



M.E.

Time to deliver



Initial findings of Action for M.E.'s 2014 survey

Foreword

M.E./CFS is a chronic disabling condition that can have a devastating effect on people's lives.

This report, based on initial findings from a survey carried out by the charity Action for M.E., demonstrates the often stark reality for the 250,000 men, women and children in the UK who live with it every day.

More than 2,000 people with M.E./CFS took part in the survey, describing the effect of the condition on their personal relationships, their employment and education, and their experience of health, welfare and social care services.

It's clear from the results that appropriate services and support for people with M.E./CFS need to be far more targeted and timely, and that more research into the biology of M.E./CFS is urgently needed. There's also overwhelming evidence that widespread ignorance about the condition is still having a huge impact on people with M.E./CFS, their carers and their families.

This report, published on M.E. Awareness Day 2014, aims to highlight the severity of the problem. We ask the public, the medical profession, the Government and the media to read and share its contents – but more importantly, to commit to working with Action for M.E. to bring about real change. The needs of people affected by M.E./CFS must no longer be ignored or forgotten.

Clare Francis
President
Action for M.E.
12 May 2014

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Executive summary

Myalgic Encephalomyelitis (M.E.), sometimes diagnosed as Chronic Fatigue Syndrome (CFS) is a long-term (chronic) fluctuating illness that causes symptoms affecting many body systems.

Between December 2013 and February 2014, 2,018 people with M.E./CFS took part in a survey run by Action for M.E., the UK's leading charity for people affected by M.E./CFS.

This report presents key initial findings under the following headings. 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.

Location, age, gender and ethnicity

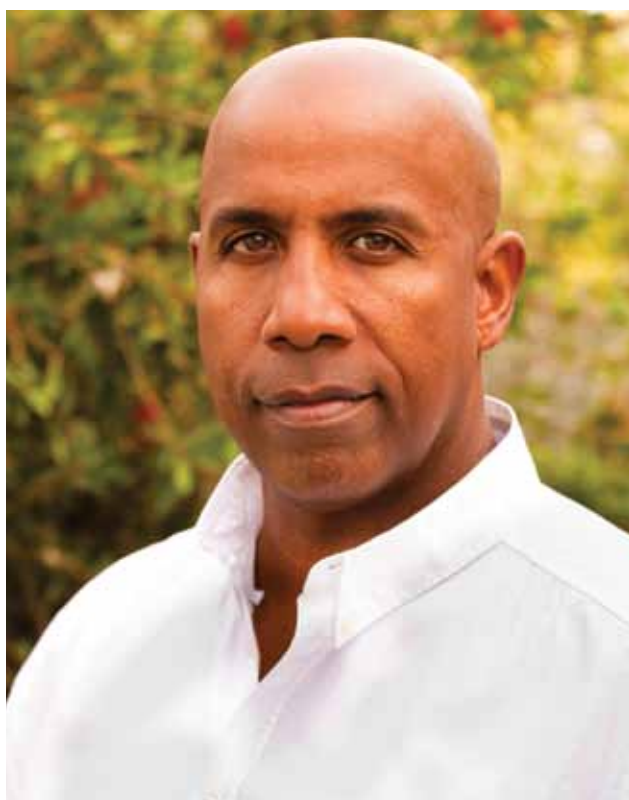
- People lived in England (84%), Scotland (10%), Wales (4%) and Northern Ireland (2%); case studies from each have been included. More than half (53%) were aged 50 or above, while 38% were aged 30 to 49 years; 82% were women and 97% told us they were White British, White Irish or White Other.

Impact of symptoms

- People told us they were mildly (36%), moderately (42%) or severely (22%) affected by M.E./CFS, and nearly two-thirds (58%) had experienced symptoms for 10 years or more.
- Around 90% of people with M.E./CFS had stopped or reduced paid work and social contact, while half had reduced or lost capacity to drive and a quarter were no longer able to leave their home independently.

Primary healthcare

- In the past 12 months, around a third of people with M.E./CFS had not seen their GP about their symptoms; around 1 in 20 people with M.E./CFS had seen them 12 times (ie. equivalent to once a month).
- Less than a third said their GP was well or very well informed about M.E./CFS, and nearly half said the service they provided was poor or very poor. GPs themselves have also identified the challenges they face with regards to M.E./CFS.



Secondary healthcare

- Specialist NHS coverage for M.E./CFS is patchy, with several areas not served at all, particularly in Scotland, Wales and Northern Ireland. More than half of people with M.E./CFS (54%) had not attended an NHS M.E./CFS clinic at all in the past five years.
- About 40% of people who had attended an NHS M.E./CFS clinic rated it as good or very good; a third rated it as poor or very poor.
- NHS consultants (ie. not part of a specialist M.E./CFS service) rated as the most well-informed were occupational therapists, immunologists and paediatricians. Those rated as providing the best service were occupational therapists, immunologists and clinical psychologists.
- Two thirds of people with M.E./CFS had used pacing as to help them manage their symptoms, a 10% increase on our 2008 survey results.
- A third of people with M.E./CFS had tried cognitive behaviour therapy; half said they found it helpful or very helpful, while around one in 10 said it made them a bit or much worse.
- Around one in five people with M.E./CFS had tried graded exercise therapy; a third said they found it helpful or very helpful, while nearly half said it made them a bit or much worse.
- People with M.E./CFS told us the most helpful complementary approach they had tried for symptom management was meditation/mindfulness, followed by yoga and massage.
- More than half were not offered any follow-up NHS support at all in addition to their chosen treatment.

Improving healthcare

- More than two-thirds said having a GP who understands M.E./CFS would make a real difference to their healthcare; more effective medication was a close second, supporting the need for more research into targeted treatments.
- The most frequently cited barriers to healthcare were lack of follow-up/ongoing care and lack of NHS specialist in the respondent's area. Nearly half said they were simply too ill to access treatment.

Welfare benefits and social care

- More than 80% of people with M.E./CFS told us they had not had a social care assessment in the past five years, causing them to potentially miss out on support.
- People find claiming the welfare benefits they are entitled to very stressful, with frequent stories of lost or delayed applications, and assessors making uninformed assumptions about claimants' capabilities. The process itself is still not suitable for fluctuating conditions such as M.E./CFS.
- Around a fifth (21%) told us their GP was not helpful when it came to providing supporting evidence for their welfare benefit application or appeal. This evidence can make a crucial difference to the success of a claim or appeal.

Employment and education

- Less than one in 10 people with M.E./CFS told us they were in full-time paid work, education or training, with only 14% in part-time paid work, education or training.
- More than a third said they received no specialist support at their work, school or college, despite measures for this being set out in the Equality Act 2010.

Carers

- More than 80% of people with M.E./CFS said their primary carer was a family member, which is likely to have a significant financial and emotional impact on the household as whole. Almost none had received a carers assessment in the past five years.
- Two thirds said their family carer was aged 50 or above, which means the burden of care is falling on older partners and parents who might otherwise be preparing to retire, or already be retired. 15% were aged 70 or above, and the oldest family carer was 91.
- Very little is known about children and young people who, while they may not be named specifically as a carer, nevertheless take on a caring role in families where one of their parents or siblings have M.E./CFS.

Severe M.E./CFS

- The impact of severe M.E./CFS can be devastating and long-lasting. Two thirds of people with severe M.E./CFS had been ill for 10 years or more.
- Nearly half had seen their GP once or not at all in the past 12 months, and more than half had not visited a specialist NHS M.E./CFS clinic at all in the past five years.
- Nearly two thirds of people with severe M.E./CFS had not had a social care assessment in the past five years.
- More than a quarter (27%) of people with severe M.E./CFS who had applied for Employment and Support Allowance in the past year had had their level of benefit reduced or removed altogether. One in five told us that their GP had not been helpful when it came to providing supporting evidence for their claim or appeal.
- Nearly one in five people with severe M.E./CFS had applied for Personal Independence Payment in the past 12 months, but more than three-quarters (77%) were still waiting to have their applications processed.

Sonya Chowdhury, Action for M.E. Chief Executive, comments:

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.

I believe the data revealed by this report can help us do this. It gives us flavour of the what it's really like to live with M.E./CFS in the UK in 2014, shaping our direction and keeping patient voice at the heart of what we do.

