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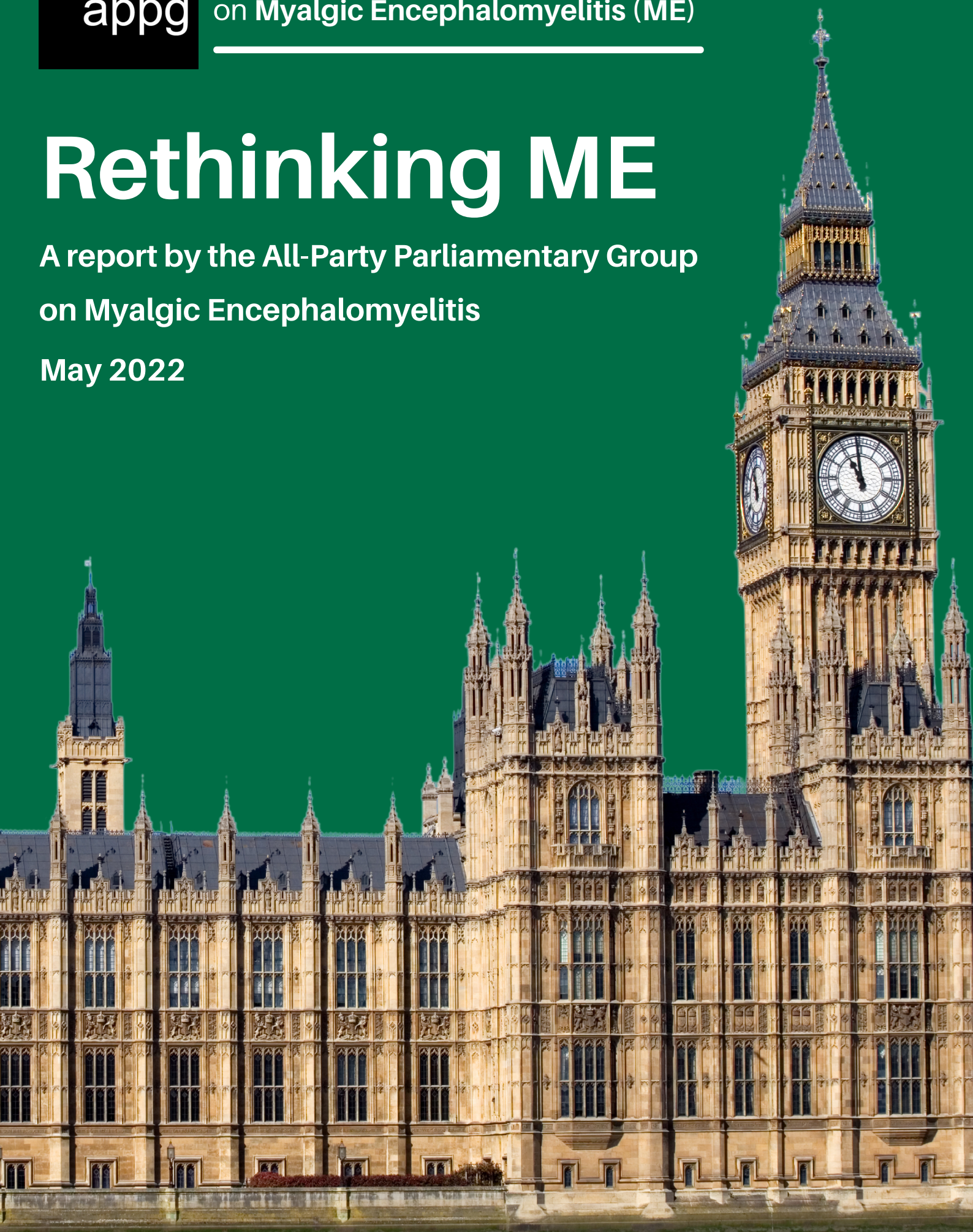
All-Party Parliamentary Group
on **Myalgic Encephalomyelitis (ME)**

Rethinking ME

A report by the All-Party Parliamentary Group on Myalgic Encephalomyelitis

May 2022



About the All-Party Parliamentary Group on Myalgic Encephalomyelitis (ME APPG)

Purpose:
To seek to improve health, social care, education and employment opportunities for people with ME and encourage biomedical research into the cause and treatment of ME.

APPG Officers:

Chair & Registered Contact: Carol Monaghan MP

Co-Chair: Baroness Finlay of Llandaff (recused)

Co-Chair: Baroness Scott of Needham Market

Co-Chair: Sharon Hodgson MP

Co-Chair: Stephen Metcalfe MP

Officer: Debbie Abrahams MP

Officer: Fleur Anderson MP

Officer: Dr James Davies MP

Officer: Ben Lake MP

Officer: Jason McCartney MP

Officer: Hywel Williams MP

APPG Secretariat:

Action for M.E.

The ME Association

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Foreword

Carol Monaghan, MP for Glasgow North West

Chair of the All-Party Parliamentary Group on Myalgic Encephalomyelitis

As far back as the 1930s, cases have been documented of individuals presenting with a spectrum of symptoms that have been difficult to attribute to a particular condition. For many of those affected, these symptoms - most notably, profound fatigue and pain, cognitive dysfunction, headaches and post-exertional malaise - appeared after a viral infection. In the 1950's the term myalgic encephalomyelitis, or ME, was coined to describe this debilitating condition.

Although there is now a well-documented history of ME, progress in treatment has been hampered by a number of factors, including the outdated opinions of some influential psychiatrists and other healthcare professionals. Many people with ME have described the treatment they have received as exacerbating their symptoms, and some report such a decline in their health that they are now bed-bound following medical intervention.

Prior to my election in 2015, I had little knowledge of ME. If pressed, I would have given a basic response that it was a condition causing tiredness and lack of energy. The tenacity of my constituents in sharing their compelling testimonies ensured that my understanding was improved. Many other MPs have become involved in the APPG following similar interventions by their constituents, and I commend the ME community and charities on the work they have done in mobilising politicians from every political party to campaign for better outcomes.

Within healthcare, attitudes are slowly shifting, but it is clear that radical action, including mandatory education for relevant health professionals, is needed to ensure appropriate medical intervention and care. This must be coupled with far greater spending on high quality biomedical research. The new NICE guideline on ME/CFS, published in 2021, has the potential to transform approaches to ME, and patient groups and charities will be watching closely to see its impact.

