



The ME Association Response to the DHSC Consultation: The Interim Delivery Plan on ME/CFS 25 September 2023

Foreword

We would like to thank everyone – people with ME/CFS, family members, unpaid carers, charity representatives, clinicians, researchers, representatives from the Department of Health and Social Care (DHSC) and other government departments and research funding organisations – for their time and dedication in working towards publication of the Delivery Plan on ME/CFS.

We welcome the Interim Delivery Plan (IDP) and how it has recognised many of the problems faced by people with ME/CFS who have experienced how health and social care is being delivered (or not delivered) and how it can be improved. In particular, the information and recommendations in the sections covering, attitudes, children, education, employment, social care, quality of life, health services, and language, are comprehensive and helpful.

Improved and accessible health and social care – based on 2021 NICE Guideline recommendations – is vital, especially as many people with ME/CFS and their unpaid carers do not have access to professional support or have disengaged from the NHS because of bad experiences or in the belief that help is not available.

We appreciate that the IDP has highlighted the long-term disparity between the scale of need for research into ME/CFS – which is desperate – and historic funding levels – which have been very limited compared to other long-term conditions.

Many of the research proposals to increase knowledge with new investment – including the need to bring in new researchers with new ideas – mirror the recommendations that have been made in several previous reports. Positive progress in this area is long overdue, and we eagerly await specific proposals that will produce epidemiological studies, diagnostic tests, and beneficial treatments.

We hope that effective implementation of the 2021 NICE Guideline on ME/CFS, the findings from the 2022 APPG on ME Report on ME/CFS, and the recommendations in the Final DHSC Delivery Plan on ME/CFS will result in:

- the removal of any remaining doubts about the reality and impact of this debilitating medical condition,
- significant improvements to health and social care service provision, and to healthcare professional's training and understanding, and,
- increased and appropriately targeted research investment.

The ME Association was represented on each of the 3 working groups. We understand just how much evidence about ME/CFS was given to the DHSC and we are grateful to have been able to contribute.

While it is understandable that the IDP needs to present a summary of that information, it is regrettable that certain issues have not been included or given as much detail as we would have liked.

We would therefore like the DHSC to improve the IDP so that the Final Delivery Plan is more encompassing and representative.

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Each of the points below relate to the headings used in: My Full Reality: The Interim Delivery Plan on ME/CFS¹.

¹ DHSC My Full Reality: [The Interim Deliver Plan on ME/CFS Consultation](#) (2023).

Contents

EXECUTIVE SUMMARY	4
a. Attitudes and education of professionals.....	4
b. After publication of the final delivery plan on ME/CFS	4
1. INTRODUCTION.....	5
a. Prevalence amendment	5
b. Description amendment.....	6
c. Symptoms amendment	6
d. Other symptoms amendment.....	6
e. Final description amendment	7
f. Illness severities amendment	7
g. Attitudes and education of professionals.....	7
2. RESEARCH	8
a. The link between ME/CFS and Long Covid.	8
b. Most of the findings in the IDP were already well known.	8
c. We need to go much further and faster and develop a far more ambitious plan.....	9
d. Other research priorities:.....	9
3. ATTITUDES AND EDUCATION OF PROFESSIONALS	9
a. "Bringing together the different stakeholders in this area is complex..."	9
b. Severe and Very Severe ME/CFS	10
c. The 2023 ME Association Count ME In Survey asked about NHS Experiences:.....	10
4. LIVING WITH ME/CFS	10
a. Quality of Life	10
b. Support for children and young people with ME/CFS.....	11
c. Provision of health services	11
d. Provision of adult social care	15
e. Provision of welfare support	15

5.	Agreed Actions	17
-	Which Actions are aimed at improving QoL and Health Services?	17
I.	Research.....	18
II.	Attitudes and education of professionals.....	18
III.	Broader actions to improve awareness and understanding.....	18
IV.	Improving statutory support	18
6.	Next steps	19
7.	Use of language in ME/CFS	19
I.	Chronic fatigue as a symptom of ME/CFS.....	19
II.	Recovery from ME/CFS.	19
III.	ME/CFS as a mental health condition.....	20
IV.	Lack of medical tests.	20
V.	No obvious signs.....	20
VI.	Using pacing to manage energy.	21
VII.	Post-exertional malaise.	21

EXECUTIVE SUMMARY

- We would strongly recommend that the Executive Summary include a description of ME/CFS written by someone who has experienced the condition over a long period of time. The IDP would benefit from this personal experience at the start of the report. Without it the report has less of an impact and people who read it – who don't know about ME/CFS – might find e.g., symptom definitions, lack appropriate context. For example:

"I was 30 years old and enjoying a 12-year career in Finance and Private Banking. I was very active and healthy and looking forward to settling down and starting a family. In 1999, I went on holiday, contracted a nasty infection, and my life changed completely. I simply could not recover. I had difficulty walking and staying upright, thinking clearly, talking, and I constantly felt like I had the Flu. I had sore throats, swollen glands, high temperatures, migraines, and sweated a great deal even in my sleep. I couldn't eat or drink properly. I lost a lot of weight. I was too weak to leave my bed for long periods of time. I was needing to sleep much more than ever before but felt worse when I woke up. My parents had to arrange a transfer to their home in Cornwall where I remained for 10 years. It has been a torturous journey. Improvements came and went. Relapses happened often. At times I was able to sustain a relative improvement only to succumb once again. My mental health suffered a great deal. There was a lot to worry about and I felt much guilt. I struggled to accept ME/CFS and to accommodate disability. My parents saved my life after I tried to kill myself. Getting early help and support from the NHS and from the DWP was impossible when I needed it the most. I just wasn't capable, and my parents didn't know where to turn. Some GPs tried to help, but most didn't know how. The Cornwall ME/CFS specialist service were great, and I was relieved when I could finally attend appointments, but I was sceptical that their approach would help. Progress in recent years has been painful, but I now seem to have reached a sustained period of improvement that has allowed me to work remotely from home. This was after 15 years of relying on a disability pension and benefits. Being able to work has only been achieved because I have a lot of paid support in place and a very understanding employer. Working again has given me purpose and improved my confidence and self-worth, but it isn't easy, and every time I experience a setback in my health, I can't help but worry it might lead to a loss of all that I have managed to achieve."

a. Attitudes and education of professionals

- We would like to see specific reference to social care professionals made here. Actions aimed at improving the situation with medical professionals are welcome as are efforts to improve the experience that people with ME/CFS have when needing to obtain a care needs assessment and with social care professionals who lack necessary education and understanding about the condition.
- We would like to have seen Actions around recruitment *and retention* of professionals mentioned here. Retention of well-trained professionals is a key concern. For people working in ME/CFS specialist services, for example, there needs to be a concerted effort to provide a career path that is attractive and aimed at retaining staff.
- Updating NHS websites (see below).

