

Action for M.E. submission to the Health and Sport Committee's call for views on Clinical Governance

Action for M.E. takes action to end the ignorance, injustice and neglect faced by people with M.E., and is the UK's leading charity for adults, children and families affected by Myalgic Encephalomyelitis (M.E.) M.E. is a long-term, fluctuating, neurological condition that causes symptoms affecting many body systems, more commonly the nervous and immune systems. M.E. affects an estimated 21,000 people in Scotland.

People with M.E. experience severe, persistent fatigue associated with post-exertional malaise, the body's inability to recover after expending even small amounts of energy, leading to a flare-up in symptoms including chronic pain. One in four of those with the condition are severely affected. This can mean that they are unable to complete activities for themselves, experience severe cognitive difficulties, extreme sensitivity to light or noise, or rely on a wheelchair for mobility.

There is no single pharmaceutical cure for M.E., instead patients can try treatment approaches in order to manage their symptoms. Because of the complexity of the illness, its fluctuating nature and the wide spectrum of symptoms, different things work for different people. Many patients manage their symptoms through pacing and energy management, which involves balancing their levels of activity and rest. Other management approaches include taking medication for alleviating individual symptoms, as well as making changes to diet and nutrition.

Our evidence to this Committee is based on:

- A 2017 survey of people with M.E. in Scotland on their healthcare and services, which we conducted to inform our response to this consultation
- Responses from Scottish Health Boards to a 2017 Freedom of Information request that was sent out to inform Action for M.E.'s report *Spotlight on specialist services*¹
- The experiences of people affected by M.E. who engage with our information and support services, including our Welfare Advice and Support Service; our ongoing consultations and surveys; our social media platforms; and our peer-support forum, M.E. Friends Online.

1. Are services safe, effective and evidence-based?

There are three specialist services for people with M.E. in Scotland; a Clinical Nurse Specialist in Fife, a service hosted at the Centre for Integrated Care in Glasgow (for outpatients only), and another service at Astley Ainslie Hospital in Edinburgh. From our survey of people with M.E. in Scotland, of those that had accessed these services, 52% felt that their health had stayed the same, 25% felt it had become somewhat worse, and 9% that it had become much worse.

M.E. is a chronic and fluctuating condition, and worse health does not indicate that these services caused the deterioration. It does reveal that at the very least these services are having an inconsistent effect, and that people with M.E. may not receive benefit from attending these services.

A number of our survey respondents highlighted their positive experiences; these responses largely referred to how services have supported their self-management. One person said that attending a service "helped me prioritise my activities and identify where I could fit in more rest periods during the day" while another commented that "advice from clinic was passed onto employer who was

¹ Action for M.E. 2017, *Spotlight on specialist services: UK healthcare for people with M.E.*, accessed on 8 August 2017 <https://www.actionforme.org.uk/uploads/pdfs/spotlight-on-specialist-services-july-2017.pdf>

supportive and permitted a long-phased return... I have 'dips' but have built up to full-time work. I do very little outside of work though."

However, other health interventions at these services did negatively impact on the health of patients. People with M.E. in Scotland have highlighted how physiotherapy has been administered in a way that did not take into account their symptom of post-exertional malaise, whereby the body does not recover normally after periods of effort and exertion (including for minimal tasks). 79% of our survey respondents said that professionals involved in their healthcare did not understand their needs as a patient with M.E.

One person said that they saw a physiotherapist "that did not understand that too much exercise caused me post-exertional malaise, I had to stop going as it made my symptoms worse." Another person said "there is very little understanding of how physio is not tolerated in severe M.E."

The *Scottish Good Practice Statement on ME-CFS*² highlights that when administering either rehabilitation and Graded exercise therapy (GET), activities that involve increasing activity levels from a patient's current baseline, it is necessary to do so carefully (ie. gradually and where appropriate from a very low baseline) and in accordance with the patient's needs and circumstances. The statement also emphasises that rehabilitation does not have to mean exercise, indicating that other types of rehabilitation than physiotherapy can be appropriate. The statement acknowledges that GET is "particularly controversial" and that patients have reported worsening symptoms. It consequently states that "it is essential that agreement and negotiation [with the patient] are at the very centre of any GET programme."

The Scottish Good Practice Statement was produced in 2010 to provide a comprehensive practice guide for practitioners on the diagnosis and clinical management of M.E., and was formally endorsed by the Royal College of General Practitioners (Scotland) and the Scottish Neurosciences Council. It is extremely concerning if M.E. services in Scotland are not complying with this Statement, and indicates an urgent need to more effectively disseminate the practice guidance.

Given that there are only three services for M.E. in Scotland, another issue with provision is that many patients do not have access to any kind of specialist healthcare intervention. This is particularly imperative given the lack of awareness of M.E. among many primary care professionals (see answer to Q3). Many people with M.E. have highlighted that they do not feel the NHS has supported them in managing their condition.

One person said that they have had to "try and cope on my own using online services from patient groups," while another worried that although they had been trying to figure things out on their own, "I am reading as much as I can but don't know if I am doing things correctly."

Others expressed how they felt about the lack of healthcare provision. One person said "I do feel I have been abandoned by the NHS" while one parent said they were "quite shocked that we've been left alone to manage the care of a ten-year-old who is too ill to be able to attend school. We have been given virtually no advice on how best to help her... it is quite distressing."