The APPG on ME spent over a year taking evidence from patients, healthcare professionals and charities to produce this report. Our recommendations are considered the starting position for Government policy, and I hope these are taken seriously by those with the power to make positive change.

Foreword

Margaret Mar, Countess of Mar

Former member of the House of Lords and founder of Forward-ME

In 2006 I was a member of the Group on Scientific Research into Myalgic Encephalomyelitis (ME) when the late Dr Ian Gibson chaired an inquiry into the status of CFS/ME and research into causes and treatment. I have been saddened to read in this current report much the same as we heard and read from witnesses in 2006. There seemed to be little progress in 15 years. All is not lost, however.

Parliamentary interest and activity have increased considerably in the past three years thanks to the wholehearted interest of Carol Monaghan MP who has devoted much of her time to encouraging other MPs to come forward on behalf of those of their constituents who suffer from ME. Her active advocacy on behalf of people with ME has been remarkable. Under her leadership the APPG has been revitalised and people with ME are trusting her.

The Inquiry looked at 5 areas that are important to people with ME. Witnesses bore testament to the neglect that had persisted for years in biomedical research and research funding. They highlighted the absence of prompt and accurate diagnosis, the ineffectual and sometimes dangerous management of the illness with graded exercise therapy (GET). As they heard, children and young people had a consistently raw deal which led to a loss of education and a social life. The biopsychosocial model of the illness has prevented many people with ME from obtaining welfare and health insurance-based benefits.

The Report makes a number of very important action points that can no longer be ignored. It must not be left to gather dust as so many APPG reports do, for it makes an important contribution to the thrust of the new NICE guideline on ME/CFS in that the Report reinforces the guideline statements that ME is a physiological disease and people with ME should be listened to and respected. This is the time for a surge of progress and collaboration that must be to the benefit of all living with and working for ME.

Executive Summary

Myalgic Encephalomyelitis (ME), also sometimes referred to as Chronic Fatigue Syndrome (CFS), is a profoundly debilitating, chronic condition that affects multiple systems within the body. [1]

The physical symptoms of ME, such as extreme pain, post exertional malaise, and cognitive dysfunction, make ME "as disabling as multiple sclerosis, systemic lupus erythematosus... and other chronic conditions". [2] Consequently, people with ME require high levels of service provision to be able to manage their condition well and live the lives they wish to. [3]

This report looks at key areas of service provision where sensitivity to the nature of ME is required. These areas were investigated over the course of five APPG evidence sessions and in further correspondence with ME patients and relevant stakeholders:

(1) Biomedical Research and Research Funding
(2) Condition Diagnosis, Symptom Management and Medical Services
(3) Children and Young People with ME
(4) Welfare and Health Insurance-based Benefits
(5) COVID-19 and the ME community.

Across each area, the ME APPG discovered that a lack of understanding of the physiological nature of ME, and the challenges faced by people with ME, is widespread amongst health professionals and the general public. At present, many services fall short of the standard required to ensure that people with ME can access a prompt and accurate diagnosis and effective condition management. Misunderstandings and a lack of consensus on how to define and categorise the condition compound the medical challenges faced by people with ME and further hinder access to support in areas including social care, welfare, education and employment.

The removal of GET as a treatment for ME is a particularly meaningful step for the ME community.

The recent publication of the new National Institute for Health and Care Excellence (NICE) guideline on ME/CFS has the potential to bring about noteworthy progress with regards to medical care for people with ME. The removal of graded exercise therapy (GET) as a treatment for ME is a particularly meaningful step for the ME community. This decision followed many years of campaigning by people with ME who called out the detrimental effects of GET despite opposition from an influential minority within the medical profession.

It is evident that the voice of the ME community is beginning to be heard within health policy and decision-making. This development comes at a time when, amongst the general public, there is a new appreciation of what it is like to live a life in lockdown and a growing awareness of long COVID, a condition which significantly overlaps with ME. These factors have contributed to a growing momentum for transformation in the way that people with ME are treated in the UK.

Whilst the release of the new NICE guideline brings the prospect of meaningful change for people with ME, we have seen with other conditions, such as endometriosis, that a positive revision of the NICE guideline does not necessarily result in swift positive change to the standards surrounding condition diagnosis, treatment, and management[4]. Therefore, the ME APPG is seeking a firm commitment from the NHS, UK and Devolved Governments that the new NICE guideline on ME/CFS will be swiftly adopted and implemented in full across the UK.

To ensure full implementation of the guideline recommendations, the ME APPG recommends that the UK and Devolved Governments each facilitate a comprehensive review of the adequacy of ME service provision falling within their jurisdiction.

The ME APPG recognises that even though the new NICE guideline goes some way to improving quality of life for people with ME, there are further issues that people with ME experience which the guideline does not, and cannot, address given its sole aim is to set out foundational principles for medical care. People with ME require major cultural and policy change to take place within all professions associated with their care and support. Accordingly, the ME APPG recommends that strategies are developed in each of the four UK nations to transform our society's approach to ME. The APPG also makes a series of supplementary recommendations which are summarised on page 8 and expanded upon in further detail within Chapters 1 - 5.

Summary of Recommendations

Executive Summary	**1**) The UK and Devolved Governments must each conduct a comprehensive review of current ME service provision with a view to implementing the new NICE ME guideline recommendations in full and creating strategies to transform the approach towards ME in health, welfare, social care, research and education.
Chapter 1: Biomedical Research and Research Funding	**2**) Coordinated research strategies must be developed to encourage high quality ME research. **3**) Government research bodies should ensure that there is a parity of biomedical funding between ME and other serious long-term conditions. **4**) Centres of ME research excellence should be established to drive forward the development of effective treatments.
Chapter 2: Diagnosis, Symptom Management and Services	**5**) Health professionals should follow the new NICE guideline for ME and ensure that ME patients do not undergo any form of GET. **6**) Updated ME medical training should be provided by the Royal Colleges and medical schools to relevant health professionals and students. **7**) Health service commissioners should review the adequacy of current ME services and take steps to ensure that service provision is carefully planned, resourced, and implemented. **8**) People with severe and very severe ME should be provided with a care package based on the basic care principles detailed in the new NICE guideline.
Chapter 3: Children and Young People with ME	**9**) Health commissioners should ensure that all children and adolescents with ME have access to correctly trained hospital paediatricians and long-term community services. **10**) The Royal College of Paediatrics and Child Health (RCPCH) should ensure that all paediatricians receive specialised training on recognising, diagnosing and managing ME in children and adolescents. **11**) An independent second medical opinion obtained by a parent or guardian of a child with suspected or confirmed ME should be fairly considered in any decisions regarding diagnosis, treatment or welfare. **12**) The Chief Social Worker (or equivalent in the devolved nations) should ensure that the guide for social workers working with children and young people with ME or suspected ME (developed by social workers in partnership with Action for M.E.) is shared with all social care departments.[5] **13**) Children and young people with ME should have a care plan, in accordance with national guidelines and/or statutory requirements, combining education and health. **14**) Schools, colleges and higher education institutions should make learning and assessment modifications for students with ME.