b. After publication of the final delivery plan on ME/CFS

- In previous decades, we have received the government's support or endorsement for reports that have highlighted issues relating to ME/CFS. We don't want to see a repeat of these previous efforts that were not effectively monitored or enforced.
- This applies to the implementation of the recommendations contained in the NICE Guideline on ME/CFS and to the Actions proposed in the Delivery Plan on ME/CFS. The Executive Summary is not clear about the purpose of the government's Delivery Plan's or who will be responsible for this Plan's enforcement.
- Delivery Plans seem to be quite common in government departments. What is their primary purpose and will the Delivery Plan on ME/CFS continue if the government changes at the next general election?
- If Actions from the Delivery Plan on ME/CFS are not completed on time or in a satisfactory manner, who will be ultimately responsible for enforcement?

- What recourse does the patient community have if Actions are not fulfilled or their fulfilment does not have the desired effect?
- There appears to be an arrangement between the Care Quality Commission and NICE². Will the CQC:
 - be responsible for any failure on the part of the NHS to implement the NICE Guideline recommendations or to create new – or improve existing – ME/CFS specialist services?
 - complete specific reviews of ME/CFS specialist services as part of its reviews on the performance and compliance of Hospital Trusts?
 - take any responsibility for the specific Actions in the Delivery Plan on ME/CFS?

1. INTRODUCTION

a. Prevalence amendment

“ME/CFS is a long-term health condition that remains poorly understood, despite affecting an estimated 241,000 children and adults in England...”

- There is a lack of reliable and up to date epidemiological evidence on the prevalence of ME/CFS³.
- We suggest that the IDP refers to a figure based on a 0.4% prevalence estimate which, based on latest ONS population estimates, suggests 226,144 people with ME/CFS in England.
- However, given that reliable data is very limited, including from the study that is referenced in the IDP, it might be better to refer to the familiar estimate of 250,000 people in the UK which equates to roughly 210,000 people with ME/CFS in England.
- The 2007 NICE Guideline on ME/CFS⁴ said:

“There is a lack of epidemiological data for the UK, so population estimates are based on extrapolations from other countries. Overall, evidence suggests a population prevalence of at least 0.2–0.4%. This means that a general practice with 10,000 patients is likely to include up to 40 people with CFS/ME; half of these people will need input from specialist services.”
- Whatever estimate is used it should be accompanied by a caveat, saying it is based on dated epidemiological evidence, which also fails to take account of the number of people with post-Covid ME/CFS. Recent research has estimated that up to 60% of people with Long Covid meet the ME/CFS diagnostic criteria⁵ and we are seeing increasing numbers of people who have been unable to recover from Covid-19 being diagnosed with ME/CFS.
- It might also be helpful if the caveat referred to the potential number of people who might meet the diagnostic criteria but who remain undiagnosed. Studies in America⁶ have estimated that up to 91% of people affected do not have a diagnosis. No similar studies have been conducted in the UK and we feel this should form part of any epidemiological research that is prioritised following this report.
- We still don't know the true number of people with ME/CFS in England or the UK. The NHS has been unable to reveal data showing the number of people with a diagnosis despite SNOMED-CT coding and repeated parliamentary questions over the last decade. This is a major failing when it comes to planning health and social care services – and a high-quality epidemiological study should be a research priority.

² NICE and CQC [release updated joint working agreement](#) (May 2022).

³ Estévez-López, E, et al. [Systematic Review of the Epidemiological Burden of ME/CFS Across Europe: Current Evidence and EUROMENE Research Recommendations for Epidemiology](#) (2020).

⁴ The 2007 NICE Guideline on ME/CFS (CG53): [Introduction](#).

⁵ Jason, L, et al. [ME/CFS and Post-Exertional Malaise among patients with Long Covid](#) (2022).

⁶ Institute of Medicine: [Beyond ME/CFS: Redefining an illness: Introduction](#) (2015).

- Finally, we would suggest that reference is made here to the greater proportion of women affected compared to men, and that the disease can affect people of all ages. The 2021 NICE Guideline⁷ said:

“Recent data from the UK Biobank suggest that there are over 250,000 people in England and Wales with ME/CFS, with about 2.4 times as many women affected as men. ME/CFS can affect people of all ages.”

b. Description amendment

“It is a complex, multi-system, chronic medical condition. It is not clear what causes ME/CFS. In many cases, symptoms are thought to have been triggered by infection, but it is not simple post-illness fatigue – it lasts longer, and even minimal mental or physical activity can make symptoms worse.”

- We suggest the initial description of ME/CFS is amended and made more encompassing given that this is the first time a description appears and how important it is that people who read the IDP should understand the condition and its challenges.

We have included language from the NICE Guideline⁸ to ensure consistency:

“ME/CFS is a complex, chronic medical condition affecting multiple body systems. It affects each person differently and its impact varies widely – from being able to carry out limited activities to substantial incapacity. It is a fluctuating medical condition in which a person’s symptoms can change unpredictably in nature and severity causing distress and disrupting lives. It can cause many different symptoms, which can be triggered or worsened by any kind of effort or activity.

“ME/CFS can prevent or restrict the ability to work or go to school, college, or university, and be severely disabling – leaving people housebound or bedbound and reliant on the care of others. It can have a detrimental effect on activities of daily living, family life, social life, and emotional wellbeing. There are therapeutic options that can help people manage ME/CFS, but an approach that helps one person may cause harm to another, so a carefully tailored plan and specialist advice is always needed.”

c. Symptoms amendment

- Symptoms should be quantified by including the criteria for suspecting ME/CFS (from the NICE Guideline)⁹.
- It is important to convey that symptoms should have a significant effect on a person’s ability to engage in everyday activities:

1.2.2 Suspect ME/CFS if:

- the person’s ability to engage in occupational, educational, social or personal activities is significantly reduced from pre-illness levels.

d. Other symptoms amendment

- Other common symptoms should be amended to be consistent with the NICE Guideline¹⁰:

1.2.4 Be aware that the following symptoms may also be associated with, but are not exclusive to, ME/CFS:

⁷ The 2021 NICE Guideline on ME/CFS: [Context](#).

⁸ The NICE Guideline on ME/CFS (NG206): [Information for the public](#) and recommendation [1.1.1 Awareness of ME/CFS and its impact](#).

⁹ The NICE Guideline on ME/CFS (NG206): [Suspecting ME/CFS](#).

