



# Close to collapse

An interim report on access to social care  
and advocacy for people with M.E./CFS



*"I don't have the strength to organise care for myself, so I am just struggling through doing what little I can. I manage to wash or bath about twice a month. My house is filthy and I am smelly. My meals are limited to the most simple, mostly microwave ready meals. At times this makes me suicidal."*

---

# Foreword

---

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

This interim report, based on findings from a survey carried out by the charity Action for M.E., demonstrates the shocking gap between the need for social care, and the provision of appropriate services, for adults in the UK with this disabling condition.

850 people with M.E./CFS took part in the survey, describing the effect of the condition on their daily lives, their need for social care, and their access to advocacy to facilitate this.

There's overwhelming evidence that the majority of people with M.E./CFS are not receiving the social care and support to which they are entitled. It's also clear from the results that, for the small number who do receive personalised and appropriate support, the benefits can be significant. However, better access to advocacy is needed to facilitate their involvement in social care processes.

This interim report will now form the basis of a formal inquiry, led by Action for M.E. and supported by the All-Party Parliamentary Group (APPG) for M.E., to gather further evidence of the challenges that people with M.E./CFS experience in accessing social care and receiving the right support for their needs. In doing so, we will identify examples of best practice, and call for changes to improve the lives of everyone affected by M.E./CFS.

**Sir Peter Bottomley**  
Chair, APPG on M.E.

---

# Contents

---

Executive summary	4
What is M.E./CFS?	6
The social care policy context for people with M.E./CFS	8
Results of Action for M.E.'s access to care and support survey	10
Methodology	10
Who we heard from	10
The gap between support needs and service provision	11
Problems encountered in social care assessments	12
Barriers to engaging with social care	13
Benefits of care and support among social care recipients	14
Access to advocacy	16
Conclusion and next steps	17
Appendix: sample characteristics	18
References	19

## Acknowledgements

Action for M.E.'s survey and this subsequent report were developed and written by:

- Catherine Hale, Volunteer Research Officer
- Sonya Chowdhury, CEO
- Clare Ogden, Head of Communications and Policy
- Emma Hypher, Communications and Policy Officer

## With grateful thanks to:

- the Whitehouse Consultancy
- Cathy Stillman-Lowe for invaluable guidance and support at all stages
- Jenny Morris for insights and feedback on earlier drafts
- Graham McPhee for assistance with data analysis
- Simon McGrath for advice on medical research into M.E./CFS
- Steven Shaw for help developing the survey.

# Executive summary

Adult social care services across the UK are failing to respond to the care needs of people with M.E./CFS. Action for M.E. surveyed 850 people with this debilitating chronic illness about their difficulties with daily living tasks such as washing, feeding themselves, getting to a local shop or maintaining social relationships.

## Key findings

There is a shocking gap between support needs and service provision.

- A staggering 97% of respondents told us they experience two or more difficulties with daily living activities listed in the Care Act 2014 for England.
- However, just 16% had received social care assessments
- Of these, only 6% had been awarded a care package.

Barriers to self-referral and fair assessment included:

- lack of clear information about social care process and entitlements (58% of respondents)
- cognitive and communication difficulties preventing engagement with social care processes (47% of respondents)
- social care processes ill-adjusted to the very poor stamina of people with M.E./CFS
- misunderstanding, misinformation and stigma surrounding the label of M.E./CFS acted as a deterrent to asking for help for 38% of respondents and was also perceived to impact on the fairness of assessments and the type of support provided.

The benefits of social care can be significant. The main benefits of having a care package, for the 6% who had one, were:

- reduction of the burden of caring on family members and on informal carers (60% of respondents)
- being better able to manage symptoms (50% of respondents), which can either be a foundation for improvement or prevent deterioration in health.

Three quarters of respondents believed their situation would be “a little better” (25%) or “a lot better” (50%) if they had someone to represent them. There was a high level of satisfaction amongst those who had used advocacy but nearly four in five respondents had not accessed advocacy.

Throughout this report, the quotations in blue highlight the experiences of people with M.E. who took part in our survey.

*“I haven’t got the energy to spare to jump through hoops to get the help from social services that I am entitled to. I can’t risk the chance of further deterioration to my health by having to fight social services to understand what I am going through and what I need”.*

*“Because of the stigma with this illness, I have little confidence; as well as the fact that it is a fluctuating illness and it is hard to make myself clear.”*

---

## The need for advocacy

Most people in our survey thought their situation would be better if they had an effective advocate to represent their needs and the 25% of respondents who had used one reported high levels of satisfaction with their service.

Yet, sadly many people encountered some of the same barriers in accessing advocacy as they did with social care, including a lack of knowledge about M.E./CFS and services that were not adjusted to their needs. With the community advocacy sector under increasing strain,<sup>1</sup> the need for better representation for people with M.E./CFS is acute and urgent.

## Why does this care gap exist?

This interim report explores some of the causes for this shocking gulf between care needs and service provision for people with M.E./CFS.

- Cognitive difficulties – severe limitations on concentration span and profound mental fatigue – in M.E./CFS are a major barrier to self-representation in the complex processes of social care.
- The acute levels of multiple disabilities that M.E./CFS can cause often make the processes of assessment and planning too strenuous for those most in need of help. A quarter of respondents said they were too ill to deal with social care services and many gave up asking for help out of sheer exhaustion because the assessment and planning system was not adjusted to their needs.
- Lack of information about entitlements and poor signposting to social care services were a major barrier to access.
- There appears to be misinformation and continuing stigma attached to the label of M.E./CFS despite the strong evidence base that should mitigate this. This may affect the outcome of assessments and the provision of appropriate care and also seems to deter people with M.E./CFS from asking for help or support. One third of respondents felt the disability resulting from their illness was not accepted as genuine.

## Summary of conclusion and next steps

This research has shown the shocking lack of access to social care and advocacy support for people with M.E./CFS.

