



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

This response is submitted by #MEAction Scotland, the Scottish arm of #MEAction UK, a not for profit organisation.

Our response is based on the two areas identified in the Foreword of the Interim Delivery Plan (IDP) where it states that the "Scottish Government is keen to understand the views of stakeholders in Scotland on aspects where there might be the potential to consider any common approaches or relevant actions within a Scottish context."

We are pleased that the Scottish Government has engaged in the process of developing the Delivery Plan and hope that it will commit to taking action to address the problems identified.

The following sections mirror the section headings used in the IDP, with the Agreed Actions included in the relevant section.

1. Introduction

The Plan does not give a **prevalence figure** for Scotland. The prevalence estimate for England uses a population prevalence rate of 0.4%; applying this to the mid-2021 population estimate for Scotland gives a figure of 21,920 people. We know that many people with Long COVID also have ME. If just 10% of those with Long COVID also meet the diagnosis for ME, then this represents a doubling of cases of ME.

The Introduction mentions the 1 in 4 adults who are **severely or very severely affected by ME**. We are, however, very concerned that the plight of those with severe and very severe ME is not addressed in the Plan, and the particular problems of being bed bound and severely energy-limited are not considered. The barriers to accessing care for those who are housebound or bed bound include being invisible to healthcare services and not being able to access GPs, healthcare or dental treatment, whether routine or emergency.

Sadly, we hear frequently from people with severe or very severe ME who tell us they have not spoken to a GP for years as their GP is unwilling to visit them at home. Dentists, opticians and occupational therapists are also essential services for the chronically ill and these services are inaccessible to many of those who need them most.

Lack of knowledge among healthcare workers means that hospitals can be dangerous places for people with ME. There have been a number of deaths in recent years in English hospitals; while we are not aware of any deaths yet in Scotland, we do regularly hear from people with severe or very severe ME who have been harmed in hospitals by incorrect treatment due to the ignorance of medical and other healthcare staff.

This is a concern in all specialties and all healthcare settings, as a person with severe or very severe ME is unlikely to be able to withstand the physical or mental toll of any hospital interaction, planned or

unplanned, inpatient or outpatient, without becoming seriously unwell for a period of days, weeks or months afterwards, unless significant adaptations are made.

The suggestion in the Case for Change section of the Introduction that **‘functional disease’ or ‘medically unexplained symptoms’** are ‘medically accurate’ is incorrect. Firstly, there is no evidence that ME is a functional disease and it is of particular concern that the Scottish Government has funded the website <https://neurosymptoms.org/en/> which states incorrectly that ME is a functional disorder. The ME Association in its response to the Plan says:

“We do not know enough about the pathoetiology of ME/CFS to state that the term ‘functional disease’ is ‘medically accurate’. Research has been published on structural rather than functional abnormalities and saying this term is accurate implies that the terms functional neurological/somatic disorder could also be correct when they are not. We recommend the term and reference is removed.”

Secondly, the term ‘medically unexplained symptoms’ is often based on the assumption that medically unexplained physical symptoms are symptoms which have no physical cause - rather than no known physical cause. It is important for the understanding of ME that both these references are deleted from the Plan.

The Case for Change section includes **the economic case for addressing ME** and this is clearly as strong in Scotland as it is in the UK. Using the figures from the 20/20 report quoted in the Interim Delivery Plan, the estimated cost of ME to the Scottish economy is £360m per annum, or £17,000 for each person with ME per year. The majority of this is productivity losses and the cost of informal care.¹ Most people with ME are of working age: the peak age of onset is between 20 and 40 years. On average the illness lasts between 3 to 9 years, but many people remain ill for several decades.² Only 12% of people with ME are in full-time paid work, education or training and a further 21% are in part-time work, education or training.³

Many people with ME enjoyed successful careers before becoming ill with ME, but are unable to continue because their energy is so depleted. They have to manage their energy across all activities, including basic activities of daily living such as washing, dressing and preparing food. Even if they can manage those tasks without help, that is often all they can do; they have little or no energy left for work. Most are also debilitated by cognitive fatigue or ‘brain fog’ affecting their ability to concentrate, follow conversations, recall facts, and make decisions.⁴

¹ 1. Hunter, R et al (2017). Chronic fatigue syndrome/Myalgic Encephalomyelitis: Counting the Cost, Optimum Health Clinic. <https://2020health.org/publication/counting-the-cost>

² Capelli et al (2010). Chronic Fatigue Syndrome/Myalgic Encephalomyelitis: An Update. <https://doi.org/10.1177/039463201002300402>

³ Action for ME (2014), Time to deliver in Scotland. <https://www.actionforme.org.uk/uploads/pdfs/me-time-to-deliver-in-Scotland.pdf>

⁴ 4. Hale, C et al (2021). “I already have a job... getting through the day”. <https://chronicillnessinclusion.org.uk/wp-content/uploads/2021/04/CfWR-ELCI-and-Work-b.pdf>

“I used to run a busy department of 20 people, but with ME this became completely impossible. I could no longer concentrate, no longer follow a discussion, no longer make decisions. Listening to people was exhausting - it was as if they were speaking to me in a foreign language. Even spending 15 minutes with someone would wipe me out for the day. I had to give up my job and take ill health retirement at the age of 54, several years before I had planned to retire.” Sarah

2. Research

The Plan states that the problems identified for ME research include: low capacity and capability among the research community to respond to research needs; low awareness of the need and scope for research; relatively low amount of biomedical research funding compared with disease burden; and lack of trust between different stakeholders.

