

Chronic Fatigue Syndrome and Long Covid: Training (5 November 2025)
https://questions-statements.parliament.uk/written-questions/detail/2025-10-27/85337

Chronic Fatigue Syndrome: Health Services (5 November 2025)
https://questions-statements.parliament.uk/written-questions/detail/2025-10-10/80762

Press material

Earlier diagnosis and better care needed for ME and Long COVID patients, report finds (University of Exeter News, 3 April 2025)
https://news.exeter.ac.uk/faculty-of-health-and-life-sciences/earlier-diagnosis-and-better-care-needed-for-me-and-long-covid-patients-report-finds/

I have ME. Here's what I wish people knew about living with it (The Independent, 22 July 2025)
https://www.independent.co.uk/life-style/health-and-families/chronic-fatigue-syndrome-me-symptoms-b2793804.html

Doctors to be trained on ME in NHS plan to transform care (The Times, 22 July 2025)
https://www.thetimes.com/uk/healthcare/article/doctors-trained-me-chronic-fatigue-8tk0mbnvb

Bedfordshire woman with ME criticises health plan for condition (BBC News, 28 July 2025)
https://www.bbc.com/news/articles/cn5k54qz3lyo

Government plan to train doctors on ME/CFS 'does not go far enough,' campaigners say (The BMJ, 28 July 2025)
https://www.bmj.com/content/390/bmj.r1585.full

Stakeholder comment

Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS): the final
delivery plan (22 July 2025)
https://www.gov.uk/government/publications/mecfs-the-final-delivery-plan/myalgic-encephalomyelitischronic-fatigue-syndrome-mecfs-the-final-delivery-plan#agreed-actions

The ME Association's statement on the Government's Delivery Plan on
ME/CFS - The ME Association (22 July 2025)
https://meassociation.org.uk/2025/07/the-me-associations-statement-on-the-governments-delivery-plan-on-me-cfs/

DHSC publishes the Final Delivery Plan on ME/CFS - Action for ME (22
July 2025)
https://www.actionforme.org.uk/dhsc-publishes-the-final-delivery-plan-on-me-cfs/

Westminster Hall debate: ME.
Wednesday 19 November at 4:30pm.
This debate will be led by Tessa Munt MP.

Live
https://www.parliamentlive.tv/Event/Index/5f8f9868-1dd6-4fc6-92c9-ad4666fe4096

Replay
https://www.parliamentlive.tv/Search?Keywords=westminster+hall&Member=Tessa+Munt&MemberId=&House=&Business=&Start=19%2F10%2F2025&End=19%2F11%2F2025

References
https://commonslibrary.parliament.uk/research-briefings/cdp-2025-0217/
https://whatson.parliament.uk/event/cal53589

The text of the debate will be available here...

https://hansard.parliament.uk/commons/2025-11-19/debates/182CFDA2-303A-4BCA-B305-22CC0730122E/WestminsterHall

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Source: UK House of Commons
Date: November 19, 2025
URL:
https://hansard.parliament.uk/Commons/2025-11-19/debates/2CF5B027-60AF-4031-B6B1-A2909CF6A745/MyalgicEncephalomyelitis
WebTV:
https://www.parliamentlive.tv/Event/Index/5f8f9868-1dd6-4fc6-92c9-ad4666fe4096
Ref: http://www.me-net.combidom.com/meweb/web1.4.htm#westminster

[Debates]

Myalgic Encephalomyelitis

I beg to move,

That this House has considered Government support for people with myalgic encephalomyelitis.

It is a pleasure to serve under your chairship, Mr Mundell. Myalgic encephalomyelitis is a complex, chronic condition affecting multiple body systems. There is currently no cure or established treatment. The symptoms of ME go far beyond chronic fatigue or being very tired; the sickest patients lie alone in darkened rooms, sometimes unable to move or to speak-or, in the very worst cases, to swallow or to digest food. Even at the mildest end of this condition, people with ME who once had lives, hopes and dreams for the future live a shadow of their former lives.

More than five years on from the start of the covid pandemic, it is timely to note how the numbers affected have increased. Approximately half of those with long covid go on to meet the diagnostic criteria for ME, so it is now estimated that 1.35 million people live with ME or ME-like symptoms. That includes healthcare workers, teachers and other key workers who kept our country running at the height of the pandemic. Add in carers, and even more are directly affected.

Importantly, there is a gendered dimension, with women five times more likely than men to develop ME. Despite the devastating toll of the condition, people with ME have endured decades of substandard and sometimes downright unsafe healthcare, with pitifully little funding for research. In spite of the lack of robust evidence to this effect, ME is treated as though the condition is psychiatric.

Cameron Thomas

I thank my hon. Friend for giving way, and for securing this important debate. According to at least one survey, about 66% of sufferers require some form of social care and, as is the case for some of my constituents, it is their own families who put their life on hold to provide that care. Will my hon. Friend join me in stating that this is just one example of how the Government must address social care if they are going to get health and social care right?

Tessa Munt

I could not agree more. For far too long, patients have been dismissed, and that care element is incredibly important, because it affects so many people.

In July, the Department of Health and Social Care published the final delivery plan for ME, a cross-Government strategy aiming to improve attitudes, bolster research and better lives. It included some positive steps: new small grants for research into repurposed medications, and the development of a new service specification for mild and moderate ME. However, overall, the consensus of the charities and patient advocates I have spoken to is clear: the delivery plan falls far short of what was needed.

Wendy Chamberlain

I am interested in what my hon. Friend says about plans in England, because in my constituency we were privileged to have an incredible ME specialist nurse, Keith Anderson, who helped countless people. Sadly, he passed away two years ago, and since then there has been no specialist support in Fife-indeed, there is no specialist ME doctor or nurse in the whole of Scotland. Does my hon. Friend agree that one of the things any plan needs to consider is training, so that, no matter where someone is in the country, they can get access to a specialist?

Tessa Munt

I agree. In fact, we do not just need specialists; we also need training for GPs and other healthcare workers.

I will highlight four areas in which we need to see much more from the Government going forward. Given the gravity of the situation, I would appreciate it if the Minister could arrange for written responses to a number of my points.

The first area is funding. If the delivery plan felt threadbare, that is because no substantive new funding was attached to it. Before the plan was published, all 72 Lib Dem MPs signed a letter expressing our concerns about the anticipated lack of funding, which of course came to pass. To put it bluntly, what patients need is transformed NHS care and a step change in research. Neither is likely to happen without investing some money.

The case for investment is clear. I urge the Minister to see this not as a sunk cost, but as an investment in a group of people who are desperate to contribute to society. We know that one in five working-age adults are out of the workforce, many because of health problems, yet remarkably there was no modelling of the demography of those living with ME for the delivery plan exercise, and neither the Department of Health and Social Care nor the Department for Work and Pensions has an estimate of what the neglect of people with ME is costing our economy.

