



# #MEAction UK's Response to: My full reality: the interim delivery plan on ME/CFS

## Introduction

This response is submitted on behalf of #MEAction UK, a not for profit organisation operating in all regions of the UK.

We thank the DHSC staff past and present who supported the Delivery Plan and the volunteers on the working groups who put so much effort into this report.

We give more detailed feedback later in this response but, after holding a community call and speaking to people with ME, the overriding impression is that there is a lack of ambition and no urgency in the agreed actions.

ME is a complex disease with a complex history which bears repeating so that we understand how some of the wrong assumptions about ME within the medical community became entrenched and avoid the same mistakes being repeated. Up to the 1980s it was considered to be a form of post-infection disease similar to polio, and research found similar biological explanations to those being uncovered today in both ME and Long Covid. Consultant neurologist, Professor Peter Behan, described mitochondrial abnormalities in 2012 and spoke of an "essential biochemical or molecular component to the illness which needs to be elucidated, and research should be along the grounds into these illnesses, rather than dealing with psychological talk-the-talk nonsense."

Unfortunately, attention was diverted to psychological explanations of the disease, government money was diverted and research stalled. We are still in the same position today. Research is largely funded by the heroic efforts of the ME community and charities, not by the MRC and NIHR.

This leads to the situation outlined in the introduction to the Plan where, 'Explaining the disease to the patient and their family is difficult as we do not know the definitive underlying cause. Expressions such as 'normal test results,' 'functional disease' or 'medically unexplained symptoms', although medically accurate..' We do not know the underlying cause because research has not been funded and a psychological explanation has been allowed to become the prevailing narrative. This narrative has crept into the introduction to the interim delivery plan. ME is not a 'functional disease' or 'medically unexplained symptoms'. It is a disease with well established symptoms as outlined in the 2021 NICE guideline.<sup>1</sup> Both these terms should be deleted from the Plan.

The stated number of people with ME in the UK of 241,000 in the Delivery Plan is an underestimate. The rise in ME since the emergence of COVID-19, and the impact of this on both current prevalence and economic burden, is not acknowledged. We estimate that this number has at least doubled due to Covid and now sits between 500,000 and 1 million people with ME.<sup>2,3</sup> Research funding available should reflect this, but at present does not.

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<sup>1</sup> <https://www.nice.org.uk/guidance/ng206/chapter/Recommendations#diagnosis>

<sup>2</sup> <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9844405/>

<sup>3</sup>

<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletin/s/prevalenceofongoingsymptomsfollowingcoronaviruscovid19infectionintheuk/30march2023>

## **Severe and Very Severe ME**

We are very concerned that the plight of those with severe and very severe ME is not addressed and the particular problems of being bed bound, are not considered. The barriers to accessing care for those who are housebound or bed bound include being invisible to health services and not being able to access GPs, routine health, vaccination and dental treatment.

GPs should have mandatory training and be instructed to provide home visits as feedback from the ME community suggests that some are reluctant to visit people with ME. Dentists, opticians and occupational therapists are essential services for the chronically ill and these services are inaccessible to those most in need of them. Training on severe and very severe ME throughout the health service should be mandatory, not optional, and implemented urgently.

Lack of knowledge means that hospitals can be dangerous places for people with ME. The recent deaths of ME patients due to incorrect medical treatment illustrate how urgent the education of medical staff is. Maeve Boothby O'Neill, a young woman with ME, died in 2021. The specific cause appears to have been malnutrition. Despite being alerted to the seriousness of Maeve's condition, the local hospital resisted appeals to insert a feeding tube during her final months.

This risk of death is not one of the past. Merryyn Croft died in 2017 of starvation. In July 2019 Lewisham NHS trust threatened Gigi Jehan with forced sectioning as she couldn't eat or speak or walk. Sami Berry was at risk of starvation in an NHS hospital in February 2023. Alice Barrett in March 2023 was also at risk of starvation in a NHS hospital.

Today, Karen Gordon is clinging onto life. Karen is currently at home suffering from life threatening dehydration and malnutrition and needs her local NHS Trust to provide I/V feeding (TPN) and I/V fluid at home without delay.

This is a deep seated problem and the NHS/Royal Colleges/Medical Schools need to be instructed to educate their members about ME, severe and very severe ME, the NICE guideline, and for it to be implemented at once. If it is optional or implemented in a leisurely way then more people will die.

## **Research**

It is stated that, 'Low capacity and capability among the research community to respond to the research needs. In some areas, there is a lack of trust between research funders, academics, charities and people with personal experience of ME/CFS.'