¹⁰ The NICE Guideline on ME/CFS (NG206): [Suspecting ME/CFS](#).

- orthostatic intolerance and autonomic dysfunction, including dizziness, palpitations, fainting, nausea on standing or sitting upright from a reclining position.
- temperature hypersensitivity resulting in profuse sweating, chills, hot flushes, or feeling very cold.
- neuromuscular symptoms, including twitching and myoclonic jerks.
- flu-like symptoms, including sore throat, tender glands, nausea, chills or muscle aches.
- intolerance to alcohol, or to certain foods and chemicals.
- heightened sensory sensitivities, including to light, sound, touch, taste and smell.
- pain, including pain on touch, myalgia, headaches, eye pain, abdominal pain or joint pain without acute redness, swelling or effusion.

e. Final description amendment

- We recommend the **final section** in the description is amended to read:

"ME/CFS can cause 1 in 4 adults at any one time to be so severely affected that they are housebound or bedbound, with little functional capacity, and in need of additional care and support from family and professionals. This acute period of illness often occurs around the time of diagnosis, can last for months or years, or be the result of a relapse.

"Given the fluctuating nature of the condition, it is not uncommon for people to experience several periods of severe or very severe ME/CFS over the course of their illness; especially when relapse is a constant risk. In rare cases ME/CFS can be fatal particularly for those who are very severely affected."

f. Illness severities amendment

- We suggest the reference here is amended (and based on the language in the NICE Guideline) to read:

"The NICE Guideline on ME/CFS provides a guide to the impact of symptoms on everyday function¹¹. It puts illness severities into 4 categories: Mild, Moderate, Severe, and Very Severe. While useful, these definitions are not clear cut as ME/CFS is a fluctuating condition, and it can affect people differently.

"For example, ME/CFS can cause the severity of individual symptoms and the degree of functional impairment to vary widely. People with the condition are likely to move between illness severities as their functional limitations improve or they relapse, but for a significant minority, improvements are not possible, and positive progress is limited."

g. Attitudes and education of professionals

- **"The absence of a confirmatory test means a diagnosis is often delayed while potential alternative causes of their symptoms are excluded."**
 - We would challenge this statement. ME/CFS should not be considered a diagnosis of exclusion - it has a defined set of symptoms and signs - but this message has not reached all healthcare professionals, and the lack of a diagnostic test is not the main reason for diagnostic delays.
 - While the 2021 NICE Guideline on ME/CFS has made the diagnostic process clearer, delays still occur, perhaps because professionals are not as aware of the condition or the Guideline as they should be. Diagnostic delays have been occurring for decades despite greater awareness and the NICE Guidelines. There is a clear need here for improved awareness and medical education.
 - Measures need to be put in place to urgently improve the situation and clear directives need to be issued by NHS England, ICBs, and the Medical Colleges to NHS primary and secondary care services. The IDP needs to clearly stress the importance of direct action

¹¹ The 2021 NICE Guideline on ME/CFS: [Box 1 Severity of ME/CFS](#).

in this regard.

- **The 2023 ME Association Count ME In Survey**¹² revealed that:
 - 82% of respondents with ME/CFS had waited more than 6 months for a diagnosis, compared to 44% of people with Long Covid.
 - waiting times had increased in recent years despite the NICE Guideline recommendation that a diagnosis should be suspected within 6 weeks and occur within 3 months.

- **“When the diagnosis is confirmed, the therapeutic options are limited to some symptom control, interventions for co-morbid conditions and lifestyle modification.”**

We would suggest this is amended to read:

“When the diagnosis is confirmed therapeutic options are available that can help with symptom control, lifestyle changes, energy management, emotional health and wellbeing, and for co-morbid conditions.”

- **Functional disease**

We do not know enough about the pathoaetiology 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.

- **Medically unexplained symptoms**

The reference to ‘*medically unexplained symptoms*’ (MUS) should also be deleted as this could lead to additional pressure on people with ME/CFS to attend MUS clinics – which is not what they want to do, and which would be ill-advised – instead of ME/CFS specialist services which is the recommended and preferred route to specialist care and support.

2. RESEARCH

a. The link between ME/CFS and Long Covid.

- The link between ME/CFS and Long Covid needs to be stated unequivocally.
- Vast amounts of money have poured into research into the possible causes and treatment of Long Covid. Much of this research has been aimed at causative factors and treatments that are also relevant to ME/CFS.
- The final Delivery Plan should therefore recommend much closer co-operation in relation to both funding arrangements and research strategy for Long Covid and ME/CFS.

b. Most of the findings in the IDP were already well known.

- The Interim Plan correctly identifies most of the reasons why research into ME/CFS has not been comparable in terms of both human resources and funding when compared to many other long-term conditions. It identifies several actions – all of which we support.
- However, most of these findings were already well known and were highlighted in The 2006 Parliamentary Inquiry prepared by Dr Ian Gibson, MP, The 2016 UberResearch Report into Research Funding for ME/CFS, and most recently, in The 2022 APPG on ME Report: Rethinking

¹² The [2023 ME Association Count ME In Survey](#) was completed by 7,303 people: 85% (6,208 people) had a diagnosis of ME/CFS. 10% (730) had a diagnosis of Long Covid. 5% (365 people) were undiagnosed but experienced the 4 core symptoms of ME/CFS. A Full and Independent Survey Report will soon be commissioned and made publicly available in early 2024.

M.E.¹³.

- For example: The Introduction to The 2016 UberResearch Report included 3 key messages from Professor Sir Stephen Holgate:
 - I. The scale and impact of ME/CFS on individuals and society is significant. Around 250,000 people in the UK have ME/CFS which is at least as disabling as multiple sclerosis and congestive heart failure. Many more people – carers, children, and family members – are directly affected by the illness each year. The economic cost of ME/CFS was estimated at £6.4 billion per year in the UK in 2006, and this figure will certainly have increased since.
 - II. Research funding has been low-level and patchy, and investment needs to be increased, particularly for high-quality studies of biological mechanisms and treatments.
 - III. The skills, expertise, and insight of researchers outside the field are required to tackle the gaps in knowledge and understanding about ME/CFS.

c. We need to go much further and faster and develop a far more ambitious plan.