I would like to look at some of the figures. The most recent estimate of the economic impact of ME was for 2014-15-10 years ago-and was carried out by 20/20health. The cost was then calculated at 3.3 billion pounds annually, based on only 260,000 people living with ME. With many more affected following the pandemic and a decade of inflation, that cost will now be much higher. Even the most conservative estimate of current numbers living with ME, excluding cases linked to long covid, puts them at 404,000 patients. Does the Minister accept, using that conservative estimate and adjusting for inflation, the annual economic impact of ME today is likely to be at least 7 billion pound? If those living with ME-like symptoms following covid are included, we could be approaching an annual cost of 20 billion pounds. Surely it is time for the Government properly to cost the impact of a condition that affects so many, rather than brush it under the carpet, and to invest accordingly.

Andrew George

My hon. Friend is making a very strong case. She will be aware that there is still significant uncertainty among many clinicians as to whether this should be treated a medical rather than a psychological condition. Does she agree that, because of the gravity and extent of cases around the country, it is important that medical services are supported to deal with those patients and their symptoms?

Tessa Munt

I accept my hon. Friend's point. Most people I speak to say that ME has nothing to do with psychiatry. We now have evidence from Edinburgh, which I will go on to in a moment, to explain exactly why that is the case.

Our counterparts in Germany have grasped the importance and scale of the challenge. Just last week, the German Government announced a national decade against post-infectious diseases, with a particular focus on ME and long covid. In Germany, an estimated 1.5 million people are living with ME or long covid. The German Government have rightly recognised post-infectious diseases such as ME as one of the greatest public health challenges of the 21st century. Last week, they committed 500 million euros - around 440 million pounds - over the next decade into research to understand the causes of post-infectious diseases and to develop treatments.

Will the Minister confirm whether Ministers in the Department of Health and Social Care have discussed that recent funding announcement and the logic behind it? I would love nothing more than to see the UK Government come up with a comparable level of commitment-or will the Government wait a decade for the German Government's conclusions before taking action?

Jim Shannon

I commend the hon. Lady on bringing this debate forward. In Northern Ireland, the figures for ME have unfortunately risen from 7,500 to 12,500 in the past few years. We have no clinical lead, no specialist services and no commission care pathways. We need research. Queen's University Belfast is really good with research partnerships. Does the hon. Lady agree we should spend the money on research and find the cure? It has been said that the cure for cancer will come in 10 years' time. The cure for ME could come too if research money were put into it.

Tessa Munt

I absolutely agree, and I thank the hon. Gentleman. The second area where I would urge the Government to go further is support for people with severe and very severe ME. It is estimated that around one in four people with ME are severely affected. ME is perhaps the only condition where the sicker someone becomes, the less care they receive from the NHS. The recent prevention of future deaths report focused on the tragic case of Maeve Boothby O'Neill, describing NHS care for severe ME as 'non-existent'.

In my work on this issue, I have collaborated closely with #ThereForME, a campaign founded by two women, Karen and Emma, who are carers to partners with very severe ME. It can be difficult to comprehend the depth of suffering that ME can bring in its most extreme forms. With his permission, Karen has shared details with me about of her husband James's day-to-day life.

Before developing ME, James, in his 30s, lived a full life and was a civil servant. Today he is completely bed-bound and spends 99% of his day alone in a dark room, unable to tolerate any noise, light or stimulation. He is hardly able to communicate and is so sensitive to touch that, despite his suffering, his wife Karen is unable to give him a hug or hold his hand. Despite an acute level of need, James is receiving next to no care from the NHS. Karen tells me that her biggest fear is that he deteriorates to the point of needing lifesaving care. She cannot feel confident that the NHS will provide it.

Mark Sewards

The hon. Member is making an incredibly powerful speech. One of my constituents, an NHS nurse, suffers with ME. He cannot play with his children, walk his dog or undertake basic activities. When he went to the NHS, he got a referral, but was told that it would be nine months before he got an appointment, which forced him to consider private options. An NHS nurse is having to use private healthcare to get results-this situation is untenable, is it not?

Tessa Munt

It is not only untenable, but completely absurd. In September 2024, on World Patient Safety Day, over 200 healthcare workers were so concerned about NHS care for ME, and particularly care for severe and very severe ME, that they wrote a letter to the Health Secretary calling for immediate action to save lives. That letter was sent 14 months ago. I am sorry to say that very little has changed since, and they did not receive a response.

Jayne Kirkham

I want to quickly mention one of those 25% of people with ME who are severely affected: my constituent Alice. She cannot leave her room, and is scared to call for treatment in case she has to go into hospital: she has been into hospital twice, but people there are not sure how to treat her and they make it worse. I simply want to empathise on behalf of my constituents, one of whom is one of the very severe cases the hon. Lady is talking about.

Tessa Munt

Probably most of us have constituents in exactly the same situation. In just over a year, two prevention of future deaths reports have been issued related to severe ME. I have already referred to one of them, regarding the case of Maeve Boothby O'Neill; the other was on the case of Sarah Lewis. Neither report has yet resulted in satisfactory action. The risk of death, specifically from malnutrition, is real and ongoing.

Earlier today I spoke with Dr Binita Kane, a private sector clinician with a special interest in ME and long covid. She told me about the case of a 25-year-old woman, a medical student, who developed severe ME after a viral infection in 2018. The young woman has been in an acute NHS hospital for 17 months with nutritional failure and has deteriorated to the point that palliative care is being instituted. Her family is being prepared for the worst-it is dreadful. She has been disadvantaged not because of the individual clinical decisions, but because she suffers from a condition for which there is no safe or established service model. There have been multiple missed opportunities to prevent her condition progressing to this stage.

Sadly, that young woman is not alone. I have heard of many other cases today, and before today. What is being done to help patients like her? In the foreword to the final delivery plan, the Minister stated that

'tragically avoidable deaths of people with ME/CFS, in England…must become never events.'

However, the plan does not clearly set out what actions the Department will take to guarantee patient safety. No one is being held to account. The plan committed the DHSC and NHS England to

'explore whether a specialised service should be prescribed by the Secretary of State for Health for very severe ME/CFS'.

I hope that the Secretary of State will do the right thing and commission that service, but it is frankly astonishing that the option of leaving this group of patients without specialist NHS care, as they are now, is even on the table.

I ask the Minister to clarify what progress has been made in commissioning such a service. That is not to mention that developing a new service from the ground up is, at best, a medium-term solution. It may take years. It is astonishing that no interim solution has been proposed to ensure that patients with very severe ME, whose lives are at risk right now across the country, do not become tomorrow's mortality statistics. How many more preventable deaths will it take? I ask the Minister to commit to work with groups such as #ThereForME to rectify the situation immediately, for example by convening a national advisory group to advise in these cases and by undertaking a full review of the lessons learned from ME deaths. Will the Minister clarify what data is being collected to better understand the number of those with ME who are affected by life-threatening complications?