Using what people with M.E./CFS have told us, this report makes a number of recommendations about how we can move forward, building on the expertise of patients, clinicians, researchers and care professionals to produce tangible results.

We are a small charity with limited resources but we are committed and passionate about working collaboratively to achieve the change that is desperately needed. Together, we can make a difference to the lives of those affected by M.E./CFS.

Introduction

What is M.E./CFS?

Myalgic Encephalomyelitis (M.E.) is a long-term (chronic) fluctuating illness that causes symptoms affecting many body systems, more commonly the nervous and immune systems. Common symptoms include severe fatigue associated with post-exertional malaise (the body's inability to recover after expending even small amounts of energy, sometimes also called payback), chronic pain, sleep difficulties, cognitive problems (collectively called brain fog) and hypersensitivity to light, smell or sound.

Within the NHS, a diagnosis of Chronic Fatigue Syndrome (CFS) or M.E./CFS is often given. We have chosen to use the term M.E./CFS throughout this survey to include people with both diagnoses.

M.E./CFS affects an estimated 250,000 men, women and children in the UK. There is much debate about its underlying cause, treatments and what does/doesn't work. There is currently no drug therapy directed specifically at M.E./CFS. Current theories about the cause of M.E./CFS include autoimmune deficiencies, viral infections, autonomic/sympathetic/central nervous system dysfunction and genetic factors, amongst others.

There is growing evidence¹ from experts in the field of M.E./CFS that a number of sub-groups exist within M.E./CFS, on the basis that individuals within these sub-groups differ in terms of their illness experience and the course their illness follows over time. This may well explain the huge variation observed by doctors in the progression of the illness and underlines the difficulty of making a prognosis.

There are a number of published diagnostic criteria² for M.E./CFS. We have chosen to refer to the National Institute for Health and Care Excellence (NICE) guideline for M.E./CFS³ and the Scottish Good Practice Statement (SGPS) for ME-CFS⁴ because these are most commonly in use by the NHS.

As there is no specific single test to detect M.E./CFS, diagnosis is made after other possible known causes for symptoms have been excluded.³ "This should be a positive clinical diagnosis made on a well-characterised constellation of symptoms," says Dr Alastair Miller, Principal Medical Adviser, Action for M.E.

How and why we surveyed people with M.E./CFS

In December 2013, Action for M.E. sent out paper copies of a 52-question survey to each of its Supporting Members. An online version of the survey was also promoted to other people with M.E./CFS via our Online M.E. Centre (www.actionforme.org.uk) and through our social media sites. The survey closed on Friday 14 February 2014, with 2,081 people having responded (1,231 online and 850 completed paper copies).

We specifically targeted adults, and as a result only 1% of respondents were under 18. However, it's important to acknowledge that M.E./CFS is a "relatively common and serious condition in children and young people, having a significant impact on their physical, emotional and cognitive well-being."⁵ Research also shows that it is a major cause of long-term school absence.⁶

As with any survey of this type, respondents were self-selecting, therefore they cannot be assumed to be representative without systematic sampling to avoid intrinsic bias. Nearly three-quarters of respondents told us they had had the symptoms of M.E./CFS for five years or more. So, the sample may be skewed to reflect the experiences of people who have been ill for a long time. Similarly, those whose symptoms improved quickly may have been less likely to take part in the survey.

Not every respondent completed the entire survey, so the percentage counts given reflect the views of those that answered a particular question. Nor does this report give detailed response data for each question.

The purpose of the survey was to collect updated data, in a structured and methodical way, to help identify:

- how people with M.E./CFS, particularly the severely affected, access healthcare and what barriers they face in doing this
- areas of good practice, to use as a benchmark for improvement elsewhere
- any changes that have taken place since a similar survey was undertaken by Action for M.E. in 2008
- what effect the welfare benefit reforms are having on the health and wellbeing of people with M.E./CFS
- what steps we can take to improve outcomes for people affected by M.E./CFS in the areas of health, welfare, education and employment.

Because of the volume of information we received, we are still analysing some of the responses, and identifying the points set out above. We will release these results in due course.

Location, age, gender and ethnicity

We asked people with M.E./CFS where they lived.

People who took part in our survey live:

- 84% in England
- 10% in Scotland
- 4% in Wales
- 2% in Northern Ireland.

These figures broadly reflect population distribution for the UK (ie. 84% in England, 8.3% in Scotland, 4.8% Wales and 2.9% in Northern Ireland).⁷

Specific results and case studies for England, Scotland, Wales, and Northern Ireland will be highlighted where appropriate; in addition we have also produced a short Scotland-specific report.⁸

We asked them for their date of birth.

More than half (53%) were aged 50 or above, while 38% were aged 30 to 49 years.

M.E./CFS is widely reported to be more common in women than it is in men, evidenced by our results for the UK as a whole:

- 82% were women
- 18% were men.

This distribution was roughly the same across England (83% women) and Scotland (78% women), though less so in Northern Ireland (73% women) and Wales (66% women).

We asked survey respondents if anyone else in their family had M.E./CFS

Around a fifth (22%) said yes. While M.E./CFS is not strictly hereditary there is some evidence for “a heritable contribution to predisposition” to the condition.⁹

We hope our data may be useful for future research in this area.

We asked people about their ethnicity.

97% of people with M.E./CFS told us they were White British, White Irish or White Other. 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^{10,11} has suggested that cultural values affect the diagnosis and management of M.E./CFS in BME communities.

Our recommendation

Everyone affected by M.E./CFS needs targeted care and support, empowering them to secure the care and support they need.

Action for M.E. will:

- aim to collaborate with agencies that work with BME communities to identify ways of improving awareness of and access to information and support for these patients and their families.

Impact of symptoms

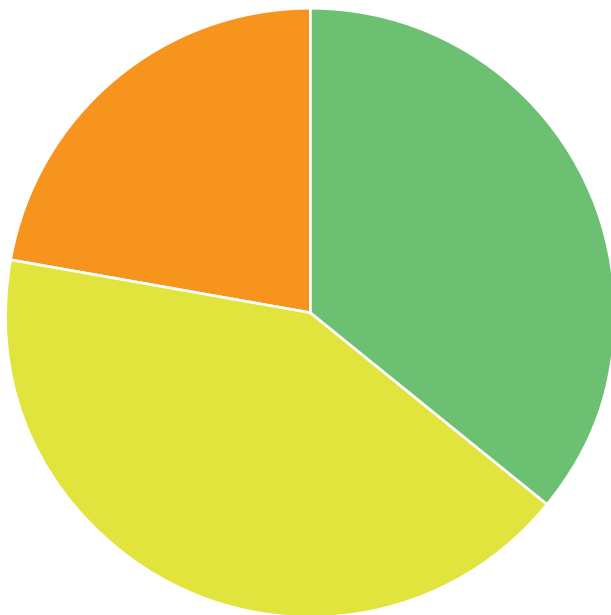
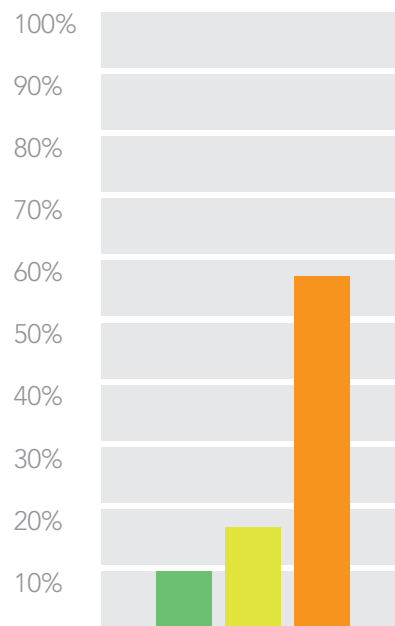
We asked people how long they had been ill.

Respondents told us they had the symptoms of M.E./CFS as follows:

- 10% for four years or less
- 17% for five years to nine years
- 58% for 10 years or more.

We also asked people how long they had experienced the symptoms of M.E./CFS, and how long it has been since they were diagnosed, and are still working on analysing this data.

However, initial results indicate that, despite the NICE clinical guideline for M.E./CFS stating that symptoms should be present for four months before diagnosis is made, a significant number of people with M.E./CFS wait much longer, potentially delaying access to specialist care and support.