In response to this, Action for M.E. will now lead a formal enquiry to further build the evidence base into social care provision for people with M.E./CFS and explore solutions to address the barriers to access and improve individual outcomes in terms of wellbeing, dignity and autonomy from social care support.

Action for M.E. has published a self-advocacy toolkit to increase the information available for people with M.E./CFS and their carers. Additionally, Action for M.E. is seeking funding to establish a national advocacy service to directly support those affected by this disabling condition.

**Please note:** Respondents to the survey came from all part of the UK, reflecting experiences of social care in England, Scotland, Wales and Northern Ireland. For the purposes of consistency in the research, questions were asked based on criteria now used by adult social care services in England.

Responses received from Scotland, Wales and Northern Ireland indicated that although arrangements for social care and social care eligibility differ from those in England, people with M.E./CFS were experiencing similar difficulties in accessing support.



# 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.

Defined by the World Health Organisation as a neurological illness, M.E. affects an estimated 250,000 people in the UK and around 17 million people worldwide.

People with M.E. experience severe, persistent fatigue associated with post-exertional malaise (PEM), the body's inability to recover after expending even small amounts of energy. PEM is now considered central key defining feature of M.E. Additional symptoms include chronic pain, sleep difficulties, cognitive problems and hypersensitivity to light, smell or sound, among other chronically disabling symptoms.

In March 2015, the Institute of Medicine in the United States recommended changing the name to systemic exertion intolerance disease, or SEID.<sup>2</sup> This has not been universally adopted. In the UK, 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 report to include people with both diagnoses.

## **"Quality of life is particularly and uniquely disrupted"**

Research shows that people with M.E./CFS experience high levels of functional impairment across physical and mental domains, scoring lower overall on health-related quality of life tests than most other chronic conditions<sup>3</sup>, including lung disease, depression, heart disease and diabetes (see figure one).<sup>4</sup>

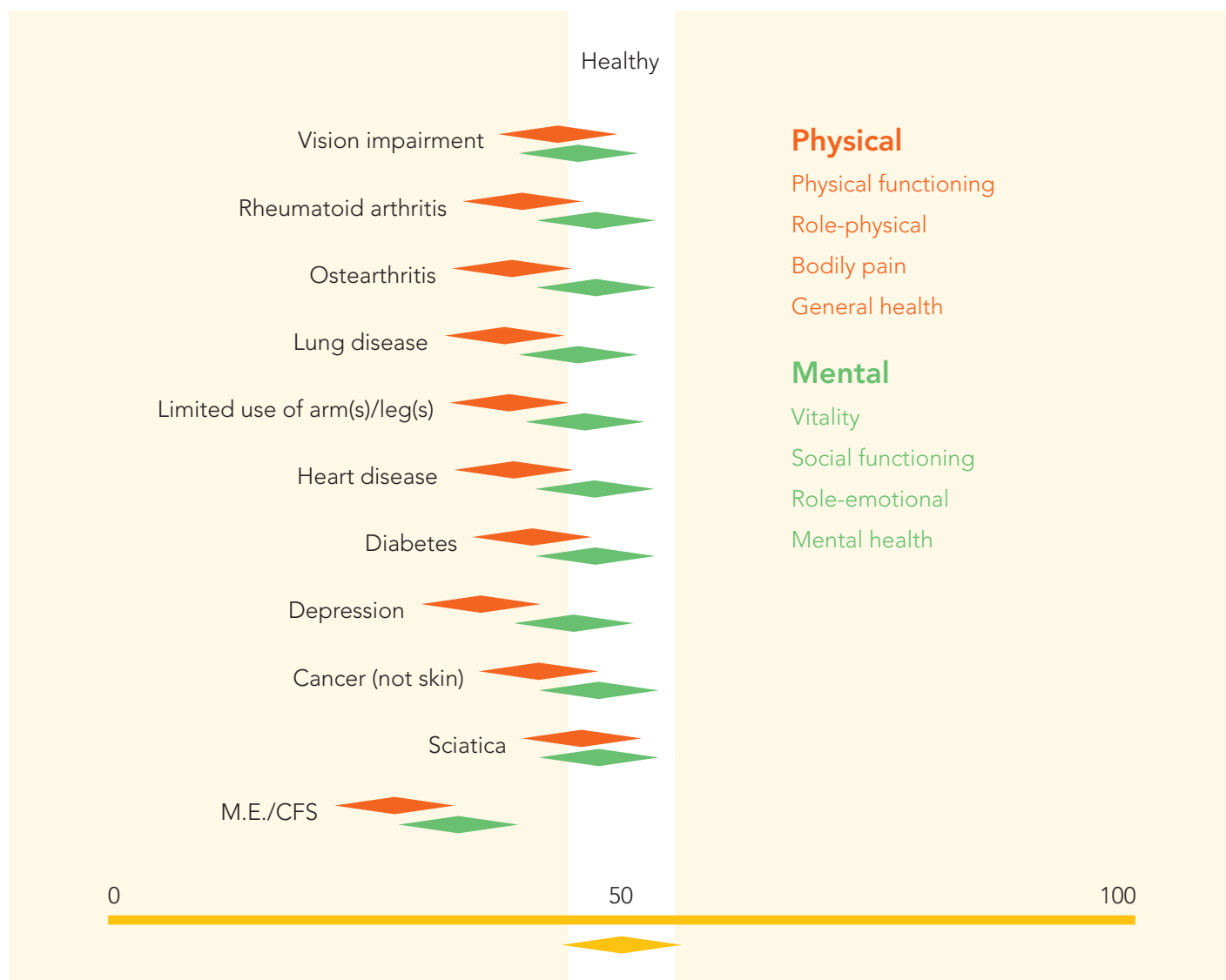
Researchers have concluded that "quality of life is particularly and uniquely disrupted"<sup>5</sup> in M.E./CFS and that patients are, on the whole, not able to retain their previous capacity to remain active and perform roles in society.<sup>4</sup>

Substantial neurocognitive impairment contributes significantly to this, including slowed information processing and memory impairment.<sup>6,7,8</sup> This "may be responsible for the disability that results in loss of employment and loss of functional capacity in social environments."<sup>2</sup>

The post-exertional malaise that characterises M.E./CFS means that, appropriate care and support is required to manage energy without exacerbating symptoms. There is some evidence that behaviour management approaches may improve self-reported fatigue for those who are mildly or moderately affected by M.E., when delivered by an experienced therapist.<sup>9</sup> However, there is no evidence that such strategies are effective for those severely affected by M.E./CFS.