The third area on which I would like to see the Government do much more is accelerating ME research. I spoke earlier about the need for investment in research and improving healthcare. For many patients, biomedical research represents their best hope of regaining their former life, yet the condition has historically received very low levels of research funding from the UK Government.

Based on parliamentary answers and official announcements, I estimate that around 10 million pound has been invested in ME research over the past 12 years. To put that figure into context, on the current numbers that is about 60p per person living with ME per year. Four times as much was spent on a helicopter for the former Prime Minister as has been spent on ME. We spent 125 million pounds - 12 times as much-on a bat tunnel for HS2. We spent 10 billion pounds - about 1,000 times as much-on personal protective equipment that turned out to be unusable. Money talks, and the record of the past decade makes it clear to people with ME that their collective futures have been valued by successive Governments at astonishingly little.

Carla Lockhart

Will the hon. Lady give way?

Tessa Munt

Forgive me, but I am going to carry on.

The final delivery plan rightly points to the need to build capacity in ME research, given the small UK research community and very few funded research projects. The University of Edinburgh's DecodeME project has been a notable exception, recently reporting groundbreaking findings that revealed distinct genetic signals in people living with ME-medical, not psychological. This gives us a solid and compelling foundation for future research. Can the Minister explain what plans are in place for future funding to capitalise on this research? Again, the delivery plan is light on actions to build UK capacity in any research. A consensus recommendation for a post-infectious disease research hub was not funded.

A joint showcase event was held earlier this month by the National Institute for Health and Care Research and the Medical Research Council, with the goal of stimulating research, yet it is not clear whether this will yield tangible results or how its outcomes will be monitored. Again, I ask the Minister what the plan is if, as seems possible, it is not a lack of information holding back capacity, but secure long-term finance to encourage researchers to build a career in the field.

The final delivery plan gestured to HERITAGE and PRIME, which were effectively pre-existing funding announcements. The only genuinely new funding announced through the plan from the National Institute for Health and Care Research for research into repurposed therapies was capped to grants of 200,000 pounds. The Government's response on this issue, including in the letter sent in response to concerns raised by the 72 Lib Dem MPs, tends to be that it is not usual practice to ringfence funds for specific conditions, and that researchers can apply for funding in open competition. Yet historical funding imbalances mean that it is not realistic to expect ME researchers to compete with researchers of diseases that benefit from more advanced research and much stronger institutional capacity.

The UK Government do, in fact, set aside funding for specific conditions when they are considered a strategic priority. Just this June, 50 million pounds of funding was announced for cardiovascular disease research to be awarded through open competition. In 2021, 50 million pounds was committed to research into motor neurone disease. If we can award ringfenced funding through open competition for those conditions, why not ME? To echo a question asked at a recent research showcase event, why is ME not considered a strategic research priority? Can the Minister clarify that?

The fourth and final point on which I would like the Government to go further is support from wider Departments, particularly the Department for Education and the Department for Work and Pensions. Children and young people are uniquely affected by ME. The condition disrupts and can derail key life stages and developmental milestones. Among educational professions, poor understanding of ME contributes to a lack of adjustments, limiting access to education and increasing school absences. The final delivery plan acknowledges the need for access to education and improved life chances among children and young people with ME, but while this is in theory a cross-Government plan, engagement from the Department for Education seems to have been extremely limited. Can the Minister outline what engagement has taken place so far and commit to speaking with colleagues in the Department for Education to ensure that they will engage with the delivery plan moving forward and ensure that children and young people with ME receive appropriate accommodations?

Meanwhile, welfare benefits are the most common issue that constituents with ME raise with me. Many have struggled for years to access the benefits they are entitled to, feeling that they are fighting a system that works against them. Like most people living with disabilities, my constituents are terrified at the prospect of future welfare reforms and losing the support that they have and rely on to meet their basic needs.

Looking at the current situation, I am indebted to a benefits adviser focusing on ME for her summary.

'People with ME face intersectional and compounding barriers when interacting with the Department for Work and Pensions (DWP). These include structural flaws in benefit design, widespread misunderstanding of their conditions, systemic disbelief, inaccessible systems, poor-quality assessment practices, and the cumulative harm of being required to repeatedly prove their illness. The current benefit system and emerging reform agenda both fail to reflect the fluctuating, energy-limiting multisystemic nature of these conditions.

And then, the Universal Credit Act 2025, together with the proposed abolition of the Work Capacity Assessment (WCA) and on-going threats to PIP eligibility, signals a fundamental shift in how disabled people meet entitlement to financial support.'

I am particularly concerned about the proposals to replace the new-style employment and support allowance with a time-limited unemployment insurance and to abolish the work capability assessment. Replacing the new-style ESA would disproportionately harm individuals who are not eligible for means-tested support, for example because their partner works. Among other harms, that would increase the risk of domestic abuse while heightening financial dependence-a particularly pressing concern, given that ME is considerably more prevalent in women.

Abolishing the work capability assessment removes critical safeguards in regulations 29 and 35 of the Employment and Support Allowance Regulations 2013 for those whose health would be seriously harmed by work or work-related activity. Those protections are vital for people with ME, who are at particular risk of harm and long-term health consequences if they push beyond their energy limits.

Time prevents me from providing more detail, but I will conclude my observations by saying that, on the whole, what people with ME want most is to recover their capacity to contribute to their families, their community and wider society. They hate being ill. An appropriate benefits system must acknowledge that and treat them with dignity and fairness. The way to get people with ME and those caring for them back into work is not to take away crucial support, but to invest in helping them to get better.

Many will be watching this debate from home, desperately hoping that we are doing everything we can to build them a better future. They deserve the assurance that the Government are committed to a clear, ambitious and, crucially, properly funded vision for change across healthcare, research and all forms of Government support. I ask the Minister for a meeting to discuss myalgic encephalomyelitis and the way forward for the 1.35 million people affected. I very much hope that today's debate represents a big step forward in delivering that for them.

[Several hon. Members rose]

David Mundell
(in the Chair)

Order. I remind Members that they should bob if they wish to be called. It is clear that we need a three-minute time limit if we are to get everybody in, but I cannot guarantee that we will.

Jo Platt

It is an honour to serve under your chairship, Mr Mundell. I declare my interest as chair of both the all-party parliamentary group on myalgic encephalomyelitis and the all-party parliamentary group on long covid. I thank the hon. Member for Wells and Mendip Hills (Tessa Munt) for bringing this important debate to the House; we work together on the APPG on ME.