We asked people about the severity of their symptoms.

The NICE guideline for M.E./CFS³ outlines three levels of severity – mild, moderate and severe – which we refer to in this survey. Other sources^{12,13} define the spectrum of severity slightly differently, from mild to moderate to severe to very severe.

It is estimated¹⁴ that around a quarter of people with M.E./CFS are more severely affected than others, a figure broadly supported by our survey results:

- 36% were mildly affected (fairly mobile, can care for themselves and can do light domestic tasks with difficulty)
- 42% were moderately affected (have reduced mobility and are restricted in all activities of daily living)
- 22% were severely affected (unable to do any, or only minimal, activities).

We asked people about the impact of their symptoms.

The symptoms of M.E./CFS can have a significant impact, and not just for those who are severely affected. People who took part in our survey told us:

- 87% had stopped or reduced paid work
- 29% had stopped or reduced education
- 92% had stopped or reduced social contact
- 22% said it affected decision to have children
- 51% had reduced/lost capacity to drive
- 26% were no longer able to leave their home independently

It's important to note that, even for those who told us they have mild M.E., 87% had stopped or reduced social contact, 82% had stopped or reduced paid work, and 31% had experienced reduced/lost capacity to drive.

People with M.E./CFS across the UK told us:

"I became ill when I was 13. I dropped mostly out of school, although I managed with the help of parents and teachers to carefully pace myself in studying for three GCSEs. Later, I went back to school part-time for three A-Levels over three years. I managed to get my degree, though my health deteriorated and in my last year I had to drop half the modules. I currently manage, with help from my mother and people paid to do household tasks, to live on my own with a cat for company. Money is a significant concern, as I have nothing other than benefits to live on, and no realistic prospect of investing in a private pension as most people my age are being advised to do. I rarely see any friends. The ones who don't have M.E. live too far away and have careers and families that occupy their time. I miss talking to people. I wish I had a partner to lean on and confide in."



"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've tried yoga and swimming but the post-exertional fatigue is too much. 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."



"I have had to give up a well-paid job as a pharmacy technician, and my husband lost his job because he had to care for me. I have two new grandchildren and cannot spend as much time with them as I want to, or have them to stay over. I also have not been able to visit my daughter or elderly father-in-law, who live in England."



"I was very sporty, playing to a high level, but since 1993 I haven't been able to resume that. When I have tried I have had mini relapses. I also have limited social activities as they take so much out of me."



We asked people about the impact of their symptoms on those close to them.

Having a chronic, fluctuating illness affects more than just the person with M.E./CFS. People told us about the impact of their condition on their family and friends, including:

- emotional strain on relationships as husbands, wives and partners take on caring roles, sometimes giving up work to do so
- pressure on elderly parents who take on caring of ill adult children
- family and friends not believing that M.E./CFS is real
- the financial implications of not being able to work, such as no family holidays
- friends drifting away as symptoms do not improve.

We look more at the impact of M.E./CFS on carers on p 25.

People with M.E./CFS across the UK told us:

"My partner is my carer, which has had a considerable emotional effect and has contributed to her being made redundant. She has lost most of her social life because she is looking after our boys and me. There has also been a serious effect upon our finances. Our sons have also been affected by me not being able to contribute to their lives. Being housebound and unable to cope on my own has meant they have not had a holiday for five years. Most of my friends, family and neighbours disappeared as soon as I was diagnosed."



"I no longer have many friends as I am unable to keep up the social contact I had before I became ill. Some of them do not understand the condition and have turned their backs on me. My family relations are very stressed and the pressure of support had taken its toll on my wife. We have almost divorced a couple of times."

"My mum picks up a huge burden because I now live back at home with her and my dad. She shops and cooks for me, on top of running the household and working in a demanding job. At 60, she can't retire yet and has to carry on despite having a long-term condition herself. I'm 34. She shouldn't have to still have to care for me at this age."



"For a number of years my daughter was, from the age of nine, my main carer while her dad was at work. My husband is now my main carer on top of a full-time job. There is still a lack of understanding about my condition amongst my extended family."

Primary healthcare

We asked people how often they saw their GP about M.E./CFS.

Because of the fluctuating nature of M.E./CFS, with new symptoms appearing and others flaring up or receding, seeing a GP regularly is recommended.

6% of respondents told us they had seen a GP 12 times (ie. equivalent to once a month) or more in the past year, though a number of people told us they were having additional or alternative telephone appointments with their GP.

However, more than half (61%) had seen their GP once (16%), twice (12%), or not at all (32%) about their M.E./CFS in the past 12 months.

This 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 assistance with welfare benefit claims.

Additionally, research¹⁵ 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.”

In the past year:

- 8% of people with M.E./CFS in Scotland had seen their GP at least once a month or more, while 29% hadn't seen them at all
- 12% of people with M.E./CFS in Wales had seen their GP at least once a month or more, while 28% hadn't seen them at all
- 10% of people with M.E./CFS in Northern Ireland had seen their GP at least once a month or more, while 19% hadn't seen them at all.

A number people with M.E./CFS undertake extensive research on their own condition and management approaches, keeping up to date with emerging evidence. While some healthcare professionals welcome their knowledge, research¹⁶ has found that, when faced with chronically ill expert patients, some healthcare professionals “were uncomfortable trusting their expertise [with] serious consequences for these patients’ ability to continue effective self-management.”

We asked people how well-informed they thought their GP was about M.E./CFS.

Less than a third said their GP was well or very well informed about M.E./CFS.

- 20% rated them very poorly informed
- 21% rated them poorly informed
- 29% rated them average
- 19% rated them well-informed
- 8% rated them very well-informed
- 3% said this was not applicable to them.

It is unrealistic to expect every GP to be an expert in M.E./CFS: it's just one of a considerable range of illnesses they are presented with. However, GPs themselves have identified the challenges they face with regards to diagnosing and treating this condition. We are also told that some people with M.E./CFS are not receiving the basic care and support that we all expect from our GP.

In a separate survey, Action for M.E. asked 50 GPs in NHS Dumfries & Galloway, NHS Fife and NHS Highland about their educational needs for M.E./CFS. Only half said they were 'fairly confident' about diagnosing it, and 82% said they had not undertaken any training about the condition. UK-wide research¹⁷ indicates that 39% of GPs find M.E./CFS the most challenging condition for referral, while 42% think the NHS will no longer provide services for M.E./CFS by 2015.

We asked people to rate the service their GP provided to them regarding M.E./CFS.

Barely a third said it was good or very good, while nearly half said it was poor or very poor.

- 28% rated the service as very poor
- 19% rated the service as poor
- 21% rated the service as average
- 17% rated the service as good
- 11% rated the service as very good
- 4% said this was not applicable to them.

As reflected in best practice guidance¹⁸ for healthcare professionals, the patients who rated their GP most highly were ones who felt they were:

- treated with dignity, kindness, compassion, courtesy, respect, understanding and honesty
- given opportunities to discuss their concerns and preferences
- involved in shared decision making and supported by healthcare professionals to make fully informed choices.

People with M.E./CFS across the UK told us:

"My GP is supportive and prescribes when needed. Also he is fairly open to requests for intervention. He trusts me to regulate medication and is willing to change it on request."



"My GP is excellent she listens and involves me every step of the way. She explains things as best she can and if she does not know she finds out. I have a good and positive relationship with her."



"My GP has always helped and has been on a course for M.E. The lack of time he is allotted for each patient is a drawback. I think the absence of facilities in Wales frustrates him."



Our recommendations

People with M.E./CFS should be able to have confidence in their primary healthcare professional. At the same time, we recognise that GPs must be supported to have a better understanding of the illness and symptom management if they are to meet patients' needs while making improvements to the efficiency and effectiveness of health (and integrated) services.

Action for M.E. will:

- develop a shared resource for patients who are newly diagnosed, their family/friends and health professionals to help them better understand the illness
- develop and deliver our Inform M.E. programme of work to raise awareness, understanding and build capacity with health and social care professionals; this will include developing specific resources and delivering webinars in Scotland in 2014-16 as part of a Scottish Government-funded pilot project
- explore working with primary health practitioners in other parts of the UK to help meet the needs identified by GPs and patients and ensure that appropriate information is available at a time that it is needed.