The one in four people with M.E. who are severely affected face additional barriers to accessing services. They may not be able to travel and attend secondary care services and as such require domiciliary care, which is not frequently available. In our report on NHS services, M.E./CFS Clinical Nurse Specialist Keith Anderson, who is based in Fife, said that he found services were split into silos,

² Scottish Government 2010, *Scottish Good Practice Statement on ME-CFS*, accessed on 8 August 2017 <http://www.scot.nhs.uk/wp-content/uploads/2015/06/GoodPracticeStatement.pdf>

which prevent effective and appropriate treatment at the right time: “The patient journey becomes so complicated and convoluted. Because of this I’ve often missed the opportunity to give guidance and advice when patients need it.”³

2. Are patients and service users’ perspectives taken into account in the planning of services?

From our survey of people with M.E. in Scotland, we found that 84% of respondents have never been asked for feedback on the services they accessed. 11% had been asked for feedback on some services but not on others, while 5% had been asked for feedback on all the services they had accessed. This suggests that the experiences of people with M.E. are not being gathered to feed into the ongoing evaluation of existing services, so as to inform current planning and future service design.

One person commented that feedback was gathered while they were completing a course of sessions at a service, and as such their condition at that time had improved. However this improvement did not continue after the sessions had ended, and they were not sent any follow-up questionnaires to monitor the long-term effectiveness of health interventions.

The lack of feedback gathered is concerning given the issues highlighted with health care for people with M.E. throughout this submission. These include inappropriate health interventions (see question 1) and a lack of respect shown to the patient’s experience and knowledge of their own condition. Without monitoring the treatment given to adults and children with M.E. in both primary and secondary care there will not be recourse to address poor quality of care wherever it occurs.

3. Do services treat people with dignity and respect?

Of our survey respondents, 24% said that they felt healthcare professionals had treated them with dignity and respect, while 19% said professionals had not treated them this way. The majority, 57%, said they had a mixed experience with professionals displaying different attitudes.

The vast majority of patients with M.E. in Scotland receive some, or all, of their M.E.-related healthcare through primary care (93% of our survey respondents). The experiences shared with Action for M.E. demonstrate that primary care professionals have varied knowledge of M.E. While one person has told us their “GP has an interest in M.E. and has kept up to date with issues,” others highlighted their negative experiences. One said that although they had a supportive GP who diagnosed their condition, “in recent years GPs often do not ask basic questions like ‘what are your symptoms?’ and appear to have no interest in M.E.”. Another said that “at least one of the GPs in my current practice does not believe M.E. is a real condition.” While these experiences in primary care are a clear contravention of patients being treated with dignity and respect, they also have wider implications for access to care for people with M.E. Primary care is the route to specialist services, and without a GP who listens to patients many patients do not have the opportunity to access further care.

Even specialist healthcare professionals in Scotland have demonstrated a lack of belief in the condition, and have disregarded the stated experiences of patients.

One person said that “M.E. is regarded by the professionals I have seen as a psychological rather than a physical problem, and although sympathetic to my situation they have no understanding of what the patient experiences and neither the time nor patience to consider it.” Another said “a neurologist told me that I had depression and my physical symptoms were imagined. My GP told me

³ *Op. cit.*

that my symptoms were caused by stress, despite my explaining that it was the symptoms that were causing the stress in the first place.” Similarly, someone with M.E. said that their doctor decided they were depressed, and refused to engage in further conversation about the similarities between M.E. symptoms and depression.

One person stated that after their experience they were “left in tears and despair because they just didn’t believe me.”

The overall picture presented by people with M.E. is of a system where clinicians repeatedly fail to treat them with dignity and respect, which often stems from misunderstanding and ignorance of the nature of M.E. as a chronic and fluctuating neurological condition.

4. Are staff and the public confident about the safety and quality of NHS services?

Throughout this response, we have highlighted a number of issues with the safety and quality of NHS services for people with M.E. These include:

- Professionals must treat patients with respect and listen to their views – too often this doesn’t happen.
- All health interventions should be safe and appropriate, which can be facilitated in part by ensuring that patients make informed choices.

A considerable number of people do not believe in the safety and quality of NHS services they have accessed for M.E. The variability of both the conduct of individual clinicians and health interventions provided to patients has created an inconsistent service for adults and children with M.E., with some experiencing adverse outcomes. While specialist services have helped some patients in managing their condition, some have offered interventions that have worsened the health of patients. Large numbers of people with M.E. do not have access to any kind of service, and have expressed their feelings of isolation, being let down by NHS Scotland and the difficulties of navigating the management of a complex condition without appropriate professional support.

In order to improve the services that people with M.E. can access, it is necessary to:

- Monitor the long-term outcomes for people with M.E. who access services, so that service planning in the future can take account of the effectiveness of health interventions
- Involve patients in service planning and design, in line with the Participation Standard set out by the Scottish Government for NHS Boards.⁴ This can be facilitated in part through the long-term monitoring outlined above, but should also require the involvement of patients through the early stages of service planning.
- Provide primary care professionals with adequate, evidence-based information on M.E. to firstly, ensure they are well-informed of the nature of the condition and the impact it has on patients and secondly, that they are able to refer patients onto any appropriate secondary services
- Ensure that services deliver appropriate and timely interventions, with the full and informed consent of the patient, that take into account the *Scottish Good Practice Statement on ME-CFS*

⁴ Scottish Health Council, *Participation Standard*, accessed 8 August 2017, http://www.scottishhealthcouncil.org/patient__public_participation/participation_standard/participation_standard.aspx#.WYmuUoTyu00