ME and related conditions such as long covid are among the most devastating illnesses of our time, yet they remain some of the most poorly understood and most neglected. Unless we confront this misunderstanding head on, we will never deliver the change that patients so desperately need.

This issue is personal to me. In 2020, I contracted long covid. The infection was mild, but the aftermath was devastating, and it changed my life forever. With long covid, I developed ME, so I know the exhaustion, isolation and gaslighting that patients face. I cannot know for sure why I improved, but I believe that one reason was early recognition. I give a big shout-out to my friend Shelley Guest, who saw that my symptoms mirrored her own. She gave me books; she shouted at me, and told me to pace myself. I am forever grateful to her.

That raises a critical question: if diagnosed and supported early enough, could ME's symptoms be managed to the point of recovery or partial recovery? My journey is not over yet. That is why research and recognition are not optional; they are essential.

James Naish

I thank my hon. Friend for her work chairing the two all-party groups. My constituent Janet contacted me about her son Richard, who was diagnosed with chronic fatigue syndrome six months ago. He is still waiting for a proper referral. Does my hon. Friend agree that an early pathway is vital, and would she encourage the Minister to outline what form that might take?

Jo Platt

Sharethis specific contribution
I agree, and I recognise every single one of those issues. As chair of the APPG, I hear about the harrowing cases of what people are struggling with on the pathway to healthcare. It is simply not good enough.

Wera Hobhouse

I hear from so many constituents that, out of those suffering from any condition, people suffering from ME have the lowest quality of life. Is it not also the case that people simply do not understand what ME is?

Jo Platt

I completely agree. As my hon. Friend the Member for Rushcliffe (James Naish) mentioned, there is confusion about what chronic fatigue is and what ME is; there needs to be differentiation and clarification on those conditions. We all understand chronic fatigue, but ME is different. It is not just tiredness; they are complex issues. Many of those who are severely affected cannot even sit upright. They are confined to darkened rooms, often tube-fed, cut off from the world and too often ignored by the very health system that is meant to protect them.

Long covid has only added to that burden. Millions are affected, half of whom meet the criteria for ME. Next Tuesday, Parliament will host the first drop-in session of the Overlapping Illness Alliance, which will raise awareness of ME, long covid and related conditions, and I urge colleagues from across the House to attend.

The Government's ME delivery plan is a welcome step. NHS e-learning service specifications and small research grants are progress, but they are not enough, particularly for severe ME. The scale of the challenge demands ambition, accountability and strategic investment. We need specialised NHS services for ME, we need urgent support for children whose education is disrupted, and we need co-ordinated action across health, social care, education and employment.

Research is central to progress. DecodeME has shown the brilliance of UK science, but funding remains far too limited. Germany has pledged €500 million to research with the aim of curing ME by the next decade. We need to be just as ambitious, but we must also confront the misinformation and bias on ME that has plagued us for decades. Patients are dying from nutritional failure because there is no commissioned service for severe ME. Some spend hundreds of pounds in hospital on private care without a proper pathway. Lives are at risk now and we cannot wait for long-term provision while patients suffer.

That is why, alongside the APPG, I am calling for the commissioning of specialised NHS services for severe and very severe ME with expertise in nutritional failure, and I would welcome the chance to meet the Government to discuss immediate solutions that can save lives today. Will the Minister commit to improving data collection so that we can better understand risks and create the foundations for effective care? The Government have taken steps in the right direction, but more must be done. As chair of both APPGs, I will continue to work with the community and the Government to do that.

Sir Jeremy Hunt

It is a privilege to speak under your chairship, Mr Mundell. I thank the hon. Member for Wells and Mendip Hills (Tessa Munt) for calling this debate.

I would like to use my short time to tell the story of a young man who made me understand the tragedy of ME six years ago. He was a very promising first-year student at Durham University called Tom. He was on track to get a first in maths. He was a big hockey player, but in his second year, he started struggling, first to walk upstairs and to climb hills, and eventually he found that he could not wash himself, eat by himself or even read. Then, to his enormous frustration, he dropped out in his third year. When all his friends were starting a new life with their first job, he had to stay at home and go through the nightmare of first trying to get a diagnosis and get someone to agree that he had a problem, and then trying to get treatment for it.

Tom felt that he was going in circles: doctors were not really persuaded and he was not getting any answers. He was very lucky because he had two remarkable parents, Alex and Denise, who could afford to go to America. In fact, they moved to America and they got him enrolled on clinical trials. This story has a positive ending, because six years on, he is doing incredibly well. He is actually thriving; he has a job and a partner, and his life is back on track-except, sadly, in America rather than here.

As the hon. Member for Wells and Mendip Hills said, there are 400,000 people with ME or with long covid symptoms that are like severe ME. For some of them, it is already too late. Maeve Boothby O'Neill and Sarah Lewis tragically lost their lives, and coroners issued prevention of future deaths notices.

Kerry McCarthy

Sarah Lewis was my constituent. I have here the prevention of future deaths report that was issued after the inquest. She took her own life, but was severely ill with ME. One thing that comes through very strongly is that she did not feel she was believed or taken seriously, or that her symptoms were recognised by the medical profession. It is so important that we challenge the medical profession to take this more seriously.

Sir Jeremy Hunt

I thank the hon. Lady for talking about that very sad case. I actually think that the NHS is better than it was because of long covid.

The real cause for hope is Edinburgh University's DecodeME study, which the chief executive of Action for ME, Sonya Chowdhury, described to me as being like a treasure hunt map with eight crosses where there is a genetic code that matches ME, but where we then have to go and dig up that treasure. That is what is now waiting to happen, and why funding is so important.

Ultimately, with the quality of research in this country, there should be no need for anyone to have to go to the United States or Germany for their treatment. During the pandemic, more lives were saved through treatments and vaccines discovered in this country than any other country in the world. We have amazing research happening here.

My plea to the Government is this: the last Government started the process by ignoring some of the scepticism in the medical community about whether ME was really a serious condition. It would be fantastic, and it would give so much hope, if this Government could now finish the job and invest in research that will transform the lives of so many people like Tom.

Alison Hume

It is an honour to serve under your chairship, Mr Mundell. A constituent recently wrote to me:

'ME has taken almost everything from me. I can no longer work, I am mainly confined to my chair or bed and, on the rare occasion that I leave the house for medical appointments, I need to use a wheelchair or walker and it often results in PEM',

or post-exertional malaise. This was the sentence that really stayed with me: 'ME has taken almost everything from me.' That seems to sum up the decimating effects of ME for the 25% of sufferers who experience the most severe symptoms. ME takes and then it takes some more, until in too many tragic cases the patient dies.

The fate of patients with severe ME has been brought home to me through my involvement with my constituent Debbie Seymour, once a working mother of two but now into her third year of being bedbound in a dark room and principally cared for by her incredible mum Sylvia, who is in her 80s. Although nurses are offering practical support, there remains a lack of knowledge about severe ME among healthcare providers and allied professions-particularly about the nature of the key diagnostic symptom of the disease, PEM.