This low capacity and capability is due to the lack of money committed to biomedical ME research by the MRC and NIHR. Research into ME needs ring-fenced government funding to enable new researchers to work on ME and allow projects to scale beyond the pilot stage. If research projects have adequate secure funding, researchers will be attracted to work on ME. Up to now the level of funding for biomedical research has been low, leading to a lack of researchers in this field. The Gibson report recommended the MRC commit at least £11 million pounds to research programmes 17 years ago but there is still no commitment to ring-fence funding for biomedical research into ME to reflect the disease's prevalence and severity. There is no mention of redressing the historic imbalance in funding which has disadvantaged those affected by the disease for decades. Funding for ME research doesn't match the prevalence of the illness or the funding available to other diseases with lower prevalence.

Research needs to be funded to reflect the population of people with ME, the symptom burden and the growing numbers of people being diagnosed after Covid infections. The increase in working age adults too sick to work is a growing financial burden for the UK. Funding also needs to be ring fenced to be used for research into the causes, treatment and prevalence of ME.

The sex bias in the disease is not considered or taken into account in allocating research funds. Approximately 75% of people with ME are female which has led to them suffering discrimination in the allocation of research funds due to their sex. Neither the MRC or NIHR has addressed this historical and current discrimination when allocating funding.

The severity of the disease is not matched by any urgency in research funding from the MRC or NIHR. Comments from clinicians involved in the care of people with ME reflect the impact of the disease.

“In my experience, (ME/CFS) is one of the most disabling diseases that I care for, far exceeding HIV disease except for the terminal stages.” Dr D L Peterson.

“I’d rather have HIV/AIDS than M.E.” Prof. Nancy Klimas, Miami

“It has to be recognised that people with ME/CFS lose their lives even if they don’t die.” Dr. Maureen Hanson: Professor in the Department of Molecular Biology & Genetics, Cornell University

No mention has been made of repurposing of therapeutics as has been explored for SARS-CoV-2 in this NIHR funded study.<sup>4</sup> People with ME have been left without treatment for far too long and there is a very strong case for the NIHR funding a study repurposing drugs for treating the symptoms of ME. This could quickly improve the very low quality of life of many of those suffering with ME. For instance, there has been confirmation that fibrinoid microclots that might damage the endothelium are present in the blood of people with ME as well as people with Long Covid<sup>5</sup> and addressing this could help relieve symptoms for people with ME.

If the government wants to build on the work already done by the DecodeME study, and the James Lind Alliance Priority Setting Partnership it must commit significant money to fund research into treatment and a biomarker.

A biomarker is needed urgently, not only for patients, but for the medical establishment to accept ME as a legitimate illness with a biomedical cause. This was illustrated when a biomarker for MS was discovered and the previous diagnosis of hysterical paralysis was discarded. There are already promising studies including one from Karl Morten at Oxford on Developing a Blood Cell-Based Diagnostic Test<sup>6</sup> but advances are hampered by the lack of government funding.

The actions are well thought out and comprehensive but, without a promise of funding and with no sense of urgency, they are well meant but ineffectual. If the actions were accompanied by a ring fenced funding and commitment to much more ambitious timings this section would be warmly welcomed.

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[https://www.io.nihr.ac.uk/wp-content/uploads/2022/01/Repurposed\\_therapeutics\\_SARS-CoV-2\\_report\\_2021.pdf](https://www.io.nihr.ac.uk/wp-content/uploads/2022/01/Repurposed_therapeutics_SARS-CoV-2_report_2021.pdf)

<sup>5</sup> <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9413879/>

<sup>6</sup> <https://www.wrh.ox.ac.uk/publications/1518377>

## **Attitudes and education of professionals**

We welcome initiatives to educate professionals about ME and believe that the starting point should be implementation of the NICE guideline on ME/CFS. The updated guideline has been published for two years and is still not widely known about or used by NHS England. We believe that there is significant reluctance in some sectors to update their treatment of people with ME in line with the new guideline and 'encouraging' and 'considering' will not help.

NHS England and the NHS Health at Work Network promise to update their webpages on ME/CFS by the end of March 2024. We question why updating a webpage should take so long when it can be quickly and simply updated by using information from the NICE guideline on ME.

A further action to produce an e-learning module on ME/CFS by end March 2024 is promised. Updated training should be made compulsory across all levels of the NHS and medical community including GPs, nurses, physiotherapists, social workers and occupational therapists.