Chapter 4: **Welfare and Health insurance-based Benefits**	**15**) The Department for Work and Pensions (DWP) should ensure that people with ME have equitable access to welfare benefits by taking steps to (1) account for the impact of ME on the ability to engage with the application process and (2) minimise potential negative health effects associated with medical assessments. **16**) Health insurers should not require people with ME to undertake GET, CBT or health assessments that require levels of activity which could produce adverse health effects.
Chapter 5: **COVID-19 and the ME Community**	**17**) Long-term health planning should consider the high number of individuals experiencing long COVID following a COVID-19 infection. **18**) Health service commissioners should ensure that there is cooperation ME and long COVID clinics to maximise patient benefit. **19**) Long COVID research projects should include ME patients as a comparative group. **20**) Further publicly funded biomedical and clinical research should be commissioned to investigate and compare a range of post-viral conditions, including ME.

Introduction

Several of the most pressing issues impacting the lives of people with ME - from medical treatments to welfare benefits - have been discussed during four landmark parliamentary debates spearheaded by the Countess of Mar and Carol Monaghan MP:

(1) "PACE Trial: CFS/ ME", House of Lords, 6 February 2013
(2) "PACE Trial: People with ME", House of Commons, 20 February 2018
(3) "ME: Treatment and Research", House of Commons, 21 June 2018
(4) "Appropriate ME Treatment", House of Commons, 24 January 2019.

The work programme of the ME APPG has endeavoured to build on these debates by seeking to improve health, social care, education, and employment opportunities for ME sufferers and encourage biomedical research into the cause and treatment of ME.

Our Inquiry

The ME APPG conducted an inquiry to gather further evidence on the challenges impacting people with ME in relation to a number of key areas of service provision:

(1) Biomedical Research and Research Funding
(2) Condition Diagnosis and Management
(3) Children and Young People with ME
(4) Welfare Benefits and Health Insurance
(5) Covid-19 and the ME Community.

These topics were investigated over the course of five APPG evidence sessions and in further correspondence with ME patients and relevant stakeholders.

The purpose of this report is to:

- Collate the evidence presented to the ME APPG during the formal inquiry by experts (including health professionals, researchers, and social workers) and people with direct experience of ME.

- Identify and demonstrate the primary issues in the five key areas outlined and make recommendations to improve the lives of people with ME living in the UK.

- Start a dialogue with the UK Government, Devolved Governments and other key stakeholders to develop novel approaches to ME in research, medical care, social care, and wider society.

Background

Myalgic Encephalomyelitis (ME), also sometimes referred to as Chronic Fatigue Syndrome (CFS), is a "serious, chronic, complex, and multisystem disease that frequently and dramatically limits the activities of affected patients", causing significant functional impairment, ill-health and disability.[6] The physical symptoms associated with ME include activity-induced muscle fatigue, pain, cognitive dysfunction, problems with the regulation of pulse and blood pressure (dysautonomia), the inability to sustain physical and mental activity, and post-exertional malaise. These symptoms are "as disabling as multiple sclerosis, systemic lupus erythematosus, rheumatoid arthritis, congestive heart failure and other chronic conditions".[7]

It is estimated 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".[8] The onset of ME is most common in the 20 to 50 age group. However, anyone can develop ME, including children and adolescents,[9] and in an epidemiological study ME was shown to be the most common cause of pupil long-term sickness absence from surveyed UK schools.[10]

ME can adversely impact on a person's ability to carry out everyday activities, and many adults of working-age with ME are unable to undertake full-time employment. Therefore, people with ME require targeted service provision, including health and social care.[11] Research by 2020 health has shown that, when lost taxes, welfare benefits, and health and social care costs are considered, "the total cost to the UK economy of ME in 2014/15 was at least £3.3 billion".[12]

For many years, several prominent medical professionals have asserted incorrectly that there is nothing biologically abnormal in people with ME, as standard biomedical testing has not uncovered abnormalities.[13] However, there is now robust scientific evidence involving a variety of advanced biomedical testing procedures demonstrating the presence of fundamental biological abnormalities in people with ME. These abnormalities are related to defective cellular energy production and the dysfunction of the immune, hormonal and neurological systems.[14] As such, the World Health Organisation (WHO), has classified ME as a neurological disease,[15] and this classification has been accepted by the National Health Service (NHS).[16]

Even though the exact causes of this complex multi-system disease are yet to be identified, the most widely reported triggers for ME are viral infections or other immune system stressors.[17] Some individuals may have a genetic predisposition to ME, as the disease has been known to affect several members of the same family.[18]

The prognosis for people with ME is very uncertain. Currently, a complete and sustained recovery is rare in adults with ME.[19] However, the outlook for children and adolescents is generally better.[20] Most people will experience a degree of improvement over time and then stabilise at a lower level of functioning than before the onset of their illness. A substantial proportion will also follow a fluctuating course with periods of relative relapse and remission.

Around 25% of people with ME are severely or very severely affected to the extent that they are bedbound or housebound at some stage during their illness pathway, with some becoming permanently disabled.[21] Those with severe or very severe ME are often neglected in relation to NHS services and social care. This group experience isolation, neglect, a lack of understanding and major barriers to accessing support.[22]

In terms of research into the underlying pathology of ME and potential treatments, there has been a serious under-funding of ME research in comparison with other long-term disabling conditions.[23] As a result, progress in understanding the underlying causes of ME and the development of biomedical treatments has been delayed. This delay has been compounded by the unnecessary emphasis on a small number of flawed but influential studies, such as the Pacing, Graded Activity, and Cognitive Behaviour Therapy; a Randomised Evaluation (PACE) Trial, which sought to confirm a psychological cause of ME and a beneficial effect for behavioural forms of treatment, such as GET.[24] These behavioural studies have now been widely discredited, with NICE concluding that evidence supporting the use of GET is of low or very low quality with a high degree of bias.[25]

The United States Centre for Disease Control, the US Agency for Healthcare Research and Quality and the US National Academy of Sciences have also rebutted the idea that ME is a behavioural condition. The Centre for Disease Control has stated that "ME/CFS is a biological illness, not a psychologic disorder. Patients with ME/CFS are neither malingering nor seeking secondary gain. These patients have multiple pathophysiological changes that affect multiple systems".[26]

There has been a serious underfunding of ME research in comparison with other long-term disabling conditions.

