



M.E. Time to deliver in Scotland



Scottish Parliament roundtable report 14 May 2014

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Introduction

Myalgic Encephalomyelitis (M.E.), sometimes diagnosed as Chronic Fatigue Syndrome (CFS) or M.E./CFS, is a long-term (chronic) fluctuating illness that affects an estimated 250,000 men, women and children in the UK, including 20,000 people in Scotland.

Symptoms include post-exertional malaise (a period of intense exhaustion that lasts for more than 24 hours following exertion) and chronic pain, plus sleep disturbance, 'flu-like symptoms such as headache, sore throat, painful lymph nodes, dizziness and/or nausea and problems with memory and concentration. M.E./CFS affects different people in different ways and symptoms can fluctuate and change over time.

Action for M.E. is a charity for people affected by M.E./CFS, led by people with M.E./CFS. Our mission is empowering people with M.E./CFS to fulfil their potential and secure the care and support they need, while working towards a greater understanding of the illness and ultimately a cure.

This report presents key initial findings from the 197 people with M.E./CFS in Scotland (out of 2,081 total UK respondents) who took part in Action for M.E.'s 2014 health, welfare, employment and education survey.

M.E. Time to deliver, our report and recommendations on UK survey results as whole, can be downloaded at www.actionforme.org.uk/timetodeliver

Not every respondent completed the survey; percentage counts given reflect the views of those that answered a particular question.

More detailed analysis is being undertaken by a team of researchers, clinicians, Action for M.E. staff and volunteers, and subsequent reports and recommendations will be produced.

In addition to working with the data you will read about in this report, and using it for our informing, influencing, empowering and supporting work, Action for M.E. drives and invests in research.

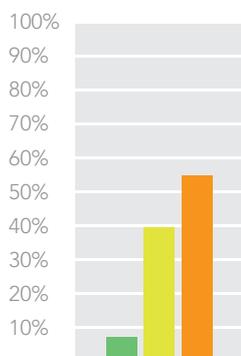
Action for M.E. is working closely with clinicians and researchers such as Professor Julia Newton at Newcastle University, alongside other charities and donors, to increase funding for pilot projects, such as the unique M.E./CFS Biobank, which has gone on to secure \$1.5 million in funding from the National Institute of Health in the United States. Mainstreaming M.E research is, for the first time, becoming a real possibility.

Who is affected by M.E.?

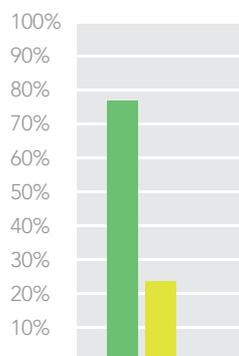
Survey respondents by Health Board



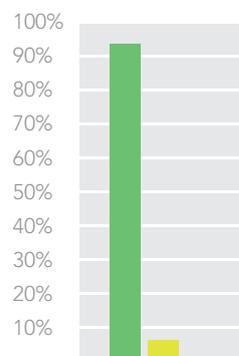
Age



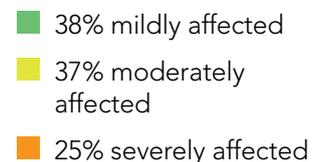
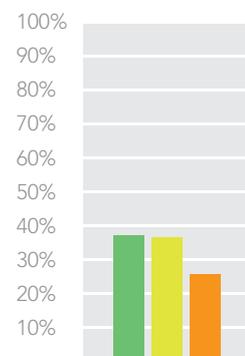
Gender



Ethnicity



Severity of symptoms



"I was an infant school teacher and kept going as long as I could, then had to give in. I never regained consistent health and was diagnosed with M.E. four years later. I have tried voluntary work but couldn't keep that up, even though it was very flexible. I have too much brain fog to drive more than short distances – I don't feel safe – and I hate the feeling of not being reliable for friends or family in need due to fluctuating symptoms. I have moments when I grieve for the life I had before M.E. but have been able to accept and adapt, largely due to my wonderfully supportive late husband who always believed me." M.E./CFS patient, Lothian

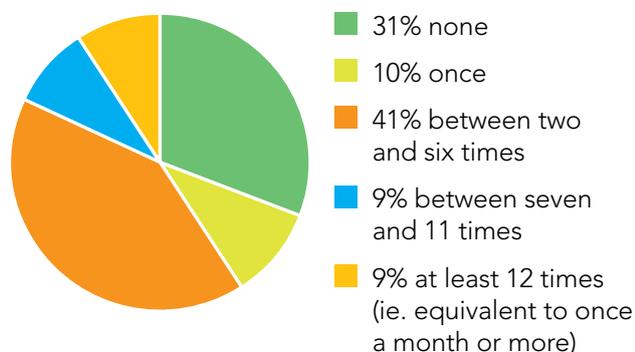
M.E./CFS is widely reported to be more common in women than it is in men.

