



Briefing for the Public Petitions Committee

Petition Number: [PE01690](#)

Petitioner: Emma Shorter on behalf of ME Action in Scotland

Subject: Review treatment of people with ME in Scotland

Calls on the Parliament to urge the Scottish Government to review the level of support for people with Myalgic Encephalomyelitis (ME) in Scotland with a view to:

- Investing in biomedical research and creating a centre of excellence for ME
- Ensuring healthcare professionals' training and education materials reflect the latest scientific evidence
- Providing specialist care for patients and discontinuing the harmful treatments graded exercise therapy (GET) and cognitive behavioural therapy (CBT).

Background

ME stands for myalgic encephalomyelitis. It is also sometimes referred to as chronic fatigue syndrome (CFS). However, there is some debate about the term used for the condition¹ and it is often referred to as ME-CFS.

ME-CFS is a long-term illness with a wide range of symptoms. The most common symptom is extreme tiredness¹. ME-CFS is more common in women and in patients aged from 35-55 years. However, it can affect men and women of any age and any ethnic group. Epidemiological evidence is lacking in Scotland but a population prevalence of at least 0.2-0.4% is widely accepted and it is thought that over 20,000 people in Scotland may be affected².

The diagnosis of ME-CFS is clinical, based on recognising specific symptom patterns. Currently, there are no specific tests available to confirm the presence of the illness. Prognosis is extremely variable. Most patients have a fluctuating course of illness with some people recovering, or improving significantly, in less than two years, while others remain ill for several decades².

¹ [NHS Choices website.](#)

² [Scottish Good Practice Statement on ME-CFS](#)

Guidelines

In 2010, the Scottish Government produced the [Scottish Good Practice Statement on ME-CFS](#) as a guide for health professionals on the diagnosis and management of ME-CFS. This was supported by two other pieces of guidance: [A quick reference clinical guide](#) and a [patient guide](#).

[NICE \(The National Institute for Health and Care Excellence\)](#) has produced a clinical guideline [chronic fatigue syndrome/myalgic encephalomyelitis \(or encephalopathy\): diagnosis and management](#). This is currently being updated and a [new guideline](#) is due to be published in 2020³.

The Scottish Government has indicated that any decision on reviewing the Scottish Good Practice Statement will be taken after the updated NICE guidelines are published, to ensure any changes are based on the most up to date clinical evidence available⁴.

Health care needs assessment of services

Also in 2010, the Scottish Government commissioned the [Scottish Public Health Network](#) to undertake a [formal health care needs assessment of services for those people who are living with ME–CFS](#). This assessment made 26 recommendations (see Annex A) including recommendations on the development of:

- the research strategy and the establishment of a centre for research excellence and dissemination.
- a specific tiered ME–CFS service
- managed clinical networks in order to ensure that there are effective and clinical services to meet the healthcare needs of people with ME–CFS.
- education packages, by NHS Education Scotland⁵ and independent organisations, to feed into undergraduate, foundation and professional training of healthcare staff across Scotland.

Research

ME Research UK is a charity which aims to commission and fund scientific (biomedical) investigation into the causes, consequences and treatment ME/CFS. They note that much of the existing research into ME has concentrated on psychological interventions designed to ‘manage’ the illness and comment that a programme of biomedical research is needed⁶.

³ It should be noted that these documents provide guidance to aid health professionals and clinicians, and are not statutory.

⁴ Scottish Government personal correspondence – May 2018

⁵ [NHS Education for Scotland](#) offers a wide range of education and training support for both clinical and non-clinical staff in NHSScotland.

⁶ [ME Research UK](#)

The Scottish Government's Chief Scientist Office and Action for M.E. have recently announced a [joint funding call for Scottish Universities to host a Ph.D. studentship in biomedical research into the underlying aetiology, diagnosis or treatment of ME](#). In May 2018, it was announced that the successful application is to be led by Professor Chris Ponting from the University of Edinburgh. The Ph.D. student funded through this initiative will use cutting edge techniques to analyse cells from the immune systems of ME patients compared to healthy controls. While not a clinical trial, this research has the potential to increase the understanding of the underlying causes of ME⁴.