In the UK, NICE has now revised its guideline on ME symptom management in line with their evidence review which demonstrated the lack of efficacy of GET and extensive patient evidence on the harmful impact it can have on people with ME.[27]

NICE
National Institute for Health and Care Excellence

There is currently no laboratory diagnostic test for ME. An ME diagnosis must be made by taking a clinical history and excluding other potential conditions, and delayed clinical diagnosis and misdiagnosis represent significant issues.[28] These issues are compounded by the "misconceptions or dismissive attitudes" of health professionals which make it incredibly challenging for a patient to gain an appropriate and timely diagnosis of ME, in addition to the lack of physician-led multidisciplinary referral services for those who require expert help with diagnosis or management.[29]

Despite many recurring issues, valuable progress has been made within the new NICE guideline on ME with regards to:

1. The basic principles of diagnosis, care, and condition management
2. The unique issues facing children and adolescents with ME
3. Recognition of the impact of severe and very severe ME
4. The lack of evidence for the use of CBT and GET as treatments for ME.

This progress has the potential to bring about positive change in the lives of many people with ME, but there are still outstanding issues to be addressed. Several of the most pressing issues are explored over the course of this report.

Chapter 1:
Biomedical Research and Funding

Biomedical research into the cause of ME and treatments for ME has been neglected for many years. This has resulted in a weak medical understanding of the condition's underlying pathology, excessive delays in the development of new diagnostic tests, and a lack of targeted treatments and management approaches.

Biomedical research funding

Poor funding levels for ME research can be attributed in part to the trend of under-investment in chronic conditions more generally and a lack of appreciation of the costs and societal implications of ME to the UK.[30] Nonetheless, there is a considerable disparity in the levels of funding ME research receives when compared to other long-term disabling medical conditions.

> *"I've worked across many different diseases, and it is clear that ME research does not get even one-tenth of the funding it deserves. The quality of life for people with ME is measurably worse than patients with other serious illnesses."*
>
> - **Professor Chris Ponting, DecodeME Principal Investigator**

Research into quality of life indicates that a typical ME sufferer may face greater disability than an individual with one of the following conditions: type 2 diabetes, congenital heart failure, back pain/sciatica, lung disease, osteoarthritis, multiple sclerosis, or numerous cancers.[31] However, when ME is compared to other diseases that are less prevalent but cause similar levels of disability, there are wide variations in funding. Multiple Sclerosis (MS), for example, is estimated to affect around 110,000 people in the UK[32], while ME is estimated to affect around 250,000 people in the UK. Despite these estimates, MS research has received approximately 20 times the funding of ME research.[33]

> *"A compelling case for funding requires a robust evidence base. And without a strong evidence base ME/CFS research receives very little funding. And with little funding, researchers cannot build a strong evidence base. It is a vicious circle that needs breaking."*
>
> - **Professor Chris Ponting, DecodeME Principal Investigator**

Behavioural vs. biomedical approach to research

Whilst biomedical ME research has been neglected for many years, there has been too great an emphasis placed on ME research based on the flawed psychosocial model of causation and management which was developed in the 1990s by several notable psychiatrists who believed that ME had a psychological or behavioural basis.[34] Despite the WHO categorisation of ME as a neurological disease and a growing biomedical evidence base showing the physiological foundations of ME, this flawed model has been perpetuated, giving rise to many of the problems associated with ME research and care.

> *"The scientific evidence now that it has a biological basis is quite compelling, but sadly, the medical profession and other related professions... haven't really caught onto that."*
>
> - **Dr William Weir, Consultant Physician in Infectious Diseases**

Poor quality behavioural research

Several publicly funded studies that were underpinned by a flawed behavioural or psychological understanding of ME produced poor quality results. The PACE trial, for example, sought to demonstrate the benefit of behavioural forms of treatment in accordance with the belief that ME is caused by deconditioning due to inactivity. The conclusions reached by PACE trial authors argued for the use of graded exercise therapy (GET), a treatment "defined as first establishing an individual's baseline of achievable exercise or physical activity, then making fixed incremental increases in the time spent being physically active".[35]

The PACE trial has been highly influential in perpetuating the use of GET, despite serious methodological inadequacies and the widespread patient reporting of the harmful effects. An evidence review carried out during the preparation of the new NICE guideline on ME/CFS found clinical trial evidence supporting the use of GET to be consistently of low or very low quality with a high degree of bias.[36] This review identified particular problems with the PACE trial, including the changing of success parameters once data collection had commenced, the use of subjective outcome measures and small sample sizes.[37] Accordingly, the new guideline no longer recommends GET as a treatment for ME.

Insufficient data

There is a lack of robust epidemiological information on the precise incidence and prevalence of ME in the UK. As such, many vital NHS ME services are missing the information they require to concentrate specialist support where it is most needed.

> *"Biobanks such as the UK ME/CFS Biobank are key infrastructures to accelerate biomedical research and provide significant savings in both time and costs. There is an ongoing need to provide high quality data and samples using standardised methods to researchers in this neglected field."*
>
> - **Dr Eliana Lacerda, CureME Assistant Professor and Clinical Lead**

Despite the need for high quality samples in this often overlooked area, biobanks are struggling for funding and have had to rely on charity research grants to sustain their work.

The problems associated with poor quality research and a lack of data are exacerbated by misperceptions within the medical field which mean that ME is still not viewed as attractive area to work in. Some early-career researchers have even been discouraged by more senior colleagues from entering the field of biomedical ME research.

Lack of ring-fenced research funding

The lack of universal agreement on the definition of ME and the underlying model of causation has led to a shortage of funding and a "paralysis of research into both the biomedical causes of and treatments"[38]. Most publicly funded ME research in the UK to date has been based on a psychological model. Biomedical research and research infrastructure has therefore relied on funding from the charity sector, making biomedical projects difficult to sustain and nearly impossible to scale-up.