The very low number of respondents from black and ethnic minority (BME) communities may reflect Action for M.E.'s membership profiles and/or challenges in reaching this particular demographic. Additionally, research^{1,2} has suggested that cultural values affect the diagnosis and management of M.E./CFS in BME communities.

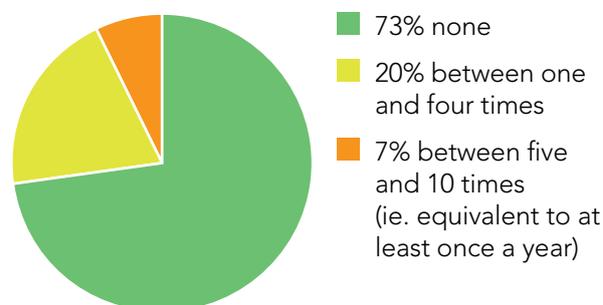
The Scottish Good Practice Statement (SGPS) for ME-CFS³ outlines three levels of severity – mild, moderate and severe – which we refer to in this report. It is estimated⁴ that around a quarter of people with M.E./CFS are severely affected, a figure supported by our survey results.

Contact with healthcare professionals

Number of times survey respondents had seen their GP in the past year



Number of times survey respondents had attended an NHS M.E./CFS clinic to see a specialist in the past five years



For those respondents who have been to a specialist NHS M.E./CFS clinic in the past five years, 50% told us it was not in their local area.

"My GP is as informed and supportive as they could be. However, we are all in the dark as to how to move forward." M.E./CFS patient, Tayside

"I go into every treatment hopeful that it will help and they do, for a short time, then it all fades and I am back where I started - only with far less money. I could have paid off my mortgage with the money I have spent on treatments and I am devastated when they fail. I try not to blame myself because I do everything that is asked of me. It's just that one thing works for one person and yet not for the next person in the waiting room. I feel so alone in managing this illness." M.E./CFS patient, Ayrshire and Arran

Specialist NHS coverage for M.E./CFS in the UK is, for many, a post code lottery. Responding to Action for M.E.'s 2012 investigation⁵ into NHS services for M.E./CFS, only two out of 14 Health Boards in Scotland confirmed that they had specialist secondary services for M.E./CFS.

We recognise the financial pressures that Health Boards face. Nevertheless, it's imperative that health inequalities be reduced for people with M.E./CFS in Scotland, with each having access to specialist NHS care in their Health Board area.

Having little or no contact with their healthcare professional means that vulnerable patients are considerably less likely, or unable to:

- have their condition monitored
- have their medication reviewed regularly
- discuss new or changing symptoms
- access support around setbacks or relapses
- seek help or assistance with welfare benefit claims.

People with M.E./CFS should be able to have confidence in their primary healthcare professional. But 82% of GPs in Dumfries and Galloway, Fife and Highland surveyed by Action for M.E. said they had not undertaken any training on M.E./CFS, while 66% told us they were not aware of the SGPS³ for M.E./CFS. It is clear that GPs must be supported to have a better understanding of the illness if they are to meet patients' needs and make improvements to the efficiency and effectiveness of health (and integrated) services.

Action for M.E. asks: "How can we work towards personalised healthcare that takes into account the specific needs and complex symptom presentation of people with M.E./CFS?"

Person-centred care and self-management

When we asked survey respondents in Scotland what would make a real difference to their healthcare:

- 74% said a better informed GP
- 31% said having more of a say in their treatment.

"First, I need a doctor to believe that I am physically ill. Second, treat me with painkillers so that I can function (move over in bed without whimpering in pain) and refer me to everyone and anyone who has knowledge of the illnesses I now have in order to have them treated. I am so tired of having spent 25 years in the wilderness, seeking treatments myself, educating myself and finding only one or two doctors who actively adore the fact that they have a well-informed patient."

M.E./CFS patient, Ayrshire and Arran

We asked them what support was offered by the NHS in addition to their chosen course of treatment.

- 70% said no support
- 12% were referred to a self-management programme.