Treatment

The [Scottish Good Practice Statement on ME-CFS](#) provides information on interventions, management and rehabilitation. In relation to graded exercise therapy (GET) it notes that:

“it is intended to redress decline in physical fitness due to inactivity. GET has proved to be a particularly controversial form of treatment about which many patients have concerns and some patients have indicated that GET has worsened their symptoms. GET makes use of an exercise programme involving a gradual increase in exercise/activity. It must be delivered by a suitably trained GET therapist with experience in ME-CFS, ideally on a one-to-one basis. Where fibromyalgia is also present, supervised aerobic exercise therapy may help physical capacity and relieve pain symptoms”.

In relation to cognitive behavioural therapy (CBT) it notes that:

“...it can be used, as in other chronic physical medical conditions, as a tool to aid people develop better ways of coping with symptoms such as fatigue, pain and sleep disturbance. CBT may be of particular value to patients when their symptoms have led to a psychological response that has compounded their problems”.

Scottish Parliament and Scottish Government Action

As part of its recent Inquiry into Clinical Governance, the Health and Sport Committee took oral evidence from Clare Ogden (Action for ME) on [14 November 2017](#)⁷. The Committee heard that:

“The “Scottish Good Practice Statement on ME-CFS” was published in 2010: when GPs were surveyed four years later, two thirds said that they were not aware of that statement...That is reflected in the patient experience, too—many patients say that their GP does not understand ME and gives them bad advice that does not help.”

⁷ [Written evidence was also received](#) – page 8 of Committee papers.

They also heard that in relation to ME:

“lots of recommendations that are made do not then become standards—in 2002 there was a short-life working group on ME, in 2007 cross-party group reports identified areas for action, and in 2010 there was a healthcare needs assessment. Lots of elements from all of those pieces of work have still not been put into practice.”

A [Members' Business debate](#) was held on the 11 May 2017 on International ME Day (S5M-05038). The Minister for Public Health and Sport commented on the Scottish Government's work with Action for ME. The Scottish Government has provided funding to the organisation to support project work aimed at making improvements in care for people with ME through increasing knowledge of the condition among health professionals and working to raise awareness, and promote self-management solutions. Action for ME were also awarded funding from the Transforming Self-Management Fund for a project which aims to build confidence and reduce isolation of people, and their carers, affected by ME and the development of a peer-mentoring, self-management support network in Scotland⁴.

Lizzy Burgess
SPICe 23 May 2018

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Annex A: Recommendations from the Scottish Public Health Network’s [formal health care needs assessment of services for those people who are living with ME–CFS](#).

1. It is recommended that the clinical, symptomatic definition of ME outlined in the Canadian guideline be adopted in Scotland.
2. It is further recommended that a symptomatic definition of CFS, based on that proposed in the NICE guideline, be adopted in Scotland.
3. a) There is an urgent need for a sound epidemiological study of ME and CFS in Scotland; in which regard consideration should be given to including ME and CFS within the Scottish Health Survey. b) Routine reporting of ME and CFS should be considered within the context of developing information systems for long-term conditions monitoring under the Quality and Outcomes Framework (QOF).
4. The existing research strategy in Scotland in relation to ME and CFS research should be reviewed by the Chief Scientist’s Office and a new strategy developed, aimed at broadening the evidence base for ME–CFS. To ensure effective communication of the existing, diverse evidence base, consideration could be given to developing a centre for research excellence and dissemination. It is recommended that to meet these expressed needs, health boards in Scotland should develop a specific tiered ME–CFS service that provides: <ul style="list-style-type: none"> - rapid and accurate diagnosis and assessment - supportive care and treatment of presenting symptoms - access to wider social and economic support.
5. It is recommended that the characteristics of such services would include a local management of care, provided by the primary care team at its heart and supported by a specialist team that can assist in the progress of diagnosis and assessment, and plan care on both a clinic and outreach basis.
6. At the present time there is insufficient research evidence on which to base a SIGN ME–CFS guideline for Scotland. However, a clinical guideline which supports effective diagnosis, signposts people with ME–CFS towards appropriate medical and therapeutic assessment and service, and provides the basis for ongoing care management is desirable. It is suggested that this is in keeping with the Scottish Good Practice Statement on ME–CFS.
7. It is recommended that the tiered model for services proposed by the CMO’s Short-Life Working Group be used as a basis for ME–CFS service development in Scotland.
8. It is recommended that a dedicated helpline and website to provide information and support for people with ME–CFS and those who care for them be established in Scotland.
9. A broadly constituted stakeholder group should be established to: <ul style="list-style-type: none"> a) create a national, core information set which can be used for people with ME–CFS and their carers b) create a national, core information set which can be used for health and social care professionals explore appropriate ways of making such information widely available.
10. NHS Boards in Scotland should develop formal, care pathways for the diagnosis, assessment and management of people with ME–CFS as outlined in the report of the CMO’s Short Life Working Group. These local pathways should be compatible with the Scottish Good Practice Statement on ME–CFS.
11. NHS Boards in Scotland should formally identify ME–CFS within their long-term conditions plan or strategy. Management of ME–CFS should be carried out in line with local arrangements for other long-term conditions, where appropriate.
12. When developing local approaches to long-term conditions management, NHS Boards should ensure that: <ul style="list-style-type: none"> a) assessment and review mechanisms are in place for people with ME–CFS, including domiciliary assessments/reviews where needed b) appropriate referral mechanisms are in place so that people with ME–CFS can receive appropriate supportive therapies c) appropriate referral mechanisms are in place so that people with ME–CFS can access