Secondary healthcare

We asked people how often they attended an NHS M.E./CFS clinic to see a specialist, and where that clinic was.

The NHS Map of Medicine for M.E./CFS¹⁹ recommends that specialist secondary care providers undertake a regular review with patients, including:

- assessing improvement or deterioration in symptoms
- assessing any adverse or unwanted effects of therapy
- consider repeating investigations
- reviewing the diagnosis, especially if signs and symptoms change.

However, more than half of respondents (54%) had not attended an NHS M.E./CFS clinic at all in the past five years. Figures are broadly similar for people with severe M.E./CFS (53%) and mild or moderate M.E./CFS (54%).

Around a third (32%) had attended between one and five times, while 7% had attended between six and 10.

Specialist NHS coverage for M.E./CFS in the UK is patchy, with several areas not served at all, particularly in Scotland, Wales and Northern Ireland. Accessing appropriate care is, for many, a post code lottery.

Action for M.E.'s 2012 investigation²⁰ into NHS services for M.E./CFS found that more of a quarter of primary care trusts/health boards did not commission specialist secondary services for M.E./CFS. A clear picture of how this may have changed in the light of recent NHS reforms has yet to emerge.

For those respondents who have been to a specialist NHS M.E./CFS clinic in the past five years, a third (35%) told us it was not in their local area. While it is encouraging to see that GPs are making the effort to seek out specialist services that may be further afield, it is of great concern that ill and vulnerable patients are being asked to travel considerable distances for treatment. Some may be simply too ill to attend. For others, it's likely have a detrimental on effect on their ability to make the most of their appointment and, in the longer-term, lead to an increase in symptoms.

We asked people to rate the service their NHS M.E./CFS clinic provided.

It's encouraging to note that 43% rated it as good or very good. However, 35% rated it as poor or very poor. Further analysis is being undertaken on this data: turn our recommendations on p 20 to find out how we plan to make sense of the results.

- 21% rated the as service as very poor
- 14% rated the as service as poor
- 22% rated the as service as average
- 23% rated the as service as good
- 20% rated the as service as good.



We asked people about other NHS consultants they have seen about M.E./CFS.

Further analysis is being undertaken on the data from these questions, but initial findings indicate which clinicians they found to be most well-informed about M.E./CFS.

Of the people who had visited an:

- occupational therapist, 51% rated them well or very well-informed
- immunologist, 49% rated them well or very well-informed
- paediatrician, 45% rated them well or very well-informed.

Conversely, of the people who had visited a:

- neurologist, 26% rated them poorly or very poorly informed
- psychiatrist, 24% rated them poorly or very poorly informed
- dietician, 17% rated them poorly or very poorly informed.

People also rated these clinicians for the service they provided in terms of their M.E./CFS. Results were as follows:

- occupational therapists, 45% rated the service good or very good
- immunologists, 35% rated the service good or very good
- clinical psychologists, 35% rated the service good or very good.

Conversely, of those respondents who had visited a:

- virologist, 30% rated the service poor or very poor
- psychiatrist, 23% rated the service poor or very poor
- neurologist, 21% rated the service poor or very poor.

We asked people about any healthcare professionals outside the NHS that they may have had contact with.

These were consistently rated higher than NHS professionals in terms of being well-informed about M.E./CFS, and for the service they provide.

Of those respondents who had visited a:

- private healthcare professional, 67% said they were well or very well-informed about M.E./CFS, and 61% rated the M.E./CFS service they provided as good or very good.
- complementary therapist, 53% said they were well or very well-informed about M.E./CFS, and 60% rated the M.E./CFS service they provided as good or very good.



We asked about management approaches people with M.E./CFS had tried in the past five years, and who had prescribed them.

Detailed analysis is still being undertaken on the data from questions about treatment and symptom management. Our aim is to understand what the results mean in context, and to use this information to improve outcomes for people with M.E./CFS. Read our recommendations on p 20 to find out more.

However, we can outline initial results and, in some cases, compare them to the results from our *M.E. 2008: what progress?* survey²¹ (see the table and graph opposite).

The NICE guideline for M.E./CFS³ defines the three approaches it recommends as follows:

- GET is “an evidence-based approach to CFS/M.E. that involves physical assessment, mutually negotiated goal-setting and education.”
- CBT is “a collaborative treatment approach. When it is used for CFS/M.E., the aim is to reduce the levels of symptoms, disability and distress associated with the condition.”
- GAT is “a person- centred approach to managing a person’s symptoms by using activity. Activities are selected, adapted and graded for therapeutic purposes to promote health and well-being.”

Pacing means managing physical, mental and emotional activity and rest in a structured way.

Exercise on Prescription is where a GP or practice nurse refers patients to leisure centres or gyms for supervised exercise programmes.

GPs are the healthcare professionals most frequently prescribing medication for M.E./CFS patients, to help with pain, mood, sleep or other symptoms such as nausea.

The most frequently self-prescribed approaches were rest (including bed-rest), vitamin and mineral supplements and dietary changes. As this is an increase of around 10% of patients using these approaches (when compared with our 2008 survey), it may indicate that more people with M.E./CFS are undertaking their own research and self-managing than six years ago.

The NICE guideline for M.E./CFS³ says that physical rehabilitation therapies GET and GAT should always be delivered by a trained therapist with experience of working with people affected by M.E./CFS.

Our survey results do show that these were most frequently prescribed by a specialist in an NHS M.E./CFS clinic. From this we may assume, although not know for certain, that it was also delivered by an NHS M.E./CFS professional.

However, it is interesting to note that, for both therapies, around 30% of respondents told us they had self-prescribed it.

One person told us: “Although my specialist service does not prescribe graded activity/exercise, I have tried to do it myself and the result is a serious relapse. Pacing, which the team do prescribe, has been the one thing that has helped the most, as well as ensuring good sleep (as far as possible) and sufficient rest.”

We asked people to describe their relationship with the healthcare professional they have seen most frequently.

We have already outlined the importance of people with M.E./CFS having a good relationship their GP on p 12. They also told us about their interactions with other healthcare professionals, including physiotherapist, occupational therapists, clinical psychologists, neurologists and other consultants.

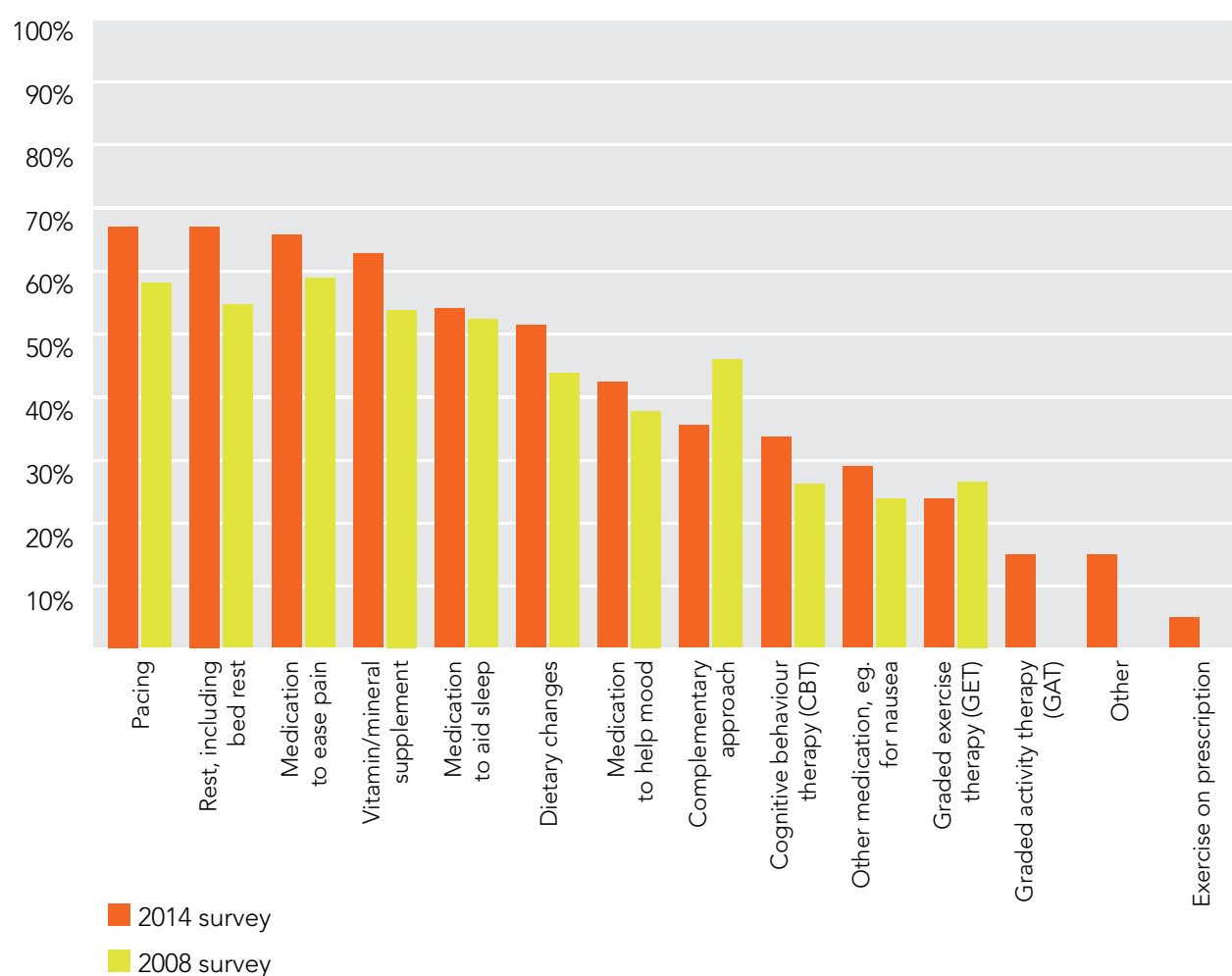
Those who were most positive about their experience consistently told us that they felt their healthcare professional offered:

- 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.

This is supported by other research²² by Action for M.E. into positive and negative experiences of physical therapies such as GET and GAT. This strongly indicated that good quality rehabilitation should be person-centred, goal-focused, based around sustainable baselines and incorporating a plan for setbacks.

Further analysis will be undertaken on the responses to this question to identify themes common to negative experiences, and how we might use these to inform our education work with healthcare professionals.

	2014 survey	2008 survey
Pacing	67%	58%
Rest, including bed rest	67%	54%
Medication to ease pain	65%	59%
Vitamin/mineral supplement	62%	53%
Medication to aid sleep	53%	52%
Dietary changes	51%	43%
Medication to help mood	42%	38%
Complementary approach	35%	46%
Cognitive behaviour therapy (CBT)	33%	26%
Other medication, eg. for nausea	29%	23%
Graded exercise therapy (GET)	23%	26%
Graded activity therapy (GAT)	15%	–
Other	15%	–
Exercise on prescription	4%	–



We asked people about the effect of the approaches they had tried on their symptoms.

Opposite are tables showing the results for conventional management approaches (top) and complementary or alternative approaches (bottom) that people with M.E./CFS had tried in the past five years.

Compared with the results of our 2008 survey, around 10% more respondents found medication to ease pain or mood a little or very helpful.

Patients also reported, overall, finding GET less helpful than in 2008 (45% then compared to 35% now).

This may be because a number of people with M.E./CFS are self-prescribing GET, rather than working with a specialist therapist (see p 16). However, it is unlikely that this accounts for every negative experience.

We continue to hear positive and negative experiences of GET from people with M.E./CFS, including those who tell us that GET caused them harm. We recognise that further investigation is needed to find why it may benefit some people and not others.

It's striking to see how highly people with M.E./CFS rated meditation/mindfulness (a practice derived from Buddhist meditation that fosters "active, open attention on the present").²³

One respondent told us: "Mindfulness meditation is very helpful in managing fatigue and obtaining quality rest as part of pacing."

NB. Less than 10% of respondents had tried tai chi, emotional freedom technique, Gupta programme, Lightning Process, kinesiology, hydrotherapy, Perrin technique, NLP, shiatsu, reverse therapy or Mickel therapy, so we have not included these in this table.

We asked people how the approaches they had tried affected them.

Analysis is still being undertaken on this data, but initial key themes include:

- medication only being tolerated in low doses, though there are exceptions to this
- professional support for approaches such as pacing, GET and GAT being time-limited; many said they were subsequently left to cope alone
- desperation has driven many to spend a lot of money trying new treatments; "I've spent a fortune over the years" was a common comment
- for some, nothing makes a long-term difference.



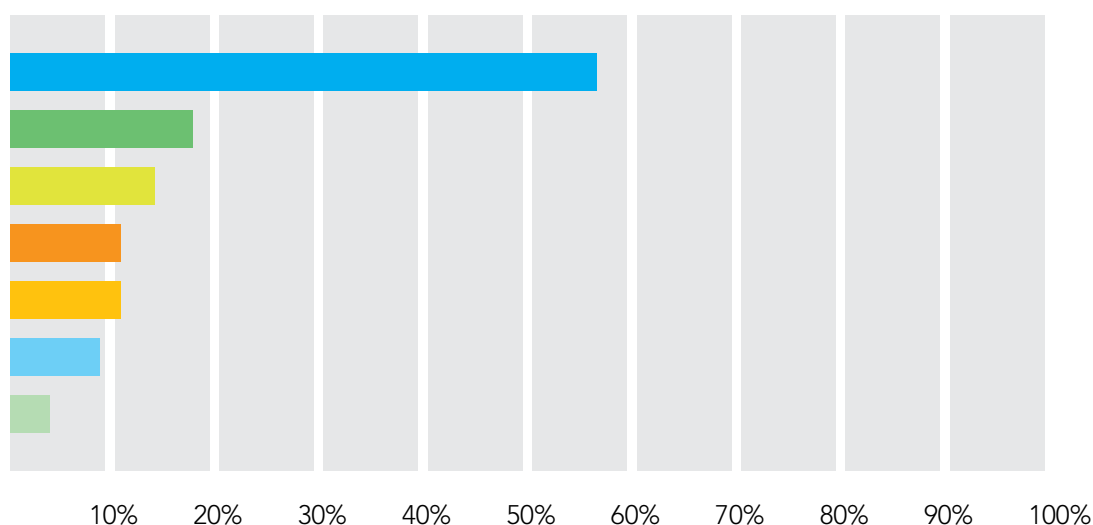
	A little or very helpful	No change	Made a bit or much worse
Rest, including bed rest	89%	10%	1%
Pacing	85%	12%	4%
Medication to ease pain	84%	12%	4%
Medication to aid sleep	79%	13%	8%
Other medication, eg. for nausea	78%	11%	10%
Medication to help mood	74%	15%	11%
Dietary changes	72%	27%	1%
Vitamin/mineral supplement	66%	33%	1%
Cognitive behaviour therapy (CBT)	54%	34%	12%
Graded activity Ttherapy (GAT)	48%	19%	34%
Graded exercise therapy (GET)	35%	18%	47%
Exercise on prescription	25%	25%	49%

	A little or very helpful	No change	Made a bit or much worse
Meditation/mindfulness	84%	15%	2%
Massage, including lymphatic drainage	72%	11%	17%
Yoga	69%	14%	18%
Reflexology	64%	27%	9%
Reiki	60%	33%	7%
Herbal medicine	56%	36%	9%
Acupuncture	54%	33%	13%
Homeopathy	47%	43%	10%

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

More than half were not offered any follow-up support at all.

- 57% said no support
- 18% group therapy sessions
- 14% one to one support
- 11% other, although many who chose this option used it to tell us a bit more about their healthcare experience (eg. "I went private due to poor NHS after service. The M.E. specialist I saw 10 years ago was no longer available due to NHS Trust changes")
- 11% referral to a self-management programme
- 9% telephone support
- 4% home visits.



Our recommendations

The data in this section on secondary healthcare raises more questions than it answers. We know that this data is very subjective, and we recognise the limitations of asking patients to encapsulate complex relationships and treatment outcomes using only a simple rating scale.

However, we think there is still valuable learning to be drawn from what people with M.E./CFS have told us, and have ambitious plans to do this.