"I was offered a group self-management course for long-term conditions in a nearby town but it was completely inappropriate as I've been village bound for years so a) I can't get there and b) even if I could it would be way too much. I can only manage things for 20 minutes at a time."

M.E./CFS patient, Tayside

Research⁶ indicates that a good relationship with the GP from the outset of the illness is very important in achieving a good outcome and avoiding severe illness.

People also told us about their interactions with other healthcare professionals. Those who were most positive about their experience consistently told us that their healthcare professional offered:

- an open-minded, holistic approach that takes physical symptoms and their emotional impact into account
- clear knowledge of M.E./CFS and experience of supporting patients with the condition
- a willingness to listen and work collaboratively with the patient.

The Patient Rights (Scotland) Act⁷ aims to improve patients' experiences of using health services and to support people to become more involved in their health and social care.

Action for M.E. asks: "How can appropriate information about self-management be shared with people with M.E./CFS to give them the best chance of recovery in the long term?"

Joined up health and social care



49% of survey respondents said joined-up health and social care would make a real difference to them.



81% not had a social care assessment in the past five years

"I was given a social worker just as the social care cuts were made. It took a year for them to tell me that there was no money for people like me." M.E./CFS patient, Fife

The new Public Bodies (Joint Working) (Scotland) Act⁸ requires Health Boards and local authorities to integrate their health and social care services, while the Social Care (Self-directed Support) (Scotland) Act⁹ obliges local authorities to offer those needing social care the option of designing their own care package.

People who took part in our survey would agree that this could be helpful. But even at a basic level, many are potentially missing out on support with personal and domestic care, aids and adaptations for their home and Personal Budgets because their social care needs are not even being assessed.

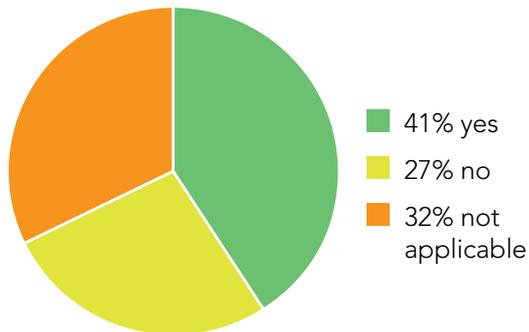
Action for M.E. asks: "What steps can be taken to improve access to joined-up health and social care for people with M.E./CFS, in order to give them the support they need to manage their symptoms?"

Welfare, employment and education

Welfare benefits

- 28% of survey respondents in Scotland were currently in receipt of ESA
- 32% were currently in receipt of DLA
- 75% of those who had applied for PIP were still waiting for their application to be processed
- 77% said they were worried about the impact of welfare benefit reforms

Was your GP helpful when it came to providing supporting evidence for your welfare benefit application or appeal?



"We could manage as my husband has his police pension and a part time job, but my benefit pays for the osteopath and all the supplements and fresh food. It would be more difficult to keep myself going without all that. If I lose DLA it will be a huge impact if we have to buy a car and insure it. It's a constant worry at the back of my mind and when a letter comes through the door my stomach turns." M.E./CFS patient, Fife

Employment and education

- 12% of survey respondents in Scotland were in full-time paid work, education or training
- 21% were in part-time paid work, education or training
- 40% said they did not receive any specialist support at work, school or college

"I can use occupational health if I need to but my employer is fairly rigid in treating all staff members the same regardless of circumstance." M.E./CFS patient, Forth Valley

Even just an initial examination of peoples' experiences of claiming welfare benefits tells a familiar story. The whole process is very stressful, lost or delayed applications are common, assessors make uninformed assumptions about claimants' capabilities, and the process itself is still not suitable for fluctuating conditions such as M.E./CFS.

Supporting medical evidence from GPs and other healthcare professionals can make a crucial difference to the success of a claim or appeal. Last year, GPs reported a 21% increase¹⁰ in requests for supporting medical evidence, having a disproportionate impact on the time GPs could spend with patients.

The Department for Work and Pensions holds overall responsibility, and must seek to improve the process and delivery of welfare benefits for people with chronic, fluctuating conditions. We note that its decision to employ a new contractor to carry out WCA,¹¹ and to accept the recommendations of the fourth independent review¹² of the WCA, offer possible opportunities for change.