Most people with M.E./CFS face considerable isolation and exclusion from society. 92% of patients surveyed by Action for M.E. in 2014<sup>10</sup> had stopped or reduced social contact and 87% had stopped or reduced paid work due to their debilitating symptoms.

UK research into the impact of M.E./CFS on employment and productivity estimated lost earnings to the UK economy of more than £102 million a year.<sup>11</sup>



**Figure one:** Scores for physical and mental function in M.E./CFS using SF-36v2 compared to healthy controls and population norms for other chronic conditions from Nacul, 2011<sup>4</sup> (Graph courtesy of *M.E. Analysis*<sup>12</sup>)

# The social care policy context for people with M.E./CFS

## The Care Act 2014

Our research took place just as the Care Act 2014 came into force as the new legislative framework for care and support in England. As such, our findings reflect respondents' experiences under the previous system, often criticised for creating a postcode lottery of access to social care.<sup>13</sup>

The people with M.E./CFS we heard from reported lack of information, difficulties with representation, not having their voice heard, unfair assessments, inappropriate one-size-fits-all services and the burden on informal carers. There is much to be welcomed in the Care Act guidance to address these problems; as follows.

- The central principle of wellbeing and the person-centred approach to achieving it. The assumption is that the individual is best placed to judge their own outcomes, goals and wellbeing and the individual's own opinions are paramount in decisions regarding their care and support.<sup>14</sup>
- A duty on local authorities to ensure that information and advice about care are available to all.<sup>15</sup>
- Greater transparency regarding eligibility through a national minimum eligibility threshold
- The statutory duty to provide advocacy is increased to facilitate involvement in care and support.<sup>16</sup>
- The duty to consider the impact of a person's needs on their whole family, including children.<sup>17</sup>

However, recent evidence of changes in social care provision since the introduction of the Care Act 2014 shows a wide gap between these principles and actual implementation. A survey by the UK charity In Control found a reduction in quality of life for more than 45% and reduced choice and control for almost 30% of social care recipients, and that local authorities are not yet meeting their duties to provide clear, accessible, accurate and tailored information about care and support.<sup>18</sup>

The goal of increasing and improving social care provision for people with M.E./CFS will be particularly challenging against the major financial crisis facing social care. Expenditure on social care by local authorities fell in real terms by 30% between 2011/12 and 2014/15,<sup>19</sup> meaning 25% fewer people accessing publicly funded social care.<sup>20</sup> Further cuts of £420 million in adult social care are predicted from 2015.<sup>19</sup>



---

## The growing reablement trend

Short-term support to maximise independence, sometimes called “reablement,” is a growing trend in social care provision. The aim of reablement is to prevent the development of on-going care needs by reskilling the individual in daily tasks and, ultimately, to make savings to local authority care budgets.<sup>21</sup>

Initially, this short term intervention was developed to facilitate transfer from hospital to home, eg. following a hip operation, but it has now become the default first response to presenting social care needs.<sup>22</sup> Recent data on the outcomes of social care referrals in England showed that out of all requests for support from new clients, 12% resulted in short-term support to maximise independence and only 8% resulted in long-term support, or Home Care.<sup>23</sup>

Although our survey was not designed to collect data on what forms of social care support were provided, qualitative analysis yielded worrying evidence of the misuse of reablement among people with severe M.E./CFS. Another patient organisation representing people with severe M.E./CFS reports the same concerns.<sup>24</sup>

Exertion intolerance is a key feature in M.E./CFS<sup>2</sup> and pushing patients to increase their activity levels outside of specialist supervision risks deterioration in symptoms and increased disability. Additionally, there is no evidence to support the expectation of “noticeable improvement” (see right) within four to six months.

The NICE guideline for M.E./CFS does not recommend rehabilitative interventions for people with severe M.E./CFS and recommends that any therapeutic programme aimed at increasing activity levels should be carried out under the supervision of specialist M.E./CFS services.<sup>25</sup>

---

*“My social worker believes that with a short term care package (four to six months) there should be ‘noticeable improvement’ in my level of independence. If there isn’t when my care is reviewed she said they will remove my carers as ‘their goal is to promote independence and not dependence.’ I’ve tried to explain that severe M.E. doesn’t work like that, I often have paralysis, I’ve orthostatic intolerance, physically can’t turn in bed etc. Managing personal care and giving me meal replacements isn’t promoting dependence as these are things I physically cannot do. She replied, ‘Well that’s the way our care system works.’”*

# Results of Action for M.E.'s access to care and support survey

## Methodology

We surveyed 848 people with M.E./CFS, 96% of whom had been diagnosed with the illness by a GP or NHS consultant. The sample was obtained through calls for evidence on people's care and support on social media, through a range of online M.E./CFS communities and through Action for M.E.'s supporting membership.

The survey was open online for six weeks in May and June 2015. Although paper copies were available to those who requested them, the sample would have been weighted towards those who are able to use a computer, or have a carer to do so for them, and who regularly access social media communities. It may thus have excluded the most severely affected and/or isolated.