- We need to go much further and faster and develop a far more ambitious plan that mirrors the way in which former Prime Minister David Cameron brought the need for research into Alzheimer's Disease to public attention by helping to set up the [Dementia Platform](#) which secured £100 million of government and pharmaceutical funding for dementia research.
- [The Dementia Discovery Fund](#) included £25m from Glaxo Smith Kline; £10m from Johnson and Johnson and £22m from the Government.
- This would be a major and widely welcomed change in research strategy for ME/CFS. It would have to be accompanied by ring-fenced research funding from the MRC and NIHR to establish Centres of Research Excellence in the same way that the National Institutes of Health in America has identified and funded several key research centres for ME/CFS.

d. Other research priorities:

- i. An epidemiological study that provides an up-to-date estimate on the prevalence and incidence of ME/CFS.
- ii. A longitudinal study that tracks symptoms, severity, and co-morbidities over several years from the point of diagnosis.
 - These are obviously expensive items of commissioned research and would require the incentive of ring-fenced funding from MRC and NIHR.

3. ATTITUDES AND EDUCATION OF PROFESSIONALS

a. "Bringing together the different stakeholders in this area is complex..."

- We suggest that it isn't 'complex' and that stakeholders have been working together productively for many years.
- DecodeME and the JLA PSP are recent examples of collaborative working but reports and surveys dating back to before the 2002 ME/CFS Working Group Report to the Chief Medical Officer¹⁴ and others since then, more than demonstrate the willingness of stakeholders to work together.
- What has been sadly lacking is any effective action on the part of NHS England, the Department of Health and Social Care, and the Government to enact any of the findings from these earlier reports which means that many of the priorities identified in the IDP have been identified before.

¹³ The 2006 Parliamentary Inquiry: [Report into the Status of CFS/ME](#). The 2016 UberResearch Report: [ME/CFS Research Funding](#). The 2022 APPG on ME Report: ['Rethinking M.E.'](#)

¹⁴ A [Report of the CFS/ME Working Group to the Chief Medical Officer](#) (Jan 2002).

- We sincerely hope that the Final Delivery Plan on ME/CFS will result in a positive and tangible change to the attitudes and education of professionals and in all the other identified priority areas.
- We would not want to look back in 20 years' time to find that all the work and effort on the part of stakeholders to produce the Final Delivery Plan did not improve the situation for people with ME/CFS.

b. Severe and Very Severe ME/CFS

- We recommend that a separate section is created that focuses on severe and very severe ME/CFS with relevant Actions around professional training for this most vulnerable group of people.
- The content should be based on the specific recommendations from the NICE Guideline on ME/CFS in chapter 1.17 Care for people with severe or very severe ME/CFS¹⁵.

c. The 2023 ME Association Count ME In Survey¹⁶ asked about NHS Experiences:

- In general, experiences with the NHS were more likely to be rated poor than good and were worse for ME/CFS than Long Covid:
 - Only 8% of those with ME/CFS rated the NHS as good or excellent, and with Long Covid it was 15%.
 - Top barriers to good care were long waiting times, not being listened to or believed, and ineffective treatments.
 - Every region in the UK scored badly. More than 50% of regions received a very poor or poor opinion. Wales, Northern Ireland, West Midlands, Southeast England, and Scotland received over 65%.
 - There are many barriers to receiving a timely diagnosis – the main ones being that people were diagnosed with a different condition, not being referred to specialists by GPs, long waits for tests or referrals, and not being taken seriously.
 - The majority of people we surveyed had experienced a lack of responsiveness from the NHS with few people feeling adequately supported. Many experienced limited help and scepticism from health professionals about their condition.
 - Findings strongly suggest the need for better understanding and training of healthcare providers, increased support for patients, and proper recognition and acknowledgement of ME/CFS (and Long Covid) by the NHS.

4. LIVING WITH ME/CFS

a. Quality of Life

- We feel it would be helpful if the IDP included comparisons of quality of life in ME/CFS with other medical conditions like Multiple Sclerosis – a condition that shares several symptoms. It is important that people understand just how disabling ME/CFS can be and the impact it can have on quality of life.
- The IDP doesn't go far enough in this regard and more detail is required.

For example:

- In 2018, a research study¹⁷ found that people with ME/CFS had reduced functional ability and a poorer quality of life compared to people with Multiple Sclerosis. People with ME/CFS were 'measurably more disabled' than those with MS, worked fewer hours, and had lower incomes.

¹⁵ The 2021 NICE Guideline on ME/CFS (NG206): [Care for people with severe or very severe ME/CFS](#).

¹⁶ The [2023 ME Association Count ME In Survey](#) was completed by 7,303 people; 85% (6,208 people) had a diagnosis of ME/CFS, 10% (730) had a diagnosis of Long Covid, 5% (365 people) were undiagnosed but experienced the 4 core symptoms of ME/CFS. A Full and Independent Survey Report will soon be commissioned and made publicly available in early 2024.

¹⁷ Kingdon, C et al. [Functional Status and Well-Being in People with ME/CFS Compared with People with Multiple Sclerosis and Healthy Controls](#) (2018)

- The 2007 NICE Guideline¹⁸ said:

"CFS/ME is a relatively common illness. The physical symptoms can be as disabling as multiple sclerosis, systemic lupus erythematosus, rheumatoid arthritis, congestive heart failure and other chronic conditions. CFS/ ME places a substantial burden on people with the condition, their families and carers, and hence on society."

- The 2021 NICE Guideline¹⁹ said:

"Everyday life for people with ME/CFS, their family and carers is disrupted and unpredictable. Many people with the condition are unemployed, and less than a fifth work full-time. Approximately 25% have severe disease and are housebound or bedbound. The quality of life of people with ME/CFS is lower than that of many people with other severe chronic conditions, including multiple sclerosis and some forms of cancer."

b. Support for children and young people with ME/CFS

- No additional comments.

c. Provision of health services

i. National health campaign

- In order to help raise awareness of ME/CFS within and outside of the NHS and social care services, we would strongly recommend that NHS England consider ME/CFS for a national health campaign²⁰ and NHS Employers include the campaign (and ME Awareness Week) in its events calendar²¹.
- We understand that national health campaigns can reach not only healthcare professionals and people using the NHS but also schools, colleges, and universities.
- We would be very willing to contribute to such a campaign perhaps around ME Awareness Week in 2024 or 2025.
- A national health campaign on ME/CFS could aim to achieve some of the following, for example:
 - reduce any remaining stigma.
 - reduce any social isolation caused by having ME/CFS as a diagnosis and let people know they are not alone.
 - help people feel more confident about ME/CFS.
 - convey the reality of ME/CFS – what we know and don't know – and what can be done to help.
 - reach more people with symptoms or with a diagnosis and encourage them to visit their doctor and seek a referral to specialist services.
 - encourage people from ethnic minority backgrounds to recognise symptoms and visit their doctor.
 - encourage people with symptoms or a diagnosis to engage with the patient community to share experiences and benefit from peer support.
 - promote the recommendations in the NICE Guideline and availability of ME/CFS specialist services.
 - increase awareness and understanding among healthcare professionals.
 - increase awareness and understanding among employers and education providers.
 - enhance the experience of working in ME/CFS specialist services leading to increased recruitment and retention of key staff.

