#MEAction Scotland Manifesto 2019

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Introduction

#MEAction Scotland, an affiliate of #MEAction UK, is a grassroots, volunteer-led movement working towards improving the lives of the estimated 21,000 people in Scotland with Myalgic Encephalomyelitis (ME). Our vision is a Scotland that understands, supports and treats people with ME.

Our purpose is:
- to build a stronger ME advocacy community in Scotland
- to raise awareness of the devastating impact of ME
- to lobby for effective support for people with ME

This document describes the areas where we propose to focus our lobbying activities in order to effect change for people with ME.

Key issues for lobbying are:
- Creation of an ME strategy
- Discontinuation of PACE-type Cognitive Behavioural Therapy (CBT) and Graded Exercise Therapy (GET) in Scotland
- Investment in biomedical research
- Education and training for healthcare professionals

- Increased accessibility to and investment in care

Our manifesto is intended to be a commitment to action: it will be regularly reviewed by the steering committee in the light of priorities identified by the #MEAction Scotland community. We will review the manifesto when #MEAction's policy and values statements are published. #MEAction Scotland will participate in the creation of such policies and values with the #MEAction community and will reflect such values in the manifesto.

1. Creation of an ME strategy

Rationale: There is no single answer to helping people with ME in Scotland due to decades of underfunding and neglect in every area of research, training and patient support. The key issues identified above feed into each other and all need to be addressed. A long term strategy is needed to address the multiple intersecting problems faced by people with ME.

Historically the patient voice and experience has not been acknowledged or included in decision making. It is essential that the patient voice is prioritised and that the strategy is led by patients. There are examples of strategies from other illnesses and disabilities, which were neglected or deemed controversial e.g autism and dementia. #MEAction Scotland volunteers can try and represent the patient voice, but are not necessarily representative of the ME community as a whole, with some more able to engage in advocacy than others. A patient led national strategy which includes and prioritises marginalised voices would ensure all voices are heard.

Change Needed:
A government funded strategy, which is led by and prioritises the voices of people with ME. The strategy will take an overarching look at healthcare, social care, education of health care professionals and investment in biomedical research. It will identify and address the needs of people with ME, including children/young people and people with severe ME in Scotland and commit to funding in a reasonable time frame.

2. Ensure that no health or social care services in Scotland offer Graded Exercise Therapy (GET) or Cognitive Behavioural Therapy (CBT) as treatment.

Rationale: PACE-type CBT and GET is given to ME patients based on the psychosocial model, which assumes that ME is caused by deconditioning and patient beliefs. This approach is rooted in historical prejudice - namely such diagnoses as hysteria and neurasthenia - the origins of which are sexist, racist, and classist. This narrative has long been used to silence and dismiss predominantly female patients, and it is time to eliminate these flawed and scientifically unverifiable theories from Scottish medical practice.

The reasons we believe CBT/GET should be removed are:

- The cardinal symptom of ME is a prolonged exacerbation of symptoms after physical or cognitive exertion. Encouraging patients to ignore and push through symptoms will lead to damaging exacerbation of the illness.
- In surveys, most patients report that GET made their condition worse.[1]
- The majority of research into CBT/GET has used the overly broad Oxford criteria to diagnose patients. This has resulted in the inclusion of *'patients who may have an alternate fatiguing illness'* (The US Agency for Healthcare Research and Quality (AHRQ)). On this basis, the AHRQ called for the Oxford definition to be retired (2014). In 2015, the US National Institutes of Health called for Oxford criteria to be retired because it could *'impair progress and cause harm'* (Green, 2015).
- The PACE trial, which is the largest trial conducted into CBT/GET, has been widely criticised due to its many logical and scientific flaws.
- Biomedical evidence refutes the theory of deconditioning. Two-day exercise testing (CPET) shows that patients cannot perform the same activity two days in a row, where healthy deconditioned people tend to do better on the second day than the first.[2] These exercise tests measure metabolic products and do not rely on patient effort. Multiple other studies show measurable differences between sedentary people and people with ME.
- For more information on the harms associated with CBT/GET see our factsheet here.

Regional NHS Boards in Scotland continue to offer CBT/GET as treatment to people with ME, despite no evidence of efficacy for CBT, and the majority of patients reporting they deteriorate during GET. Furthermore, evidence demonstrates differences between deconditioned people and people with ME.

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[1] Geraghty, K., Hann, M. and Kurtev, S. (2017) 'Myalgic encephalomyelitis/chronic fatigue syndrome patients' reports of symptom changes following cognitive behavioural therapy, graded exercise therapy and pacing treatments: Analysis of a primary survey compared with secondary surveys', Journal of Health Psychology. doi: 10.1177/1359105317726152.

[2] Snell, C.R., Stevens, S.R., Davenport, T.E. and Van Ness, J.M. (2013) 'Discriminative Validity of Metabolic and Workload Measurements for Identifying People with Chronic Fatigue Syndrome', *Physical Therapy*, 93 (11), pp. 1484-1492. doi: 10.2522/20110368

Change Needed:
We call for an immediate end to CBT/GET and their removal from the Scottish Good Practice Statement. Whilst we support the use of appropriate psychological therapy aimed at supporting patients, we condemn the use of CBT based on the psychosocial model, which assumes that ME is perpetuated by patients' beliefs and deconditioning. We call for the immediate end to CBT and GET as treatment for ME patients.