In the survey we asked people with M.E./CFS about:

- their daily lives and their need for social care support
- how they were able to access primary healthcare and welfare benefits
- using advocacy services.

For the purposes of this interim report, we have chosen to focus specifically on social care need and service provision, making reference to the impact of advocacy on this. We are continuing to examine the remaining data and will publish further findings in due course.

## Who we heard from

The age and illness duration profile of the respondents matched that of a long-term illness with low recovery rates. The majority were in the 40-64 age bracket.

We asked respondents to rate the severity of their symptoms in the past three months:

- 26% of respondents rated their M.E./CFS as "Mild: you are fairly mobile, can care for yourself and can do light domestic tasks"
- 41% as "Moderate: you have reduced mobility and are restricted in all activities of daily living"
- 30% as "Severe: you are unable to do any, or only minimal, activities for yourself and you are bed or house bound most of the time"
- 3% as "Very severe: severe symptoms on a continual basis. Bedridden, unable to live independently and require full time support and supervision with all aspects of personal care."

Respondents were fairly evenly distributed around the UK with a bias away from the cities, as London and the Midlands (ie. Birmingham) were less well represented than they should be.

(See the Appendix on p 18 for more information on the sample characteristics.)

## Difficulties with day to day living



## The gap between support needs and service provision

We sought to measure the care needs of people with M.E./CFS using the same criteria now used by adult social care services in England for assessing eligibility. This includes a list of activities of daily living. If respondents reported difficulty with two or more of the activities because of their M.E./CFS they would meet two out of the three eligibility criteria.<sup>i</sup>

In total, 97% of respondents had two or more difficulties with activities of daily living. This means that, if their difficulties were found to have a significant impact on their wellbeing, the vast majority of respondents would have eligible support needs under the Care Act 2014 for England.

Respondents had on average six out of 10 of the difficulties with daily living listed in Care Act 2014.

Additional data from our survey showed that 65% of respondents could not independently and reliably access primary healthcare settings such as GP surgery, dentist or optician.

Only 16% of respondents had had a social care assessment or review in the last five years

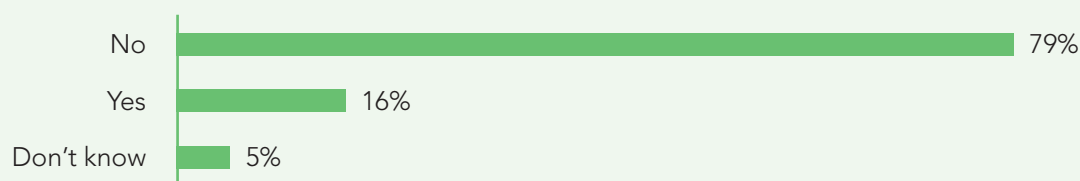
Just 6% said they received a care package from their local authority.

Thirty four of those received their care package in the form of Direct Payments (meaning they received a cash payment from their local authority to arrange their own care services)

Of the 49 respondents who were receiving a care package, 58% rated their M.E./CFS as severe, 7% as very severe and 25% rated their M.E./CFS as moderate.

There is a significant gap between the support needs of people with M.E./CFS and the statutory provision for those needs. Only 14% of respondents told us they didn't need care or support in their daily lives. With only 6% receiving a care package, this leaves an estimated 80% of respondents with self-reported care needs not met by their local authority. Less than a third were having these needs met by family members or friends.

### Have you had a social care assessment or review in the past five years?



## Problems encountered in social care assessments

We asked the 16% of respondents who had undergone a social care assessment or review in the last five years for their experiences; 55% said they had not been able to give a clear account of their needs.

We received considerable further information about difficulties with self-representation from this group.

### Communication difficulties

Cognitive problems, often related to “brain fog,” were a common cause of communication difficulties.

### Lack of stamina

Social care procedures are simply not sensitive and flexible enough to accommodate the acute levels of physical and mental impairment that can accompany M.E./CFS.

### Not just “tired all the time”

Only 42% of this group felt that the social care professional assessing their needs accepted their disability as genuine.

Among the common forms of misunderstanding, lack of understanding, or dismissal of M.E./CFS we heard about from respondents were:

- the perception that M.E./CFS is a common form of fatigue that best remedied through exercise meant their report of their care needs was not taken seriously
- lack of understanding of fluctuating needs and post-exertional malaise
- misdiagnosis of primary depression.

It was beyond the scope of this research to look in more detail at cases where M.E./CFS has been wrongly interpreted as a primary psychiatric disorder.

Action for M.E. has received other reports of disability in people with M.E./CFS being mistakenly attributed by social care professionals to severe depression or anxiety where this has led deprivation of liberty proceedings under the Mental Health Act. Further research is needed to determine frequency and outcomes in these situations.

---

*“I worry about being able to express myself effectively if I am suffering from brain fog, fatigue from attending an appointment, or not finding the right words to put my points across.”*

---

---

*“I am a former support manager and so I am aware of my rights but getting social workers to understand is very difficult. They do not take into consideration that I cannot communicate on the phone.”*

---

---

*“The social worker told me that ‘everyone gets tired’”*

---

---

*“My care manager didn’t understand that I was too sick and overwhelmed to talk about my needs”*

---

---

*“I was refused [a care package] despite appealing. They said they needed more evidence, yet they would need to spend a couple of days actually with me to appreciate how my symptoms fluctuate throughout the day.”*

---

---

*“There was little or no understanding of relapses and pay back lasting days after doing anything physical or brain use.”*

---

---

*“The community service worker mistook my cognitive symptoms for depression or anxiety. She told my consultant that I was afraid of activities of daily living. It was recommended I see a psychiatrist and I was questioned under guidelines of Mental Health Act and I thought I was about to lose my freedom.”*

---

*“The social worker said I should go swimming every week and do more exercise, even though she could see I couldn’t even stand up without falling onto the floor and my legs were going into visible spasms on that day.”*

## Barriers to engaging with social care

Nearly four in five respondents to our survey had not had a social care assessment or review in the past five years. We asked this group about their reasons for not engaging with social care.