¹⁸ The 2007 NICE Guideline on ME/CFS (CG53): [Introduction](#).

¹⁹ The 2021 NICE Guideline on ME/CFS: [Context](#).

²⁰ NHS England: National [marketing campaign](#) partnerships, NHS [launches lifesaving sickle cell](#) campaign, NHS [partners with Morrisons to put vital cancer awareness messaging](#) on underwear labels.

²¹ NHS Employers: [Events calendar](#).

- promote professional training and information resources within the NHS and social care services.
 - provide a range of posters and information booklets about ME/CFS for use by GP surgeries, ME/CFS specialist services, and hospitals.
 - promote information and support services for people with ME/CFS provided by the charity sector.
- We have tried repeatedly in the last decade to get NHS England to hold a national campaign raising awareness of ME/CFS, but they did not engage with us. If the DHSC and NHS are serious about changing the situation for people with ME/CFS, then a national health campaign should be one of the Actions in this IDP.
 - With the Final Delivery Plan on ME/CFS being published in Spring 2024, we feel a national health campaign would be an excellent opportunity to raise awareness and reinforce the work that has been done since the Right Honourable Sajid Javid, MP, announced the Delivery Plan in May 2022.

ii. Delayed diagnosis

- For comments in regard to delayed diagnosis and appropriate support refer to the Introduction (g) above.

iii. Age of onset

“...but the majority of people with ME/CFS become ill between the ages of 20 and 40...”

- We suggest that rather than link this statement to an NHS website, it is further detailed and then qualified by links to published research.
- However, we suggest the following would be suitable language for the IDP:

“All ages, ethnicities, and social classes can be affected by ME/CFS. The most common age of onset is between 13 and 15 in children and between the early 20s and mid-40s in adults. It is rare for people below the age of 7 and above the age of 60 to attract a new diagnosis. ME/CFS has been shown to be a major cause of long-term sickness absence from school.”
- A large study from Norway²² found two peaks of onset: between the ages of 10-19 and 30-39, for example (other studies are available²³), and 2 studies²⁴ examined long-term sickness absence in schools.

iv. The NICE Guideline on ME/CFS

“NICE Guidelines are not mandatory but present the latest advice based on the available evidence.”

- We suggest that this sentence is replaced with a more encompassing and relevant description (based on the NICE Guideline on ME/CFS²⁵):

“While the NICE Guideline on ME/CFS is not mandatory, when exercising their judgement, professionals and practitioners are expected to take it fully into account, alongside the individual needs, preferences and values of their patients or the people using their service. Local commissioners and providers of healthcare have a responsibility to enable the guideline to be applied when individual professionals and people using services wish to use it.”

²² Bakken, IJ, et al. [Two age peaks in the incidence of CFS/ME: a population-based registry study from Norway 2008-2012](#) (2014).

²³ Rowe, et al. [Diagnosis and Management in Young People: A Primer](#) (2017).

²⁴ Dowsett & Colby. [Long-term sickness absence due to ME/CFS in UK schools](#) (1997). Crawley, et al. [Unidentified CFS/ME is a major cause of school absence: surveillance outcomes from school-based clinics](#) (2011).

²⁵ The NICE Guideline on ME/CFS (NG206): [Your responsibility](#).

- A major defect in the Interim Plan is the failure to draw attention to the problems that are occurring in relation to implementation of the recommendations in the NICE Guideline on ME/CFS.
- The ME Association is being very active in contacting clinical leads, chief executives, and health service commissioners to draw attention to failures with existing ME/CFS specialist services. In particular:
 - inadequate or no provision for people with severe and very severe ME/CFS.
 - the failure to create any new specialist services in parts of England (and in Wales, Northern Ireland and Scotland) where none currently exist.
 - dated website information and inappropriate language in existing specialist service descriptions.
- This postcode lottery is unacceptable and has been occurring for decades. It is not something that can be left to the charity sector to resolve.
- The DHSC, NHS England, and each of the 42 Integrated Care Boards (ICBs) need to take prompt action to ensure that effective implementation of the NICE Guideline is taking place and that existing ME/CFS specialist services are improved – and new services created – to provide appropriate and tailored support to the patient population including, in particular, people with severe or very severe ME/CFS who are the most vulnerable.
- We don't feel the IDP goes far enough in this regard.
- **The 2023 ME Association Count ME In Survey²⁶ asked about the NICE Guideline:**
 - Results indicated that there hasn't been any noticeable improvement in NHS or social care support or service provision since publication of the NICE Guideline on ME/CFS in 2021.
 - 72% of those with ME/CFS were aware of the NICE Guideline, but 65% stated they had not noticed a difference in healthcare support.
 - People with a diagnosis reported having to inform and educate their healthcare providers about the Guideline's recommendations and said that there is much work still to be done if we are to see an overall improvement in healthcare support.
 - There are no practical guidelines for professionals to follow that interpret the Guideline's recommendations and there is a lack of empathy and understanding about how great an impact ME/CFS can have on day-to-day activities.
 - The top recommendations to improve the NICE Guideline were:
 - specific guidance for healthcare professionals to enable practical application of the recommendations.
 - clarity about the fluctuating nature of ME/CFS and the impact on a person's ability to engage in activities of daily living.
 - empathy: introduce 'lived experiences' to the Guideline so that professionals can better understand the impact of this medical condition and the need to tailor care accordingly.
 - introduce a wider range of symptoms and a better understanding of how ME/CFS can interplay with other conditions such as allergies and the impact it can have on mental health.
- **The 2023 ME Association Count ME In Survey asked about NHS ME/CFS Specialist services:**
 - Experiences were more positive, with 47% of those with ME/CFS having used a hospital-based service. Overall, 42% felt the service provided was good or excellent.
 - Those diagnosed in the last few years were likely to have received support from a specialist service for information and/or a diagnosis. However, many people that had lived with ME/CFS for longer did not receive **any** NHS support at all.

²⁶ The [2023 ME Association Count ME In Survey](#) was completed by 7,303 people: 85% (6,208 people) had a diagnosis of ME/CFS. 10% (730) had a diagnosis of Long Covid. 5% (365 people) were undiagnosed but experienced the 4 core symptoms of ME/CFS. A Full and Independent Survey Report will soon be commissioned and made publicly available in early 2024.