3. Investment in biomedical research

Rationale: ME biomedical research has been significantly underfunded for many years, both in the UK and overseas. The UK Medical Research Council has highlighted ME as a priority area for research but, despite this, the level of research funding remains very low. The last research funded by the Scottish Chief Scientist's Office (CSO) was the PACE trial (2007-2011). This funding consisted of £250,000 for the PACE trial research and £165,055 to NHS Lothian for 'Excess Treatment costs'.

In 2018 the Scottish Government announced it would provide funding of £45,000 for a three-year PhD project (the rest of the funding was provided by Action for ME). Whilst this funding is welcomed, it is less than £1 per patient per year. This figure is very low; for example the comparable UK figure is £80 per patient per year for multiple sclerosis, a condition in which patients have a better median quality of life than people with ME. [3]

Underinvestment in research has resulted in a lack of knowledge about the causes and mechanisms of ME, a lack of diagnostic markers, and no effective treatments.

Change Needed:
A commitment to investing in a sustained programme of biomedical research by the Scottish Chief Scientist's Office and other relevant bodies, which is proportional to the disease burden.

- Commitment by the CSO to ring fence investment of £1 million a year in biomedical research. This would equate to approximately £48 per patient in Scotland.
- Establishment of a Scottish Centre of Excellence/centre without walls/collaborative research centre, with research and clinical care responsibilities. The Centre should help provide epidemiological analyses to inform clinical research and to provide effective

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[3] Hvidberg, M (2015) The Health-Related Quality of Life for Patients with Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS) *Plos One*,2015 Jul 6;10(7):e0132421. Available from: doi: 10.1371/journal.pone.0132421.

support and symptom management for patients. It should also identify strategic needs for collaborative research with national and international partners.

4. Education of healthcare professionals

Rationale: A wide range of organisations are responsible for the education and training of healthcare professionals in Scotland. These organisations all teach ME based on the psychosocial model, that ME is perpetuated by unhelpful beliefs (fear of activity) and/or deconditioning, and that it can be effectively treated with CBT/GET. GPs are currently the key healthcare professionals offering support and treatment for people with ME. Training of GPs is the responsibility of the Royal College of GPs, supported by NHS Education Scotland (NES), the specialist health board responsible for education and training of the healthcare workforce in Scotland. The roles of the three key organisations responsible for education are summarised below.

Medical Royal Colleges

The Medical Royal Colleges, including the Royal College of GPs, set the curricula for postgraduate and CPD training/education across the whole of the UK. The initial research we have conducted into the Royal College of GPs shows that the online module that teaches GPs about the *“presentation, diagnosis, assessment and ongoing management of CFS/ME”* uses the psychosocial model with a focus on the deconditioning theory. The current module recommends CBT/GET based on the PACE trial. The course was developed as part of the ‘Metric’ research project, funded by the National Institute for Health Research (NIHR).

University Medical Schools

Undergraduate curricula are set by the universities’ medical schools. A recent report from the TYMES Trust revealed that *“all five medical schools in Scotland teach ME as if it were a behavioural problem that can be ‘fixed’ through psychological interventions and management regimes such as cognitive behavioural therapy (CBT) and graded exercise therapy (GET)”*.[4]

NHS Education Scotland (NES)

NES develops material based on the curricula of the Medical Royal Colleges. NHS Education Scotland (NES) is an education and training organisation with the responsibility for developing

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[4] http://thirdforcenews.org.uk/blogs/if-the-government-wont-take-me-seriously-who-will [Last accessed 24/10/18]

and delivering education and training to the healthcare workforce in Scotland. Their remit falls into 2 main areas of activity: undergraduate education and postgraduate education.

Change needed:

- NES: should establish a training framework for ME, similar to its Autism Training Framework (see NES Annual Report 2016/2017), which should include a patient led working group.
- NES: creation of a continued professional development CPD module for GPs
- NES: current materials held in Psychological interventions in Physical Health to be changed as they contain misleading and potentially harmful information, including advice on using CBT ‘adapted for ME’ and graded activity (referring to Graded Exercise Therapy from the PACE trial.
- Royal Colleges: Scottish Government should call upon the Royal Colleges and medical schools to report on their approach to ME.
- Medical Schools: develop education programmes based on the appropriate organic disease model of ME, specifically for medical and allied professional undergraduate students.
- All ME education and training relating to the diagnosis of ME must be based on the International Consensus Criteria/ Canadian Consensus Criteria.
- CBT/GET must be removed from all NES education and training materials.
- All organisations’ education and training materials must comply with the classification of ME by the World Health Organisation in its International Classification of Diseases. A number of publications have identified distinct neurological changes in patients with ME.

5. Increased access to and investment in care for patients.

Rationale: The current state of care for patients in Scotland is urgent and critical. There are no specialist hospital consultants and only one specialist nurse in the country. Care is the responsibility of GPs who receive little or no training in ME, and what they do receive is often inaccurate and potentially harmful. The result of this lack of specialists means that patients are often referred by GPs to multiple consultants for investigation of their symptoms. We believe that having appropriately qualified ME specialist consultants would reduce the cost of care as referrals for individual symptoms would be reduced. Care and education go hand in hand. Therefore, with a significant investment in education, investment in care should be increased. ME patients deserve appropriate care. New Health and Social Care Partnerships (HSCPs) will influence the provision of care for ME patients, we intend to engage with these Partnerships, to use this as an opportunity for advancements of care.

Change needed:

- Funding for posts for specialist ME consultants in the fields of neurology and immunology.
- Clinical support for people with ME, including those severely unwell, through the provision of specialist nurses in each of the regional NHS Boards. The number of posts should reflect the population of the area.

- Identify the wider support needed by people with ME and assess how best this can be provided.