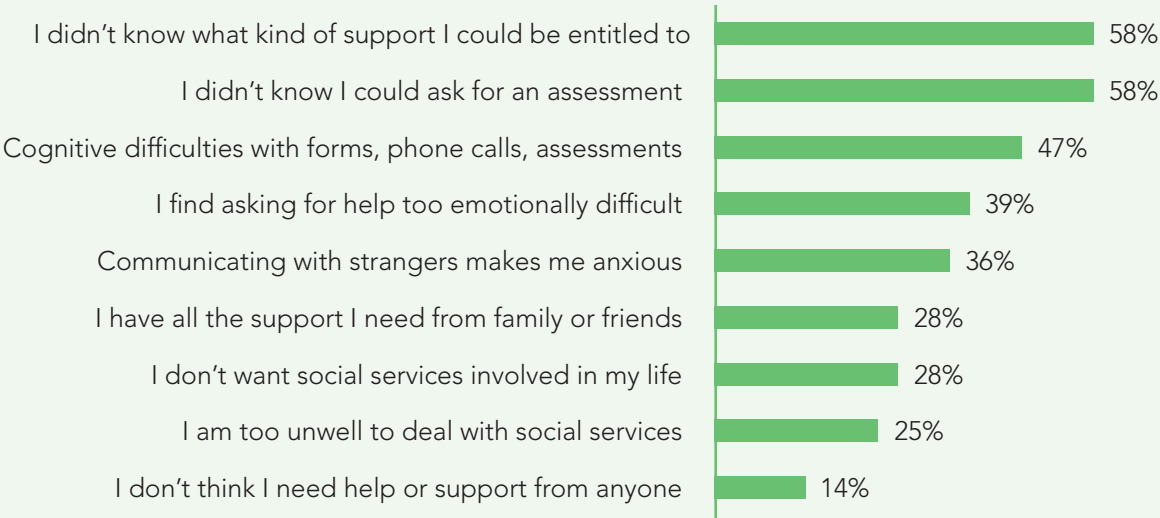
Only 14% felt they did not require care or support, while 28% felt they had enough support from informal care networks. For the remainder, barriers to engaging with social care were made up of:

- lack of information about entitlements and referral procedures: these were the biggest factors preventing engagement. More research is needed to determine whether the biggest problem lay with local authorities' failing to publicise information about entitlements and services, or a lack of signposting about potential eligibility from GPs or secondary care NHS services.
- difficulties with self-representation: cognitive difficulties in dealing with the bureaucracy of care processes was a deterrent for almost a half of this group of respondents. Social anxiety featured for 35% of them. A quarter said they were too unwell in general to cope with engagement with social services. The need for independent advocacy appears to be indicated in these situations. However, it remains to be seen whether people with M.E./CFS will meet the criteria for statutory independent advocacy under the Care Act in England.
- possible stigma attached to the diagnosis of M.E./CFS: we wanted to understand whether a sense of stigma or shame could be a barrier in asking for support, and 40% of this group of respondents said that asking for help was too "emotionally difficult."

*"My M.E. affects my speech. Any interaction requires huge effort and causes deterioration."*

*"The mental strain of the process lead to severe physical pain and I broke down and I was in tears. I did explain to the social worker what had happened. I think however that the social worker decided for herself that I was depressed."*

### Why have you not had a social care assessment?



*"I actually find it more exhausting trying to explain my condition to someone else who usually hasn't even heard of M.E. let alone is able to understand it in order to get their support or practical help than I do just trying to sort things out by myself. Consequently I have avoided applying for certain things that may be of help in the long run, eg. social services."*

To understand more about the nature of this “emotional difficulty” we asked whether those who experienced it agreed with a number of statements:

- 88% agreed that they worry that the assessor wouldn’t understand their condition and their needs
- 84% agreed that they worry in case the assessor won’t believe that they are genuinely disabled
- 84% agreed that they worry that they wouldn’t be considered deserving of help or support

It is beyond the scope of this report to investigate the historical factors behind the possible prejudicial treatment experienced by people with M.E./CFS.

However, half of the respondents to this question offered further evidence indicating it was a significant factor in avoiding social care assessments. Common themes were:

- “I’m fed up with being judged.”
- “Because of the stigma with this illness, I have little confidence and the fact that it is a fluctuating illness and it is hard to make myself clear.”
- “I feel that my condition isn’t seen as a disability by the social services, ie. I look fine.”
- “I’m concerned that drawing too much attention to myself might end up with me being pressurized into having inappropriate treatment or wrongly being labelled as mentally ill when I’m not.”

### Benefits of care and support among social care recipients

We wanted to investigate how statutory care and support improved the wellbeing of the 49 respondents with M.E./CFS who received it.

The table below shows the responses to the question: “What difference does having social care support make to your life?”<sup>ii</sup>

In addition, 51% said having a social care package gave them increased choice and control in their daily lives.

	Agree	Neither agree nor disagree	Disagree
There is less strain on family members or close friends	60%	2%	16%
I am better able to cope with my symptoms	49%	19%	21%
I can play greater role in family life	38%	19%	25%
I am more able to do activities that I enjoy	38%	11%	40%
Having social care support has helped me increase my baseline activity	33%	19%	37%
I am better able to look after my children	17%	6%	13%
I can play a greater role in my community	17%	17%	47%



## Reducing strain on family members

The greatest benefit of social care support on people with M.E./CFS is in reducing the burden on informal carers. In a separate survey, Action for M.E. found that 86% of respondents with M.E./CFS received daily care from a family member.<sup>10</sup> Research shows that M.E./CFS takes a large toll on the quality of life of carers, especially on their mental wellbeing.<sup>4</sup>

## Coping with symptoms and preventing deterioration

Personal care support is crucial in supporting dignity and wellbeing for people with severe and very severe M.E./CFS. Because of acute post-exertional malaise, difficulties with communication and extreme sensitivity to noise and light common with severe M.E./CFS, it is vital that care planning is personalised<sup>26</sup> and that the person's involvement in care planning is facilitated through appropriate representation. Worryingly, over one half of those who were receiving a care package said their key social care professional did not understand how M.E./CFS affected their daily life.