Too often, sufferers of severe ME are required to fit into NHS pathways and procedures that suit the system but take little account of the human being at the centre of them. I welcome the Government's delivery plan on ME. One of the stated aims is for the Department of Health and Social Care and NHS England to explore whether there should be a specialised service for very severe ME. NHS England is in the process of being dismantled, so could the Minister confirm in her summing up that that exploration will still go ahead? The desperate experiences of so many people highlight a lack of research into the disease. Perhaps the Minister can reassure my constituents in Scarborough and Whitby that there is a future in which the ringfenced funding granted for research into other illnesses can be extended to ME.

In conclusion, I have felt helpless when it comes to supporting my constituents who suffer from severe ME, and their families and carers. I am putting my faith in this Labour Government to drive forward the research to find a cure for this devastating disease and to improve specialist care for seriously ill ME patients such as Debbie, before it is too late.

Adam Dance

It is a pleasure to serve under your chairmanship, Mr Mundell. I thank my hon. Friend the Member for Wells and Mendip Hills (Tessa Munt) for securing this vital debate and for her campaigning on this issue. In the brief time I have today, I will share the story of Iona, who was finally diagnosed with ME in 2019 after being unwell since 2014. Her ME comes with a range of horrible symptoms from physical and mental fatigue to muscle weakness. She was housebound for four years and cannot do anything independently. However, she told me that the biggest barrier to support is other people's limited or incorrect knowledge of ME, which is damaging. She says:

'As a chronically ill young woman…I am constantly looked down on and dismissed, while at the same time expected to act as if I am not disabled'.

Mr Tom Morrison

One of my constituents, Nick, has ME and has described feeling as though he is stuck in a well without anyone to pull him out. Does my hon. Friend agree that there needs to be more action from Government, the NHS, businesses, schools and colleges to counter the misunderstanding and neglect that ME sufferers receive?

Adam Dance

I agree. It is really important that the Government provide more support for ME, because it affects the lives of a lot of people.

Adam Jogee

I am grateful to the hon. Gentleman for giving way, from one Adam to another. I want to give a shout out to ME Group Staffordshire, which does wonderful work in supporting my constituents and people in the surrounding areas, and does so much to challenge the stigma that many people living with ME face on a daily basis, as the hon. Gentleman talked about. As the Minister looks to provide the support that we are all calling for today, I hope that she will consider extending it to those groups and communities that support people with ME, including some of my constituents.

Adam Dance

I agree that we need lots more support groups across the country. It is really good that the hon. Member has one in his constituency.

Iona's school offered her no help; indeed, it told her that she would fail all her GCSEs. She went to her GP and other doctors many times but was told that she was 'anxious and did not know it', that she 'did not want to go to school', that she 'was depressed' or even that 'nothing was wrong' with her at all. Anyone who knew Iona knew that that was ridiculous. She is a positive, determined, intelligent and hard-working person, and it is only because of her determination that she finally received support-she got it only because she and her family kept pushing for it. People should not have to be medics or administrative experts to get the support that they need.

Even after Iona received some support, limited knowledge meant that she was told to do graded exercise therapy, which did her more harm than good. Eventually, the Somerset ME service provided helpful advice and medical letters that unlocked support in education and from the council. However, that service is a short-term service that cannot provide medical care, and Iona has often found that GPs do not understand the nature of the service. Today, she still receives little or no medical help.

It is great that the NHS has rolled out training on ME, but people such as Iona who have ME and who have lost trust in the health system need to know how we can monitor the uptake of that training to change attitudes and reduce stigma among the medical profession. That is so important, yet more broadly the ME delivery plan lacks clear accountability structures, has no proper way to measure impact and has no clear deadline to meet. I hope that the Minister can respond to those concerns today.

Greater funding and support for research are also vital. Germany has pledged €500 million to research ME and find a cure for it. It is time that this country also stepped up and showed the same ambition. We owe Iona and all those with ME at least that much. In fact, Iona herself wants to contribute to such research and is now at university, studying hard after achieving fantastic results at school. People with ME are not asking for much; they just want to be believed and to receive the support they deserve. It is about time they got that support.

David Mundell
(in the Chair)

With apologies to other Members who wished to speak, I now call the Lib Dem spokesperson.

Helen Maguire

It is a pleasure to serve under your chairship, Mr Mundell. I thank my hon. Friend the Member for Wells and Mendip Hills (Tessa Munt) for securing this vital debate on such an important issue as myalgic encephalomyelitis. This chronic condition completely changes people's lives, as we have heard today.

My constituent, who loved her job as a nurse, was diagnosed with ME in 2019. She has been left unable to work, relies on a mobility scooter to get around and is often confined to her bed for days on end. Since her official diagnosis, she has experienced constant muscle pain all over and severe headaches that frequently prevent her from sleeping. Despite her battle with myriad health challenges, one GP asked her, 'What do you expect me to do about it?' Reading that stopped me in my tracks but-even worse-that reaction is not isolated. I contacted the local NHS trust on behalf of my constituent, and its locally commissioned NHS chronic fatigue services, which include ME, have been suspended as they cannot cope with the number of referrals.

Chris Murray

The experience of the hon. Lady's constituent mirrors that of my constituent Emily in Edinburgh. Even though health is devolved, we face the same situation. Does the hon. Lady agree that even though Edinburgh is leading the way in research-as the right hon. Member for Godalming and Ash (Sir Jeremy Hunt) said-we need to look into people's experience of dealing with health services?

Helen Maguire

I absolutely agree.

David Mundell
(in the Chair)

Order. I should say that interventions on the spokespeople will not lead to them having any additional time.

Helen Maguire

My constituent's experience builds into the bigger picture of a healthcare system that is simply not set up to support those with the most complex and devastating conditions. People with ME who rightly rely on health professionals for advice, support and solutions cannot be abandoned just because their diagnosis does not fit into a one-size-fits-all treatment plan.

David Chadwick

We have heard just how little money is being spent on research, comparatively speaking. As has already been mentioned, the DecodeME study is identifying genetic signals linked to immune and neurological pathways, offering real clues to the biological mechanisms of this disease. Does my hon. Friend agree that the Government must finally adopt a strategic and properly funded research programme?

Helen Maguire

I absolutely agree with my hon. Friend.

Although I welcome the Government's final delivery plan for ME and chronic fatigue syndrome, and I recognise the contribution of the ME community in shaping it, I remain deeply concerned that the plan falls short of delivering the meaningful change that is urgently needed by people living with those conditions. I therefore reaffirm the calls rightly made by my hon. Friend the Member for Wells and Mendip Hills. In particular, the plan fails to set out dedicated funding to encourage early career researchers to specialise in ME research, or strategies to keep established researchers in the field. Those things are vital to develop new pathways that enable people to better cope with their diagnosis and, most importantly, improve their quality of life.