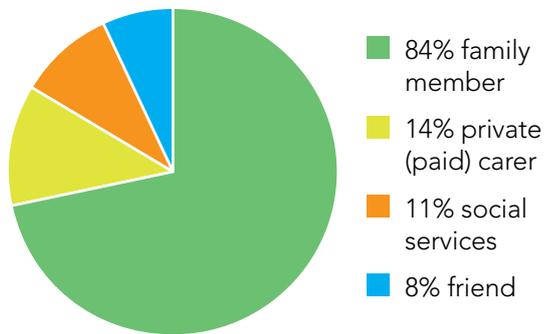
Research¹³ funded by Action for M.E. and the National Institute for Health Research estimates lost earnings of more than £102 million a year to the UK economy as a result of M.E./CFS.

While there are limits to the reasonable adjustments that employers can realistically be expected to make, we know from experience that providing support at the right time and in the right way can enable people to either stay in work or to leave their current employment on positive terms. At present there is no specialist employment support for people with M.E./CFS.

Action for M.E. asks: "How can people with M.E./CFS be supported to access the welfare benefits they are entitled to? For those that are improved enough to consider a return to work, how can support and information specific to the particular needs of those with M.E./CFS be shared with them, their colleagues and their employers?"

Carers

People providing care to help survey respondents with daily activities (some chose more than one option)



"My primary carer is my mother and caring for me has devastated her. She is exhausted from the daily grind of watching her only adult child suffer so much. I hate to have to tell her that something else is hurting and could she just... She looks, almost always, as though she could burst into tears."

M.E./CFS patient, Ayrshire and Arran

84% of people with M.E./CFS said their friend or family carer had not received a carers assessment, including all the carers who were under 18.

Research¹⁴ by Carers UK has found that 70% of carers are more than £10,000 worse as a result of caring, while 30% had seen a drop of £20,000 a year in their household income.

In order to improve support for carers, the Scottish Government has set out its intention to be "proactive in ensuring that carers know about the right to request a carer's assessment and that up-to-date information on carers' support is available."¹⁵

There are specific needs for those who take on a caring role for people with M.E./CFS. In part these are due to the fluctuating needs of M.E./CFS, but they also relate to the needs of carers themselves.

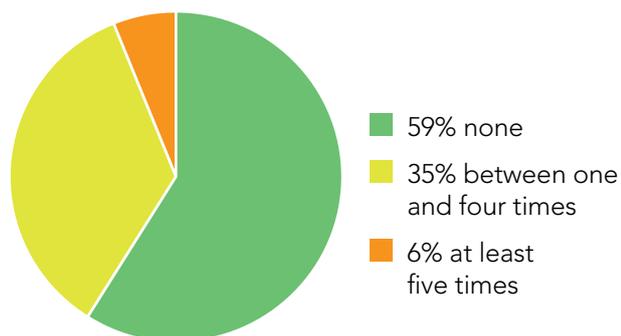
Action for M.E. asks: "How can access to information about carers rights and entitlements be improved, and how can GPs and other healthcare professionals be supported to recognise and signpost carers to appropriate sources of help and support?"

Severe M.E./CFS

48% of survey respondents with severe M.E./CFS in Scotland said their GP was poorly or very poorly informed about M.E./CFS. In the past year:

- 24% hadn't seen their GP at all
- 40% had seen their GP between one and six times
- 3% had seen their GP between seven and 11 times
- 11% had seen their GP at least 12 times

Number of years respondents with severe M.E./CFS had attended an NHS clinic to see a specialist in the past five years



"My husband takes care of me. I am mostly bedridden, and get out perhaps once a month, frequently less. I eat my meals in bed. I've lost contact with most of my friends as I cannot even have a telephone conversation as I am too weak. My family are the only contact I have and I live vicariously through them."

M.E./CFS patient, Forth Valley

60% of people with severe M.E./CFS had not had a social care assessment in the past five years, with 8% being given a Personal Budget (it's not clear if this was just because of their M.E./CFS, or if additional conditions were taken into account).

The SGPS for M.E./CFS³ acknowledges that people with severe M.E./CFS require "a very individualised approach, with care being delivered in the patient's own home as much as possible. It is vital for clinicians to be aware that there is very little research evidence on management of such patients and that simple extrapolation from other patient groups is usually inappropriate."

Research¹⁶ indicates that the number of patients who reported a bad relationship with their GP was significantly higher among those with severe M.E./CFS, before and after diagnosis.

Action for M.E. asks: "Severe M.E./CFS is a complex condition. How might targeted support and care be provided to this patient group?"

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