

Survey of people with Myalgic Encephalomyelitis (ME) to explore their use and experiences of physiotherapy services in the UK

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At least 250,000 people live with Myalgic Encephalitis (ME) in the UK which compares to 100,000 living with Multiple Sclerosis. In 2019, a survey by MEAction of just under 2,000 people with ME identified that over 50% of people who attended specialist ME clinics were unsatisfied with the services they received, including physiotherapy. People with ME are also seen in regular musculoskeletal, community, neurological and paediatric physiotherapy services but the views of People with ME related to these wider services are not known.

As physios for ME, we therefore wanted to identify people with ME's experiences of physiotherapy services throughout all areas of physiotherapy practice. We wanted to understand the perception of our profession and gain an understanding the effectiveness of treatment for people with ME.

A survey comprising of open and closed questions was devised by the Physios for ME team with feedback from people with ME and representatives of the ME Association. The ME Association website hosted the survey in July 2019. An information sheet was provided on the website and consent assumed if participants completed the online survey. All data was anonymous and data held securely on the University of Leicester databases. Qualitative and quantitative data analysis was completed by the four physiotherapy researchers from physios for ME.

441 People with ME completed the survey, with respondents ranging from paediatric to adult and mild to severe ME. Themes included: types of treatments, co-morbidities, symptoms, positive experiences and negative experiences

54% had a negative experience. 53% said symptoms were worse after physiotherapy. 70% of those who had a positive experience said it still did not help their symptoms.

Of those who had physiotherapy, 46% found it to be a positive experience, but over half (54%) had a negative experience. The positive stories described physiotherapists who would work in partnership with their patients, were open to learning about the disease and taking the time to listen and adapt treatment depending on how the symptoms were responding.

The negative stories highlighted a lack of knowledge of the abnormal physiological responses to exercise in this patient group and a refusal to listen to patients and to review and adapt treatment based on reports of increased symptoms post intervention.

In terms of the effectiveness of physiotherapy, only 11% of respondents reported that their symptoms improved, whereas a worrying 53% reported that physiotherapy made their ME symptoms worse. Even within those who reported a positive experience of physiotherapy, 70% said it still didn't make their ME better.

From the personal stories we also received via email, Twitter and Facebook as a result of the survey, we were able to build a sense of the kinds of treatment people with ME were receiving. Various forms of exercise were described, as well as manual treatments like joint mobilisations and massage. Some people received physiotherapy as a direct intervention to their ME symptoms, whereas others encountered physiotherapists for secondary problems such as joint pain.

In relation to the types of treatments the responses varied. For example, some people responded very well to massage and found it gave them pain relief, but others reacted poorly and experienced more pain. While any mention of graded exercise therapy was included in a negative account, some people reported benefits from various low level activities like core stability work. This really showed how every person with ME is unique and that any treatment plan must be specific to the individual, not a standardised approach.

One of our favourite responses was someone whose entire encounter with a physiotherapist involved them changing the configuration of their pillows. Although fleeting, this one act allowed the person to sleep more comfortably, which had a really positive impact on their quality of life. It is these small but effective management strategies that we feel physiotherapists can excel at, and we should be exploring more for this patient group.

We recognise that this is a small sample of PwME and further research is needed to fully understand the experiences of PwME of physiotherapy.

Overall the results suggest the general relationship between physiotherapists and people with ME is poor, but indicates there is potential to improve. It is imperative that physiotherapists are aware of the latest exercise physiological evidence so they can treat and advise people with ME about how to exercise safely and without adverse effects if appropriate.

Alternatively physiotherapists could use their skills and expertise to provide management solutions that can have a benefit to quality of life. For more information, please visit our website www.physiosforme.com where you can access specific resources for physiotherapists including more about the latest evidence regarding exercise and other physiotherapy treatments that can support people with ME.