Funding is also needed to step up education and training to improve understanding of the condition across the public sector and to pilot new approaches that strengthen the quality of care. Recent figures estimate that over 400,000 people in the UK have ME, and around 50% of the 1.9 million people in the UK with long covid are thought to have symptoms that are similar to ME. Those figures make it clear that there is a desperate need for research to develop better treatment options and training for doctors, carers and wider healthcare workers.

We cannot ignore the fact that making those changes is a big task. Under the previous Conservative Government, cuts only made supporting people harder-from slashing health services to letting wait times pile up and overseeing a horrifying breakdown of community services-so it is no wonder that more people are suffering without support. That is why I urge this Government to make sure that the final delivery plan delivers real change for people living with ME and invests properly in research to change the course of diagnosis and treatment for good. For my constituent and for people living with ME across the country, we must take serious action to ensure that their experience with the healthcare system is rooted in dignity and care.

Dr Luke Evans

I try to take a positive outlook. The one thing the pandemic did was shine a spotlight on the likes of long covid and ME, and I know from my medical career how difficult that can be. I would like to thank Sajid Javid, who in 2022 announced the plan for ME, and I congratulate the Minister because she brought it to fruition on 22 July 2025. There are some similarities between the NHS 10-year plan and the ME plan: the ME delivery plan is fantastic, and a lot of people agree with it, but, importantly, there has been a lack of delivery. Action for ME has said:

'The Plan also lacks clear accountability structures with no mechanisms to measure impact or deadlines to hit. We are concerned that despite this well-meaning Plan being published, it will have no material impact on the historically stigmatised and ignored ME community. Action for ME wants to work with MPs, Ministers and Officials to improve its implementation.'

It went on to say that the delivery plan on ME/CFS fails to include a 'strategic approach' to ME research. However, that was not the only group to say so; the ME Association said:

'There is no clear ambition or strategy to drive consistent implementation of the NICE guideline recommendations'

across ICBs. It went on to say:

'Severe and very severe ME receives minimal attention, despite known risks during hospital admissions'.

It also said:

'Several of the Plan's own deadlines have already passed, and it is unclear what progress has been made.'

In the short time that I have, I want to focus my questions on two areas: action and accountability. The first concerns the questions that those living with ME will have, particularly when it comes to the changes around the Department for Work and Pensions and what that will look like in the light of the imminent Timms review. I would be grateful to understand what plans the Government have for both Departments to discuss what this will look like, given the scale of the problems facing the 400,000-plus people with ME/CFS in this country.

Secondly, turning to the actual plan, we need to look at what actions will be delivered. I am keen to look at the section called 'After publication of the FDP', because it goes on to say that

'we will monitor the actions included in it. The DHSC secretariat will continue to engage with the Task and Finish Group in an appropriate form as required'.

Given the debate today, is that required, and what form will it take?

The document also goes on to say that a

'sub-group will be created to focus on improving care for those with ME/CFS.'

Has that group been created, and how many times has it met? It further states:

'We recognise the needs of those with ME/CFS and we remain dedicated to developing our approach as new research emerges and as we seek further engagement.'

Could I press the Minister on what that engagement is? Who is it with, and what does it look like? At the end of the day, there is a plan here and we do agree with it, but it is the actions and accountability within it that are truly going to make a difference.

ME may challenge the body, but it never diminishes a person's worth or their hope that they carry. That is critical. When we have such a great plan, it is the action that is going to take it forward.

The Parliamentary Under-Secretary of State for Health and Social Care (Ashley Dalton)

It is a pleasure to serve under your chairship, Mr Mundell. I congratulate the hon. Member for Wells and Mendip Hills (Tessa Munt) on securing this debate, and pay tribute to her for her continued advocacy on behalf of people living with myalgic encephalomyelitis. Her work has ensured that the voices of those affected are heard at the highest levels of Government, and I am happy to accept her invitation to meet her and stakeholders, and the invitation from my hon. Friend the Member for Leigh and Atherton (Jo Platt), the chair of the APPG.

I thank all hon. Members who have contributed today, and I particularly acknowledge all the constituents they have referred to. They all deserve the very best care from our NHS. I will endeavour to respond to as many of the issues raised as I possibly can. If I have not covered something, my officials will take notes and follow up in writing.

Rachael Maskell

I am really grateful to the Minister. We know that, at the heart of this, we need to ensure that all clinicians have a basis of training, and that is certainly missing at the moment. We see misdiagnosis, and we see some provision, including fatigue clinics, providing the wrong interventions. Will she ensure that there is a strategy around training clinicians and making it mandatory?

Ashley Dalton

I will come later in my remarks to the training that is being rolled out as part of the delivery plan.

Myalgic encephalomyelitis-better known as ME-and chronic fatigue syndrome, which I will refer to from now on as ME/CFS, is a condition that affects an estimated 390,000 people in the UK. Its symptoms can be profoundly debilitating, impacting every aspect of daily life, from work and education to family and social life. For those with severe or very severe ME/CFS, even basic tasks such as sitting up, eating or speaking can become impossible. We recognise the devastating impact this condition has on individuals and families. For too long, people with ME/CFS have faced stigma, misunderstanding, disbelief and inconsistent care.

Fleur Anderson

The Minister is a passionate advocate for women's health. Does she agree that the reason for this disease often being overlooked and for the stigma she has talked about is that women are five times more likely than men to get it? Will she support clear funding, accountability and deadlines within the welcome plan that has been delivered, and a service for very severe ME for all ICBs?

Ashley Dalton

I recognise my hon. Friend's points, and I will cover some of them in my remarks. She will be aware that the women's health strategy is currently being refreshed, so we hope to dovetail wherever possible.

I want to set out the steps that this Government are taking to change the misunderstanding, stigma and inconsistent care that patients have experienced. Through our ME/CFS final delivery plan, we will deliver better care, boost research and ensure that every person living with ME/CFS is treated with dignity and compassion.

First, let us acknowledge the reality. ME/CFS is a complex multi-system condition. Its fluctuating nature makes diagnosis and management challenging. Historically, services have been extremely varied, and in some cases patients have felt dismissed or rejected by the healthcare system. That is unacceptable. We have heard those concerns loud and clear through our extensive consultation on the interim delivery plan and through ongoing engagement with patients, carers, clinicians, researchers and charities. Last year's prevention of future deaths report following the tragic death of Maeve Boothby O'Neill further highlighted the urgent need for reform, pointing to a lack of specialist beds and inadequate training for clinicians. We cannot and will not allow such failings to continue.