services that can meet specific, symptomatic needs.
13. When developing local approaches to long-term conditions management, NHS Boards should ensure that both rehabilitation services and specialist, symptom-specific services have sufficient capacity to support people with ME or CFS in addition to the many other people with long-term conditions for whom they will be providing care.
14. Local arrangements for transition to adulthood should be extended to cover the needs of young people with ME–CFS. These arrangements should be included in local care pathways.
15. NHS Boards in Scotland should develop, or assist the development of, self-management programmes to support people with ME–CFS. These programmes should be subject to appropriate quality assurance: <ul style="list-style-type: none"> a) for the NHS, such quality assurance should be provided by NHS Quality Improvement Scotland b) for the independent or third sectors, guidance on quality assurance should be developed on a wide, partnership basis.
16. Consideration should be given to developing an appropriate regulatory framework for the provision of self-management programmes by independent or voluntary sector providers as for independent healthcare providers.
17. Consideration should be given as to how best to assist the development of consultant posts for ME–CFS at NHS Board or NHS Regional Planning Group level across Scotland. These consultants should lead multidisciplinary teams to provide services at Tier 3.
18. Consideration should be given as to how best to provide an appropriate skill-mix in medical provision as part of the multidisciplinary teams to provide services at Tier 3.
19. NHS Boards or NHS Regional Planning Groups should prioritise the development of consultant-led services, supported by a Tier 3 multidisciplinary team for ME–CFS. Consideration should be given to a more detailed workforce plan in the medium term. In establishing multidisciplinary teams, the NHS Boards or NHS Regional Planning Groups should: <ul style="list-style-type: none"> a) ensure that once staff are appointed, an appropriate period of staff training is funded to allow an effective service to be established b) ensure that multidisciplinary teams have a suitable lead in time to develop effective collaborative working arrangements with local services at Tier 2.
20. NHS Boards and NHS Regional Planning Groups should develop managed clinical networks in order to ensure that there are effective clinical services to meet the healthcare needs of people with ME–CFS
21. NHS Boards and NHS Regional Planning Groups, working with key stakeholders, should decide how best to ensure the development of such clinical networks for ME–CFS both regionally and across Scotland.
22. NHS Boards should ensure that services which operate at Tier 2 for ME–CFS should have the opportunity and capacity to participate in the development and operation of the clinical networks at regional and national level.
23. NHS Quality Improvement Scotland should work with all interested parties to develop service standards for ME–CFS services in Scotland. Consideration should also be given to developing specific standards for clinical networks as part of this development.
24. NHS Education Scotland should work with independent ME–CFS organisations to develop solutions to ME–CFS issues which would be included within education packages. These should be fed into undergraduate, foundation and professional training of healthcare staff across Scotland.
25. The third sector and independent sector agencies that work with and for people with ME–CFS should explore how best they can develop educational support for healthcare providers modelled on the approaches of similar agencies.
26. The existing research strategy in Scotland in relation to ME and CFS research should be reviewed by the Chief Scientist's Office and a new strategy developed, aimed at broadening the evidence base for ME–CFS. To ensure effective communication of the existing, diverse evidence base, consideration could be given to developing a centre for research excellence and dissemination.