It is also good news that the British Association of Social Workers will support awareness-raising about the needs of people with severe/very severe symptoms of ME/CFS. However, training about the needs of the severe/very severe symptoms should be implemented across all sectors of health and social care and patients/patient groups should be involved in devising training. The burden of care imposed on families by the lack of understanding of very severe ME is not acknowledged in the Plan and needs to be addressed. The commitment that the Law Commission will review existing social care legislation relating to disabled children should be extended to adults.

We also welcome the fact that the General Medical Council will include ME/CFS in the scope of the Medical Licensing Assessment that will be launched in 2023. All medical students graduating from UK universities from the academic year 2024–25 and international doctors will have some understanding of ME but doctors already working in NHS ME clinics will not have mandatory training so there is likely to be a considerable time before clinicians treating people with ME have their training brought into line with the current guideline.

The Royal College of Physicians will ensure training on ME/CFS keeps pace with research and guidance in the core postgraduate training for primary and secondary care physicians which is a welcome improvement. To foster trust between patients and clinicians we suggest that patients and patient groups are involved in the design of any training on ME.

However, this update in training will have limited value if it is not accompanied by increased research money into the causes and treatment of ME.

## **Living with ME/CFS**

### **Children and Young People - Education**

We welcome the recognition that the child and their family are experts by experience: a young person with ME will usually know better than anyone how much they can do on any given day without bringing on a worsening of symptoms (i.e. post-exertional malaise, or PEM). It should also be noted that younger children, especially those in their pre-teens, may need support to pace their activities to avoid triggering PEM and we believe this is a core responsibility of all adults involved in the child's care.

We welcome the DfE promise to update the guidance on [education for children with health needs who cannot attend school](#). Schooling for children with ME is often hard to obtain as the emphasis is on attending school in person which can be difficult or impossible for children and young people with ME.

However, the updated [remote education guidance](#) from the DfE clashes with the above guidance and is problematic for children and young people with ME as it does not acknowledge that ME is a chronic condition that can persist for many years. Several of the provisions directly disadvantage children and young people with ME whose only education might be remote.

Children and young people with ME may rely on remote education over long periods and the guidance stating that, 'Pupils absent from school and receiving remote education still need to be marked as absent in the register' causes problems for pupils and families.

The statement that, 'Provision of remote education should be made as a short-term solution' should not apply if a person is suffering from ME. ME is a chronic and fluctuating condition and it should be acknowledged that many children and young people are not able to attend school due to the illness over extended periods of time. It also states that, 'Remote education should not be viewed as an equal alternative to attendance in school, and providing remote education during a pupil's absence does not reduce the importance of bringing that absence to an end as soon as possible.' This guidance causes real issues for families and schools as a pupil with ME may need extended provision of remote education, and many succeed well in doing so.

Emphasis should be on children gaining an education, where they are well enough, not attendance at school. Attending school in person, with all its physical and social demands, takes a huge amount of energy for a person with ME and can quickly use up any energy that they had for the day. The statement in the IDP that 'the starting principle should be for the child or young person to spend as much time as they can accessing face to face learning' and the expectation that they should be 'supported to maximise their attendance' could be problematic for children and their families as in reality it is precisely this focus on attendance which leads many children and young people with ME to be pushed to do more than their health allows, often with disastrous consequences for their long term health.

Early diagnosis, even if not yet confirmed, is essential in supporting children's education as schools need medical input to be able to support their pupils. We are unclear who is accepted as a suitable authority by the DfE, schools and the DHSC for diagnosing ME and suggest that a GP's advice should be considered reliable particularly when a child is still waiting for a diagnosis. Schools often insist on waiting for formal diagnosis from a consultant which can take several months. This delay can lead to unnecessary involvement from social services, due to concerns from the school about absences, and in some cases a serious worsening of the child's health due to the school's lack of understanding of ME. Clarity is essential to ensure families and young people are supported.

We welcome the examples of tailored adjustments that schools and colleges should consider, and we recommend that there could be more emphasis here on the principle of flexibility. For example any timetable that is agreed must be flexible enough to allow for the individual to be able to attend a class on one day but not the next day, or to be able to complete say 10 hours of learning one week but no hours the following week. Some children may have to take a break from education altogether.

The DHSC should liaise with the Department of Education and Local Authorities about the difficulties in obtaining an Education, Health and Care Plan (EHCP); with social services about threats of safeguarding when children are unable to go to school; and with GPs about supporting families.

OFSTED and examination boards must be included in discussions about updating guidance and children and young people as concessions such as extra time, breaks, delayed starts and in some cases home-based assessment are often needed to allow pupils to progress in their education.

Local councils need to be included in training and discussions about ME as children and young people with ME are often prevented from obtaining ECHPs as ME is not accepted as a legitimate special educational needs and disability (SEND). Easy and early access to an ECHP would support their education and allow them to learn at home, on-line or take a break from education until well enough to resume.