> *"We have carried out research to understand the disease in more detail, particularly into muscle, immune system, central and peripheral mechanisms. In our research projects we have found clear abnormalities. But all this research has been funded by charities and allows small-scale projects. Not the large-scale, comprehensive projects that these patients so deserve that will ultimately allow the much more co-ordinated care and support."*
>
> - **Professor Julia Newton, University of Newcastle Clinical Professor**

However, significant signs of improvement are now visible within the field of biomedical research. The DecodeME study by the ME/CFS Biomedical Partnership, for example, recently secured £3.2 million in funding from the Medical Research Council (MRC) and the National Institute for Health Research (NIHR)[39]. This large study aims to analyse the DNA of 20,000 people with ME in order to determine whether there is a genetic component and, if so, help identify causative mechanisms, diagnostic biomarkers, and potential approaches to treatment.

RECOMMENDATIONS

Further biomedical research is essential to improve understanding of underlying disease mechanisms in ME, discover diagnostic biomarkers, and develop treatment strategies aimed at the underlying disease process.

The ME APPG makes the following recommendations to improve biomedical research into both cause and management of ME:

- Coordinated research strategies must be developed to encourage high quality ME research. Areas should include (1) biomedical research into underlying ME disease mechanisms, (2) clinical research and treatment trials, (3) support for the development and submission of ME research applications and (4) incentives for the involvement of early career researchers.

- Government research bodies should ensure that there is a parity of biomedical research funding between ME and other serious long-term conditions.

- Centres of ME research excellence should be established to drive forward the development of effective treatments, learning from the projects of other nations, including the initiatives of the US National Institutes of Health, now incorporated into the National Academy of Sciences.

Chapter 2:
Diagnosis, Symptom Management and Medical Services

Health professional awareness

Despite the scientific evidence showing that ME is a biomedical condition, there is still an inaccurate understanding of ME being perpetuated by small groups within the medical and psychological professions. As a result, a sizeable proportion of health professionals still take a sceptical or even hostile view of ME.

According to a large 2005 survey of GPs in England, over two thirds of GPs recognised ME as a clinical entity,[40] however, nearly one third were either sceptical of, or did not acknowledge, ME as a clinical entity. Despite published guidance for GPs that recognises ME to be a legitimate medical condition, "confidence with making a diagnosis and management was found to be low".

Since 2005, there has been insufficient evidence to show that the understanding of the causation and management of ME has improved amongst GPs and other medical professionals.[41] This can be linked to the failure of the medical education establishment to update teaching in line with the ever-expanding evidence base demonstrating that ME is biomedical multisystem disease rather than a psychological condition. A 2021 exploratory study into ME education in medical schools demonstrated the inadequacy of current teaching with 64% of respondents acknowledging the need to update ME education and acquire new educational materials.[42]

Patient experience

A lack of health professional awareness of how to both diagnose and manage ME has had a significant negative impact on patient experience. For many individuals, the most difficult aspect of coping with ME, other than the associated debilitation, is the failure of professionals to take the condition seriously. People with ME often report being disbelieved or treated poorly when they raise any concerns.

> *"Medical professionals don't think ME/CFS is necessarily their problem... with ME CFS, the 'do no harm' oath that Doctors take seems to be forgotten about, and patients often report feeling unbelieved or treated negatively or as malingering."*
>
> - **Professor Julia Newton, University of Newcastle Clinical Professor**

When the previous NICE guideline (2007) was in place, ME patients were recommended to undergo GET. Many of these individuals were ignored by their health professionals when they reported that GET caused an exacerbation of their symptoms, and this paternalistic approach led to unnecessary patient suffering, isolation and anxiety. It is therefore a relief for many within the patient community that NICE has now removed the recommendation for GET from the new guideline.[43] However, there are concerns that some medical professionals will act in contravention to the new guideline by continuing to prescribe GET to patients under another name.

Late diagnosis and misdiagnosis

Poor ME awareness amongst healthcare professionals, alongside the lack of a laboratory diagnostic test, has resulted in late diagnoses and misdiagnoses. Additionally, as certain ME symptoms are akin to those that develop with other conditions, healthcare professionals may not have the confidence to make a clinical ME diagnosis which involves a process of carefully considering other conditions that produce similar symptoms.

As a result, people with ME can experience a long and agonising wait before a correct diagnosis is reached. This is particularly concerning given that ME symptoms are often debilitating at an early stage of the illness pathway. Without an early diagnosis and appropriate advice on symptomatic management, the patient prognosis is poor. For example, one parent of an adult daughter with ME told the APPG that after a series of misdiagnoses over several years whereby doctors thought her daughter had migraines, depression, and sensitivity to medication, she was finally diagnosed with ME.

> *"My daughter was diagnosed with ME, but still nothing was done. She was offered CBT which she took, but that was really no help. She ended up bedridden and frightened in a dark room. She can't stand light, she can't look at phones, she can't listen to anything because her sensitivity is so drastic."*
>
> - **Parent of adult daughter with ME**

The ME APPG therefore welcomes the emphasis on prompt and accurate diagnosis within the new NICE guideline. The guideline outlines when to suspect a diagnosis of ME in primary care, the need for a diagnosis where symptoms have been present for three months, and the importance of subsequent referral to a specialist team to confirm the diagnosis and develop an individual care and support plan. Without the adoption of the guideline recommendations in this area, late diagnoses and misdiagnoses will remain commonplace.

Condition management

Until biomedical research progresses to a stage where new treatments can be developed, activity/ energy management, based on the principles of pacing, is essential. However, many health professionals in both primary and secondary care are still unsure about how to implement these principles to manage the symptoms of ME, leaving patients without the support they require.[44] Educating health professionals on effective forms of symptom management and the harmful nature of GET is made more difficult when some doctors still believe incorrectly that ME fatigue is caused by deconditioning and inactivity.

Geographical disparities in medical care

There is currently a postcode lottery across the UK for accessing hospital-based referral services for ME, and in some areas, referral services are almost non-existent. Within England, for example, during 2004 - 2006, the Department of Health's Service Investment Programme provided £8.5 million in funding for the creation of 13 clinical network coordinating centres, 36 local teams for adults and 11 local teams for children and young people.[45] When this funding ended, the number of clinics steadily decreased over time, and the remaining clinics are no longer integrated in a meaningful way.