Action for M.E. will:

- host a number of roundtable meetings with clinicians and researchers to discuss the data on specialist services and treatment/management approaches, asking them what it can tell us, what stands out for them, and if it can help shape hypotheses for future research. This work will be presented later in the year, in the December edition of our membership magazine *InterAction*.
- sponsor a PhD student to undertake a small qualitative study, examining experiences of those who have attended specialist NHS services for M.E./CFS.

Improving healthcare

We asked people what would make a real difference to their healthcare.

A considerable majority told us that having a GP who understands M.E./CFS would make a difference; more effective medication was a close second.

- 69% said better informed GP
- 62% said more effective medication
- 45% said joined-up health and social care
- 30% said home visits
- 28% said having more of a say in their treatment
- 12% said telehealth.

That's why one of Action for M.E.'s research priorities is targeted treatments. Within the UK, researchers are starting to gain more insight in relation to specific symptoms but more detailed investigation into specific treatments targeted to specific individuals is desperately needed.

We asked people what barriers they had experienced in accessing NHS services (GP, specialist clinic or consultant) for M.E./CFS, and what would help overcome them.

Detailed analysis is still being undertaken on the responses from those who chose the 'other' option, and on what would help people overcome these barriers.

Initial results show that:

- 49% said lack of follow-up/ongoing care
- 49% said lack of NHS specialist in my area
- 43% said too ill
- 38% said long waiting times for treatment or referral
- 36% said distance/travel time to service
- 32% said lack of information
- 28% said other (results still being analysed to identify key themes)
- 15% said lack of transport to service
- 13% said length of treatment session(s)
- 11% said cost of transport
- 8% didn't want to use any of the services on offer.



Welfare benefits and social care

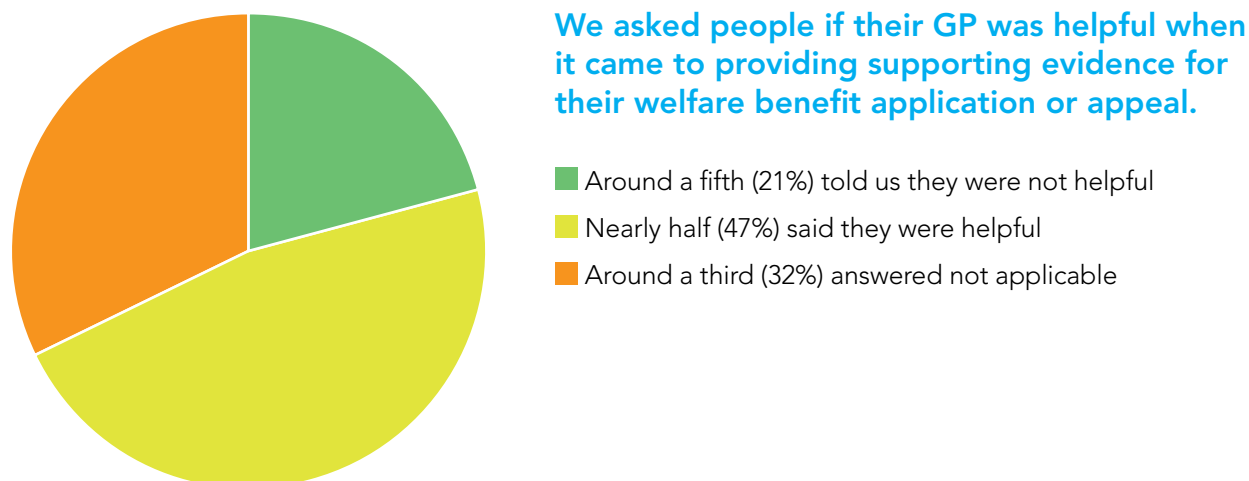
We asked people which benefits they had applied for in the past 12 months, and about their experience of dealing with the Department of Work and Pensions, and/or the agency (Atos or Capita) contracted by them, during the claim process?

We are still undertaking detailed analysis on these questions.

However, 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.

One respondent told us: "They always send generic letters and I end up having to phone when the information I need isn't on it. It can be frightening when you read something you're not expecting before you realise it doesn't apply to you. Getting through on the phone has got more difficult. It always feels like they assume you are lying until you can prove otherwise."

We welcome the Government's recent announcement of the early termination of its contract with Atos, with Minister for Disabled People Mike Penning MP stating²⁴ that his department is "committed to learning the lessons from these past failures and ensuring they are reflected in the design and management of future contracts."



Supporting medical evidence from GPs and other healthcare professionals can make a crucial difference to the success of a claim or appeal.

Decision makers at the DWP and assessors who carry out face-to-face assessments may have little knowledge of M.E./CFS and are very unlikely to have any specialist knowledge. Face-to-face assessments may be very short – an assessor might see a claimant for as little as 20 minutes. In some cases, decisions are made without them being assessed in person at all.

There is a "contractual obligation"²⁵ for any GP who has issued a fit note to provide a medical report in relation to that patient's claim for ESA when asked to do so. Last year, GPs reported a 21% increase²⁶ in requests for supporting medical evidence, having a disproportionate impact on the time they might spend with patients.

Action for M.E. is pleased to note, therefore, that the Government's recent response²⁷ to the fourth independent review of the Work Capability Assessment (WCA) accepted a recommendation to continue to work with the British Medical Association to redesign and simplify the process by which GPs can submit supporting medical evidence.

However, we are very concerned that those people with M.E./CFS who do not have a supportive GP are at a huge disadvantage.

Minister for Disabled People Mike Penning MP has also acknowledged²⁸ that there is an issue of supporting medical evidence arriving too late, and not being made best use of.



We asked people if they had had a social care assessment in the past five years.

A considerable majority (82%) said no. This means that people with M.E./CFS are potentially missing out on support with personal and domestic care, aids and adaptations for their home and Personal Budgets

Personal health budgets are an NHS Mandate commitment and one of the tangible ways the NHS can become dramatically better at involving people, and empower them to make decisions about their own care and treatment.²⁹

Our recommendations

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, and to accept the recommendations of the fourth independent review of the WCA, offer possible opportunities for change.

Action for M.E. will:

- extend our Welfare Advice and Support Service³⁰ to reach 11,000 people per year through telephone and online support, specialist welfare advice and publications
- build capacity by developing resources to share our welfare benefits expertise with paid and voluntary welfare advisers from local M.E./CFS support groups; this will ensure that more people have access to the specialist knowledge they need
- build on our collaboration with other fluctuating conditions groups (such as the Disability Benefits Consortium³¹) to contribute to the ongoing reform of the WCA process
- promote our existing factsheet, *Supporting medical evidence for people with M.E./CFS*,³² which people with M.E./CFS can give to their GP to help them understand why this evidence is so important
- aim to share the results of our analysis with Minister for Disabled People Mike Penning MP to improve delivery of welfare benefit assessments in future.

Employment and education

We asked people if they were employed or in education.

Research³³ 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.

Only 8% of respondents told us they were in full-time paid work, education or training, and 14% in part-time paid work, education or training. Figures for those in part-time paid work, education or training were higher in Scotland (21%) and Wales (24%).

We asked people what specialist employment or educational support they had received.

More than a third said they received no support at all, despite employers and education providers being obliged to make reasonable adjustments for employees or students defined as disabled – a description that includes those with M.E./CFS – under the Equality Act 2010.

Those who did tell us about the support they received revealed a wide range of experiences. These demonstrate that targeted support, taking the specific needs of M.E./CFS into account, is most helpful.

Universities were more frequently mentioned as providing considered and appropriate support, including specialist disability tutors, dictation software for writing essays, class note-takers, extra permitted absences, modified exam and assessment methods, subsidised transport and help with applying for Disabled Students Allowance.

People with M.E./CFS across the UK told us:

"My employer expressed a willingness to offer a phased return to work from sick leave (following two Occupational Health reports and a report from my GP), and to offer reasonable adjustments. However, the adjustments offered did not correspond to my symptoms and needs, and my employer was not willing to negotiate terms, so my employment was ultimately terminated."



"Access to Work pay additional costs of travel as I need to attend a team meeting once a month. It also provided an occupational exam by a physiotherapist at home. As a result I got a desk, chair and office equipment supplied by my employer."