In July, we published the ME/CFS final delivery plan, marking a significant milestone in our commitment to improving lives. The plan is built around three core themes: boosting research, improving attitudes and education, and enhancing care and support. With a clear commitment to ensure that people with ME/CFS can live as independently as possible and see their overall quality of life enhanced, that plan will help us to take an important step towards achieving that, but we acknowledge that there is more to do. We will continue to build on the foundation of those actions well beyond the publication of the plan. It is the springboard-the beginning, not the end.

Although the final delivery plan does not include every suggestion received through the consultation responses or through the task and finish group, it does not mean that those proposals will not be considered in the future, subject to resource and funding. We look forward to continuing those conversations.

Dr Luke Evans

The Minister attended the task and finish group, as did I. Will it meet again to consider that?

Ashley Dalton

I will come to the task and finish group in my remarks.

Research is the key to unlocking better treatments and improving quality of life. As has been mentioned, we have seen progress through projects such as DecodeME, the world's largest genetic study of ME/CFS, which is funded by the National Institute for Health and Care Research and the Medical Research Council. Preliminary findings from the study indicate genetic differences in eight areas linked to the immune and nervous systems in people with ME/CFS. That discovery of specific genetic signals may help us to understand the biological pathways involved in ME/CFS in the future.

However, we need to go further. That is why the plan includes a funding offer and a commitment to continue working with researchers, industry and patient groups. New awards announced this year include funding for repurposed treatments and 845,000 pounds for a large infrastructure project called PRIME, or, to give it its full name, Building Infrastructure for Patients, Researchers and Industry for ME/CFS.

Together with the MRC, we are actively exploring next steps in ME/CFS research. For example, earlier this month we co-hosted the research showcase event for post-acute infection conditions, including ME/CFS. It brought together people with lived experience, researchers, clinicians and funders to help to stimulate further research in this field. We are now considering the discussions that took place at the showcase to explore the next steps to stimulate further research. The output of that event will be circulated as soon as possible.

The final delivery plan also sets out actions to improve access to specialist services-to provide better support for children and young people, and their families, and to address employment challenges. It aligns with our 10-year health plan, which includes the roll-out of neighbourhood health services, bringing care closer to home and ensuring that multidisciplinary teams can support people with complex conditions such as ME/CFS.

Provision varies across the country and we are determined to reduce those inequalities. The final delivery plan includes actions to improve service mapping and workforce training so that every patient, regardless of postcode, can access the care they need. NHS England is working closely with the Department to support ICBs in commissioning equitable evidence-based services. Two of the most important actions in the plan are focused on NHS services. NHS England has already started its work on co-designing resources for systems to improve services for mild and moderate ME/CFS.

Dr Evans

Given that NHS England is due to be abolished, who will take that on?

Ashley Dalton

While NHSE is in the process of being dismantled, all its functions continue, and the new Department of Health and Social Care will continue all its work. None of that is being got rid of; it is simply being brought together into a more efficient, new Department of Health and Social Care. The Department will continue to meet a group of key stakeholders to move the work forward on mild and moderate ME/CFS in the coming weeks. Additionally, I confirm that the DHSC has already started conversations with NHS England to explore a specialised service prescribed by the Secretary of State for Health and Social Care for severe ME/CFS. That work will continue.

Changing attitudes is as important as changing services to many people with ME/CFS who have faced disbelief or stigma. As outlined in the plan, we will address that by launching a public awareness initiative to improve understanding of the condition and the support available. We will work with schools, employers and social care providers to ensure that children and adults with ME/CFS receive the information and support that they need.

John Milne

Will the Minister give way?

Ashley Dalton

I will not, as time is short.

To support healthcare professionals in diagnosis, as set out in the final delivery plan, the Department has worked with NHS England to develop an e-learning programme on ME/CFS for all healthcare professionals. The aim is to support staff so that they can provide better care and improve patient outcomes.

The plan was not developed in isolation. It reflects thousands of consultation responses and the input of the cross-sector task and finish groups. We repurposed the task and finish groups into a new post-publication stakeholder engagement group, and we look forward to working closely with it during the all-important implementation phase.

I recognise that some stakeholders feel that the plan does not go far enough, but let me be clear: this is not the end of the journey; this is simply the foundations. Our work does not stand alone; it stands on the broader ambition to transform the NHS from a sickness service into a health service. We are working with the DWP and the Department for

Education to ensure that all the issues raised are considered, in particular during the Timms review.

ME/CFS has been overlooked for far too long. We are determined to change that. To everyone living with ME/CFS and to your families and carers, I say this: we hear you; we value you; we believe you; and we are committed to making the system work better for you and with you. Together, we can build a future where everyone receives the care, respect and support that they deserve.

David Mundell
(in the Chair)

Tessa Munt, you have one minute to wind up the debate.

Tessa Munt

Thank you, Mr Mundell, but I have little to say. I am delighted to hear what the Minister had to say, and I will be holding her feet to the fire. I wish to continue this campaign, and I will work with others on it. One of the things I omitted to say at the beginning was that I am a member of the APPG on ME. I should have declared that, so I seek your forgiveness for not having said so.

I am delighted by a number of the things that the Minister has been able to say. I thank everyone who contributed to the debate-I should probably have asked for a two or three-hour debate. In particular, I point to a phrase of the former Secretary of State, the right hon. Member for Godalming and Ash (Sir Jeremy Hunt), about digging for treasure, I think. It is so moving to have heard so many important stories of people who are suffering. We really have to do something about this.

[Motion lapsed, and sitting adjourned without Question put (Standing Order No. 10(14)).]

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[Written Answers]

Chronic Fatigue Syndrome: Lincolnshire

Sir John Hayes

To ask the Secretary of State for Health and Social Care, what steps he is taking to support people with ME in Lincolnshire.

Ashley Dalton

The Lincolnshire Partnership NHS Foundation Trust's Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Service is a specialist service which provides assessment and advice on myalgic encephalomyelitis, also known as chronic fatigue syndrome (ME/CFS), management strategies.

This service is available to adults and children. The ME/CFS service team consists of a wide range of skilled staff, including consultant clinical psychologists, assistant psychologists, specialist occupational therapists, and rehabilitation staff.

At a national level, the ME/CFS Final Delivery Plan, which the Department published in July, includes an action for the Department and NHS England to explore whether a specialised service should be prescribed by my Rt Hon. Friend, the Secretary of State for Health and Social Care, for very severe ME/CFS. Officials from the Department have commenced discussions with NHS England on how best to take forward this action.

NHS England has also started its work on co-designing resources for systems to improve services for mild and moderate ME/CFS. It will meet a group of key stakeholders to progress this in the coming weeks.