These problems have been identified in several reports commissioned by the Scottish Government over the past 21 years.

- In 2002 the Chief Medical Officer led a Short Life Working Group (SLWG) looking at the development of services for ‘CFS/ME’. One of the key findings in the report was that there was a ‘limited research base on which to make fully informed decisions on how CFS/ME can be treated and managed’ and the report included a recommendation for the development of research in Scotland.
- In 2010, the Scottish Public Health Network (ScotPHN) undertook a healthcare needs assessment (HCNA) for adults with a diagnosis of ME/CFS, using as a reference point the 2002 SLWG report. The conclusion of the 2010 report was that the SWLG recommendations had not been implemented and further recommendations were made relating to the development of a research strategy for ME/CFS and the development of a Centre for Research Excellence and Dissemination.
- In 2020 - 18 years after the SWLG report - a further study was carried out by ScotPHN to review what, if anything, had changed in provision for ME/CFS patients. This report concluded that the recommendations of the 2010 HCNA report had not been implemented and that “The funding provided by the Scottish Government to establish a James Lind Alliance Partnership to identify the top 10 research questions on ME-CFS is welcome. Ensuring these priorities inform the delivery of this recommendation will be critical”.

It is clear from these reports that in Scotland there is no issue with awareness of the need for research funding as this has been consistently identified since 2002. Furthermore, Professor Chris Ponting from Edinburgh University is currently leading the world’s largest study into ME/CFS (DecodeME), suggesting that Scotland has the research capability and community to undertake research. We believe the key problem in Scotland lies with the lack of funding for research provided by the CSO. Having part-funded the James Lind Alliance Priority Setting Partnership for ME/CFS (published in May 2022) we hope that the CSO will now consider ways of encouraging applications from researchers to address years of underfunding of research for ME/CFS.

The agreed Research Actions are welcomed, but, without a promise of funding and with no sense of urgency, they are well meant but ineffectual. We hope that the Scottish Government will commit to a similar range of actions and recognise the urgent need for actions and funding commitments.

3. Attitudes and education of professionals

The problems identified in this section also apply to Scotland and have been highlighted in the Scottish Government reports mentioned in the previous section. In the 2002 SLWG report, for example, one of the key recommendations was that there should be 'education and training of all professionals.'

#MEAction Scotland has raised these issues with the Scottish Government, the Clinical Priorities Team and NHS Education for Scotland (NES) on numerous occasions over the past five years.

We welcome initiatives to educate professionals about ME and believe that in Scotland the starting point should be implementation of the NICE guideline on ME/CFS, which recommends how to diagnose ME and how to manage the condition based on the best evidence available. The updated guideline was published two years ago in October 2021, and, despite commitments from the Scottish Government, has still not been implemented.

The Scottish Government currently funds Action for M.E. to promote a CPD module on ME/CFS developed by Dr Nina Muirhead. Whilst this is to be welcomed, there is a need for a far wider commitment to funding to increase the knowledge of all professional staff working in health and social care services.

NHS Education for Scotland (NES) committed to producing a Practice Based Small Group Learning module on ME/CFS for GPs in 2018: this module is yet to be published. We would like to see a much greater commitment from NES to producing up to date education and training on ME/CFS education for the NHS, health and social care sector and other public bodies.

The commitment of the British Association of Social Workers to support awareness-raising about the needs of people with severe/very severe symptoms of ME/CFS is promising and we hope the Scottish Government will encourage this.

Training relating to 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.

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 the NHS 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 commitment of the Royal College of Physicians (RCP) to ensuring that training on ME/CFS keeps pace with research and guidance in the core postgraduate training for primary and secondary care physicians is a welcome improvement. It is not clear if this commitment is from the Royal College of Physicians London or from all three RCPs. We hope that the Scottish Government will ensure that this commitment includes the Royal Colleges of Physicians in Edinburgh and Glasgow.

4. Living with ME/CFS

Children and Young People - Education

We welcome the recognition in the Interim Delivery Plan 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.

Every child and young person has the right to access education appropriate to their needs. There is strong evidence that young people with energy-limiting conditions (where they are well enough) can succeed with education given the right blend of flexible learning delivery. For some, this will mean a hybrid home/school approach. For others it will mean entirely home-based learning with reasonable adjustments to enable assessment – for example, those with short-term memory impairment may need formative rather than summative assessment. Those pupils who are too unwell for any schooling should be supported to stay in the system, not least for the sake of their wellbeing and inclusion and in the hope that their health may improve over time and they can re-engage.