Inequalities in access to care can largely be attributed to a lack of sustained funding but also skills shortages. There are many areas across the UK without access to physicians or specialist GPs working in ME-related specialisms even though these doctors are required to form the specialist teams recommended in the new NICE guideline; this is in large part due to retirement.

> *"We aren't seeing young physicians and consultants with an interest in ME coming through to fill the specialist gaps."*
>
> - **Dr Sue Pemberton, Yorkshire Fatigue Clinic Therapy Director**

Severe and very severe ME

Severe and very severe ME affects approximately 25% of people with ME.[46] This cohort are housebound or bedbound at some stage in the progression of their illness, often requiring a wheelchair and unable to do basic household tasks without assistance.[47] At the very severe end of the spectrum, people with ME may also require tube feeding.[48]

Most of these patients are unable to access primary or secondary care for a number of reasons:

- Many GPs are reluctant or refuse to carry out home visits to people with ME.
- There are very few hospital-based referral centres with domiciliary services for people with severe ME.
- There are currently no dedicated physician-led in-patient services for the assessment and management of severe ME operating according to the biomedical understanding of the disease.

As a result of these factors, many people with severe ME lose all contact with NHS support. In addition to experiencing medical neglect, these individuals often face great difficulties in accessing social care.

RECOMMENDATIONS

Every ME patient requires empathy, understanding and support from health practitioners and policymakers alike, alongside prompt diagnosis and appropriate management based on their individual needs.

Many issues that have been of concern to the ME community, such as late diagnosis and GET, are being addressed in the new NICE guideline.[49] This guideline covers the basic principles of care, early and accurate diagnosis, activity management and the removal of CBT and GET as recommended treatments for the underlying disease process in ME.

The ME APPG recommend that the following steps be taken for the ME community to benefit from the new and updated NICE guideline:

- Health professionals should follow the recommendations in the new NICE guideline on ME/CFS and ensure that ME patients do not undergo any form of GET as treatment. Patients should instead be encouraged to stay within their 'energy envelope' when engaging in any mental or physical activity.

- Updated training on ME, which is based on a biomedical model of causation, should be provided for both pre-and post-registration health professionals:

    - The Royal Colleges should ensure that those working in primary care and relevant medical specialities receive postgraduate training on ME.

    - Medical schools should provide compulsory ME training for undergraduates.

- Health service commissioners should carry out a review to identify the current level of service provision for people with ME and take steps to ensure that local ME service provision is carefully planned, resourced, and implemented. This should include:

    - Multidisciplinary hospital-based referral services that contain the full range of health professionals that are recommended in the new NICE guideline.

    - Clinics that are based on models of good practice, such as the Yorkshire Fatigue Clinic.[50]

- People with severe and very severe ME should be provided with a care package based on the basic care principles that are recommended in the new NICE guideline:

    - GPs should carry out home visits to ensure these patients are not neglected, and hospital-based services should cater for those with severe ME.

Chapter 3:
Children and Young People with ME

Myalgic Encephalomyelitis can affect both children and adolescents. An epidemiological study showed ME to be the most common cause of pupil long-term sickness absence from surveyed secondary schools.[51]

Health professional awareness

Paediatricians do not always have the experience or confidence necessary to diagnose ME in children and adolescents.[52] Without a prompt clinical diagnosis, the parents or guardians of a child with ME are left without formal medical evidence of their child's condition and are open to intense scrutiny.

Fabricated and Induced Illness claims

Munchausen Syndrome by Proxy (MSBP) is a mental illness and form of abuse whereby a mentally ill person falsifies or causes an illness or injury in a person under his or her care.[53] Though MSBP is difficult to quantify and has been subject to debates regarding definition and prevalence, cases are rare.[54] However, following the 2001 decision by the Royal College of Paediatrics and Child Health (RCPCH) to replace MSBP with a novel umbrella term, fabricated and induced illnesses (FII), hundreds of families of children with ME have faced child protection investigations following allegations of FII.[55] Dr Nigel Speight, Consultant Paediatrician, told the APPG that the extension of the FII diagnostic criteria in 2013 to include perplexing presentations and medically unexplained symptoms as criteria for the diagnosis of FII has resulted in this drastic increase in cases.

> *"ME families are sitting ducks for this condition. Any family of children with ME whose paediatrician has not made a diagnosis is automatically suspected of fabricated illness."*
>
> - **Dr Nigel Speight, Consultant Paediatrician**

In the eyes of a health professional who lacks experience and knowledge of ME, a child with ME may have perplexing and medically unexplained symptoms which fulfil the FII diagnostic criteria. Actions, such as being absent from school, disagreeing with medical opinions, seeking second medical opinions, or requesting health professional visits to stop because of undue pressure to undergo GET, have been used as evidence of FII. Disturbingly, the APPG has heard reports that diagnoses of FII have been made by professionals who have neither met nor examined the child.

> *""We were coping day to day with our child's diagnosed illness, understanding their needs and we had the support of a trusted consultant. Everything fell apart when the new paediatric doctor suspected FII... we were guilty until proven innocent."*
>
> - **Parents of a child with ME**

Intervention by social services

FII allegations or other issues resulting from the lack of an appropriate diagnosis may be followed by inappropriate referrals to social services and, on occasion, invasive child protection proceedings. These proceedings are exceedingly difficult to challenge once they have been commenced, and many families have been disbelieved and threatened by social services.

In very severe cases, court orders have been used to admit children with ME to hospital for inappropriate physiotherapy and other damaging treatments. In 2019, for example, there was a high-profile case in Lewisham where a child's paediatrician could not make sense of the severity of her ME symptoms, such as requiring tube-feeding in a darkened room. While FII was not alleged in this case, the child was labelled with a psychiatric disorder, pervasive refusal syndrome, and her parents were accused of colluding with her. The child's paediatrician referred the case to social services to acquire a court order to admit her to a psychiatric unit.[56]

In cases where FII is alleged, even if parents are cleared of any wrongdoing, the experience of undergoing child protection proceedings can be incredibly distressing.

> *"Even though the outcome of the conference cleared us of Fabricated and Induced Illness, neglect and abuse, it was such a traumatic experience that we are left in a state of shock. We were under suspicion for so long, and the accusations were so terrible. With the possible threat of removing our children, we were pushed over the edge."*
>
> **- Parents of a child with ME**

Education and other impacts

Pupils and students with ME often have energy limitations and cognitive difficulties which make it difficult for them to take part in educational activities at the same rate as their peers. For example, they may find concentrating and information processing difficult, and they may exhibit recurring patterns of medically unexplained absence due to difficulties in obtaining an appropriate diagnosis.