A tailored care plan also has an important role to play in activity management in M.E./CFS.

A key aspect of therapy for M.E./CFS is stabilising daily routines by avoiding a "boom and bust" pattern of activity.<sup>27</sup> This may create a foundation for improvement in symptoms, or prevention of deterioration. Respondents were almost equally divided in agreeing and disagreeing that social care had enabled them to increase their activities levels.

However, any therapeutic intervention aimed at gradually increasing activity levels must be carried out by a specialist M.E./CFS therapist.<sup>25</sup> Therefore a short-term care package aimed at maximising independence is unlikely to be suitable for people with M.E./CFS.

## Social participation

Social care provision was moderately effective in enabling participation in family life and leisure activities. The outcomes for participation in the community were low. This is probably because 75% of those receiving a care package were severely or very severely affected with M.E./CFS and the debilitating symptoms of this condition would likely prevent access to the community.

However, the majority of people with moderate M.E./CFS experience social isolation and difficulty accessing local services and may benefit from support with mobility, access and social participation. Access to social care should not be restricted only to people with severe M.E./CFS.

---

*"I am ashamed to ask anyone to the house as it is such a mess and dirty. My wife is too busy with work, looking after her dad, looking after me and looking after our 15 year old son. So she does not have time to keep house clean and tidy."*

---

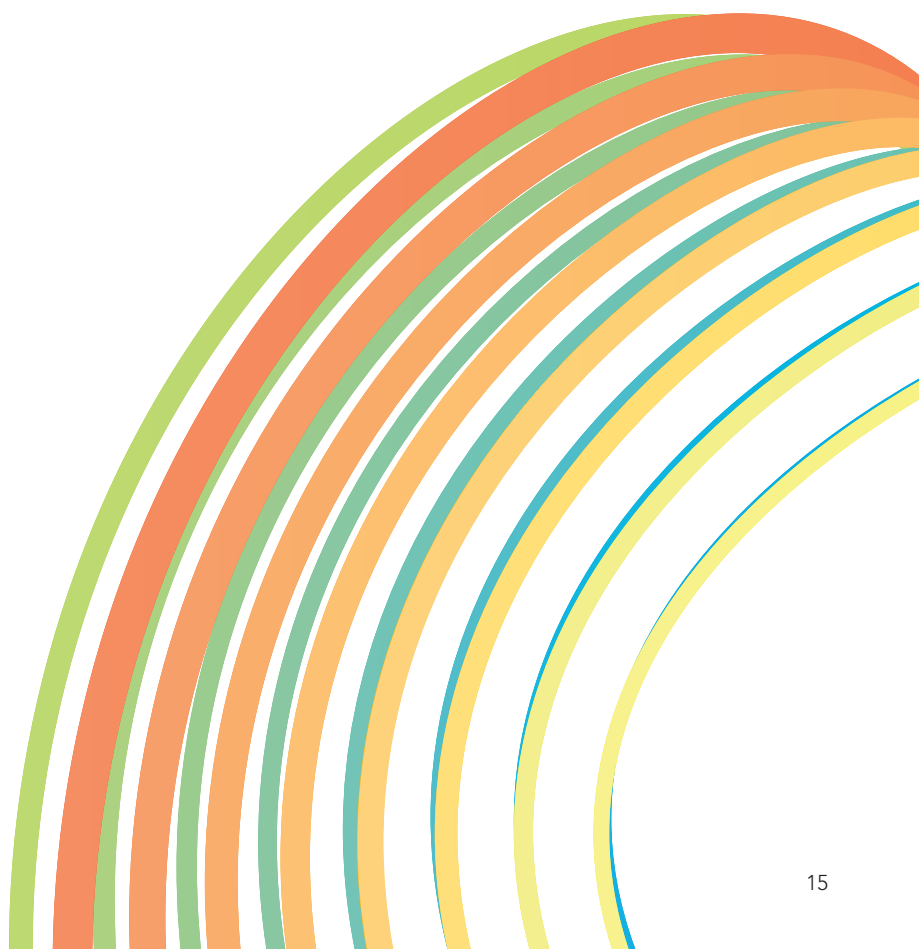
---

*"I feel like the plan has been made by somebody with no experience in dealing with my condition"*

---

One respondent told us that, as a result of her care package:

*"My symptoms are better controlled so I feel much less ill. I am able to predict my energy levels more accurately and have fewer swings between relapse and over activity."*



## Access to advocacy

### What is advocacy?

Independent advocacy is concerned with maximising people's involvement in decisions about their lives. Independent advocacy is taking action to help people understand information, express their needs and wishes, secure their rights, represent their interests and obtain the care and support they need. Advocates work in partnership with the people they support and take their side. Advocacy promotes social inclusion, equality and social justice.<sup>28</sup>

People with M.E./CFS face substantial barriers in accessing and engaging with social care processes due to cognitive impairment, severe levels of illness and the perceived stigma attached to their diagnosis.

Only 31% said they felt capable and confident of expressing their own feelings and needs, indicating a high level of need for representation. When we asked people in which aspect of their lives they most needed someone to represent them, accessing social care came second, after accessing disability benefits.

### Advocacy was greatly valued but not often received

Three quarters of respondents thought their situation would be "a little" (25%) or "a lot" (50%) better if they had an independent advocate to represent them.

Only 23% had ever used an advocate. Most of the experiences of advocacy service users we received were in relation to disability benefits rather than social care.