"I am studying (for about 20 minutes, three times per day) with the Open University. They have been tremendously supportive. I have two hours study assistance per week. I was given software, offered equipment, and given funding for my extra printing costs. I receive study material on audio CD, and spiral bound. I have taken an exam at home over three days in half hour sessions with study periods. I am receiving funding for my education. My exam was printed on coloured paper. I have one-to-one tutorials either via the phone or sometimes in person at home. They've done everything in their power to make it as easy as possible for me to study."



Our recommendations

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. will:

- establish a pilot project in partnership with health and employment specialists to support people with M.E./CFS to, where possible and appropriate, stay in or access employment
- use the data we have gathered, and our existing resources³⁴ for employers and employees with M.E./CFS, to inform the ongoing revision of NHS guidelines on M.E./CFS and work³⁵
- expand our existing resources by exploring the possibilities of webinars and online films focusing on employment.

Carers

We asked people with M.E./CFS who they received daily care from.

A majority (84%) told us it was from a family member, which is likely to have a significant financial and emotional impact on the household as whole.

Research³⁶ by Carers UK has found that 70% of carers are more than £10,000 worse off as a result of caring, while 30% had seen a drop of £20,000 a year in their household income.

We asked people to tell us the age of their main carer.

Two thirds (66%) said their family carer was aged 50 or above, which means the burden of care is falling on older partners and parents who might otherwise be preparing to retire, or already be retired. 15% were aged 70 or above, and the oldest family carer was 91.

At the other end of the scale, 1% of family carers were aged between 11 and 17, while 6% were aged 18 to 29. However, very little is known about children and young people who, while they may not be named specifically as a carer, nevertheless take on a caring role in families where one of their parents or siblings have M.E./CFS.

Many young carers remain 'hidden' from health, social care and education services, partly because services must do more to identify them, but also because families fear that children will be taken into care.³⁶

We asked people if their carer had had a social services carers assessment.

The Government has been exploring ways to better support carers, including "carer assessment support workers based in GP practices who help to identify carers and signpost them to support services, carer liaison teams, carers' leads in clinical teams and a range of support materials."³⁷

However, 93% 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.



Our recommendations

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. will

- work with an NHS M.E./CFS Service to pilot a targeted resource for the friends and family of people with M.E./CFS, building on our existing booklet, *Caring for somebody with M.E.*³⁸
- develop a resource for children and young people who have a close family member with M.E./CFS who require care, working with carers groups as appropriate
- undertake further work to assess the needs of older carers
- work collaboratively with national carers groups to raise the profile and understanding of M.E./CFS.

Severe M.E./CFS

The impact of M.E./CFS at its most severe can be devastating. Patients are usually house and/or bedbound, and only able to provide the most basic levels of care for themselves, if at all. Some can remain ill for a long time: 77% of survey respondents with severe M.E./CFS had experienced symptoms for five years or more, and 65% for 10 years or more.

People with M.E./CFS across the UK told us:

"I have virtually no life outside the home and very little social interaction. I used to love going abroad but haven't been on holiday at all for about 10 years. My husband has to look after me which has impeded his life. I have never been able to hold my grandson or interact with him as I wish. I am worried my son and daughter will only remember me like this."



"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 because I am too weak. My family are the only contact I have and I live vicariously through them."



"It's been incredibly difficult to deal with. There is a lack of understanding which adds to anxiety. There's no safety net. It has turned my mother and stepfather's lives upside down and negatively affected my relationships with my father and sister, who lack empathy."



"I feel cut off from the world and depend greatly on my husband and two children. My family had never thought in a million years that they would be looking at future like this. I used to be a balanced, organised person with zest for life."



Primary healthcare and severe M.E./CFS

9% of people with severe M.E./CFS had seen their GP 12 times or more in the past year (ie. equivalent to at least once a month). Nearly half (48%) had seen them once or not at all.

Research¹⁵ 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." It also found 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.

Secondary healthcare and severe M.E./CFS

The NICE guideline for M.E./CFS³ acknowledges the importance of a flexible, regularly reviewed care plan for people with severe M.E./CFS, noting that management of it is difficult, complex and requires specialist expertise.

However, more than half of people with severe M.E./CFS (53%) had not visited a specialist NHS M.E./CFS clinic at all in the past five years. A third (33%) had been between one and five times (ie. equivalent to at least once a year).

When it comes to managing symptoms, it's important to note that "there is very little research evidence on management of such patients and that simple extrapolation from other patient groups is usually inappropriate."⁴

Our survey shows that people with severe M.E./CFS do find certain approaches helpful, however. Results for pacing, rest, medication to aid pain, mood, nausea or sleep, vitamin/mineral supplements and dietary changes were broadly similar to results for all three levels of severity as a whole (see p X).

However, people with severe M.E./CFS told us that with CBT and physical rehabilitation therapies (GET, GAT and exercise on prescription) were less helpful. Neither the NICE guideline³ nor the SGPS⁴ recommends these treatments for severe M.E./CFS.

We asked people with severe M.E./CFS who had prescribed these treatments for them. CBT, GET and GAT were most frequently prescribed by specialists in NHS M.E./CFS clinics, while exercise on prescription was most frequently prescribed by GPs. People with severe M.E./CFS also told us that:

- 20% had self-prescribed CBT
- 29% had self-prescribed GET
- 33% had self-prescribed GAT
- 20% had self-prescribed exercise on prescription.

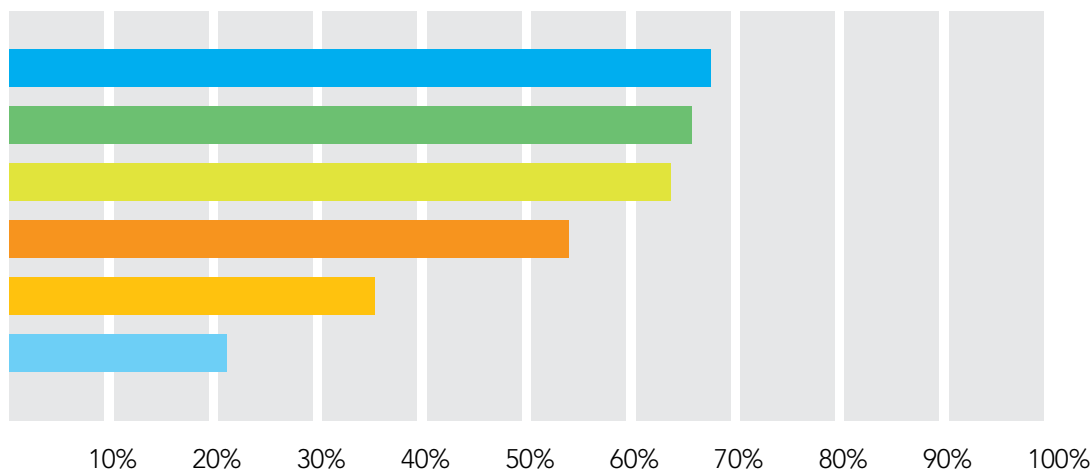
Some respondents chose more than one option for this question, perhaps indicating that they had been prescribed (or self-prescribed) a particular approach more than once. It's also not clear from these initial results if people were severely affected when they tried these approaches.

More work must be undertaken to follow-up what people with severe M.E./CFS told us before we can draw accurate conclusions about this data.

Improving healthcare for severe M.E./CFS

When we asked people with severe M.E./CFS what would make a real difference to their healthcare:

- 68% said a better informed GP
- 66% said more effective medication
- 63% said home visits
- 53% said joined-up health and social care
- 36% said having more of a say in their treatment
- 21% said telehealth.





Welfare benefits, social care and severe M.E./CFS

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

Personal Budgets can be an excellent way of ensuring that people with severe M.E./CFS have their complex and specific needs appropriately met.

44% of people with severe M.E./CFS had applied for ESA in the past 12 months. Of these, more than a quarter (27%) had had their level of benefit reduced or removed altogether. Worryingly, one in five (21%) told us that their GP had not been helpful when it came to providing supporting evidence for their claim or appeal.

34% of people with severe M.E./CFS had applied for DLA in the past 12 months. Of these, 8% had had their level of benefit reduced or removed altogether.