Source: UK House of Commons
Date: November 25, 2025
URL:
https://questions-statements.parliament.uk/written-questions/detail/2025-11-20/93262
Ref: http://www.me-net.combidom.com/meweb/web1.4.htm#westminster

[Written Answers]

Fibromyalgia: Work Capability Assessment

Richard Foord

To ask the Secretary of State for Work and Pensions, what assessment he has made of the accuracy of the symptom lists used in disability and capability assessments for people with fibromyalgia; and whether his Department plans to update that guidance.

Sir Stephen Timms

The Personal Independence Payment (PIP) assessment and the Work Capability Assessment (WCA) are functional assessments. They do not evaluate claimants based on their medical diagnosis or health condition alone and claimants are not assessed against a set symptom list for a condition when attending an assessment. Instead, the assessment focuses on how a claimant's condition affects their mobility and ability to carry out everyday activities.

The Department for Work and Pensions (DWP) is committed to ensuring that individuals with Fibromyalgia and other health conditions receive high-quality, accurate assessments. All health professionals (HPs) undergo comprehensive training in disability analysis. Their focus is on understanding the functional impact of a claimant's condition, rather than its clinical diagnosis.

To support this, DWP provides suppliers with core training and guidance materials on Fibromyalgia. These resources include detailed clinical and functional information relevant to the condition to assist HPs in delivering informed and accurate assessments.

Additionally, all training and guidance materials are currently undergoing a comprehensive review and update. A dedicated team is leading this work to ensure that all materials are aligned with national best practice standards. Independent clinical experts are being engaged to provide external quality assurance, helping to ensure the content remains accurate, relevant, and consistent.

Source: UK House of Lords
Date: November 25, 2025
URL:
https://questions-statements.parliament.uk/written-questions/detail/2025-11-13/hl11926

https://questions-statements.parliament.uk/written-questions/detail/2025-11-13/hl11927
Ref: http://www.me-net.combidom.com/meweb/web1.4.htm#westminster

[Written Answers]

Chronic Fatigue Syndrome

Baroness Scott of Needham Market

To ask His Majesty's Government what assessment they have made of the adequacy of NHS care for patients in England with severe and very severe myalgic encephalomyelitis; and what steps they are taking to improve it.

To ask His Majesty's Government what steps they are taking to ensure that hospital and community services effectively prevent and manage malnutrition among people with severe and very severe myalgic encephalomyelitis in England.

Baroness Merron

We published the final delivery plan for myalgic encephalomyelitis, also known as chronic fatigue syndrome (ME/CFS), on 22 July, which focuses on boosting research, improving attitudes and education, and bettering the lives of people with this debilitating disease.

The commissioning of ME/CFS services is the responsibility of local integrated care boards based on the needs of their local population. The ME/CFS Final Delivery Plan includes an action for the Department and NHS England to explore whether a specialised service should be prescribed by my Rt Hon. Friend, the Secretary of State for Health and Social Care, for very severe ME/CFS. Officials from the Department have commenced discussions with NHS England on how best to take forward this action.

To support healthcare professionals in the diagnosis and management of conditions like ME/CFS, the National Institute for Health and Care Excellence (NICE) published guidance for ME/CFS in October 2021, a copy of which is attached.

It recommends that people with ME/CFS should be referred for a dietetic assessment by a dietitian with a special interest in ME/CFS if they are losing weight and at risk of malnutrition. The guidance also states that clinicians should recognise that symptoms of severe and very severe ME/CFS may mean that people are unable to eat and digest food easily and may need support with hydration and nutrition, and that the support provided could include oral nutrition and enteral feeding.

NICE guidelines are evidence-based, informed by clinical expertise, and represent best practice. Although NICE guidelines are not mandatory, healthcare professionals are expected to take them fully into account.

Source: UK House of Commons
Date: November 27, 2025
URL:
https://questions-statements.parliament.uk/written-questions/detail/2025-11-24/93979

https://questions-statements.parliament.uk/written-questions/detail/2025-11-24/93980
Ref: http://www.me-net.combidom.com/meweb/web1.4.htm#westminster

[Written Answers]

Chronic Fatigue Syndrome: Greater London

Dr Rosena Allin-Khan

To ask the Secretary of State for Health and Social Care, what steps he is taking to support people with myalgic encephalomyelitis in South West London.
To ask the Secretary of State for Health and Social Care, if he will make an assessment of the adequacy of myalgic encephalomyelitis treatment in South West London.

Ashley Dalton

We published the myalgic encephalomyelitis, also known as chronic fatigue syndrome (ME/CFS), final delivery plan on 22 July 2025. The plan focusses on boosting research, improving attitudes and education, and bettering the lives of people with this debilitating disease, including those in South West London.

The ME/CFS final delivery plan includes an action for the Department and NHS England to explore whether a specialised service should be prescribed by my Rt Hon. Friend, the Secretary of State for Health and Social Care, for people with very severe ME/CFS across England. Officials from the Department have commenced discussions with NHS

England on how best to take forward this action.

NHS England has also started its work on co-designing resources for systems to improve services for mild and moderate ME/CFS, including for patients in South West London. It will meet a group of key stakeholders to progress this in the coming weeks.

To support healthcare professionals in the diagnosis and management of ME/CFS, as set out in the final delivery plan, the Department has worked with NHS England to develop an e-learning programme on ME/CFS for healthcare professionals, with the aim of supporting staff to be able to provide better care and improve patient outcomes. All three sessions of the e-learning programme, with sessions one and two having universal access, whilst the third session is only available to healthcare professionals, are now available at the following link: https://learninghub.nhs.uk/catalogue/mecfselearning?nodeId=7288

Source: UK House of Commons
Date: November 28, 2025
URL:
https://questions-statements.parliament.uk/written-questions/detail/2025-11-19/92854

https://questions-statements.parliament.uk/written-questions/detail/2025-11-19/92855
Ref: http://www.me-net.combidom.com/meweb/web1.4.htm#westminster

[Written Answers]

Pupils: Chronic Fatigue Syndrome

Lee Anderson

To ask the Secretary of State for Education, what discussions she has had with (a) primary and (b) secondary schools on support for pupils

living with ME.
To ask the Secretary of State for Education, what steps she is taking to ensure teachers receive the necessary training to support pupils with ME/CFS.

Georgia Gould

The department engages regularly with schools on a range of issues.

Schools should ensure they are aware of any pupils with medical conditions and have policies and processes in place to ensure these can be well managed. Governing bodies must ensure that the arrangements they put in place are sufficient to meet their statutory responsibilities and that policies, plans, procedures and systems are properly and effectively implemented. This includes the duty under Section 100 of the Children and Families Act 2014 to make arrangements for supporting pupils with medical conditions and the duties under the Equality Act 2010.

Policies should set out how staff will be supported in carrying out their role to support pupils, including how training needs are assessed and how training is commissioned and provided. Any member of school staff providing support to a pupil with medical needs should have received suitable training.