In our experience the school system in Scotland is not sufficiently able to accommodate illness that is unpredictable, illness that is not managed by medication, illness that affects mental energy and short-term memory, or long-term home-based learning:

- There is limited and patchy access to the flexible type of provision that pupils with ME need in order to progress with their education. Scotland does not have an equivalent to the EHCP system in England. Where flexible provision does exist it is not always offered at the point of need and does not offer a broad-based curriculum. For example, an offer that is limited to English and Maths may be inaccessible to someone whose neurocognitive impairments mostly affect their ability to process words and numbers.
- Among teaching and guidance staff, knowledge and understanding of chronic and energy-limiting illnesses is underdeveloped. This leads to long delays in assessing needs and putting provision in place, failure to support pupil attainment and failure to support social development and inclusion. In some cases, school-enforced attendance schedules are causing long-term damage to health. Without adequate information and training it is easy for school staff to assume that regular/increased attendance should be the goal. This can be very detrimental to long-term health for a child with ME: the emphasis should be on enabling the child to access suitable education, not to maximise in-person attendance.

We welcome the inclusive principles underpinning the recent Independent Review of Qualifications and Assessment. We think there is an opportunity to address the issues we have set out above as part of the Scottish Government's education reform programme, and request that in addition to other common types of additional learning needs, these reforms seek to take account of those with chronic and debilitating long-term energy-limiting illnesses including ME. Beyond policy considerations, the infrastructure and training to support these needs must then be proactively addressed on a Scotland-wide basis.

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. The more well-informed further and higher education institutions are on the needs of students with ME, the better they will be able to make appropriate adjustments to facilitate their access to and successful participation in further and higher education. Education and awareness-raising are therefore critical to ensure people with ME are given the opportunity to realise their potential, including those who may have missed out on parts of their schooling due to their illness.

Children's Social Care

The 2022 Scottish Stakeholder Review of the ME/CFS NICE Guideline noted that parents of children and young people with ME in Scotland 'were concerned about allegations of Fabricated or Induced Illness (FII)' and 'described their wariness in interacting with medical professionals' and suggested that some parents are too scared to accept care because of 'the potential safeguarding consequences.' It was also noted that the absence of specialist services in Scotland was perceived to increase the risk of false allegations.

The response from #ME Action UK to the Interim Delivery Plan notes that 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' and goes on to discuss the need to address this sensitively and as a matter of priority. This is also a matter of priority for the children with ME and their families in Scotland, particularly in the absence of ME specialists in Scotland who can provide expert medical opinion on a child's case.

Provision of health services

The lack of provision of specialists and/or services for ME in Scotland is one of the significant differences between England and Scotland. This lack of care and support of people with ME in Scotland was highlighted in the SLWG 2002 report. The 2010 HCNA and the 2020 review of the HCNA confirmed that nothing had changed in the provision of services and the development of care pathways. Most recently the report on the survey of NHS Boards issued in Autumn 2022 said 'More than half of the NHS Boards that responded to this survey did not have specific ME/CFS referral pathways, and only one had a specifically trained ME/CFS staff nurse'. The report goes on to state that only two NHS Boards (NHS Fife and NHS Greater Glasgow and Clyde) reported that they had ME/CFS services in place, although #MEAction Scotland is aware of a service in NHS Lothian (NHS Lothian did not respond to the survey). It should be noted that the NHS Fife service was run by a specialist nurse who is currently off on long term sick leave and the NHS Glasgow service reported that it is treating patients with treatments that are specifically not recommended by the NICE guideline.

This situation is shocking and we call on the Scottish Government to address this urgently, working with stakeholders, including the NHS Boards, clinicians, other healthcare professionals and the patient community/organisations to establish pathways for people diagnosed with ME and ensure that people with ME are treated by professionals who have received relevant training on the 2021 NICE guideline.

Provision of adult social care

In Scotland, free personal care has been extended to people of all ages, thanks to Frank's Law. However adults with ME/CFS and their carers still struggle to access the social care support to which they are entitled. We welcome the acknowledgement of this in the Plan.

Many people with ME struggle with daily living tasks such as personal care, preparing food, washing clothes, cleaning 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 specific to England and Wales and, therefore, makes no mention of the Scottish ADP or CDP and does not acknowledge the structural issues with the existing assessment processes for both UK and Scottish welfare support. Assessing activities in isolation, rather than assessing how a person's disability affects them overall, results in many people with ME struggling to get the help that they need.

The Scottish Government has already heard in its 2023 consultation on ADP about the need for a more flexible and holistic approach to the ADP decision making process⁵. This is particularly important for adults and children with ME where doing any activity impacts on the person's ability to do another activity.

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 e.g. to pay for ready meals and a cleaner.

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<https://www.gov.scot/publications/adult-disability-payment-consultation-mobility-component-analysis-responses/pages/2/>

In addition, people with ME suffer from post-exertional malaise or PEM. The impact of this is that a person may be able to walk 20 metres one day, but having walked that distance they may be incapacitated for hours, weeks or longer.

The current UC/ESA/ADP/CDP assessment processes do not 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 or ADP would do nothing to address this issue.

Action 21 lists a number of changes which the DWP intends to implement to improve access for everyone. We welcome the progress which Scotland has already made with the move to ADP and we urge the Scottish Government and Social Security Scotland to continue to seek improvements in these areas.

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.