18% of people with severe M.E./CFS had applied for PIP in the past 12 months, but more than three-quarters (77%) were still having their applications processed. That this is taking so long, putting vulnerable people under financial and emotional pressure while they await the outcome, is of great concern.

Detailed analysis

Detailed analysis on the following severe M.E./CFS data is still being undertaken:

- physical, mental and financial impact of symptoms
- barriers to accessing NHS services, and what might help overcome these
- relationships with the healthcare professionals
- effects of treatment and management approaches
- experience of the welfare benefit application process.

Our recommendation

Because severe M.E./CFS is such a complex condition, providing targeted support and care to this patient group is a challenge that must be met with creativity and collaboration.

Action for M.E. will:

- hold a symposium on severe M.E./CFS in 2014, to present our detailed analysis and work with others to develop actions to challenge the inequalities that exist for this specific group of people with M.E./CFS.

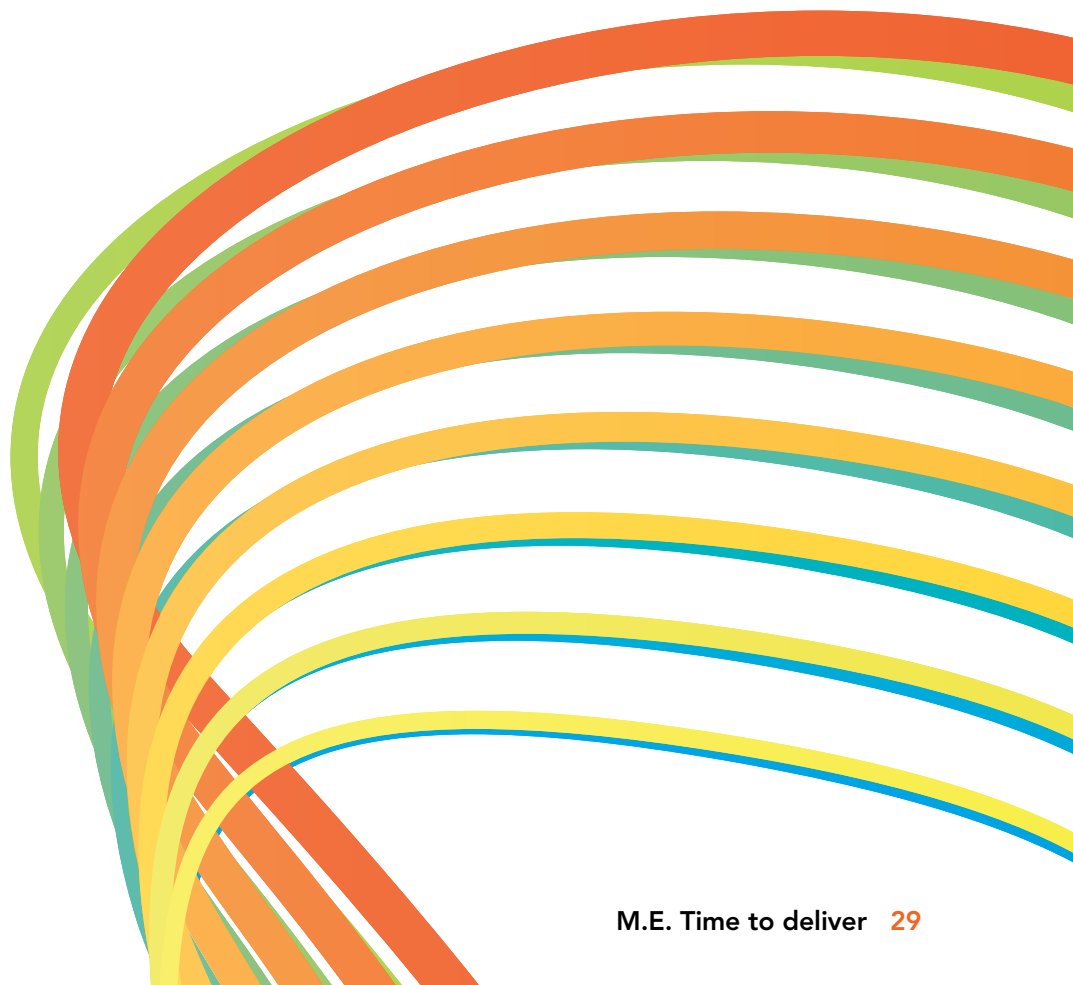
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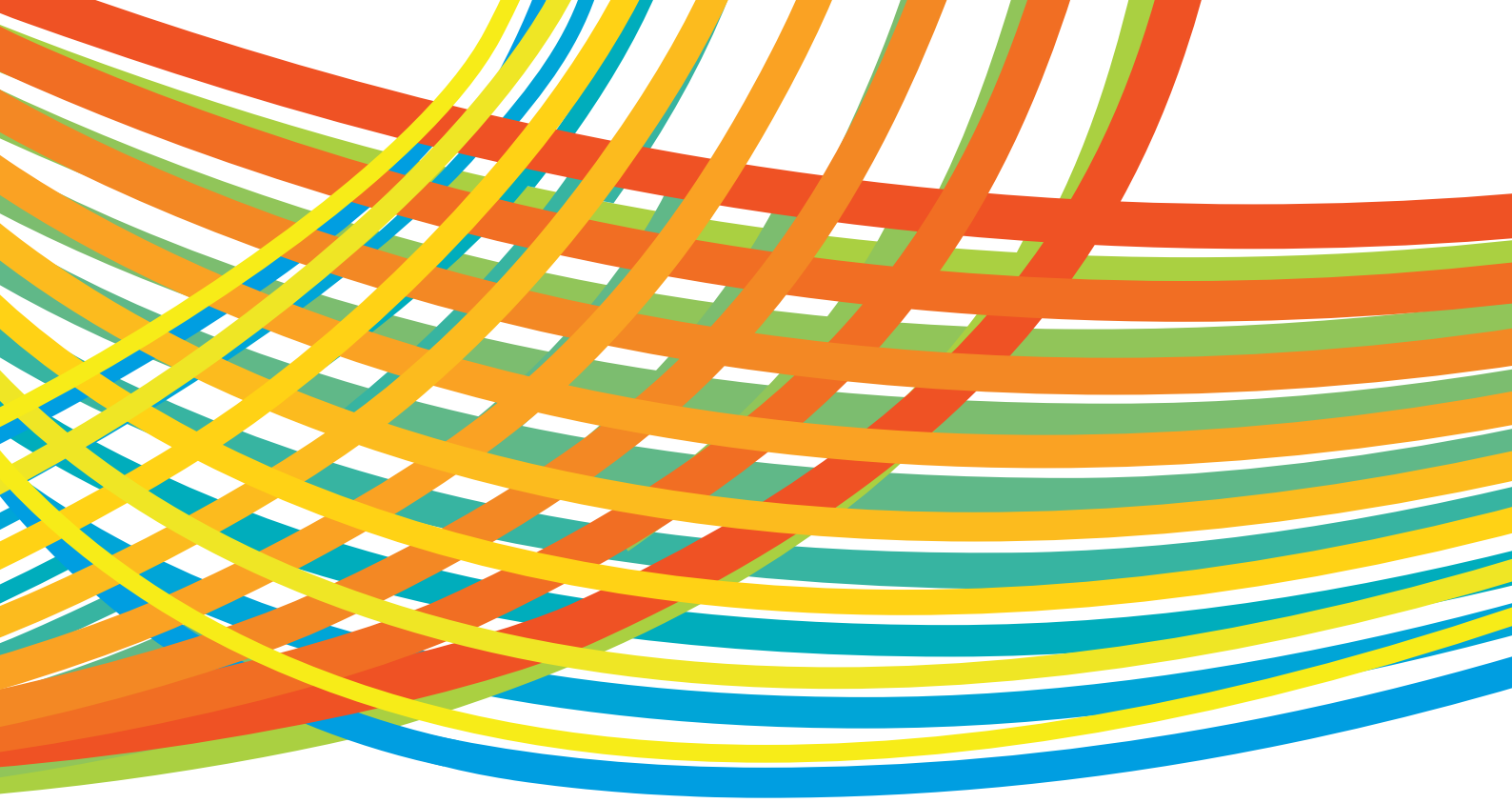
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