### **Further and higher education and training (18 plus)**

As ME is a chronic illness many young people with ME are behind their peers and need extended opportunities to access learning. Access to an ECHP extends access to education to 25 years old so it is important that children with ME are given access to one.

### **Children's Social Care**

The Plan does not identify how the second Problem Statement will be addressed, i.e. "children and young people with ME/CFS and their family can face inappropriate safeguarding referrals to children's social care and investigations".

This is a very real issue for children and families across the country. At best, this causes immeasurable stress for families. At worst, it can result in a very sick child being unnecessarily removed from their family, causing untold damage to their physical and mental health.

The British Association of Social Workers (BASW), in its recent Practice Guide on Fabricated and Induced Illness

([www.basw.co.uk/system/files/resources/fabricated\\_or\\_induced\\_illness\\_-\\_a\\_practice\\_guide\\_for\\_social\\_workers.pdf](http://www.basw.co.uk/system/files/resources/fabricated_or_induced_illness_-_a_practice_guide_for_social_workers.pdf)), is critical of the Royal College of Paediatric and Child Health (RCPCH) guidance on Perplexing Presentations (PP) / Fabricated and Induced Illness (FII) in Children

([www.rcpch.ac.uk/news-events/news/new-guidance-perplexing-presentations-fabricated-or-induced-illness-children](http://www.rcpch.ac.uk/news-events/news/new-guidance-perplexing-presentations-fabricated-or-induced-illness-children)) and in particular about the lack of evidence on which it is based. The BASW guide notes that Fabricated and Induced Illness is very rare and that 'If social workers were to follow the RCPCH guidance, the proposed assessment criterion for FII is likely to cast suspicion on many families who are not harming their children'. It goes on to comment that the RCPCH guidance is at odds with the NICE Guideline for ME/CFS section on Safeguarding in several respects including its inclusion of alerting factors such as parents advocating/communicating on behalf of their child and/or disagreeing with or refusing to accept the proposed health and education rehabilitation plan.

On launching the 2021 guidance, the RCPCH Safeguarding Officer said "It is very rare for parents or carers to deliberately induce illness in a child by, for example, poisoning them or withholding treatment. Most cases are based on incorrect beliefs or misplaced anxiety which, unchecked, can cause children to undergo harms ranging from missing school and seeing friends, to undergoing unnecessary and painful or even harmful tests and treatments.' The guidance introduces a new and wider interpretation of FII which includes 'any clinical situation where the parent or carer's actions are aimed at convincing doctors and other professionals that a child is more seriously ill than is the case.' ([New guidance on perplexing presentations and fabricated or induced illness in children | RCPCH](http://www.rcpch.ac.uk/news-events/news/new-guidance-perplexing-presentations-fabricated-or-induced-illness-children))

Given that it can be difficult to see the full extent of how ME affects a person without seeing them regularly, and given the evident need for a much greater awareness and understanding of the illness

across the medical profession, it is easy to see how a case of paediatric ME could give rise to inappropriate safeguarding alerts in the context of this guidance. We understand this is a complex and difficult issue to tackle and we ask that it should be addressed sensitively and with the involvement of all stakeholders as a matter of priority to avoid further harm.

The commitment that the Law Commission will review existing social care legislation relating to disabled children, to improve clarity for families about the support that they are legally entitled to, ensuring that local authorities know what they are expected to provide, and families know how to access support is needed, but we are concerned that there is no time scale provided.

### **Provision of health services**

We support the aim that, 'DHSC will work with stakeholders to consider how to better support health commissioners and providers to understand the needs of people with ME/CFS, what local service provision should be available and how existing national initiatives to improve accessibility of health services can be adapted or best utilised for people with severe or very severe ME/CFS - by July 2024.'

However, there is no detail about how this work should be undertaken or any mechanisms to ensure that health commissioners take part in the process. There should be a much more detailed timeframe and list of stakeholders in the final plan to ensure that all sectors of the NHS are on board. New provisions need to be designed with input from stakeholders and will only happen when there are budgets specifically attached to them. The budgets allocated for services need to be included in the final plan.

### **Provision of adult social care**

We welcome the recognition that adults with ME/CFS and their carers struggle to access social care support. Many people with ME struggle with daily living tasks such as personal care, preparing food, washing clothes, keeping the house clean and shopping. These tasks can be completely overwhelming for someone with only a miniscule ration of energy to allocate each day. Many people with ME depend on others to care for them. Family members struggle to provide care while also holding down a job; many have to give up work to care for their family member.