### Barriers to accessing advocacy

Sadly, some of the difficulties respondents faced in accessing social care were replicated when they sought representation from an advocate. The main barriers we identified to securing an advocate were as follows.

Services were poorly signposted: 61% said they didn't know how to find an advocate

Poor health prevented them from traveling to appointments with an advocate

The advocacy services offered couldn't accommodate their very poor mental and physical stamina.

The efficacy of local advocacy services may be reducing. The National Institute for Health Research reports that the community advocacy sector is facing increased demand coupled with cutbacks and closures.<sup>29</sup>

### Advocates' knowledge of M.E./CFS

70% of respondents who had accessed advocacy were satisfied or very satisfied with the outcome of the service they received. Those who expressed the greatest satisfaction told us how important the advocate's understanding of M.E./CFS was.

---

*"The advocate I used once didn't understand how tiring M.E. was and actually made me more ill."*

---

*"I can't even access CAB services where I live. I was told that I would have to travel and "pop-in" to a large centre on the off chance of seeing someone or to make an appointment."*

---

*"Healthwatch have offered some telephone support and the offer to attend a meeting but I have not been well enough to have the meeting. It is very difficult when your energy is limited and problems drag on for years, which is very stressful. If I were well I could probably sort the issues out but everything takes so long when your energy is limited to an hour on a good day or less than zero during worse times."*

---

*"I had excellent help from local welfare advisors some years ago who came to the house. But all such help [was] cut by the local authority to save money several years ago."*

*"If there was an advocacy service, I'd use it for help, definitely. For filling in forms etc and to go to any assessments if and when necessary, as it makes me more ill worrying."*

---

# Conclusion and next steps

---

This research has shown the shocking lack of access to social care and advocacy support for people with M.E./CFS.

In response to this, Action for M.E. will now lead a formal inquiry to further build the evidence base into social care provision for people with M.E./CFS and explore solutions to address the barriers to access and improve individual outcomes in terms of wellbeing, dignity and autonomy from social care support.

We will seek to host a series of consultations and roundtables with people with M.E., carers and key organisations and policy/decision-makers in order to:

- obtain a more detailed evidence base in relation to positive and negative experiences of accessing and receiving social care support and, as part of this, build a bank of case studies to inform what works and what needs to change
- explore the need and potential for specialist advocacy in improving social care outcomes for people with M.E./CFS
- use the output of the above to inform our strategic priorities for 2016-19 and allocate resource and capacity to enable us to implement agreed actions.

We will seek to collaborate as widely as possible with other organisations and most importantly with people affected by M.E.

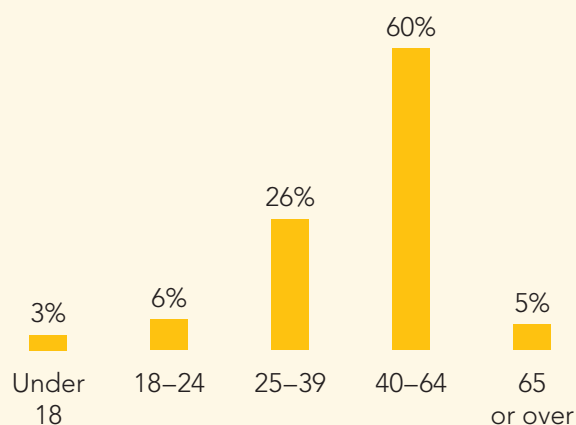
Alongside this, Action for M.E. has published a self-advocacy toolkit to increase the information available for people with M.E. and their carers to help them navigate the system and increase the potential for securing the support they needs. Additionally, Action for M.E. is seeking funding to establish a national advocacy service to directly support individuals.

*"I was lucky enough to have an advocate for a short time who understood severe M.E. which helped a lot with an assessment of needs for carers."*

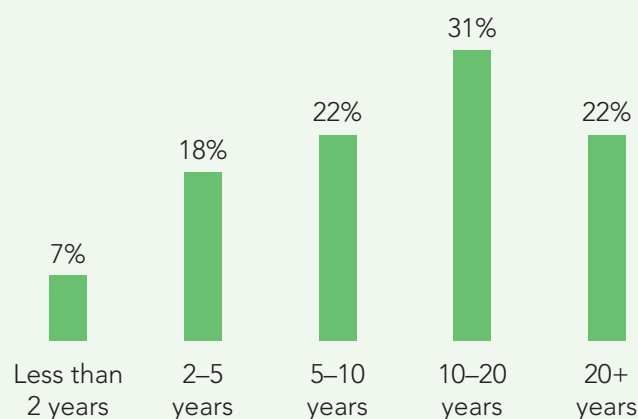


# Appendix: sample characteristics

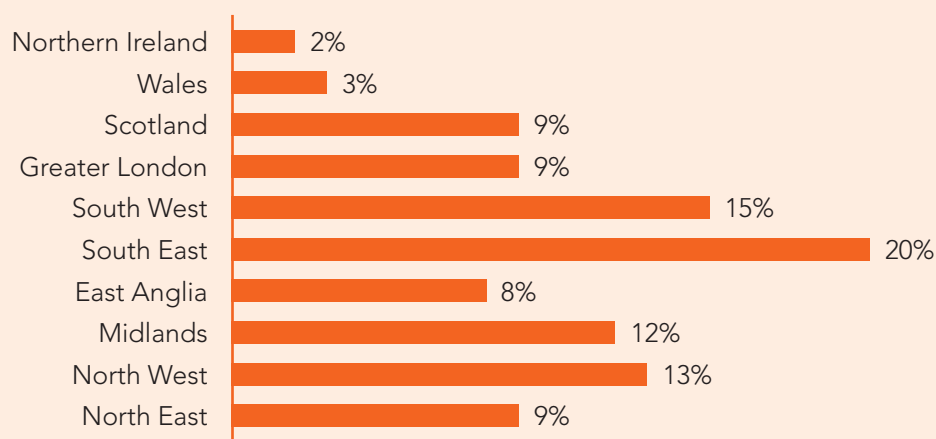
## Which age group are you in?