The mainstream education system often does not deliver for these children and young people, and it can even be detrimental to their health and wellbeing. Some have reported feeling pressured by their educational institution to return too early after a relapse even though this may exacerbate ME symptoms, further hinder recovery and obstruct academic performance.[57]

RECOMMENDATIONS

The ME APPG supports the recommendations in the new NICE guideline with regards to the basic principles of symptom management, safeguarding and care for children with ME. The ME APPG also makes the following recommendations in light of evidence provided to the APPG by health professionals, social workers, policy makers and the parents of children with ME:

- Health commissioners should ensure that all children and adolescents with ME have access to correctly trained hospital paediatricians and long-term community services.
- The RCPCH should ensure that all paediatricians receive specialised training on recognising, diagnosing and managing children and adolescents with ME to avoid misdiagnosing FII.
- An independent second medical opinion obtained by a parent or guardian of a child with suspected or confirmed ME should be taken into account in any decisions regarding diagnosis, treatment or welfare.
- The Chief Social Worker (or equivalent in the devolved nations) should ensure that the guide for social workers working with children and young people with ME or suspected ME (developed by social workers in partnership with Action for M.E.) is shared with all social care departments to ensure that children are not unnecessarily subjected to child protection procedures due to a lack of understanding of ME.[58]
- All children and young people with ME should have a care plan, in accordance with national guidelines and/or statutory requirements, that combines education and health.
- Schools, colleges, and universities should make learning and assessment modifications for students with ME. Home-based tuition and remote interactive lessons should be provided for those who are unable to attend classes.

Chapter 4:
Welfare and Health Insurance-based Benefits

ME is likely to have a substantial impact on an individual's capacity for work due to the fluctuating nature of the condition which can make sustaining a normal working pattern exceptionally difficult.[59] Some people with ME cannot work at all due to the severity of their symptoms, and they may require access to welfare benefits and/or health insurance-based benefits.[60]

Welfare benefit rejections

It is clear from the evidence presented to the APPG that too many people with ME are being refused Employment and Support Allowance (ESA) and Personal Independence Payment (PIP) by the Department for Work and Pensions (DWP). Those who are refused ESA or PIP can take the decision to appeal, and many people with ME who have taken this action have gone on to win their case, indicating flaws in the initial system. However, some are unable to pursue this avenue as going through the complex appeals process, which requires a considerable amount of preparation from the claimant, would exacerbate their symptoms. As a result, many people with ME are existing without the financial support they need.

Welfare benefit assessments

According to Ann Innes, Welfare Rights Adviser to the ME Association, DWP medical assessment "tests are not fit for purpose to assess how somebody with ME is functionally impaired in a real-world condition" as these assessments do not adequately take account of:

Condition variability throughout the day

- As ME symptoms can vary within a day and between days, 'snapshot' inferences based on how someone looks or what they can do at assessment, or on a 'good day', can be erroneous and inapplicable to general circumstances.

The length of time an activity can be maintained

- People with ME have often been scored by assessors as being able to carry out a descriptor task even though they would be unable to carry out that task for a significant period at any point during the course of the day due to their fluctuating symptoms.

Other cumulative factors that could impair cognitive ability

- One descriptor often used in ESA and PIP assessments is the ability to count change. Some people with ME who are able to count change correctly in an assessment may not be able to when they are in a busy supermarket due to the effects of noise and bright lights on their cognitive function. Therefore, this type of descriptor does not take account of the detrimental impact of some environments on the symptoms people with ME experience and cannot accurately measure everyday capabilities.

The after-effects of carrying out a task

- Post-exertional malaise is a key feature of ME which can appear following the completion of a cognitive or physical task in an assessment.

Issues in providing sufficient supportive medical evidence

- Some people with ME have been penalised by assessors for being unable to provide supportive medical evidence. These assessors have failed to account for the inadequacy of ME clinical services which results in many individuals losing contact with the medical profession.

Several further issues relate to the perpetuated false understanding of ME as a psychological illness. People with ME reported to the APPG that they were disbelieved by their assessors even before their assessment had commenced. Moreover, they mentioned that the comments they made during their DWP medical assessment differed greatly from those recorded in their medical assessor's report, resulting in inaccurate conclusions. This represents a significant problem as decisions made by DWP regarding benefits are based primarily on the assessment report.

Repeated assessments also place additional strain on people with ME over the longer-term.

> *"Repeated assessments are a huge drain on people with ME. They put them back considerably, in terms of their health, and there is evidence to show that if somebody has had ME for more than five years that the prognosis is likely to be poor, and yet people are routinely reassessed every two or three years."*
>
> - **Ann Innes, Welfare Rights Adviser to the ME Association**

Another ongoing issue that ESA claimants face is with the associated complex paperwork (i.e. the ESA50 questionnaire)[61]. People with ME often require additional support to complete this paperwork due to the cognitive dysfunction they experience, and it may take time to find someone to provide support before the submission deadline.

Health insurance-based benefits

People with ME have been pressured by their private health insurers to undertake a course of GET, despite detrimental effects, in order to keep their insurance-based health and disability payments. Additionally, some health insurers have required people with ME to participate in inappropriate and potentially harmful medical evaluations to determine their work capabilities and assess their claims. These medical evaluations have included Chronic Pain Abilities Determination (CPAD) assessments which aim to measure an individual's physical and cognitive abilities through a series of tests involving physical exertion[62]. This type of testing is unacceptable given that any activity which stretches an ME patient beyond their energy limits can result in long-term health damage over and above the short-term symptoms of intense pain and post-exertional malaise.

RECOMMENDATIONS

After considering the evidence provided to the ME APPG by health professionals, social workers, benefits advisers, policy makers, and people with ME, the APPG makes the following recommendations with regards to welfare benefits and health insurance:

- The Department for Work and Pensions (DWP) should ensure that people with ME have fair and equitable access to welfare benefits by taking steps to (1) account for the impact of ME on the ability to engage with the application process and (2) minimise potential negative health effects associated with medical assessments. These steps should involve:

  - ensuring that claimants can carry out activities repeatedly and reliably without risking adverse health impacts and are scored fairly

  - accepting supporting information from accredited medical professionals, other health and social care professionals and carers

  -providing an extension for completion of ESA paperwork in line with those provided for PIP applications

  - ensuring that medical assessors understand and work within the NICE guideline which explicitly states that GET should not be recommended or required.