One issue which is not recognised in this section is the detrimental impact of having a high turnover of social care staff. The energy required to explain tasks to each new member of staff is huge for someone with ME, and can leave the person exhausted for the rest of the day, outweighing all the benefits of having the carers. Good social care for a person with ME requires a small team of carers, each of whom gets to know the needs of the person so they can carry out the activities with minimal interaction. This need for consistency should be recognised when a care package is put together.

It would also be worth noting that person-centred care for a person with ME may mean setting up multiple short visits rather than one longer visit; eg if having a shower uses all their energy then they might not be able to tolerate any further care on that day, and would need the carer to return on another day to complete other care activities.

### **Provision of welfare support**

This section is seriously flawed as it completely fails to identify the structural issue with the assessment process for awarding welfare support such as ESA/UC and PIP and by extension also Blue Badges, affecting people with ME and other energy limiting conditions. This needs to be explained in the document, accompanied by an action to address it in future.

Under the current system, people are assessed on discrete activities such as washing, dressing, preparing food, and walking, but the assessment process does not consider how performance on one activity can affect performance on another. Points are awarded if a person is unable to complete an activity on 50% of days, with no reference to whatever else they are doing. This is a problem for a person with ME who may be able to do each activity in isolation but not in combination. For example on any given day they may be able to do two out of three of the activities washing, dressing and preparing food, but if they wash and dress on the same day then they are completely unable to prepare food because their limited energy has been spent and they need to spend the rest of that day in bed. Using the current assessment process the person would be found not disabled for all three descriptors, whereas in fact their disability is hugely constraining, leaving them with significant extra costs eg to pay for ready meals and a cleaner.

For the mobility components, taking a compartmentalised view means that people with ME are routinely rejected for Blue Badges, or don't even apply because they can see the criteria don't fit. This renders them housebound as they cannot afford to squander their precious energy walking 50 metres.

The current system doesn't recognise cognitive dysfunction or 'brain fog' as a disability, yet it is massively disabling. Even simple tasks, such as following a conversation, ordering a repeat prescription or responding to an email can be beyond the limits of someone with ME.

The current WCA to assess whether someone is fit to work is particularly problematic. There is no consideration for the cumulative impact of activity, the time taken up by resting, or the unreliability of performance due to the fluctuating nature of the condition. A person may be able to carry out all activities of daily living including washing, dressing, preparing food, and keeping their house in order, but the effort required to do those activities is all-consuming and they need to spend all remaining time resting. They therefore have no capacity to work and need to be supported to live at that level, with no expectation to look for work. Others will be well enough to take on a few hours of work, but not full time work; this also is not recognised in the current system. Replacing the WCA with descriptors from PIP does nothing to address this issue.

### **Provision of employment support**

This section should also include employment support for carers, many of whom have to reduce their hours or work more flexibly to enable them to support their family member with ME.

It would be useful to have more DWP guidance for employers on how to adapt jobs for people with ME, as most are unfamiliar with the particular challenges of living with ME. For example, after a period of absence from work a person with ME is unlikely to manage a typical phased return over 4-6 weeks and should be offered a much more gradual return over a significantly longer time. They may never be well enough to return to the hours they worked previously, and may need to move to a role of lesser responsibility to accommodate both cognitive dysfunction and energy limitations.

### **Satisfaction with Consultation Process**

Whilst we are satisfied with the process of consultation, we are disappointed at the limited timescale for completion of what is a very complex survey.

The feedback in the community call conducted by #MEAction UK and Scotland was that the survey questions were confusing. The survey was complex and appeared to ignore the needs of those with ME who have limited energy to respond to consultations.

We do not believe that the survey used to conduct the consultation is at all satisfactory. The survey uses a mix of a rating scale and open ended comments for each chapter. The use of a four point rating scale to cover an entire chapter is very unsatisfactory as it does not allow for respondents who have mixed views on the contents of the chapters. A five point scale with ratings for each of the key sections of the chapters would have been more effective and less confusing. This is also a problem with the section on Agreed Actions where it is likely that respondents might have mixed views on the actions and therefore find it difficult to select a level of agreement relating to all the actions.

Furthermore, it was disappointing that there was no summarised version suitable for those with severe/very severe ME rather than the 'easy read' option, a format which is principally used for those with learning disabilities.

An added complexity was the lack of reference points (numbered sub-sections or paragraphs) making it very challenging to reference a particular section or even just navigate through a very long document. It would have benefited from a properly formatted pdf version with numbered sub-sections, page numbers etc. A pdf generated from a web page is nowhere near as accessible as one which has been properly formatted.