## How long have you had M.E/CFS?



## Which part of the UK do you live in?



The NICE criteria<sup>25</sup> for severity were used, with an extra category for very severe, ie. Severe symptoms on a continual basis. Bedridden, unable to live independently and require full time support and supervision with all aspects of personal care.

## How have you been in the last three months?

Very severe: severe symptoms on a continual basis. Bedridden, unable to live independently and require full time support and supervision with all aspects of personal care

3%

Severe: you are unable to do any, or only minimal, activities for yourself and you are bed or house bound most of the time

30%

Moderate: you have reduced mobility and are restricted in all activities of daily living

41%

Mild: you are fairly mobile, can care for yourself and can do light domestic tasks

26%

---

# References

---

- i The question clarified the nature of “difficulty” following the statutory guidance: “‘Difficulty’ means either you can’t do it, you need help from family, friends or carer to do it, or doing it causes you significant pain, anxiety or distress, or takes you significantly longer than normal.’ We did not ask about the impact of these difficulties on respondents’ wellbeing so the data collected is only an indication of potentially eligible care needs.
  - ii Percentages do not total 100% here because respondents could select “Not Applicable,” eg. 65% of respondents selected Not Applicable to the statement about parenting.
- 1 NIHR School for Social Care Research (2013) *The impact of advocacy for people who use social care services*
  - 2 Institute of Medicine (2015) *Beyond M.E./CFS: redefining an illness*
  - 3 Hvidberg et al (2015) The health-related quality of life for patients with M.E./CFS. *Plos One*. 10(7)
  - 4 Nacul et al (2011) The functional status and well-being of people with M.E./CFS and their carers. *BMC Public Health*. 11:402
  - 5 Andersen (1997) The quality of life of persons with CFS. *The Journal of Nervous and Mental Disease*. 185(6):359-67
  - 6 Majer et al (2008) Neuropsychological performance in persons with CFS: results from a population-based study. *Psychosomatic Medicine*. 70(7):829-36
  - 7 Capuron, L ( 2006) Cognitive dysfunction relates to subjective report of mental fatigue in patients with CFS. *Neuropsychopharmacology* 31(8):1777-84
  - 8 DeLuca, J (1993) Information processing efficiency in CFS and multiple sclerosis. *Archives of Neurology*. 50(3):301-4
  - 9 White, PD. (2011) Comparison of adaptive pacing therapy, cognitive behaviour therapy, graded exercise therapy, and specialist medical care for CFS: a randomised trial. *The Lancet*. 377(9768):823–836
  - 10 Action for M.E. (2014) *Time to Deliver: initial findings from Action for M.E.’s 2014 survey*
  - 11 Collin et al (2011) The impact of CFS/M.E. on employment and productivity in the UK: a cross-sectional study based on the CFS/M.E. national outcomes database. *BMC Health Services Research*. 11:217
  - 12 [www.facebook.com/pages/ME-Analysis](https://www.facebook.com/pages/ME-Analysis)
  - 13 Fernandez and Snell (2013) *Survey of fair access to care services (FACS) Assessment criteria among local authorities in England*. LSE PSSRU
  - 14 Care Act 2014 Section 1 (3)
  - 15 Department of Health (2014) *Briefing note: independent advocacy under the Care Act 2014*
  - 16 [www.voiceability.org/the\\_care\\_act/care\\_act\\_advocacy](http://www.voiceability.org/the_care_act/care_act_advocacy)
  - 17 Department of Health (2014) *Care and support statutory guidance: issued under the Care Act 2014*
  - 18 In Control (2015) *Promoting people’s right to choice and control under the Care Act 2014*
  - 19 Association of Directors of Adult Social Services (2015) *ADASS budget survey 2015*
  - 20 The King’s Fund (2015) *The Budget: health and social care funding*
  - 21 Social Care Institute for Excellence (2013) *Maximising the potential of reablement*
  - 22 Social Care Institute for Excellence (2010) *Reablement: emerging practice messages*
  - 23 Health and Social Care Information Centre (2015) *Community care statistics: social services activity, England 2014-15*
  - 24 Brownlie, H (2015) *Home care is the theme for Severe M.E. Day on August 8th*. Phoenix Rising <http://phoenixrising.me/archives/27607> (accessed 25 August 2015)
  - 25 National Institute of Health and Care Excellence (2007) *Diagnosis and management of CFS/M.E. in adults and children*
  - 26 The 25% M.E. Group (2015). *Home care delivery: looking after people with M.E.*
  - 27 British Association for CFS/M.E (2015) *Therapy and symptom management in CFS/M.E.*
  - 28 Social Care Institute for Excellence [www.scie.org.uk/care-act-2014/advocacy-services/commissioning-independent-advocacy/at-a-glance/index.asp](http://www.scie.org.uk/care-act-2014/advocacy-services/commissioning-independent-advocacy/at-a-glance/index.asp)
  - 29 NIHR School for Social Care Research (2013) *The impact of advocacy for people who use social care services*



42 Temple Street  
Keynsham  
BS31 1EH

T 0117 927 9551

E [admin@actionforme.org.uk](mailto:admin@actionforme.org.uk)

[www.actionforme.org.uk](http://www.actionforme.org.uk)

 [www.facebook.com/actionforme](https://www.facebook.com/actionforme)

 [www.twitter.com/actionforme](https://www.twitter.com/actionforme)

**Registered charity**

Registered charity in England and Wales no. 1036419

Registered in Scotland no. SC040452

Company limited by guarantee, registered in England no. 2906840

©Action for M.E. November 2015