- 29% of those with ME/CFS that hadn't used a specialist service said it was because there wasn't one nearby.

v. Severe and very severe ME/CFS

- There is very patchy – at best – provision of healthcare services for the people who are most affected by ME/CFS.
- Very few existing specialist services are commissioned to provide the kind of help to those severely and very severely affected that is recommended in the NICE Guideline.
- It shouldn't be the case that family members representing the most vulnerable must fight to receive health or social care support. This doesn't happen with other long-term conditions that seem to be taken more seriously.
- The IDP could reverse this situation if the DHSC directed NHS England and ICBs to commission specialist services to provide care and support to the most severely affected and if local authorities were directed to provide specific training to social care professionals and make social care more easily accessible.
- Whilst we acknowledge that there are several short references to severe and very severe ME/CFS in the IDP it is very disappointing to find that this subject does not have its own section.
- The NICE Guideline committee recognised the importance of addressing severe and very severe ME/CFS, and the IDP should do the same. We need to ensure that the worst affected receive the best possible care and support.
- Chapter 1.17.1 of the NICE Guideline²⁷ should be the basis for a separate section in the IDP with appropriate Actions created that recognise the needs of people with severe and very severe ME/CFS who are in need of NHS and social care services.

vi. Integrated Care Boards (ICBs)

“The formation of integrated care boards...”

- We think this paragraph should be amended and based on the Kings Fund explanation²⁸ to read:

 “The formation of Integrated Care Systems (ICSs) provides a new opportunity to better co-ordinate care across various parts of the health and social care system.

 “There are 42 ICSs covering populations of between 500,000 to 3 million people in England. ICSs are partnerships that bring together NHS organisations, local authorities and others to take collective responsibility for planning services, improving health and reducing inequalities.

 “Integrated Care Boards (ICBs) are a key part of an ICS. They allocate the NHS budget and commission services for the population, taking over the functions previously held by clinical commissioning groups (CCGs) and some of the direct commissioning functions of NHS England.”

vii. Impact: how we will know when this interim delivery plan has delivered on health services

We will know that the provision of health services has improved when the following conditions are in place:

- We recommend the following condition is included:

²⁷ The 2021 NICE Guideline on ME/CFS (NG206): [Care for people with severe or very severe ME/CFS](#).

²⁸ The Kings Fund: [Integrated Care Systems Explained](#).

"Existing ME/CFS specialist services have been reviewed and new services commissioned that are compliant with the NICE Guideline on ME/CFS and provide equal access to specialists for children and adults of all illness severities regardless of where a person might live. At the point of discharge, continuity of care should be a priority and care and support plans should be in place and responsibility for regular patient review and follow-up passed to a designated GP and/or social care provider. Each specialist service will offer remote access and home visits to people with ME/CFS for whom travel to a local service is not possible or is ill-advised."

d. Provision of adult social care

i. Implementing the Care Act

- We suggest that reference is made to Implementing the Care Act for People with Fluctuating Long-term Conditions²⁹. This was a collaborative guide produced by the ME Association, Action for M.E. and other charitable organisations.

ii. Social care experiences

- **The 2023 ME Association Count ME In Survey asked about Social Care experiences:**
 - Relatively few (10% of those with ME/CFS) received any social care support.
 - Those that did were most likely to have had a successful care needs assessment, adaptations made to their home, or been provided with disability aids.
 - Those with ME/CFS were less satisfied with social care provision than with NHS specialist services. 27% said they had a good or excellent experience.
 - Those with Long Covid reported excellent support and communication but there were significant challenges. 38% said they had a good or excellent experience.

e. Provision of welfare support

- This section is not satisfactory as it reads more like an item of promotional material for what the DWP wants to achieve in general.
- It fails to recognise the very real difficulties that many people have in relation to staying in work and leaving work because of ME/CFS, and when making applications for disability-related benefits – ESA/UC, PIP etc. – and being refused.
- It fails to recognise the very real difficulties that many people with ME/CFS experience when applying for disability aids and adaptations, local authority Blue Badge parking, and disabled bus passes.
- Of all the sections in the IDP we feel this one least reflects what was discussed in the working group meetings and has too much emphasis on returning to or remaining in work which is just not possible for many people.
- People with ME/CFS want to work. There has never been any question about their motivation. But most people cannot work or have limited capability to work because of the functional limitations and disability caused by ME/CFS.
- The 2021 NICE Guideline³⁰ on ME/CFS said, for example:

"Many people with the condition are unemployed, and less than a fifth work full-time. Approximately 25% have severe disease and are housebound or bedbound."
- A research study³¹ from 2018 revealed that:

"Six months before illness onset, the profiles of hours of study and work for people with

²⁹ [Implementing the Care Act for People with Fluctuating Long-term Conditions](#) (2015)

³⁰ The 2021 NICE Guideline on ME/CFS: [Context](#).

³¹ Kingdon, C et al. [Functional Status and Well-Being in People with ME/CFS Compared with People with Multiple Sclerosis and Healthy Controls](#) (2018).

ME/CFS and people with Multiple Sclerosis were similar, suggesting that prior to disease onset people in both disease groups were equally active in work and study. Moreover, the pre-illness profiles were similar to those of the Healthy Controls.

"Disease onset had a greater impact on employment among people with ME/CFS than among people with MS, in both working status and number of hours worked. While over 89% of people with ME/CFS had been employed before disease onset, this reduced to 35% after illness onset, which compares with 93% of people with MS before and 60% of people with MS after disease onset."

- We don't feel the message has been taken on board or the reality of the situation conveyed in the IDP. We would like to see far more weight given to supporting people who are unable to work and who need welfare benefits to help them cope with unemployment and the extra costs of being disabled.
- If the DHSC feels that it does not have any evidence relating to the difficulties that people with ME/CFS face when obtaining benefits, evidence can be found in the APPG on ME Report: Rethinking M.E.³², Minutes for meetings of the Forward ME Group³³ – where we have met with representatives from organisations that carry out DWP assessments – and a summary of an APPG on ME meeting in 2019 with Justin Tomlinson, MP, a former DWP Minister³⁴.
- We would like the IDP to specifically mention the welfare support available to unpaid carers. Although mentioned, the focus in this section of the report is on people with ME/CFS. While we feel the benefits available to unpaid carers are inadequate and the qualifying criteria too strict, we know that many carers are not aware of – or accessing the support – that is available.
- We have reservations about the DWP decision to remove Work Capability Assessments for people on UC/ESA (we also think the announcement in the IDP is premature) and will be responding to the current Government consultation on The Work Capability Assessment in due course.