- Health insurers should not require people with ME to undertake GET, CBT or health assessments that require levels of activity which could produce adverse health effects.

Chapter 5:
COVID-19 and the ME Community

According to Dr Nina Muirhead, Director of Doctors with ME, the Covid-19 pandemic can be viewed as both "a catastrophe and an opportunity" for the ME community. The pandemic has been challenging for people with ME in a multitude of ways, particularly as they experience immune system dysfunction. However, the shift to virtual platforms has, in some ways, enabled easier access for people with ME to medical consultations, work and education. Periods of societal lockdown have also increased empathy and understanding towards people with ME who are often trapped at home.

Long COVID

Over the course of the global COVID-19 pandemic, many individuals have been affected by what has now been termed as 'long COVID'. Long COVID can affect anyone who becomes infected with the virus, not only those who require hospital treatment.[63] As the number of COVID-19 cases continues to rise across the UK, long COVID presents an increasingly significant public health burden.

The overlapping nature of ME and long COVID

A number of health professionals - understanding that ME can be triggered by a viral infection - predicted at an early stage of the pandemic that a sub-set of people with COVID-19 would experience longer-term adverse health consequences.[64]

Whilst both long COVID and ME are heterogeneous conditions, they exhibit several clinical and pathological overlaps. Both conditions present fluctuating and multisystem symptoms, and the most common long COVID symptoms - extreme fatigue, cognitive dysfunction, problems with pulse and blood pressure regulation, and sleep disturbances - are experienced by people with ME.[65] As a result, people with long COVID have, in some areas across the UK, had access to ME services for help with condition management.

Opportunities for learning

In the UK, a great deal of biomedical research is now being funded into both the cause and treatment of long COVID. This contrasts with a sustained lack of ring-fenced funding for ME biomedical research.

The current interest in long COVID has presented an opportunity for the research community to develop a better understanding of other conditions which may develop post-virally, including ME, and finally put an end to the narrative that these conditions are psychological in nature.

Collaborative research into post-viral conditions such as long COVID and ME is, therefore, essential to finding effective forms of management and treatment.

> *"The next step has to be including people with CFS and ME into the long COVID trials going on. We need to know now that the interventions that are going to be proven to be beneficial for long COVID are across the board".*
>
> **- Dr David Strain, British Medical Association COVID-19 Response Team Lead**

While long COVID research is ongoing, long COVID patients have been learning from tried and tested ME management techniques, such as rest and pacing, in order to avoid condition relapses.[66] Accordingly, many ME charities are at the forefront of providing resources and support to the long COVID community on issues such as condition management.

RECOMMENDATIONS

It is important that people with post-viral conditions receive suitable care and support. The ME APPG makes the following recommendations drawing on the expertise of the health professionals, researchers, and people with ME who gave evidence to the APPG:

- Long-term health planning, policy and financing should consider the high number of individuals experiencing long COVID.
- Health service commissioners should ensure that there is cooperation between ME and long COVID clinics to maximise patient benefit.
- The National Institute for Health Research (NIHR) should ensure that funding is provided to long COVID research projects that include ME patients as a comparative group.
- Further publicly funded biomedical and clinical research should be commissioned to investigate and compare a range of post-viral conditions, including ME.

Concluding Remarks

People with ME require major cultural change to take place within all professions associated with their care and support. Sadly, false and outdated understandings of ME still circulate within medical and public discourse, making it more difficult, and often impossible, for people with ME to access the services to which they are entitled. Whilst there is still a long way to go, the ME community and their advocates within the medical profession and wider society have made significant strides in challenging erroneous understandings and pressing for improved care.

With the recent publication of the new NICE clinical guideline on ME/CFS, the APPG is confident that a turning point has been reached. The guideline sets the precedent for a medical shift away from a problematic behavioural or psychological understanding of ME and towards a more holistic biomedical or physiological understanding, as evidenced by the removal of harmful GET as a treatment for people with ME and the new focus on energy management. Our primary report recommendation, therefore, seeks to ensure that the new guideline is swiftly implemented in full by relevant health services.

As ME is multifaced in nature, people with the condition require support and investment across multiple health and research disciplines as well as welfare, social services and education. The findings of this report highlight that there has been a long-term disconnect between the treatment deserved by people with ME and what they experience in reality. This disconnect stems from myriad factors, most notably, a lack of understanding of the biomedical nature of ME amongst many professionals associated with caring for and supporting people with ME, the absence of sustained research funding to develop our understanding of the underlying disease mechanisms, and a scarcity of evidence-led clinical services.

We are confident that the implementation of the 20 report recommendations would facilitate biomedical research, advance clinical services, educate professionals associated with caring for people with ME (including children and young people) and improve access to welfare and wellbeing support.

We view these recommendations as a starting point on which to build creative strategies across the governments of the UK, service providers and research institutions for the transformation of our society's approach to ME. Furthermore, we wish to see the UK take a pioneering stance towards ME research and a compassionate attitude towards people with ME at a time when we are seeing an increasing trend in the development of ME-like symptoms as a result of COVID-19.

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- **Dr Nigel Speight** - Consultant Paediatrician, Specialist in Paediatric ME, Forward ME member
- **Mr Tony Crouch** - Social worker, Forward ME Member
- **Dr Sue Pemberton** - Yorkshire Fatigue Clinic Therapy Director and Specialist Occupational Therapist
- **Ms Ann Innes** - Consultant Welfare Rights Adviser to the ME Association
- **Dr William Weir** - Consultant Physician in Infectious Diseases, Forward ME Member
- **Dr David Strain** - University of Exeter Senior Clinical Lecturer, Devon ME/CFS Specialist Service Consultant, British Medical Association COVID-19 Response Team Lead, Action for M.E. Medical Adviser
- **Dr Nina Muirhead** - Dermatology Surgeon in the Buckinghamshire Healthcare NHS Trust, Doctors with ME Director, Forward ME Member

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Appendix

Inquiry evidence session details

- Biomedical Research and Funding – 3 March 2020, 13:00 to 14:00, Portcullis House
- Children with ME – 16 June 2020, 10:00 to 11:00, Virtual
- Welfare Benefits and Economic issues – 7 October 2020, 16:30 – 17:30, Virtual
- Diagnosis and Management – 17 November 2020, 9:30 to 10:30, Virtual
- Covid-19 and the ME community – 19 April 2021, 11:00 to 12:00, Virtual

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