f. Provision of employment support

- We would suggest that the problems extend to supporting people with ME/CFS and their unpaid careers to reduce working hours and to leave work because of limited capability and caring responsibilities and suggest this is included in the Problem Statements.
- One of the most popular items of literature that we produce as a charity is titled 'Employment Issues and ME/CFS'³⁵. It is also one of the most detailed booklets. There is a clear demand for information and support that relates to people having to leave work completely or in part or make adaptations to the way they worked previously in order to return to the workplace as disabled individuals.
- Best practice
 - It would be useful if the DWP included behaviours and actions from employers that also relate to having to leave work because of ill-health and disability, and when trying to negotiate ill-health early retirement.
 - Providing information about how an employer can assist someone with ME/CFS in terms of knowing their rights, having to reduce hours, work more flexibly, take sick leave, or leave work, without feeling unduly pressured, would be helpful.
 - It has become increasingly difficult trying to navigate the many hurdles now in place to achieve ill-health early retirement and obtain a disability pension. Guidance for employers and pension providers in relation to ME/CFS specifically, and long-term fluctuating conditions more generally, would be very welcome.

³² The 2022 APPG on ME Report: '[Rethinking M.E.](#)'.

³³ Forward-ME: [Meeting minutes](#).

³⁴ The ME Association: [Meeting with Minister raised important concerns about welfare benefits for people with ME](#) | 26 June 2019.

³⁵ The ME Association: [Employment Issues and ME/CFS](#) (December 2022).

- Income protection insurance
 - As mentioned in the APPG on ME Report: Rethinking M.E.³⁶, there should also be reference in the IDP to the problems faced by people with ME/CFS who try to make a claim on insurance-based income protection policies.
 - Like ill-health early retirement, the hurdles now in place from insurance providers and the lack of awareness and understanding about ME/CFS can mean that claims are not approved which means an even greater dependence on disability benefits.

5. Agreed Actions

- **Which Actions are aimed at improving QoL and Health Services?**
 - It is not clear from the IDP which of the Agreed Actions will be aimed at improving Quality of Life and Health Services for people with ME/CFS. These were both central issues raised by the Living with ME/CFS working group. If the DHSC feels that the Actions shown *will* have a positive impact in these areas, then it would be helpful if they were clearly indicated.
 - In section 4 (c) above, we recommended an additional condition be included that would improve health services and could lead to improved quality of life of people with ME/CFS.
 - We strongly suggest that it is developed into an Agreed Action and specific funding is made available to carry out these necessary improvements (as it was in 2003 when the network of ME/CFS specialist services were created by the Department of Health and more recently when NHS England provided central funding to establish Long Covid Clinics).

For example:

Agreed Action: Health Services

"The DHSC and NHS England will provide central funding and direct ICBs to complete a review of and improve existing ME/CFS multi-disciplinary specialist services to ensure they are appropriately resourced to meet local demand and are compliant with the 2021 NICE Guideline on ME/CFS. New specialist services will be commissioned in areas where no services currently exist. ICBs and specialist services will work with local people and routinely involve them in any decisions about local service provision. The NHS care pathway, clinical approach, literature and website information will be standardised and compliant and subject to regular review. All specialist services will provide equal access to children and adults with suspected or confirmed ME/CFS and provide suitable and tailored services to all illness severities. At the point of discharge from a specialist service, ICBs will ensure that continuity of care is a priority – that care and support plans are in place – and responsibility for regular patient reviews and follow-ups will be passed to a designated GP at the patient's surgery and/or a social care provider. All patients will be able to seek additional referrals to specialist services as required. Specialist services will be commissioned to provide remote access and home visits to people who are physically unable to travel, and hospitals and GP surgeries will be directed to provide extra and appropriate care for people who are severely or very severely affected and who require in-patient or primary care support. Deadline: End 2024."

- In England, while we have a very much appreciated network of ME/CFS specialist services, there doesn't appear to be any central guidance in place, and individual services seem to operate independently. This means that, for example, the management advice a person receives can differ depending on which service they are referred to and the specialisms of the staff employed. The same is true of service literature and website information. BACME is making strides in trying to bring specialist services and the staff who work in them together and should be supported in their efforts by the DHSC and NHS England. But the situation is clearly unsatisfactory as it can affect the quality of care and support a person receives.

³⁶ The 2022 APPG on ME Report: '[Rethinking M.E.](#)'.

- Specialist services that are provided by – or commissioned by – the NHS and ICBs should be operating in concert with one another. The 2021 NICE Guideline and the DHSC Delivery Plan provide a valuable opportunity to improve services across the country and ensure the care provided is the very best it can be. It would be extremely disappointing if this opportunity was wasted, and we would very much welcome an announcement about additional funding for the improvement of existing – and the commission of new – specialist services in England.
- We asked questions (Executive Summary (b) above) about the Care Quality Commission and whether it might be engaged to review ME/CFS specialist services and their compliance with the NICE Guideline recommendations. Such monitoring might also improve health services and lead to improved quality of life.
- The ME Association has engaged Professor Sarah Tyson, Dr Keith Geraghty, Dr Pete Gladwell, other ME/CFS clinicians, and people with ME/CFS, to complete a research project that will create a series of Patient Reported Outcome Measures for ME/CFS that we hope can be used by all specialist services in England. Such monitoring will help improve specialist service performance and the experience of people who are referred to them.

I. Research

- We strongly agree with the Actions proposed in this section, subject to the comments made above (section 2 (a-d)).

II. Attitudes and education of professionals

- We strongly agree with the Actions proposed in this section, subject to the comments made above (section 3 (a-c)). However:
- **Action 8:** We understand that there will be 3 e-learning CPD modules made available. We were represented at the first meeting this week with Dr David Strain and representatives from NHS England.
- We were concerned that the funding available for what is a key action is very limited. A successful series of e-learning modules can really help improve attitudes and education about ME/CFS.
- Funding restrictions should not be permitted to limit the scope of this project, and we would urge the DHSC and NHS England to release more funding as soon as possible.
- We hope that this first major development to come from the Delivery Plan is not a sign that the Government is unwilling to commit adequate levels of funding to solve the acknowledged problems in ME/CFS.
- **Action 9:** The deadline of the end of March 2024 is unacceptable.
- It has already been 2 years since the NICE Guideline was published. Updates to the central NHS webpages should have happened before now – and their development should not require a DHSC Delivery Plan Action.
- The ME Association would be happy to work with NHS England and the NHS Health at Work Network on a suitable update to their websites for ME/CFS and we think a deadline of December 2023 would be more reasonable.

III. Broader actions to improve awareness and understanding

- We strongly agree with the Actions proposed in this section and would refer DHSC and NHS England to the suggestion of a national health campaign in section 4 (c) above in regard to Action 16.

IV. Improving statutory support

- We strongly agree with the Actions proposed in the section.

6. Next steps

- We welcome the Actions proposed in this section and would be very happy to be part of the Research Working Group and the new ME/CFS Delivery Group.
- Please get in touch and let me know how we can help:
Russell.fleming@meassociation.org.uk
 Head of Communications, The ME Association.

7. Use of language in ME/CFS

I. Chronic fatigue as a symptom of ME/CFS.

- We are very aware that the comments shown in regard to chronic fatigue and chronic fatigue syndrome have led to misleading, erroneous, and discriminatory messages about the nature of ME/CFS.
- 'Chronic fatigue' is a symptom of many medical conditions. The NICE Guideline defines the related symptom as:
 "Debilitating fatigue that is worsened by activity, is not caused by excessive cognitive, physical, emotional or social exertion, and is not significantly relieved by rest."
- A common interpretation of this symptom might be 'chronic exhaustion', but this doesn't convey just how debilitating it can be in ME/CFS. We suspect that most people who are asked to describe the symptom will use similar language, but then put it in context of their own experience e.g.:
 "I have a medical condition. It feels like I have the Flu and I am often exhausted. Sleep doesn't seem to help very much, but I can't seem to stay awake for long. I suffer from other symptoms as well that mean I have problems with my memory, concentration, and communicating. I can't walk very far. I am not able to do the kind of activities I could do before or in the same way, and I have to carefully use my limited energy."

II. Recovery from ME/CFS.

- Improvement is a better word than recovery.
- Improvement is possible. It should relate to a relative improvement in functional ability. The fluctuating nature of ME/CFS means that improvements can be short-lived, and an individual is likely to experience many improvements and setbacks or relapses over the course of their illness. Sustained improvement is the goal and preferably over a long period.
- Rehabilitation would be another word that attracts different interpretations and requires a specific definition in the context of ME/CFS. The World Health Organisation³⁷ has made rehabilitation a priority and explains it as follows:
 "Rehabilitation helps a child, adult or older person to be as independent as possible in everyday activities and enables participation in education, work, recreation and meaningful life roles such as taking care of family. It does so by working with the person and their family to address underlying health conditions and their symptoms, modifying their environment to better suit their needs, using assistive products, educating to strengthen self-management, and adapting tasks so that they can be performed more safely and independently. Together, these strategies can help an individual overcome difficulties with thinking, seeing, hearing, communicating, eating or moving around."
- There are of course people with ME/CFS who believe themselves recovered, and this should be welcomed, and their experiences embraced, but we don't have much insight into what

³⁷ The World Health Organisation: [Rehabilitation](#).

might have contributed to their improved status or for how long they remain in this recovered state.

III. **ME/CFS as a mental health condition.**

- ME/CFS is not a mental health condition. It is a complex neurological condition that limits a person's ability to initiate or complete normal everyday activities.
- Any medical condition can have an impact on an individual's mental health, but especially one that is poorly understood, can't be proven by a blood test, and has historically attracted a devastating and erroneous stigma.
- We are all conditioned to recover relatively quickly from e.g., an infection, or to be effectively treated by 'modern medicine' so when we are unable to recover fully in a short timeframe and conventional testing doesn't reveal a quantifiable problem, doubt can become an issue. The individual can question their own symptoms as can professionals and wider society.
- People with ME/CFS need to be treated holistically, just as people with Multiple Sclerosis and other neurological conditions are treated holistically. Conditions that affect functional ability and can have such a devastating impact on people's lives can understandably cause mental health challenges.
- We need to change the conversation and focus on improved education and understanding. The old stigma associated with ME/CFS is in decline. The 2021 NICE Guideline has helped, as will the Actions in the DHSC Delivery Plan on ME/CFS, and we are hopeful that future research will as well.

IV. **Lack of medical tests.**

- ME/CFS is not a diagnosis of exclusion. The 2021 NICE Guideline has made diagnosis much clearer, and the impact of the condition is now easier to understand.
- ME/CFS is not the only medical condition that doesn't have a specific blood – or other – test.
- It is equally important that a patient receives a thorough examination and review of their medical history. The impact of symptoms on functional ability should be considered.
- Medical professionals should carefully consider what they say when reporting that testing has not revealed other contributory health conditions. Patients are just as likely to want a positive test result.
- Expectations should be managed appropriately, and language carefully considered, as the wrong language at this early stage can damage ongoing relationships and lead to a breakdown in trust.
- Lack of positive testing for other conditions should be viewed positively, as it can help confirm ME/CFS as the primary concern and allow medical professionals to concentrate their efforts on supporting the patient in the best possible way and by referring them to an ME/CFS specialist service.

V. **No obvious signs.**

- We would argue that while ME/CFS is 'invisible' to an extent, the impact of the condition can be very visible.
- People are no longer able to engage in normal everyday activities; they are limited in what they can do. They may be unable to take care of themselves. They can be unable or restricted in their ability to walk. Their cognition and ability to communicate can be affected. They might have to avoid a social life.
- The impact of ME/CFS might be most visible to family and friends but should be visible to GPs who have known the person for a long time, and to work colleagues – if the person has been able to remain in work or has returned to work.

- There are many other medical conditions for which there are no obvious signs, rheumatoid arthritis, fibromyalgia, diabetes, celiac disease, lupus, Sjogren's syndrome, migraines, Crohn's disease, and mental health conditions, for example.
- Greater awareness and understanding continues to improve experiences for people with these 'invisible' medical conditions and for people with ME/CFS.

VI. Using pacing to manage energy.

- Pacing is about prioritising the activities an individual is able, needs, or wants to do, within the limits of their available energy, that does not cause an increase in symptoms or lead to a crash or relapse.
- Pacing is not limited to ME/CFS but is used by people with Long Covid, Multiple Sclerosis and Sleep Apnea, for example, and other conditions where limited energy needs to be carefully managed.
- Increased awareness and understanding about the impact of ME/CFS and how it can significantly reduce a person's ability to initiate or complete everyday activities will continue to reduce any associated stigma and inappropriate comments.
- Greater awareness of other fluctuating medical conditions where effective management includes pacing will improve societal understanding.

VII. Post-exertional malaise.

- Post-exertional malaise can be a hard symptom to understand if you don't have ME/CFS.
- "If I do too much physically or mentally on one day, I can feel a lot worse the next day or the day afterwards and might experience a setback or relapse. So, I try and pace my activities to try and avoid making my symptoms worse. This means I have to carefully consider the activities I can do, and it will likely take me longer to start or finish them."

END